Roads Taken
Recollections, Words, and Images from Meaningful Work

Selected Stories, Essays, & Letters 1988-2012
For The Durnbaugh Lectures at Elizabethtown College
November 8, 2012

D. Holmes Morton M.D.
Pediatrician

Oil Paintings by Sarah McRae Morton
Photographs by Mary Caperton Morton
To the memory of William Carlos Williams &
To the Children who ask for our help then teach us to Care.
Pastoral
William Carlos Williams
Pediatrician
1883-1963

When I was younger
it was plain to me
I must make something of myself.
Older now I walk back streets
admiring the houses
of the very poor:
roof out of line with sides
the yards cluttered
with old chicken wire, ashes,
furniture gone wrong;
the fences and outhouses
built of barrel-staves
and parts of boxes, all,
if I am fortunate,
smeared a bluish green
that properly wheathered
pleases me
best of all colors.

No one
will believe this
of vast import to the nation.
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The Death of Enos Fisher

As I walked out of an Amish farmhouse into cold rain and darkness, I paused to think about the dead boy and the gathering of people in the room behind me.

The father sent word that the boy died and I went to the home to sign the death certificate. Carriages and wagons of friends and family were parked along the lane. From where I first stopped I watched black figures move ahead of horses to the barn and then to the house. Through dark windows I could see light from an open door at the center of the house. As I stepped into the kitchen a figure in the lighted room motioned and said "Morton we are here."

From the doorway I saw that the harsh white light from a lantern above the bed made the hands and face of the dead boy cold blue-white. Bright silver light flashed from new coins placed over his eyes. But then I saw that the lantern light was softened in colors of the quilt gathered around him and the light was golden on his hair and on the hair of the children who played quietly on the end of his bed. The now softened light washed over the faces of those seated shoulder to shoulder around the room who one by one shook my hand. Several said, "I have heard Dr. Morton’s name often and now I am glad to meet you."

"When did he die John?" "Oh, not so long ago. Maybe he is still warm." Then the father took the boy's hand and turned it in his with the gentleness used to hold a baby bird. The father's hand was large and thick from heavy work. The skin over the palm and fingers was stained and cracked and looked like the bark of an oak. The boy's hand was so small. "No," he said, "he is cold now." Then he placed the lifeless hand in mine.

I sat on the chair by the bed for more than an hour. The boy's mother said just two days ago his grandfather carried him out to the barn to watch the milking and he pulled the tail of a cat and laughed. And yesterday as she read to him he pointed to pictures and softly made the sounds of animals as pages were turned. But today he was awake only a little while. At first his breathing was harder, then was weaker, and, toward evening, just faded. He didn't seem to suffer. He found peace.

I talked about how difficult it is to care for children who have illnesses that are not understood and cannot yet be treated. I said that as a doctor and scientist when each new therapy fails I must somehow renew my efforts to learn more. Then the boy's grandfather spoke. As he spoke he smiled and looked first at me then the children on the bed. He said, "we will be glad if you can learn to help these children but such children will always be with us."
They are God’s gifts. They are important to all of us. Special children teach a family to love. They teach a family how to help others and how to accept the help of others."

We talked about the boy’s sister who had lived a little longer and about other special children who had come and gone before. And of those ill like this boy who were living still but may not live through winter. We were thankful for the health of their new baby. Then we talked about the harvest just finished, the needed rain falling outside, the weddings of November, and signs that winter would be long. John said, "we are glad you came. Thanks for your help."

As I looked back into the house, I remembered the children at play on the deathbed and what the grandfather said. His few words would change the way those children, and I, would remember the life and death of the boy. I understood that the gathering in the room was not only a ceremony about death and life after death but was the means by which the family would both endure and be strengthened by the loss of a child. That was the boy’s gift to his family and to all of us who knew him.

Special children hope to suffer less and lead fulfilled lives through the help of others. Within their families and communities they are not merely the object of compassion and love but often are the very source. Such children shape the Amish and Mennonite cultures and inspire work such as that at the Clinic in important and forceful ways. We should not underestimate the value of their lives, however brief or however difficult. We should not assume that the Plain cultures, or our own cultures, would be better without them.

These special children are not just interesting medical problems, subjects of grants and research. Nor should they be called burdens to their families and communities. They are children who need our help and, if we allow them to, they will teach us compassion. They are children who need our help, if we allow them to, they will teach us to love. If we come to know these children, as we should, they will make us better scientists, better physicians, and thoughtful people.
The Crossing
Amos’ Child
Amish friends, Amos’ family, spent Saturday afternoon at our home last summer. Amos asked me about a small telescope on our back porch. I explained that my children and I used it to look at mountains and craters of the moon and the rings of Saturn. Amos didn’t know that men had walked on the moon 13 times but seemed neither surprised nor impressed by the fact. He asked, "Have you thought much about why the stars are there? Do you think God made the moon and stars just to look at? What is the moon for?"

Amos & Susie Miller had five special children. They asked many times Why does God give us these children? What are special children for? Modern genetics does not provide an answer for Amos and Susie. The science does not even allow the question. But within cultures that endure for hundreds of years, as the Plain cultures have, there are answers to such questions. For the Amish people beliefs, faith, events, stories, work, histories, the elderly, children, and the stars do have purposes. I believe that if we are to provide adequate care for special children of the Plain people then we must appreciate the place these children have in their families and communities.

I well remember my first visits to the home of Amos. I could see the rusted wheel chair of a child beside the plow in the barn that I walked past and I thought it likely that I had found the right farm.

Are you Amos Miller? I asked.
Amos said, That’s what they say. Who are you?
My name is Holmes Morton. I am a doctor. John and Ida Lapp told me about your children. They are like Daniel. I think I know what causes such children to be crippled.

Amos, You say you are a medical doctor?
Yes. I said.

Amos, we haven’t heard of you. Other doctors thought they knew about these children too. Have you ever heard of Dr. McKusick? He was here before. He studied our children at John’s Hopkins, spent a lot of money, and couldn’t give us an answer.

Yes. I know Dr. McKusick. The disorder I suspect is not one for which he would have tested. I said.

Amos, well, you can come in. My supper is on the table but I am sure my wife will want to talk to you.
Years after my first visit Susie still told others, I was so surprised when Amos let Dr. Morton in the house. Amos can be tough with salesmen, especially, when they come at suppertime. Amos went to the door determined to send him away so we could finish our supper. At first, I just couldn’t imagine why Amos let him in.

Amos remembers, Morton talked for more than an hour. He said he thought he knew what happened to John and Ida’s Danny and suspected that our children were crippled by the same disease.

He didn’t even want money. I could tell by his car he wasn’t one of those money doctors. I never saw a doctor drive an old car like that. He didn’t even want blood, just some urine from the crippled children. He said there was something in the urine that would explain why our children were crippled.

We didn’t believe him. After 18 years with five crippled children. So many doctors, so many hospitals, so many tests without answers, then, a young doctor knocks on our door and offers to do a test for free. He said he was just interested in trying to help such children. How could we believe him?

Susie remembers, when Dr. Morton came back with the test results Amos was not at home. I was ironing. He sat in the rocking chair by the window. He said the test showed what he thought it would. The test gave the explanation about why our children were crippled. I just kept ironing. For a long time I could not say anything but I just shook inside. I thought about our sons who died, first Sylvan, then Levi, and about our other crippled children. I thought about unborn children and the hope that they might now have. I just shook inside. After all these years how could it be? It was so hard to believe because of the way it happened. Yes, I remember the first day Dr. Morton came to our house and how surprised I was when Amos let him in.

Susie told me, the death of Sylvan was especially hard for Amos. He had become Amos’ child. Sylvan was 6 months old when he became helpless. It happened so fast. He had a cold. In the morning he had a fever, at noon when I put him down for his nap he seemed normal, but, when I got him up at 3 o’clock he was helpless. He was limp, couldn’t hold his head, he could no longer sit, or take a bottle normally. I was so young then and by then Levi was helpless and Elmer had to be cared for too. There was not any thing I could do but ask Amos to take care of Sylvan. He fed him and got up at night for him. Even when Sylvan was small Amos took him to the barn to do the milking, and to the fields on the plow and the hay wagon. Sylvan was Amos’ child.

Sylvan died on a Sunday afternoon when we were on our way to visit friends. It happened along the Bartville Road not far from David Fisher’s. Amos looked back in the carriage and saw that Sylvan was still. He said “Susie I don’t think Sylvan is breathing!” He
stopped the carriage in the middle of the road and handed me the reins. I had the baby on one arm and had to hold the horse with the other arm while Amos ran back to pick-up Sylvan. Amos said “He is dead Susie. Sylvan is dead.”

We went to the next farm house. They took us in and comforted us. I just did not know what Amos would do without Sylvan. It was almost more than he could bear.

The day after Sylvan died was the great snow storm of 1978. We didn’t know if we would be able to bury him but the men worked hard to get the road open to the cemetery and the grave dug. We buried him while snow blew over us and it was very cold.

Not long ago when I drove through that part of the county to make a house call, I stopped at the cemetery where Sylvan is buried. I could imagine the day of his burial - the snow falling, blowing, covering the headstones, covering the fresh earth from the grave, falling into the grave, onto the horses and carriages along the fence. I could see people in black walk past the open coffin. I could see the blue-white face and hands of the dead boy. The snow fell onto his face and hands and did not melt. From time to time as people filed by, Amos would gently use his bare hand to brush the snow from Sylvan’s face. The sound of the earth falling on the pine coffin was softened by snow and by the time the family drove away the grave was filled and hidden under snow.

I thought, my work began then. Ten years before I came to Amos Miller’s door. Even before I was a doctor. The work began with the life and death of an Amish boy who had become his father’s child. Amos would have sent me away if it were not for his love of Sylvan, for Susie said, Amos was tough on salesmen who came at suppertime. At first, she was so surprised when he let me come in. dhm, Strasburg PA April 1994

RUTHIE

Age 40 years and a few weeks before her death. She was disabled by Glutaric Acidemia at age 6 months during an infection with chicken-pox.
When I work with the mass spectrometer in my laboratory at the Clinic, I often pause to look through the window near my desk. Last summer blue birds, gold finches, and a pair of nesting orioles often caught my eye. One evening in the fall after the corn was harvested, I watched six deer, a red fox, and a skunk forage through the field all at one time. On the first warm day of Spring the window was open and I heard the calls of wild geese and stopped to watch their high northward flight. I have also watched the sun rise over the field in all seasons after long worried nights at work because of a sick child. I especially like to watch Jake Stoltzfoos or his son-in-law work in the field with a team of mules. Jake and Sam plow, plant, and harvest with four small red mules. You may think, such a contrast, the work of a doctor, analytical chemistry, biochemistry, efforts to understand how an inherited disorder injures the brain of an infant, all within 100 feet of an Amishman's fieldwork with mules. Such contrast, you say. Yes, I say, but these people and their way of life have much to teach us.

I have come to respect the labor in the field. Jake worked his land for 30 years and last year his young son-in-law took over the farm. The field helped Jake and Naomi feed 12 children and gave them all, taught them all, meaningful work. The work there also fed many generations of livestock and, at the same time, fed many generations of wildlife. The field was cleared more than 100 years ago. The Amish people have worked the fertile land around the Clinic for 300 years with the same simple, low cost, labor intensive, high yield methods of farming. Last Spring as I walked through the freshly plowed field I found a flint arrowhead and was reminded that before Amishmen the woodland was harvested in another way by another people. History and timelessness come through my window like Spring air and sunlight, like the calls of wild geese, to remind me that my work here too takes its place in time.

When Jake's mules turn at the end of a row, he often looks to see if I am at my window and waves. We can each respect the work of the other. He knows I measure the usefulness of my work against the usefulness of his. He knows that I measure the success of my work, not in terms of lectures, publications, grants, or income, but in terms he understands. He has grandchildren with the disease that I study and we hope that they can live to work in the field.

_dhm Spring 1994_
Croquet

I stopped to see Jacob and Nancy Zook yesterday. Mrs. Zook called before breakfast to say that she planned to make pies that day and some would be made with my family and me in mind. She said, I know you are busy but don’t let your pies wait overnight. They will be ready by noon.

Her husband Jacob is 74 years old and is a wagon maker. He took me to his shop to show me a wagon that he would finish by the week’s end. The Zook wagons are well known to the Amish people of Lancaster as heavy flat-bed farm wagons that last. The wheels and frame are metal, the wagon bed is 3 inch thick smooth pine with tight tongue and groove joints bolted to oak cross-beams and side-rails. Jacob says it is more efficient to work on three or four wagons at a time. He can put together 4 wagons in a week but on average he finishes one a week. He started making wagons when he was 34 years old when their children were old enough to help with the farm chores and gave him time for other work. Jacob said he recently made repairs on the first wagon he made which has been in use on a neighbor’s farm for 40 years. In his lifetime Jacob Zook has made more than a thousand wagons and much good work has been done with them.

Two of Jacob and Nancy’s grandchildren died from a genetic disorder called by the Amish people pigeon breast disease. As the disease progresses muscles of respiration fail, the ribs are pulled inward and the sternum is pushed upward until the chest assumes a shape like that of a bird’s chest. Death is caused by respiratory failure but is usually hurried by pneumonia. Most of the children die in winter. The first of Jacob and Nancy’s grandchildren, Jerry, lived 4 years. I did not know Jerry, he had died before I began to work in Lancaster County. The second grandson, John Ray, I saw on the day he was born. Jake, Sadie, and I knew he had the disease before he was a week old. He lived only a year. The disorder has not been described in the medical literature but is the most common of the recessive disorders that I see at the Clinic - over 4 generations more than 30 families have had children with the disorder, more than 70 children have died. We suspect an abnormality in the calcium ion channels that regulate muscle contraction and relaxation. Research continues. Our efforts to treat the disorder are now focused upon the use medications that selectively block chloride and calcium ion channels. Some trials have failed, progress is slow, uncertain.

As I left Jacob and Nancy’s house and drove out the farm lane, I remembered the night in winter. I came home at midnight. Caroline said What happened? I thought you were going to
Jakes and then come home for supper. I hoped you would be home with the children so that I could go out to finish buying for the children’s Christmas.

Yes, I know. I didn’t forget. When I got to Jakes John Ray was very sick. He has pneumonia. I took Jake and him to the hospital.

Caroline said, I thought Jake and Sadie didn’t want him in the hospital. They wanted him to stay at home.

Yes, but he shouldn’t die on Christmas. I wasn’t sure he would last the night. Everyone at the house was sick. Sadie and the three other children. All vomiting. Nancy had been there all day. Mostly holding the baby but Nancy was sick herself. Jake’s unmarried sister Susie came to help so Nancy could go home to rest but she didn’t make it home. She started vomiting and fell in the road. Fortunately Jacob was still in the shop and found her on his way into the house. When I came along Jacob was trying to lift her but couldn’t and she was too weak to stand. She was covered with mud and snow and vomit. I don’t know how long she had been there before Jacob found her. I was afraid she had had a heart attack or had broken her hip. Her arm was broken but that was all. Jacob and I put her on a child’s wagon, balanced her half sitting, and got her into the house and onto the couch. I splinted her arm with newspaper and scotch tape then went to Jakes to get Susie so she could stay with Nancy and help her change her clothes while Jacob went for a neighbor to take her to the emergency room to have her arm set. Nancy kept saying I am alright now, I am alright, Doc just go see the baby, go see John Ray. You must do something for him. He is just cries all the time and his mother is too sick to tend to him.

John Ray had been vomiting and couldn’t drink, He had pneumonia too. Children with pigeon breast disease all die with pneumonia. I told Jake the way things were I didn’t think the baby would last the night. As soon as your neighbor takes your mother to the emergency room, Susie can come back and help Sadie and the other children. Then you and I can take John Ray to the hospital for oxygen, antibiotics, get his fever down, get him rehydrated then we can bring him home again. He won’t have to stay there, I promise you, even if he worsens. I will get him home. He shouldn’t die now, not on Christmas.

I just hope I can get him out of the hospital before he dies. The nurses seem to understand. He was breathing easier and had fallen asleep by the time I left. Jake was asleep by his bed in the chair. I’m sure they had slept little for several days. By the time I finished my notes and orders and talked with the nurses, Nancy’s arm had been set. Simple break, above the wrist. I gave them a ride home. She is worried that it will hurt when she quilts. That is her quilting hand.

Caroline, poor people. I guess our children should be satisfied with what we have.
Oxygen and antibiotics held back death a few weeks. John Ray died after Christmas, after his first birthday, at home, peacefully.

In summer Jake and Sadie invited my family and me to supper. Jacob, Nancy, and Susie were there. Our talk often turned back to the boys who were no longer with us. The purpose of the day was not to forget the children but to remember them.

After supper we went out to play croquet in the meadow by the house. The wickets were placed far apart and the field was long and wide as though for some extraordinary game. I remember our voices, the crack of hard-stuck wooden balls, the sounds of children barefoot, laughing and running through high grass of the meadow and into the corn, the songs of meadow birds and crickets, all mixed and diffused into evening's air and carried into the fields beyond as a kind of music and song. I remember the great graceful Percheron mares and their colts running through the meadow, as though some part of our game, and the barn swallows turning, turning, turning against the rich summer greens of earth and blues of sky. And, I remember the warm light of summer evening that washed over everything and over us.

When the daylight faded Jake brought out lanterns and we played on into the night each with our own small light. I thought, someone on the distant hill, watching our lanterns move back and forth across the meadow might, if she watched long enough and knew the game, realize that we were playing croquet. From there too, she might have watched my car come and go those winter days and, if she knew the nature of my work, she imagined the sadness of my task. When carriages gathered on the frozen meadow row by row black against snow she would have known death had come, and, watching carefully from the distance, she might learned something about the customs of Amish people at the time of death. But there is more to know than can be learned from such distant, high places. More to know about these people, about work such as theirs and mine. More to know than just the name of a game played on a meadow one evening in summer.

dhm November 1994
Draft 7 November 25, 1994
Draft 8 March 5, 1995
Draft 9 April 16 Easter, 1995
The Eye of the Storm
These are the days in August I remember. Anyone watching from a window, would see me move between dark and day, between earth and sky, immersed in first light and mists. Painted silver-white by the morning itself. I have imagined how a dove must feel as she flies through morning.

Memories of my work in Lancaster County have become entangled remembrances of late summer mornings. First light seems to arise from the land itself. Diffuse, soft, a light woven of mists and shadows and the soft purples and white lace of meadow flowers. In first light, the land and sky are fused and trees appear to gather substance from the air itself and hang strangely above the land suspended by black limbs.

The light of morning is interwoven with an incessant songs of crickets and cicadas and chirps of song birds, broken by a cacophony of calls of crows, quail, geese, and the sharp cries of the mocking-birds. More distant, the sounds of the work in barns, voices of children who are driving in the cows for milking, a rooster, cries of calves, and, beneath all of this, more faint still, the soft murmurs of mourning doves and meadow brooks, both always to me sound like whispering voices.

The air of first light is heavy with smells of fresh cut hay and corn and earth, all wet with dew, and with the sweet bitter odor of new tobacco hung high in the rafters of hot barns to dry, and with smoke from cook stoves. The air is heavy too with the evocative smell of honeysuckle that has always reminded me of perfume, and youth.  

**Strasburg Morning**

*dhm August 1996*
Acceptance

Remarks after receiving the Albert Schweitzer Prize for Humanitarianism
Johns Hopkins University
October 1993

I am honored and happy to have the work at the Clinic for Special Children recognized by the Schweitzer Prize. I thank Randy Testa who nominated me, the family of Alfred Toepfer, and the members of the committee who awarded the Prize.

There are several people who in an immediate way share this Prize with me. My wife Caroline and I together decided to establish the Clinic. Without her ideas, her hard work, and her understanding, the Clinic would not be. Richard Kelley was my mentor. He taught me much of what I know about genetic diseases and much credit for the scientific work done at the Clinic goes to Rick. Without his help and friendship the Clinic would not be. Enos & Anna Mae Hoover, Amos & Susie Miller, Rebecca Huyard, and others in the Huyard family understood the need for a clinic for special children long before the idea was widely accepted within the Amish and Mennonite communities. Without their prayers and their work the Clinic would not be. I also must thank again a writer named Frank Allen, whose words helped the dreams of all of us become real.

The Prize is also a tribute to my teachers. A few of them are here today. I was never an easy person to teach. I doubted, questioned, and argued my way through an unusual education. My interests in people and art, medicine and science, which are the sustenance of my work each day, were fostered by a few teachers of literature, writers, scientists, and doctors. I remember them as gifted teachers and thoughtful people.

After the letter came from Dr. Richardson about this award, I began to read about Albert Schweitzer. The Prize has caused me to think about the work and words of a great person. That alone was a valued gift. Dr. Schweitzer’s example always now will be in my thoughts about our work at the Clinic.

By age 30 Albert Schweitzer had advanced degrees in music and theology. He was recognized in Europe as an authority on the music of Bach, his theological books were widely read, and he taught at the University in Strasbourg. Yet he then turned away from a life as an academic. At age 30 he decided to learn medicine and surgery and go to Africa as a missionary doctor. He studied for eight years to obtain his Medical degree. When he was 38 he and his wife went to a remote region of western Africa to start a clinic. His first operating room was fashioned from a chicken coop and his patients stayed in thatched huts with dirt floors. He
repaired hernias and broken limbs, treated diseases of malnutrition, and, in a time when medicine had little to offer, he cared for those who would die of malaria, sleeping sickness, tuberculosis, leprosy, and malignancy. His difficult work at Lambarene continued for more than 50 years until his death at age 90. His writings make me think that his work was sustained by his ideas and his ideas were ever renewed and enriched by his work. I would say that is why his work endured.

Will our work at the Clinic last as his did? I too was 38 when I went to Lancaster County to work with the special children. If I am blessed with as many years as Albert Schweitzer then I have 47 more years to work at the Clinic. The Clinic for Special Children is in a timber frame building with a roof of barn-slate. Such buildings have lasted hundreds of years. We are found at the end of a long lane in the middle of an Amish farm and there are hitching posts in the parking lot. Dr. Schweitzer would have understood why the Clinic is there - it is where it is needed. The natural histories of diseases we treat make preventative care and ready access to special care essential. He also would have understood that it is important that the Clinic was built and is supported by people whose children need the care that the Clinic provides. Our work and lectures have started to change medical practice in Lancaster County. Midwives, nurses, and doctors who staff the local hospitals and other clinics in the region are better informed about genetic disorders. They know that some disorders, which are elsewhere rare, are common in Lancaster County and should be recognized by a general practitioner. More important, they have learned that some of these conditions can be effectively treated and they know we are available to help. These are encouraging signs that the Clinic will last. Nonetheless, I believe that ultimately our work will be sustained by the children we help. I want to tell you more about the special children.

Albert Schweitzer's writings about his reverence for all life have led me to think about an aspect of our work that is often overshadowed by scientific efforts, here and elsewhere, to describe and prevent genetic disorders. As I care for children with complex, sometimes lethal, inherited disorders, I am impressed by the hopes and worth of these children. The Plain People call them God's Special Children.

Amish friends, the Amos Millers, spent Saturday afternoon at our home a few weeks ago. Amos asked me about a small telescope on our back porch. I explained that my children and I used it to look at mountains and craters of the moon and the rings of Saturn. Amos didn’t know that men had walked on the moon 13 times but seemed neither surprised nor impressed by the fact. He asked, "Have you thought much about why the stars are there? Do you think God made the moon and stars just to look at? What is the moon for?"
Amos Millers had five special children. Amos & Susie asked many times *Why does God give us these children? What are special children for?* The answer offered by modern genetics is not a sufficient answer for them. Scientific medicine does not even allow such questions. But these questions are asked, and can be answered, by the Plain families who have special children.

For us to understand the significance of such questions we must acknowledge that the world view of the Plain people is different from that of most of us and that these communities of the Amish and Mennonite people are not simple and antiquated cultures. To quote John Hostetler:

*The Amish people are neither relics of a bygone era nor a people misplaced in time. They have reached conclusions different from most moderns about how to live in today’s world. Their past is alive in their present. They are a different form of modernity.* (Amish Society 1983)

Within cultures that endure for hundreds of years, as these have, beliefs, faith, events, stories, work, histories, the elderly, children, and the stars do have purposes. I believe that if we are to provide adequate care for special children of the Plain people then we must appreciate the place these children have in their families and communities. You will better understand what I mean if I take you on a house call. To do that I will read part of a letter I wrote last year to Jim Hopkins, who is here tonight and who 25 years ago taught me to read fine books.

As I walked out of an Amish farmhouse into cold rain and darkness, I paused to think about the dead boy and the gathering of people in the room behind me.

The father sent word that the boy died and I went to the home to sign the death certificate. Carriages and wagons of friends and family were parked along the lane. From where I first stopped I watched black figures move ahead of horses to the barn and then to the house. Through dark windows I could see light from an open door at the center of the house. As I stepped into the kitchen a figure in the lighted room motioned and said "Morton we are here."

From the doorway I saw that the harsh white light from a lantern above the bed made the hands and face of the dead boy cold blue-white. Bright silver light flashed from new coins placed over his eyes. But then I saw that the lantern light was softened in colors of the quilt gathered around him and the light was golden on his hair and on the hair of the children who played quietly on the end of his bed. The now soft light washed over the faces of those seated shoulder to shoulder around the room who one by one shook my hand. Several said, "I have heard Dr. Morton’s name often and now I am glad to meet you."
"When did he die John?" "Oh, not so long ago. Maybe he is still warm." Then the father took the boy’s hand and turned it in his with the gentleness used to hold a baby bird. The father’s hand was large and thick from heavy work. The skin over the palm and fingers was stained and cracked and looked like the bark of an oak. The boy’s hand was so small. "No," he said, "he is cold now." Then he placed the lifeless hand in mine.

I sat on the chair by the bed for more than an hour. The boy’s mother said just two days ago his grandfather carried him out to the barn to watch the milking and he pulled the tail of a cat and laughed. And yesterday as she read to him he pointed to pictures and softly made the sounds of animals as pages were turned. But today he was awake only a little while. At first his breathing was harder, then was weaker, and, toward evening, just faded. He didn’t seem to suffer. He found peace.

I talked about how difficult it is to care for children who have illnesses that are not understood and cannot yet be treated. I said that as a doctor and scientist when each new therapy fails I must somehow renew my efforts to learn more. Then the boy’s grandfather spoke. As he spoke he smiled and looked first at me then the children on the bed. He said, "we will be glad if you can learn to help these children but such children will always be with us. They are God’s gifts. They are important to all of us. Special children teach a family to love. They teach a family how to help others and how to accept the help of others."

We talked about the boy’s sister who had lived a little longer and about other special children who had come and gone before. And of those ill like this boy who were living still but may not live through winter. We were thankful for the health of their new baby. Then we talked about the harvest just finished, the needed rain falling outside, the weddings of November, and signs that winter would be long. John said, "we are glad you came. Thanks for your help."

As I looked back into the house, I remembered the children at play on the death bed and what the grandfather said. His few words would change the way those children, and I, would remember the life and death of the boy. I understood that the gathering in the room was not only a ceremony about death and life after death but was the means by which the family would both endure and be strengthened by the loss of a child. That was the boy’s gift to his family and to all of us who knew him.

Special children are people who hope to suffer less and lead fulfilled lives through the help of others. Within their families and communities they are not merely the object of compassion and love but often are the very source. Special children shape the Amish and Mennonite cultures and inspire work such as that at the Clinic in important and forceful ways. We should not underestimate the value of their lives, however brief or however difficult. We should not assume that the Plain cultures, or our own cultures, would be better without them.
These special children are not just interesting medical problems, subjects of grants and research. Nor should they be called burdens to their families and communities. They are children who need our help and, if we allow them to, they will teach us compassion. They are children who need our help, if we allow them to, they will teach us to love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people. If we know these children as we should then the Clinic for Special Children will likely endure. Our work, like Dr. Schweitzer's, will be sustained by our ideas and our ideas will be ever renewed and enriched by our work.

Note: After the ceremony on October 27 several people asked if I would give them a copy of the talk. Unfortunately, except for the part taken from the letter to Jim Hopkins, my notes for the talk were little more than a rough outline. The above text is based upon my notes, presents the content and theme of the talk, but is not a transcript. HM Strasburg, PA December 24, 1993.

Albert Schweitzer MD

The Musician
The Bear and the Mint
Raising the Clinic November 17, 1990
Best of All Colors
About the lecture Best of All Colors

From a letter to Dr. Mary Ann Carmack, March 26, 1996

What can I tell you about my talk? The title is from a poem by William Carlos Williams but it is a minor poem of his - I wouldn’t expect anyone to recognize the line or be able to guess why I chose Best of All Colors for a title. You should probably just say that I was asked to give the talk because of the essay Through my window. My talk will in part be an explanation of why that essay was written, what the essay means to me. The talk may be more interesting to those who have read Through my window.

More? You did make an unusual choice for a lecturer, in more ways than one. Unusual I think for a large university hospital to ask a pediatrician in solo practice in a rural area to talk about his work taking care of broken children. Few there aspire to take my place. Unusual too in that I was not destined to be a doctor, but, I doubt you could know that just from my essay. As a young person I fooled with fate - in 1969 I was at the bottom of my class in high school, flunked all my science courses, left without graduating, and went off to work in the merchant marine. Ten years later I started medical school at Harvard. I find the practice of medicine difficult. I have questioned whether I am by nature a compassionate person. I often wonder what else I could have, or should have, done. To be the kind of doctor I can accept I must work very hard at the job - at the science and art. Fate has punished me for being out of place in my work by being kind - this is the way of the Amish people too. She sent Frank Allen to make my work seem to millions of people interesting and important before it was either. She gave me the Albert Schweitzer prize so that others would compare me to a truly great and compassionate person, and, so that I would learn about him too. She made my work in Lancaster County the object of prayers of many devout and admirable people - it is a great responsibility to be in the prayers of such people. My essay Through my window was about, and my talk there in April will be about, how I endure difficult work and such kindness. From where can compassion come if not from the heart? (As a gift from special children.) I suppose, finally, an answer to that question will be the substance of the talk. dhm
There are individuals within every community who make the community better for others. I mean better in the sense of being more humane. Rudene was, and would have been, such a person. Her loss is a loss for all of us. *Never send to know for whom the bell tolls. It tolls for thee.*

If a community is to endure the loss of someone such as Rudene DiCarlo then others must feel her loss, remember her, and resolve to take her place. Resolve to take her place in her community as a physician, as a teacher, and as a thoughtful & compassionate person.

I was invited to talk here today by Rudene’s friends. Rudene, her illness, her suffering, her untimely death had a profound effect upon those who established this lectureship in Rudene’s name. They have **resolved to take Rudene’s place within this community.** For having known Rudene, they are better physicians, better people, that was Rudene’s gift to them for their friendship. I expect that much of what is finally worthwhile and enduring about our lives becomes defined in this way. Our single lives gain the most lasting meaning when understood in terms of friendships and work that simply prove, over time, to have been helpful to others.

The title of this talk, *Best of all colors*, apparently has caused some discussion. I told Mary Ann Carmack that the title was a line from a minor poem of William Carlos Williams and that no one would be expected to guess my reason for the title.
Pastoral
William Carlos Williams
1883-1963

From the collection of poems by William Carlos Williams (To Him Who Wants it), 1917. Carlos Williams was by the time this poem was published, at age 34, established as a general practitioner in Rutherford New Jersey. He would work there the rest of his life.

When I was younger
it was plain to me
I must make something of myself.
Older now I walk back streets
admiring the houses
of the very poor:
roof out of line with sides
the yards cluttered
with old chicken wire, ashes,
furniture gone wrong;
the fences and outhouses
built of barrel-staves
and parts of boxes, all,
if I am fortunate,
smeared a bluish green
that properly wheathered
pleases me
best of all colors.

No one
will believe this
of vast import to the nation.

When I drive my children to school, we pass the William Carlos William’s shed, smeared a bluish green. I regularly start reciting the poem before the shed is in sight. Paul, age 9, shakes his head, oh no, here goes dad again, here comes the shed. Paul & Sarah laugh and join my recitation of the poem to hurry it along. The day after Dr. Carmack wrote to ask that I send a title for this talk, Paul and I passed the shed and I told him, I am going to call the talk I am working on Best of all colors. He asked, Why would you do that? I explained to him, Much of my work each day is ordinary. Some of my work is difficult and sad. As I work I watch for, listen
for, glimpses of something beautiful or meaningful - a sunset, trees against sky at dawn, a bird song, a child's poem, a leaf that soars out away from a tree further than the other leaves, the bright eyes of a new calf or colt. To see such things makes my work more meaningful and, at times, helps me endure the difficult work. I think that was what Carlos Williams did as he worked with the poor of Paterson New Jersey. That is what the best of all colors means to me.

This Painting by Sarah was done in memory of the 5 Amish Girls killed at the Nickel Mines School, and the composition is based upon a photograph by the renowned photographer Bill Coleman, but it immediately bring to my mind a passage I wrote in a notebook in 1988, which I called “Justification” in the Lecture at Stanford.
The poem by Carlos Williams reminds me of a passage I wrote in the margin of a notebook during one of my first trips to Lancaster County in late Summer 1988.

**Justification**

Children at play
Run through dark green fields
Dressed in bright purples and blues
Wrapped in laughter and youth and sunlight
Run with the summer wind.

When this work stops, when I am gone from here, when I am old, I will want such memories. My children may read my notes and understand my work here differently. They may find a belated tolerance for my absences. More important, such notes may make them pause in their work to watch children run and laugh.

When asked how he found the time & energy to carry-on on a busy solo general practice and write. Carlos Williams remarked: the actual calling on people, at all times and under all conditions, the coming to grips with the intimate conditions of their lives, when they were being born, when they were dying, watching them die, watching them get well ...has always absorbed me....That is why as a writer I have never felt that medicine interfered with me but rather that it was my very food and drink, the very thing that made it possible for me to write... We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing .... For a moment we are dazzled. (from The Autobiography)

In summer of 1988 Lancaster County was a place I visited rather than the place I lived. My time there pulled at me, held my thoughts. At the hospital in Philadelphia my interest in the Amish children with glutaric aciduria was not highly regarded - unfundable work it was called. Not the kind of work that would bring grant income to the department. In Lancaster County I was welcomed - parents and health care providers were interested in my ideas about how children with glutaric aciduria could be helped. I went home from Lancaster County with the sense I was needed there.
The Practice - at the Clinic for Special Children

I work as a pediatrician. I mostly provide care for infants and children who have complex problems. Most of my patients have genetic disorders and most are children of the Plain people, the Amish & Mennonite people, of Lancaster County Pennsylvania. Much of my daily work as a pediatrician and biochemist is ordinary, such work is done elsewhere by pediatricians and laboratory technicians. However, to the family in rural Lancaster County who needs such care, and for the individual child who needs such care, and for me, the work is extraordinary. I have found what Wendell Berry calls meaningful work.

When I see an ill Mennonite neonate, the illness is four times more likely to be caused by maple syrup urine disease (MSUD) than group-B streptococcus. The first infant I evaluated in Lancaster County to rule out MSUD was instead a neonatal presentation of another recessive disorder, Hirschsprungs disease.

Last year I was asked to evaluate an ill neonate who had a sibling with Hirschsprungs disease. That infant had classical MSUD.

My second winter in Lancaster I admitted a 14 year old boy with classical MSUD and a flu-like syndrome. A more careful evaluation revealed a history of morning headaches and a head tilt - he had acute gastroenteritis, MSUD, and a posterior fossa tumor.

This winter I admitted a 1 year old girl with a skull fracture and type 1 Crigler-Najjar disease. A review of her family history revealed that her mother has brittle teeth and her mother’s brother and two nieces have a dominant form of osteogenesis imperfecta. My patient has both classical Crigler Najjar disease and a dominant form of osteogenesis imperfecta. A few weeks ago this child’s sister, who also has Crigler disease, presented with acute chest pain - gall stones, bilirubin pigment stones. We now know that 4 of 7 of our young patients with Crigler disease have stones.

I follow a family with isolated aldosterone deficiency due to methyl oxidase II deficiency - the father and six of his children are affected. A paternal second cousin was brought to me at 1 month of age severely dehydrated, serum sodium 117 mEq/L, potassium 7.5 mEq/L. Naturally, at first, I assumed she had the same disorder as her cousins. However she was also mildly virilized and hyperpigmented. Family history revealed a paternal uncle with abnormal genitalia and no beard. The infant has another cause of aldosterone deficiency and adrenyl insufficiency - 3 beta-hydroxysteroid dehydrogenase deficiency.

I follow several families who have children with type 6 glycogen storage disease. A first cousin of one of these families, a 14 year old girl with a history of cyclic vomiting and a sibling who died at 6 months of age with hypoglycemia, was sent to me to see if she also GSD type 6. That of course is not the clinical course of this relatively benign form of GSD. She, and her
sister who died with a liver described as infiltrated with fat such as that seen in Reye syndrome, have medium chain acyl dehydrogenase deficiency (MCADD).

Last winter a second cousin of this girl became encephalopathic at 4 days of age. This infant did not have MCADD but had MSUD. Yes I looked for both and will not be too surprised the day I find both.

Last year Edwin Naylor sent four well infants for evaluation because of positive neonatal screens for 3-OH-isovaleryl carnitine - each infant had detectable, but non-diagnostic, concentrations of 3-methylcrotonylglycine in the urine. We soon learned that the pathological metabolites derived not from an enzyme deficiency in the infant but from the mother. All four mothers had isolated 3 methyl-CoA carboxylase deficiency - one of these women had developed a fatty liver of pregnancy, another had a chronic fatigue syndrome, the other two were asymptomatic.

Two infants presented with classical blue-berry muffin syndrome - neonatal erythroblastosis with extramedullary hematopoiesis - one had pyruvate kinase deficiency, a defect in the glycolytic pathway of the red cell, & the other had mevalonic acidemia, mevalonate kinase deficiency a defect in the cholesterol synthetic pathways.

An Amish mother called three weeks ago to ask if I could do anything about itching in her 18 month old son. Any other problems? He was born with a frontonasal encephalocoel, had surgery at three months of age and needed to be transfused twice because of post-operative bleeding. The bleeding stopped after they gave him vitamin K. He was circumcised a year later, was admitted to another hospital because of bleeding and again responded to vitamin K. His serum choleglycine was >4000 ug/dl (nl <60). Itching, hemorrhagic disease of the newborn, and increased bile salts in an Amish child is Byler disease, a bile salt transport defect. In 2 years I have seen 4 cases of hemorrhagic disease of the newborn - all Byler syndrome.

I have seen three children & a young adult, all related, in the past year who presented with catastrophic intracranial hemorrhages due to arteriovenous malformations. Jimmy Argires, a Lancaster neurosurgeon, tells me that in 20 years he has operated on more than 40 cerebral a-v malformations and knows of many more people in Lancaster County who didn't make to surgery - it occurred to him recently that these av malformations were mostly in people of Amish descent. This will probably prove to be a dominant cerebrovascular malformation syndrome.

Last spring I diagnosed Wilms tumor in an Amish 1 year old. Last month I saw a 2 year old with aniridia and the chromosomal deletion associated with Wilms. We now know of 4 other Amish children who have been treated for Wilm tumors within the past 4 years - 5 cases of Wilms tumor and one at risk by known deletion from a population of approximately 8000 children.
Mine is the kind of practice that keeps you worrying, thinking, and learning.

I consider the genetic disorders I see each day at the Clinic for Special Children no less treatable than the disorders which are the mainstay of any modern medical practice. That statement usually surprises other physicians. Of the 31 inherited biochemical disorders seen at my Clinic over the past 5 years only 4 are invariably lethal. Three are minor biochemical variants of little clinical significance and 23/31 (74%) are treatable disorders. Of these 23 treatable disorders 11 (50%) can now be diagnosed in the asymptomatic neonate through Dr. Naylor’s supplementary screening program.

A survey done by Dr. Paul Beeson several years ago used ten categories to rate the efficacy of treatment for 362 diseases described in the 1975 edition of Cecil’s Textbook of Medicine. Dr. Beeson found that 22% (79) of therapies were worthless (chemotherapy for pancreatic cancer) and 22% (77) of therapies were classified as highly effective (immunizations for childhood diseases, treatments for vitamin deficiency diseases, penicillin for pneumococcal pneumonia.) 28% (102) of therapies were said to provide symptomatic relief or were curative in a very limited sense (therapy for drug addiction and surgery for lung cancer) and 28% (104) were called effective and helpful therapies, (anticonvulsants for seizures, medications for heart failure, insulin and diet therapy for diabetes mellitus). (Reference Beeson PB, Changes in medical therapy during the past half century, Medicine 1974; 59:79-98)

Recently I used Dr. Beeson’s system to assess the treatability of the genetic conditions seen at the Clinic. I found that approximately 20% of the 50 genetic disorders seen at the Clinic for Special Children between 1989 and 1995 are readily diagnosed, highly treatable, and should cause little morbidity and mortality - examples include aldosterone deficiency due to methyl oxidase II deficiency, medium chain acyl-CoA dehydrogenase deficiency, type 6 glycogen storage disease, phenylketonuria, congenital hypothyroidism, & hereditary spherocytosis.

Approximately 20% of the disorders I see are lethal - infantile nemalin rod myopathy, severe recessive microcephally, GM1 ganliosidosis, & mevalonic acidemia. Although a disease may be ultimately untreatable and lethal, infants and children who have such disorders often live months or years. They have, and suffer with, ear infections, dehydration and thirst, hunger and malnutrition and many other common miseries. They, and their parents and siblings, require skillful and thoughtful care. We must provide such care. Osler said such is our work.

The other 60% of disorders are those wherein early recognition and careful management allow children to lead more normal lives: effective care reduces disability, reduces the need for wheel chairs, physical therapy, special education, and reduces the number of hospital days per year. Careful clinical observations continue to provide new, useful insights into the natural history of these diseases and improve therapies and outcomes: type 1 glutaric
aciduria, maple syrup urine disease, pyruvate kinase deficiency, classical Crigler-Najjar disease, dominant osteogenesis imperfecta, Bartter syndrome, adrenal insufficiency due to 3 beta-hydroxysteroid dehydrogenase deficiency.

I have become a strong advocate for neonatal screening for inherited disorders. A child with MCADD, or MSUD, or GA1 is not better off if the condition goes unrecognized. Morbidity and mortality are too high in undiagnosed cases. Nor do I accept the arguments that families are better off not knowing their infants have cystic fibrosis or Duchene dystrophy. Delaying diagnosis until an affected child is severely malnourished or disabled or until multiple children in a family are affected does not ease the pain of diagnosis. Such delays only increase the complexity and cost of care. Timely recognition and appropriate care are important for treatable and lethal disorders. If in our society we have prejudices & business practices that in effect deny children with genetic diseases access to medical care, then we should change those practices and prejudices.

We should not pretend that we are protecting the interest of our patients when we ignore the fact that genetic disorders are part of the human condition and part of our daily work.

Huntington disease is often discussed as a disorder for which genetic testing may do more harm than good. I do not think even these arguments will bear-up in time. I doubt that those who are at risk for Huntington’s disease and choose not to be tested are better off - medically or psychologically. The burden of the condition is in the terrible nature of the disorder itself, not in our ability to test for the disorder. If there is hope for people with Huntington disease, as is true for glutaric aciduria which affects the same nuclei in the basal ganglia, that hope depends upon recognition of the condition before degeneration of the caudate is advanced.

That hope also depends upon patients and doctors who are concerned about the fate of affected people and do clinical & basic research and provide care. I can tell you for my work that the compassion and the drive that carries such work foward is often engendered by the initial sense of anguish and hopelessness that patients, and doctors, feel when a potentially lethal disorder is recognized.

Our efforts to understand the natural history of genetic disorders are important. Careful descriptions of the natural history suggest opportunities for timely and effective interventions. The natural history also makes apparent that certain interventions must be timely if they are to be effective - a gene transplant, by whatever means, to treat glutaric aciduria or Crigler-Najjar disease will not be helpful if large regions of the brain are destroyed before the gene-transplant takes place. We need to treat the patient, prevent expression of disease, not just correct disordered biochemistry.
Because we can now describe genetic disorders at the molecular level, we should not assume that this description is in any sense a complete characterization of the genetic disease. The abnormal gene may not be the ultimate determinant of disease and correction of the gene may not be the ultimate treatment of disease. The expression of gene, function and dysfunction, is complex and depends upon many variables that are not genetic - diet & nutrition, infection, injury, exposure to medications and environmental toxins. There are many examples of genetic diseases wherein treatment by control of non-genetic variables is both effective and immediately available. For many disorders manipulation of the gene will finally prove to be too little, too late, and at a price too high.

A story

I study writing in the same way I study the violin, perhaps for the same reason. Wallace Stegner, who is one of the writers I most admire, said the best way to learn to write is to find something you care about deeply and write about that. I write a few stories. They too are gifts from children.

The story that follows began as a story about a child with a lethal genetic disease and was at first written to express my sense of helplessness and anguish before this child and his disease. Over the two years since the boy died the story has been rewritten twelve times. A different understanding of the care of the child has emerged. Croquet is now a story about what the child in his short life gave those of us who cared for him. It is a story about friendships that allow me to endure difficult work. It is a story about a child as the source of compassion in a family and community. A story about how one child, now gone, continues to help others.

Croquet

I stopped to see Jacob and Nancy Zook yesterday. Mrs. Zook called before breakfast to say that she planned to make pies that day and some would be made with my family and me in mind. She said, I know you are busy but don’t let your pies wait overnight. They will be ready by noon.

Her husband Jacob is 74 years old and is a wagon maker. He took me to his shop to show me a wagon that he would finish by the week’s end. The Zook wagons are well known to the Amish people of Lancaster as heavy flat-bed farm wagons that last. The wheels and frame are metal, the wagon bed is 3-inch-thick smooth pine with tight tongue and groove joints bolted to oak cross-beams and side-rails. Jacob says it is more efficient to work on three or four wagons at a time. He can put together four wagons in a week but on average he finishes one a week. He started making wagons when he was 34 years old when their children were old enough to help with the farm chores and gave him time for other work. Jacob said he recently
made repairs on the first wagon he made which has been in use on a neighbor’s farm for 40 years. In his lifetime Jacob Zook has made more than a thousand wagons and much good work has been done with them. His is admirable work.

Two of Jacob and Nancy’s grandchildren died from a genetic disorder called by the Amish people 
*pigeon breast disease*. As the disease progresses the muscles become fibrous and inelastic. The intercostal muscles shorten and pull inward and away from the sternum until the chest assumes a shape like that of a bird’s chest. Death is caused by respiratory failure but is usually hurried by pneumonia. Most of the children die in winter. The first of Jacob and Nancy’s grandchildren, Jerry, lived 4 years. I did not know Jerry, he had died before I began to work in Lancaster County. The second grandson, John Ray, I saw on the day he was born. His parents and I knew immediately that he had the disease. At birth, even before birth, the infants have unusual tremors of the limbs and face, not unlike those seen in infants with tetany caused by low serum calcium concentrations. After an episode of tremors the muscles have an unusual dough-like feel, similar that of rigor mortis. The disorder has not been described in the medical literature but it is the most common of the recessive disorders that I see at the Clinic. Over several generations more than 30 families have had children with the disorder, more than 60 infants have died. We suspected an abnormality in the calcium ion channels that regulate muscle contraction and relaxation. Our first efforts to treat the disorder focused upon the use medications that selectively block chloride and calcium ion channels. These trials stopped the tremors and gave us brief hope but the medications failed to halt the progress of the disease. Research continues.

As I left Jacob and Nancy’s house with our pies and drove out of the farm lane, I remembered a night a year before in late December. I came home after midnight and Caroline asked *What happened? I thought you were going to Jake’s and Sadie’s and then come home for supper. I hoped you would be home with the children so that I could go out to finish buying for the children’s Christmas.*

Yes, I know. I didn’t forget. When I got to Jake’s John Ray was very sick. He has pneumonia. I took Jake and him to the hospital.

Caroline said, *I thought Jake and Sadie wanted to keep him at home.*

Yes, but he shouldn’t die on Christmas. I wasn’t sure he would last the night. Everyone at the house was sick. Sadie and the three other children. All vomiting. Nancy had been there all day. Mostly holding the baby but Nancy was sick herself. Jake’s unmarried sister Susie came to help so her mother could go home to rest but Nancy didn’t make it home. She started vomiting and fell in the road. Luckily old Jacob was still in the shop and found her on his way into the house. When I came along Jacob was trying to lift her but couldn’t and she was too weak to stand. She was covered with mud and snow and vomit. I don’t know how long she had been there before
Jacob found her. I was afraid she had had a heart attack or had broken her hip. Her arm was broken but fortunately that was all. Jacob and I put her on a child’s wagon, balanced her half sitting, and got her into the house and onto the couch. I put a splint of newspaper and scotch tape on her arm then went to Jake’s to get Susie so she could stay with Nancy and help her change into dry clothes while Jacob went for a neighbor to take her to the emergency room. Nancy kept saying I am alright now, I am alright, Doc just go see the baby, go see John Ray. You must do something for him. He just cries all the time and his mother is too sick to tend to him.

John Ray had been vomiting and couldn’t drink. He had pneumonia too. You know children with pigeon breast disease all die with pneumonia. I told Jake the way things were I didn’t think John Ray would last the night. As soon as your neighbor takes your mother to the emergency room, Susie can come back and help Sadie and the other children. Then you and I can take John Ray to the hospital for oxygen, antibiotics, get his fever down, get him rehydrated then we can bring him home again. He won’t have to stay there, I promise you, even if he worsens. I will get him home but he shouldn’t die now, not over Christmas.

I just hope I can get him out of the hospital before he dies. The nurses seem to understand. He was breathing easier and had fallen asleep by the time I left. Jake was asleep by his bed in the chair. I’m sure they had slept little for several days. By the time I finished my notes and orders and talked with the nurses, Nancy’s arm had been set. Simple break, above the wrist. I gave them a ride home. She is worried that it will hurt when she quilts. That is her quilting hand.

Caroline, poor people. I guess our children should be satisfied with what we have.

Oxygen and antibiotics held back death a few weeks. John died after Christmas, after his first birthday, at home, peacefully.

In summer Jake and Sadie invited my family and me to supper. Jacob, Nancy, and Susie were there. Our talk often turned back to the boys who were no longer with us. The purpose of the day was not to forget the children but to remember them.

After supper we went out to play croquet in the meadow by the house. The wickets were placed far apart and the field was long and wide as though for some extraordinary game. I remember our voices, the crack of hard-stuck wooden balls, the sounds of children barefoot, laughing and running through high grass of the meadow and into the corn, the songs of meadow birds and crickets, all mixed and diffused into evening’s air and carried into the fields beyond as a kind of music and song. I remember the great graceful Percheron mares and their colts running through the meadow, as though some part of our game, and the barn swallows turning, turning, turning against the rich summer greens of earth and blues of sky. And, I remember the warm light of summer evening that washed over everything and over us.

When the daylight faded Jake brought out lanterns and we played on into the night each with our own small light. I thought, someone on the distant hill, watching our lanterns
move back and forth across the meadow might, if she watched long enough and knew the game, realize that we were playing croquet. From there too, she might have watched my car come and go those winter days and, if she knew the nature of my work, she imagined the sadness of my task. When carriages gathered on the frozen meadow row by row black against snow she would have known death had come, and, watching carefully from the distance, she might learned something about the customs of Amish people at the time of death. But there is more to know than can be learned from such distant, high places. More to know about these people, about work such as theirs and mine. More to know than just the name of a game played on a meadow one evening in summer.

More than two years have passed since we played croquet on Jake’s meadow. Jake and Sadie have another child who is healthy. My visit to first examine the new baby was a joy for all of us. Our work at the Clinic is in part supported by an auction held each year by Amish and Mennonite people. Jake and Sadie manage the food stands at the auction. In the fall after John Ray died, his grandfather Jacob donated a new farm wagon and his grandmother made a quilt for the auction. I have often remarked that many who support the Clinic are parents whose children could not yet be helped by medical science but who received a kind of care through the Clinic that was much needed and is often neglected.

I have been told that special children are gifts from God. I have been told that special children are punishments from God. I have heard scientists and doctors refer to these children only in terms of their genetic defects, aloof and with no human insight, as though the life of a child can be reduced to such terms. My experiences have made me think in a different way about these children and their short, often difficult, lives. I cannot say why these children come and go upon Earth but I do know that they change the lives of those who know them. Such children have been my most important teachers. I have learned more from them than I did from many instructors in medical school who were by reputation great teachers. These children have reshaped time and again the way I practice medicine, both the science and the art of it. I have heard sermons by ministers about compassion, I have heard fine lectures about ethics and medicine, but no sermon or lecture has taught me as much as a single special child. These little children can change whole communities of people in ways that last far beyond their brief lives. They are not merely the focus of compassion but often are compassion’s very source. Special children enrich the world in ways that many who are blessed with longer lives do not. They have much to give us, to teach us, about themselves and about ourselves.

Carlos Williams said - We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing ... For a moment we are dazzled.
Horse, Sarah McRae Morton
Advice from a doctor, dying young

Remember Rudene’s advice
Sit down, close by,
to talk and listen and to touch
wear a name tag,
be sure the patient knows who you are
and what your name is,
call if you say you will call,
do what you say you will do.
Don’t underestimate the significance of what you say,
remember that the words of a doctor,
may have great significance to a patient.

I think Rudene would agree if I added
Take time for your patient, apply yourself to her problems
  make time to listen,
  make time to think,
  make time to learn,
learn from each case as you did when you were a student
because you are a student of medicine, the science and the art of it,

acknowledge your mistakes
acknowledge your failures
when you fail, feel the loss and make time to grieve
when your patient has been helped
try to understand what helped, who helped.

Care for your patients.
Remember what Dr. Peabody said “the secret of caring for a patient is caring for the patient.”
FINIS:

If a community is to endure the loss of someone such as Rudene Di Carlo then others must feel her loss, remember her, and **resolve to take her place. I want to leave you with a final thought.** Some of those who will miss Rudene the most are not here today - I refer to the children for whom she would have cared. From time to time, to remember her, assume the care of a child with complex and difficult problems - take the case no one else wants, the case no one else has time for, we all know of these children. As you work, remember Rudene, learn what such special children have to teach, accept the gifts of a special child. You will see then the *Best of all colors.*

**Help in a Community**
The Clinic as a Paradigm of Translational Medicine

The translation of genetic information into patient care begins with a commitment to care for the patient. Frances Peabody in a lecture to Harvard Medical Students in 1927 remarked, *One of the essential qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.*

Our work at the Clinic for Special Children over the past 17 years has emphasized a commitment to caring for patients who have inherited disorders. The humanitarian need for our work is apparent, but the scientific importance of our daily work should not be underestimated. Many facets of the natural history of genetic disorders only become apparent to physician-scientists who care for individual patients over long periods of time and who are interested in biology, pathophysiology, and the practice of medicine in the most general sense. The identification of underlying molecular lesions alone usually provides little insight into the phenotypic diversity that we encounter in patients in Lancaster County. The complex neurological syndromes of Glutaric Aciduria, Maple Syrup Urine Disease, and Phenylketonuria arise from single gene mutations, but the complex mechanisms of brain injury and dysfunction are linked to vulnerabilities during critical periods of early brain development. In patients with Glutaric Aciduria episodes of metabolic illness that cause acute striatal necrosis in a 12 month old infant are well tolerated in the 6 year old and adult. The unbalanced amino acid transport into the brain that leads to mental retardation in the infant with Maple Syrup Urine Disease or Phenylketonuria will cause attention deficit disorder and mood disorders in teenagers and presenile dementia in older adults. Single gene disorders give rise to disease states through the disruption of critical biological processes such as metabolic adaptation to fasts and infectious illnesses, cell volume regulation, brain amino acid homeostasis, and postnatal brain growth and development. Scientists who work as physicians and care for many patients with the same genetic disorder over long periods of time develop a different understanding of genetic disease than scientists who study disease mechanisms in cell cultures in the laboratory. It is often through the daily work of a physician caring for a patient that new opportunities for treatment are realized.

The every day practice of medicine is the true frontier of Translational Genetics. The medical care of a child with a genetic disorder is no different than the care of a child with other complex medical problems - diabetes mellitus, depressive illness, rheumatoid arthritis, seizures, and many other chronic troubles come to mind. As with the majority of diseases
treated by physicians, there are few perfectly treatable genetic disorders. Nonetheless, improved understanding of disease mechanisms, combined with accessible and effective medical care can often decrease suffering, improve function, reduce dependency upon others, and otherwise limit the effect of disease, genetic and acquired, upon the life of a patient. "Such is our work," William Osler said. The understanding, the acceptance of the fact, that many common illnesses arise from genetic predispositions, but are nonetheless treatable, may ultimately be the most important contribution of the Plain Communities and our Clinic for Special Children to Translational Genomic Medicine.
Roads Not Taken

Mary Caperton Morton
The Cello and the Brain

A lecture about the study of complex problems
National Youth Science Camp of West Virginia
July 22, 2005

INTRODUCTION

His mother said we hoped he was not like our others. He seemed all right. He sat-up and walked when he should have. But then it happened. He was 18 months old. He had a cold and a fever. He seemed tired, so, I put him down for a nap after lunch. When I checked on him two hours later he was helpless. He couldn’t hold-up his head or swallow, he couldn’t sit, no strength was left. We knew then he was like the others; there was no other reason for it.

Amos and I just sat together and cried for a long time before we took him to the doctor. We knew the doctor would send us to the hospital. But, we knew that after all the pain and tests and money there wouldn’t be any answers. Nothing could be done for him either. (The mother of an Amish infant with Glutaric aciduria in 1988, From Amos’ Child)

My lecture will be about infants who have an inherited disorder of biochemistry called Glutaric aciduria, type 1. Glutaric acid is a five carbon dicarboxylic acid, which accumulates within the brain and other organs, and derives from the deficiency of a dehydrogenase enzyme in the degradation pathway of two essential amino acids, Lysine and Tryptophan. The genetic disease is characterized by sudden, stroke-like injuries within a region of the brain called the basal ganglia that leaves infants helpless. Injury of the basal ganglia occurs before 18 months of age, older children who have escaped injury are normal.

I will describe my work as a physician to provide medical care for these children, understand the disease, and translate that understanding into a new therapy to prevent brain injury. The lecture presents information from molecular biology and biochemistry, neuroanatomy and neurochemistry, which are used to develop a complex pathophysiological model of the disorder. It is a complicated lecture, not unlike I would give to experienced physicians and neurobiologists. I expect the students at the Camp to feel a little overwhelmed by the difficulty of the problem. I explain that I have studied this disorder for 17 years. My medical career has been consumed by the effort. I tell them about the simple clinical observations that led me 17 years ago to believe that the injury should be preventable. I explain that medical care has improved over 17 years – 80% of children now escape injury, but, still in 20%, treatment fails.
Woven into the lecture are fundamental ideas about the relationship between medicine and science, genetics and biology, experiment and knowledge. I want students to remember underlying themes within the talk, rather than the facts about the genetic disease itself.

One theme is about the difference between the Learning that they have done in school, and are obviously very good at, and the more difficult, sustained effort to learn about a disease from experience, observations, and experiment. I compare the difference between these two forms of learning to the difference between listening to the Bach Suites for Solo Cello, and learning to play them.

Another theme of my lecture is about how the experience of talking with the Amish mother, quoted above, shaped the course of my medical career. Her observations about Glutaric aciduria in her five affected children provided the first evidence that the brain injury could be prevented. What she told me about the natural history of the disease has defined my approach to medical practice and research throughout the past 17 years. I discuss the complex relationship between a gene mutation and a disease to emphasize that the Answers we obtain in medicine and science are fundamentally dependent upon the Questions we choose to ask, and the Answers that satisfy our sense of what it means to understand.

Themes about Time always flow through my talk - Time as a force in Biology - Age of Human Language as compared to the Age of the Language of Genes. I talk about how Time and new Technology will affect their work. I warn them to be careful when they think about their future studies. The course of my life, my current work as a doctor, the Questions that I have asked and Answered, were unimaginable when I was their age. Technology and Information, upon which I depend every day, has changed in remarkable and unpredictable ways over the past 40 years. The very Language of the Questions and Answers that are fundamental to my current professional life didn’t exist when I was their age. More important, those critical experiences, observations, and experiments that defined for me what Questions were Important, and what Answers were Meaningful, would come 20 years later, and years after my Schooling was finished.

Finally, I tell them that whatever form their education takes in the years that follow, that education must allow them to Learn, long after the Schooling is finished, and sustain them through a lifetime “difficult learning.”

WHY DO I GO BACK TO THE SCIENCE CAMP EACH YEAR?

I am from Fayetteville, West Virginia. The histories of my parent’s families intermix with the history of the State from the time of the Civil War. West Virginia and its People have Histories with shadowed corners. In history books, and in the daily news, the Place does not always have a polished image. The Science Camp was started 100 years after the formation of the State from Virginia. I have always thought the Camp presents in a positive way the Region
and People of West Virginia to a group of intelligent and talented students, most whom otherwise would know little about the Place. I am sure that having more than 2000 such students visit West Virginia over a 40-year period has contributed in many good ways to the History of West Virginia. I liked having the name D. Holmes Morton become part of the Camp’s history, and I am sure my West Virginian namesake would have like that too.

From my point of view as a teacher, the Camp is important because it changes the lives of the students. The friendships formed here, and the professional contacts with lecturers and camp instructors, are often lasting and influential. Many of these students have never walked through deep woods with virgin timber, or climbed mountains, or swam in a clean, wild river. At the Camp they experience, and learn how to enjoy such places, and, for many, for the rest of their lives they will return to, and care deeply about what happens to, forests, mountains and rivers in West Virginia and elsewhere. The Camp changes the way these students think and express themselves. I can see that happening all around me when I am part of the Camp in musical groups, through conversations at meals, funny skits after supper, serious discussion groups about career choices, and life’s choices. I have always hoped my lectures change the way a few of the students think about some aspect of science, biology, or the practice of medicine. Over the 19 years that I have come to the camp I have talked to almost 1000 of the brightest people in the United States. What a remarkable opportunity for any teacher. If even a few of these talented people have remembered something from my lecture that influenced the way they asked Questions, or thought about difficult problems, or care for a patient with a complex illness, then my lectures were worth my time.

Most who give lectures, as part of our professional work would agree, that the person who learns the most from a lecture is the lecturer. The themes that run through my Camp talks are interesting for me to revisit, think about, and attempt to explain in a new and better way. The lecture describes experiences and questions that determined the course of my work as a physician who cares for children with genetic disorders. I talk about the complex relationship between disease causing gene mutations, and the natural history of a genetic disorder, and, I explain to them how an understanding of this relationship becomes the foundation for the practice of genetic medicine. I always tell them about Time as a Force in Biology, the enduring Language of Genes, and the ever changing Language of Technology and Knowledge that will allow them, years later, to ask Questions that are new and important, and which, at this point in their lives, are unimaginable.

Finally, I come back to the Camp because there is an irony about my lecturing there that I enjoy. Many who give lectures at the Camp were themselves once Camp students - I was not. At age 18, I was at the opposite end of an educational experience than theses students. I was last in my class, not first. I have a GED, not a high school diploma. At their age, I had little apparent scientific aptitude, and no particular interest in biology or medicine. There were
no expectations that I would practice medicine, or struggle with fundamental questions about genetics and neurobiology. I tell the students about this simply to emphasize how unpredictable the course of their careers and lives will be. I explain that my lecture has been about experiences and questions that have interested me deeply, and thereby transformed my life. Seventeen years ago I drove to a place called Lancaster County Pennsylvania to examine a boy with a rare genetic disorder called glutaric aciduria. I was curious, interested, I wanted to learn more about the boy and his disease. Unexpectedly, all of my work for 17 years evolved from the knock on Amos Miller’s door.

William Carlos Williams, pediatrician and poet, wrote - (As we work) we catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing ... For a moment we are dazzled. I tell them about the relationship between Dr. Williams work and his poetry and stories. I tell them that in the next years of their lives they must watch carefully, listen carefully, and search carefully for experiences and questions that will lead them forward into their lives. Search for work that is interesting and meaningful – this Search, more than anything else, is the foundation of your education.

DIFFICULT LEARNING:

(Play the Sarabande Suite V in C minor from JS Bach’s Suites for Solo Cello)

In the Wenzinger Edition of the Bach Suites for Solo Cello are printed on 35 pages and contain approximately 360 lines of music. Pablo Casals’ recording of all six Suites runs for 2 hours and 10 minutes, Mstislav Rostropovich’s recording totals 2 hours and 27 minutes. This music was written by Johann Sebastian Bach in 1720, but was unknown to 19th or 20th century cellist until Pablo Casals, at 13 years of age, in 1890, found a copy of the music for the six Suites in a used bookstore in Spain. There is no history to suggest that the Suites had ever been played in concert in their entirety. Pablo Casals from age 13 studied the Suites everyday as part of his practice routine. Casals was arguably the 20th century’s greatest cellist, yet, it was 25 years before he played the one of the Suites in a public concert, and it was 35 years before he recorded all six cello suites.

The Sarabande of Suite V in C minor, which just I played, has 4 lines and 107 notes. There are 39 notes in the first section, and 68 in the section. Each section is repeated once. Casals plays the piece in 2.8 minutes and by Mstislav Rostropovich in 3.5 minutes. Rostropovich wrote, I have played the Sarabande from the Fifth Suite throughout my life. It never ceases to amaze and delight me. This single voice composition lasts only a few lines, but for me it represents the quintessence of Bach’s genius. In its darkness of melodic design it is so unusual that it resembles contemporary music. Just the idea embodied in the first line is so incredible. The
melody winds its way in the same rhythm, same breath, same pulsation as your heartbeat. However slowly I play I always have the same sense of the eternal flow of the movement…. When you finish the Sarabande, Time seems to be going on at the same pace, and your breathing continues in the same rhythm...

I have studied this short piece for five years. I have played it at least once everyday, more than two thousand times. I also study the Prelude of the first and second Suites, and the Allemande of the 6th. In reality, much of the music will always be unplayable for me.

I began to study the violin, and then the cello, in June of 1996 at age 46. To the horror of my wife and children I gave my first concert only one week after starting to play the violin. I had been ask to speak to the graduating class of a school for children with learning disabilities, the Janus School in Lancaster. Before that gathering of supporters, teachers, parents and children, who anticipated sage remarks from a physician - I played poorly, awkwardly, the theme from Dvorak’s New World Symphony. I was able to convince them that we can all be shown to have learning disabilities if given the right test or task. A few weeks later I was here at the Science Camp - talking to students at the other end of the educational spectrum. I played the violin again, same message. Significant Learning is difficult. Any person, who does not have difficulty learning, is not trying to learn anything that is very difficult.

If I would ask you to listen to a CD of the Bach Cello Suites and become familiar enough with the music to name the number and key of one of the Preludes or a Sarabande that kind of learning would present little difficulty. and is typical of most school work. In contrast, if I ask you to learn to play this same music, well, and from memory, with an appreciation for the complexity of the music and with the kind of controlled expression that makes the cello playing of Pablo Casal’s distinctively different from the playing of Mstislav Rosropovich, you would find this a difficult assignment, regardless of your musical aptitude. My message to you is that the most significant learning that you will do over your lifetime is similar to learning to play the Bach’s Cello Suites. Significant learning takes sustained effort, sustained interest, tolerance of frustration, and tolerance of failure. I do not have much musical aptitude. I have a poor ear for music, yet, my sustained interest, my stubborn determination to learn, my willingness to practice day after day, the great value I assign to the task of learning the cello, allows me to develop skills over time. The talented student who has no interest, makes no effort, assigns no value to the task of learning to use his or her talent, will never play the Cello Suites.

I am going to tell you about an inherited biochemical disorder called glutaric aciduria, type 1. I care for more than 80 children with the disease, which is the largest group of clinic
patients in the world. Over a 15 year period I have worked to care for these children and understand their disease - emergency care, laboratory work, research, writing teaching, relearning biochemistry, relearning, endocrinology, learning and relearning neuroanatomy. It is a safe estimate that most days for the past 15 years I have spent at least two hours working with some aspect of this disease. Many days, I have worked 18 hours or more trying to keep a child alive and limit the injury the disease causes to the brain. Over 15 years I have spent more than 10,000 hours learning about this disease. For comparison, the average college course gives 40 hours of exposure to a subject. I study the cello just as I study medicine. For me the learning process is all the same. I am not only looking for skills or information, I want insight, understanding. (2008 was my 22 year lecturing at the Science Camp)
Letter to a Student

Trinity College
July 24, 2007

You and your classmates will travel many different roads to meet in a Place and a Community called Trinity College. From a student who made his journey to the College many years ago from the small town of Fayetteville West Virginia, welcome.

President Jones invited me to write a letter to you. I am at a time in my life when I am occasionally asked how I found what my friend Wendell Berry has called “Meaningful Work.” You are at a time in your life when moving away from familiar people and surroundings will cause an uneasy feeling and a new awareness of Future. Even with the benefit of hindsight, I remain impressed with how unknowable my Future was when I had your vantage point as a new Trinity College student. Moving forward through my remembered past, my Future resolves into discrete experiences, choices, and turning points. I also recall many roads not taken.

TO COLLEGE: My first visit to Trinity was 32 years ago in January 1975. Frank Kirkpatrick, Henry DePhillips, and Dirk Kuyk, all still Professors at the College, interviewed me for admission to the College’s innovative Individualized Degree Program. I was an unlikely applicant to Trinity College. I had dropped out of high school. My grades were poor, standardized test scores were unremarkable, and neither indicated an aptitude for science. No one imagined I would become a physician. I had been away from school for 6 years. First, working as a boiler man on steam-powered ore boats on the Great Lakes, then, in 1970, near the end of the Vietnam War, I was drafted into military service and reluctantly joined the US Navy, to do the same work.

When I first left high school I imagined I would become a writer, but over the years I had written little. As a past time at sea I read widely and studied complex problems. In this way I had developed an interest in the subjects of neurobiology and developmental psychology. Apparently, letters of support from two former high school teachers, my application essay and admission interviews indicated that I had some non-traditional promise as a college student. Dr. Kirkpatrick told me at the end of my meeting with him that I would be accepted into the Individualized Degree Program and that, in fact, I could start my studies at Trinity immediately.

I was an older student, 24. For three years I lived alone off-campus in a small apartment at 117 Oak Street, near the Capital. I walked or rode a bicycle to the College library daily, where I spent so much time the staff eventually paid me to work at the reference desk.
Challenged by the sense that I may be out-of-place at Trinity, and might well fail my courses, I was a serious student from the first. I soon appreciated that College was a reprieve, not only from hard work in the engine rooms of ships, but also from the social chaos of the 1960s.

My parent’s generation was your age during the Great Depression and during World War II – I was aware that those difficult times affected them in many ways. My generation remembers the day President Kennedy was shot, Bobby Kennedy was shot, Martin Luther King was shot. I remember a door in the movie theater in my small-town, which was owned by the Principal of my Grade School, that said in large letters “Colored.” That door led to a dirty balcony where black people were expected to sit. I remember too my 8th grade Civics teacher, who was the only black school-teacher in my town, the only school teacher with a PhD, too. I recall little, if anything, about the subject she taught, but I remember her dignified manner. If she ever went to that theater, I am sure she walked through the “White Only” door. My generation remembers the days other African Americans walked and ran through the streets of Mobile, Philadelphia, Washington, and many other cities. We remember too the Vietnam War protests in Chicago, and students shot and killed by the Federal Troops at Kent State College. We find names of our childhood friends on a long black wall in Washington - the name on Panel 16W, Line 15 of the Vietnam Memorial is William David Sirocco Jr. Bill was age 20, the current age of my son, when he stepped on a land mine, was maimed terribly, suffered, and bled to death on forgotten ground in Binh Duong, Vietnam. By the time I started Trinity, the imaginary boundaries that Bill and other boys patrolled, the maps they carried, the military mission of November 1, 1969, and, soon, the whole county of South Vietnam had faded into what our Secretary of Defense Robert McNamara would later, too much later, call “The Fog of War” – McNamara’s enlightenment came toward the end of his long life, and far beyond the time of his responsibilities when such insights about war could have protected Bill Sirocco. I am aware that those difficult times of the 1960s affected me in many ways.

I started dating Caroline, my wife, during my final two years at Trinity. She was in graduate school at the Harvard School of Education. She had spent a year in Vietnam with the Red Cross. Afterward, worked to establish, and find money for, preschool programs in small coal towns of southern West Virginia. Both of us had returned to school in the mid 1970s, in part, hoping to find places of reason within a world that had too often appeared to us unreasonable, or worse, indifferent. At the doors of the classrooms and libraries of Trinity and Harvard we left much behind. We were serious students, searching for “Meaningful Work.” It would be 12 years, and three children, later before Caroline and I found that work in a Place and a Community called Lancaster County Pennsylvania.

Four and one-half years after my January interviews, I graduated with majors in Biology and Psychology. I went to Harvard Medical School, studied Pediatric Medicine at Children’s Hospital in Boston, and Biochemical Genetics with Richard Kelley at Children’s
Hospital of Philadelphia and Johns Hopkins. Today, I work at a non-profit clinic that my wife and I founded called the Clinic for Special Children. We care for children who have genetic disorders, many of which disrupt the growth and development of the brain. The Biology and Chemistry programs at Trinity strengthened my interests in medical science through excellent courses in Biochemistry, Human Physiology and Analytical Chemistry, and provided a foundation for my later studies of inherited metabolic diseases. William Mace’s courses in Developmental Psychology and Experimental Vision Research required critical thinking about the assumptions behind experimental designs, extensive reading about the historical and philosophical basis of scientific reasoning, and, in all of his classes, Dr. Mace required careful writing. I have always found it remarkable that at no other time in my education was I asked to think in a critical way about scientific methods, about the errors in logic and experiment that result in flawed systems of scientific information, or about the reasons for sudden and broad shifts in paradigms of scientific research, which are found throughout the history of science.

I am reminded each day of the importance of my education at Trinity. Although I make a living as a Pediatrician, my daily work is enriched and sustained by broad interests in the humanities and sciences. Years later I would write, I was never an easy person to teach. I doubted, questioned, and argued my way through an unusual education. My interests in people and art, medicine, and science, which are the sustenance of my work each day, were inspired by a few teachers of literature, writers, scientists, and doctors. I remember them as gifted teachers and thoughtful people. The influence of important teachers endures as friendships do and shows in our work long after schooling ends……..The longer I am away from school the more aware I am of the importance of these few teachers to my education and my work. (dhm, From the Lecture Meaningful Work, Virginia Episcopal School, April 1994) Many of my important teachers were at Trinity College. An important part of your education will be to find your teachers.

FUTURE & EDUCATION: Moving forward through my remembered past, I realize that the directions of my endless education, the nature of my current work as a physician, the scientific questions that I have asked and answered, could not have been anticipated when I had your vantage point. Medium chain acyl dehydrogenase deficiency and glutaric aciduria type 1, two genetic disorders that have consumed much of my professional life, had not been discovered in 1976. The use of tandem mass spectrometry to do population screening of newborns for these, and dozens of other inherited disorders, which is now routine, was not feasible until the early 1990s. Much of the information about amino acid metabolism in the brain, and the technologies for brain Magnetic Resonance Imaging and Positron Emission Tomography, which recently have provided crucial insights into the biochemical and vascular mechanisms of brain injuries in infants with glutaric aciduria, were all technologies in their infancies, awaiting the
development of high speed computers. The vast storehouse of information in the Genome Project found in the public data bases of the National Center for Biotechnology Information (NCBI) were not only non-existent in 1975, they were not imagined. The very language of the questions and answers that are fundamental to my current professional life did not exist when I started my studies at Trinity.

If you Google “NCBI” and select National Center for Biotechnology Information <http://www.ncbi.nlm.nih.gov/sites/entrez> you will find the search window for PubMed. There enter “GCDH” and you will pull-up 46 references including: Multimodal imaging of striatal degeneration in Amish patients with glutaryl-CoA dehydrogenase deficiency. *Brain*. 2007 Jul;130(Pt 7):1905-20. Epub 2007 May 3. By Strauss KA, Lazovic J, Wintermark M, Morton DH. Our paper is there, free, for you to print and read. If you put in the search term “MTHFR deficiency” you will have 427 references, one of which is by Strauss KA, Morton DH, Puffenberger EG, Hendrickson C, Robinson DL, Wagner C, Stabler SP, Allen RH, Chwatko G, Jakubowski H, Niculescu MD, Mudd SH. Titled Prevention of brain disease from severe 5,10-methylenetetrahydrofolate reductase deficiency. *Mol Genet Metab.* 2007 Jun;91(2):165-75. Epub 2007 Apr 3. This paper too is free for you to print and read. If you pull down GENE in the data based menu on the left side of the page, then put in the gene symbol MTHFR, the gene sequence and the protein structure will appear. When Erik Puffenberger in our lab sequenced MTHFR to look for the disease causing mutation reported in this paper, he pulled up the sequence of MTHFR, linked out to PRIMER, designed and ordered the PCR primers on-line, received them in two days, then, sequenced the gene in two days and found the mutation - base-pair change at position 1129 C->T (R377C) - all for a cost less than $200. Not very long ago a graduate student in molecular biology would work for years to locate and sequence a single gene.

From GENE you can link to data bases that show pathways of protein to protein interaction with MTHFR, relevant biochemical pathways, data bases that list known mutations in the human gene. You can compare the conserved regions of the gene and protein of MTHFR in humans, chimps, dogs, mice, rats, chicken, fugu, zebra fish, and, recently, the opossum. This kind of comparative data across species has generated a literature that includes book a by the biologist Sean Carroll *Endless Forms Most Beautiful* that explores the molecular basis of pattern formation in embryology, which depends upon a family of genes common to all multi-cell life and therefore are primitive in a deep evolutionary sense. A search in PubMed of “mitochondrial DNA AND human populations” yields more than 1000 references that use the gradual changes of the maternally inherited DNA of mitochondria as molecular clocks or molecular fossils to trace the origins of human populations - methodologies discussed in the remarkable book by Jared Diamond *Guns, Germs and Steel, The Fates of Human Societies* and Bryan Sykes’ *The Seven Daughters of Eve; The Science the Reveals our Genetic Ancestry. The
NCBI data bases also include the complete sequence of the mitochondrial DNA of the brook trout, information which my daughter Mary and I will use to estimate how long two isolated mountain-top populations of brook trout have been separated by geological barriers that have long prevented upstream migration, at least since the most recent ice age 10,000 years ago, but probably much longer. Molecular information about the age and relatedness of life forms also stimulated recent books such as Francis Collins’ The Language of God, and Sean Carroll’s The Making of the Fittest, and E.O. Wilson’s The Creation: An Appeal to Save Life on Earth. Collins, the Director of the Human Genome Project, explores the broad implication of modern molecular biology with reference to his own Christian beliefs. Sean Carroll not only argues that modern molecular biology provides overwhelming support for Darwin’s Theory of Evolution, but directly confronts religious leaders and educators who suggest that creationism is a scientifically viable alternative to evolutionary biology. Wilson’s book is a biologist’s expression of reverence for life, and an appeal for people of all cultures and beliefs to understand the deep interdependence of life forms.

The NCBI databases contain a deep storehouse of raw data. When connected to these databases a personal computer becomes a library and a Bioinformatics research laboratory. The term Bioinformatics means many different things, but these databases appear to be a new form of public knowledge, a new manner of recalling information, a new way to ask and answer questions. Routine use of the NCBI site began at our Clinic about 10 years ago, when Erik Puyffenberger came to work in the Clinic’s laboratory, and the databases have since fundamentally changed the practice of medicine in our small Clinic, which is in the middle of an Amish farm, far from university laboratories and libraries.

Beyond the unanticipated emergence of such technology, the other reason my Future was unknowable in 1975 was because the personal experiences, observations, and the children I cared for as a young physician, that collectively defined for me the important questions, and defined too what answers were meaningful, would unfold over a period 20 years - long after my formal education at Trinity College was finished. All this is to say that your uncertainty about your Future is well justified. Whatever the immediate goals of your Education at Trinity College in the next four years, what you learn must allow you to continue to learn from experience and reason long after lectures have stopped. Your Education must allow you to sustain what I have called “Difficult Learning.”

DIFFICULT LEARNING: If I ask you to listen to the Bach Cello Suites and become familiar enough with the music to name the Suite number and key of one of the Preludes, that assignment presents little difficulty. It is typical of much ordinary school work. In contrast, if I ask you to learn to play this same music, well, from memory, with an appreciation for the complexity of its musical structure, and with the kind of controlled expression that makes the
cello playing of Pablo Casal’s distinctively different from the playing of Matt Haimovitz, you would find this a difficult assignment, regardless of your musical aptitude. The most significant learning that you will do over your lifetime is similar to learning to play the Bach Cello Suites. Difficult Learning takes sustained effort, sustained interest, tolerance of frustration, and, in my work, the ability to recover, and learn from, great failures.

In the Wenzinger Edition of the JS Bach Suites for Solo Cello is printed on 35 pages and contain approximately 360 lines of music. Pablo Casals’ recording of all six Suite runs for 2 hours and 10 minutes, Mstislav Rostropovich’s recording totals 2 hours and 27 minutes. This music was written by Johann Sebastian Bach in 1720, but was unknown to 19th or 20th century cellists until Pablo Casals, at 13 years of age in 1890, found a copy of the music for the six Suites in a used book store in Spain. There is no history to suggest that the Suites had ever been played in concert or in their entirety. Pablo Casals from age 13 studied Bach’s music everyday as part of his practice routine. Casals was arguably the 20th century’s greatest cellist, yet, it was 25 years before he played one of the Suites in a public concert, and it was 35 years before he recorded all six cello suites – playing from memory.

The Sarabande of Suite V in C minor has 4 lines and 107 notes. There are 39 notes in the first section, and 68 in the second section. Each section is repeated once. The piece is played by Casals in 2.8 minutes and by Matt Haimovitz in 3.5 minutes. I have played this piece on my cello thousands of times, last year I played the piece on a 1697 Stradivarius Cello. The music remains enjoyable to play, it has a mysterious quality. I also work to learn to play the Prelude and Sarabande of the First Suite, the Prelude of the Second Suites, and the Allemande of the 6th. In reality, much of the music of the Bach Cello Suites is too difficult and will remain for me unplayable. This is the nature of “difficult learning.”

I do not have much musical aptitude. Yet, my sustained interest, my stubborn determination to learn, my willingness to practice day after day, the great value I assign to the task of learning to play the cello, has allowed me to develop some of the necessary skills over time. The apparently talented student who has little interest, makes little effort, assigns no value to the task of learning to use his or her talent, will never play the Cello Suites - regardless of his or her native abilities.

The intelligent student who has little interest in his or her studies, beyond completion of an assignment and a test, assigns little value to the process of learning, will not solve difficult problems whose solutions require sustained effort, tolerance of uncertainty, and where the reward of hard work is as often failure as success. Over the past 18 years I have spent more than 20,000 hours of my life working to understand the effects of maple syrup urine disease and glutaric aciduria upon the brain. Working to develop methods of diagnosis and treatment that will rescue patients from the metabolic crisis that cause coma, brain edema, strokes, mental retardation, and a lifetime of disability. Medical care for these problems is now
available, but success came at a high cost in terms of time and money. But, failure has higher costs, and long suffering too. (dhm, Notes from a lecture at the National Youth Science Camp, The Cello and the Brain.)

Midnight, January, 15, 1997 - Half asleep, I am waiting for amino acids to finish running. A blood sample was brought in by a hired driver from a hundred miles away. A sample from a new baby who has maple syrup urine disease. He is not ill, and because of timely diagnosis, he can be easily treated. His sister will be happy to have a brother to share her special diet and formula with. He is the fourth child for these young parents, their first son, the second of their children with the disease. His mother is 25 years old and has four children, two with this disease. How much of the next 20 years of her life will be given to this child and his trouble? How many hours of my life will he claim? I always think of that as I examine a newborn with maple syrup disease or glutaric aciduria or Crigler-Najjar disease - each child takes, needs, defines another piece of my life, a few more hours from nights and holidays, a few less hours of needed rest or reading or writing or playing the cello. Meaningful work? Yes. No doubt what I know, what I learn helps these children - interesting life, interesting work too. Exile too? Yes. Child by child, hour by hour as I am needed, my future is taken, decided, shaped. Yours too? Unaware, have these children already begun to take your time, your life? Was that part of the cost of coming here, searching for, seeing, meaningful work? Was that the ultimate cost of looking into the eyes of such children? Will you give them that much? (dhm, Letter to a medical student)

MEANINGFUL WORK: When asked how he found the time & energy to carry-on a busy solo general practice and write, William Carlos Williams remarked: the actual calling on people, at all times and under all conditions, the coming to grips with the intimate conditions of their lives, when they were being born, when they were dying, watching them die, watching them get well ...has always absorbed me....That is why as a writer I have never felt that medicine interfered with me but rather that it was my very food and drink, the very thing that made it possible for me to write....

We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing .... For a moment we are dazzled. (William Carlos Williams from The Autobiography)

In clerkships of medical school and during my residency in Pediatrics, I realized that my manner of independent learning and my enjoyment of the study of complex problems was a great advantage to me, and to my patients. Children with puzzling medical problems became my Teachers. I often recalled the remark by the Harvard Physician Francis Peabody, The Secret of Caring for the patient is Caring for the Patient.
The humanitarian need for our work at the Clinic for Special Children is apparent, but the scientific importance of our daily work should not be underestimated. Many facets of the natural history of genetic disorders only become apparent to physician-scientists who care for individual patients over long periods of time and who are interested in the practice of medicine, pathophysiology, and biology in the most general sense. The identification of underlying molecular lesions alone usually provides little insight into the phenotypic diversity that we encounter in patients in Lancaster County. The complex neurological syndromes of Glutaric Aciduria, Maple Syrup Urine Disease, and Phenylketonuria arise from single gene mutations, but the complex mechanisms of brain injury and dysfunction are linked to vulnerabilities during critical periods of early brain development. In patients with Glutaric Aciduria episodes of metabolic illness that cause acute striatal necrosis in a 12 month old infant are well tolerated in the 6 year old and adult. The unbalanced amino acid transport into the brain that leads to mental retardation in the infant with Maple Syrup Urine Disease or Phenylketonuria will cause attention deficit disorder and mood disorders in teenagers and presenile dementia in older adults. Single gene disorders give rise to disease states through the disruption of critical biological processes such as metabolic adaptation to fasts and infectious illnesses, cell volume regulation, brain amino acid homeostasis, and postnatal brain growth and development. Scientists who work as physicians and care for many patients with the same genetic disorder over long periods of time develop a different understanding of genetic disease than scientists who study disease mechanisms in cell cultures in the laboratory. It is often through the daily work of a physician caring for a patient that new opportunities for treatment are realized.

The every day practice of medicine is the true frontier of Translational Genetics. (dhm, from The Clinic for Special Children as a Paradigm of Translational Medicine. 2007)

TURNING POINTS: My work in Lancaster County Pennsylvania began, unexpectedly in June 1988 with a drive from Philadelphia to an Amish home to examine a boy with a inherited disorder called glutaric aciduria type 1. Glutaric aciduria was then believed to be a very rare metabolic disorder. None of the physicians at Children’s Hospital had diagnosed or seen a child with the condition. The Amish boy’s parents told me that there were many children similar to Danny in the Amish community. Most, like their son, appeared to be normal at birth, but between six and eighteen months of age were suddenly stricken with a form of paralysis, which was later often called by physicians “cerebral palsy.” The boy’s parents gave me names of these children, and I began to regularly visit Amish farms in Lancaster County to find the children with glutaric aciduria, and learn more about the biochemical basis of the quick and lasting brain injury that it caused. My early clinical impressions about the natural history of glutaric aciduria suggested the disorder might be treatable. But, as is true for many similar inherited biochemical disorders, the success of any treatment ultimately depends upon finding, and
caring for, asymptotic newborns. My preliminary studies in Lancaster County led to an
invitation from Hugo Moser and Richard Kelley to spend a research year at Kennedy Krieger in
Baltimore. In the Spring of 1989, after learning that my proposed research about glutaric
aciduria would not be supported by NIH or Johns Hopkins, Caroline and I founded the non-
profit organization called Clinic for Special Children, and we began to work in Lancaster
County in December of 1989.

The idea of the Special Child was part of the culture of the Amish and Mennonite
Communities long before I came to Lancaster County. My understanding of the influence of
these children upon the cultures came later, in part, through the experience of caring for an
Amish boy with a lethal muscle disease. The boy died at home. I went out to the house to
pronounce him dead and sign the death certificate so burial could take place.

From the doorway I saw that the harsh white light from a lantern above the bed made the
hands and face of the dead boy cold blue-white. Bright silver light flashed from new coins placed
over his eyes. But then I saw that the lantern light was softened in colors of the quilt gathered
around him and the light was golden on his hair and on the hair of the children who played
quietly on the end of his bed. The now softened light washed over the faces of those seated
shoulder to shoulder around the room who one by one shook my hand. Several said, “I have
heard Dr. Morton’s name often and now I am glad to meet you……”

I sat on the chair by the bed for more than an hour……I talked about how difficult it is to
care for children who have illnesses that are not understood and cannot yet be treated. I said that
as a doctor and scientist when each new therapy fails I must somehow renew my efforts to learn
more. Then the boy’s grandfather spoke. As he spoke he smiled and looked first at me then the
children on the bed. He said, “we will be glad if you can learn to help these children but such
children will always be with us. They are God’s gifts. They are important to all of us. Special
children teach a family to love. They teach a family how to help others and how to accept the help
of others. (dhm, From The Death and Life of Enos Fisher)

The above passage was first written in a letter to a high school writing and art teacher
of mine, James Hopkins. In my letter to Mr. Hopkins I wrote about the extraordinary light and
shadows in Enos’ room, and the interesting juxtaposition of Faith and Science that my
presence in this home represented. This story recently inspired a series of paintings by my
daughter Sarah. As Sarah trained as a painter at the Pennsylvania Academy of Fine Art, she
often translated the imagery in my stories, and from her childhood experiences in Lancaster
County, into paintings. Like my stories, Sarah’s paintings have helped capture the imagination
of people who otherwise would have little interest in the scientific work being done at the
Clinic.
A few months later this letter to Jim Hopkins and the story *Death and Life* became the central theme of my acceptance speech for the Albert Schweitzer Prize at Johns Hopkins in October 1993. I will accept the Schweitzer Prize for Humanitarianism. I am honored and happy to have the work at the Clinic for Special Children recognized in this way. The Prize gives me the opportunity to reflect upon an aspect of my work that is at times overshadowed by scientific efforts, here and elsewhere, to describe and prevent genetic disorders. In my work caring for children with complex, sometimes lethal, inherited disorders, I am impressed by the hopes and worth of these children. They hope to suffer less and lead fulfilled lives. Within their families and communities, they are not merely the object of compassion and love but are the very source. The Plain People call them God's Special Children. They shape the Amish and Mennonite cultures and inspire work such as mine in an important and forceful way, which would have been of interest to Dr. Schweitzer as a humanist and physician. (dhm, From the Acceptance Letter for the Schweitzer Prize to Dr. William Richardson, President of John Hopkins University, June 1993)

The story about Enos was later included in a collection of essays about work at the Clinic called *Through my Window*, which was published in 1994 in a journal called *Pediatrics*. The essays were translated into at least 16 different languages. I have had letters about the writings from physicians and parents around the world who wanted to tell me that the essays expressed something for them that was helpful and true. In 1999 the story about Enos led to research by Les Biesecker’s research group at the National Institutes of Health to uncover the disease-causing gene mutation, now known to be a defect in the gene TNNT1, which encodes a protein called Troponin T1. The laboratory of the muscle physiologist JP Jin at Northwestern University has studied Enos’ disease for many years and has described the disease process at the molecular level in great detail in an effort to find new opportunities for treatment. If we finally can help these children, this help will be because of the time I sat by the bedside of Enos, and because of his wise grandfather’s words. This help will come because of a letter to a teacher who taught me about the use of light in painting and the use of words, because of a painter’s translation from words to images on canvas. Because of a new complex technologies that developed years after the boy’s death and allowed new insight into cellular mechanisms, and, most importantly, because this child in his need united people from many different cultures and abilities in a common effort to be helpful. This is the nature of my work, through it I am reminded each day of the importance of my education at Trinity College.

MACARTHUR: A man named Will Miller called the Clinic at a prescheduled time, 4 PM on September 13, 2006. My wife was told he would be calling on behalf of a Chicago magazine, which was not true and was intended to conceal the actual purpose of his call. Mr. Miller is an investment banker and is a member of the Board of Directors of the MacArthur Foundation. He
said, “I have the pleasure of telling you that you have been awarded a MacArthur Fellowship.” He asked that I immediately telephone Daniel Socolow, Director of the MacArthur Fellows Program.

Mr. Socolow said congratulations, and that a letter from the MacArthur Foundation would arrive the next day by Federal Express, just to prove these telephone calls were not an elaborate joke. Then, he briefly explained the selection process for a MacArthur Fellowship, which involves a mysterious process of seeking nominations for possible Fellows from individuals who are affiliated with the MacArthur Foundation, but, who always remain anonymous to the public and the Fellows. No one can apply for a MacArthur “Grant,” names cannot be sent directly to the Foundation, the initial selection process depends upon being named by these individuals. Once a person is accepted as a potential Fellow, this initiates a long investigation that includes requests for letters of support from a number individuals who know the nominee and know about her or his work. The selection of Fellows is based upon information collected from many different sources and the final selection of 20-25 Fellows each year is made by a 12-member board. Mr. Socolow suggested the entire process was both very complex and secretive.

His remarks about the purpose of the Fellowship were intriguing. Your Fellowship carries with it no obligations to the Foundation of any kind. It is a concrete expression of our confidence in you and your future work. You may use the Fellowship in any way you deem most appropriate. He explained that the selection committee found that I had done unusual and interesting work, but that the Fellowship was not an award or a prize for past work. It was a Fellowship for future work. Our hope is that this Fellowship will provide you with a period of increased freedom and opportunity.

FINALE: My wife and I are at a time in our lives when we see in our children the influence of our choices, and our work. Our son Paul plays the Bach Cello Suites on a classical guitar with musical skill and an ease that I can only dream of. He looks for his music in the complex compositions for guitar by Heitor Villa-Lobos, and Pavlo Barriros. Sarah’s ability to translate experiences and words into paintings came, in part, from years of study to develop technical skills with lines, shadows, composition, and color. But, her art has a restless quality too. She is watching for an instant, an image, that expresses the idea of Carlos Williams’ We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing .... For a moment we are dazzled. Her artistic search seems familiar to me. It is a search for “Meaningful Work.” Mary moves quickly around a laboratory sequencing genes of people, or trout, with ease, but, as a biologist she is more at home along a mountain stream than in a laboratory. She sees falling water with the eye of a geologist too. She knows the ancient records of mountain building and erosion. She can name exposed strata and predict
the forms of fossils found in each ledge. As a biologist she can think about the consequence of interrupted migrations of trout from the Atlantic into inland fresh water streams. Streams that ever-so-slowly rose with mountain tops, and finally held a but few of the ancient progenitors of today’s Brook Trout. Separated from the ancients by not only by Place but by adaptations within a finely woven net of sunlight, dark and seasons, ranges of weather and temperature, water, dissolved minerals, and cycles of forests and insects. Linked to the ancients by continuous life and by a fine thread of genes to be read by Mary's generation like the Rosetta stone. She will take her knowledge of Biology, Geology, and Genetics to graduate school in journalism where she will learn to write about scientific problems, as a professional, as her father never did.

Writing to you now about the course of my education I have the advantage of hindsight, but you, and my own children, have the far greater advantage of possibilities. Much of the important work at the Clinic will be done by younger people, like my fellow Pediatrician Kevin Strauss, a brilliant student of biology, and a fine artist too, who started medical school at Harvard 15 years after I did. And, Erik Puffenberger whose PhD in Molecular Biology and Population Genetics provided him with skills in the laboratory and a remarkable working knowledge of the maze-like organization of the NCBI databases. As I write this letter, I am aware too that if our work in Lancaster County has a lasting effect upon the care of children elsewhere with similar problems, and upon Genomic Medicine, this effect will come about because our papers, essays, and stories were read, and were found interesting, by students of the next generation - You.

Having your name added to the list of Trinity College students makes you part of the collective history and future of the School. You bring with you too, as I did, the history and future of your family, town, and culture. Accept the uncertainties of your Future, but watch for Turning Points, those important experiences that will gradually give shape to your Future. Search at Trinity College for your important teachers. Learn how to learn beyond the classroom. Learning from success is important, enjoyable, but you will soon need to learn from failures too. Write carefully, write thoughtfully about important problems, make enduring friendships with other students and your teachers, play music, draw, paint, in some way that suites your nature, actively search for Meaningful Work. Your effort is important to all of us who are part of the Place and Community called Trinity College.

Sincerely,

D. Holmes Morton M.D.
In Pierre’s Workshop
Pierre Moisy’s “Castelbarco Cello”
The Trinity College Concert and MacArthur Fellow Lecture

Sunday, November 11, 2007

3:00 p.m.
Matt Haimovitz, Solo Cellist
Selections from the J.S. Bach Cello Suites, resonant after reading Shakespeare, and Ligeti’s Sonata for Cello
With opening recital on classical guitar by Paul Martin
The Trinity College Chapel

5:00 p.m.
D. Holmes Morton, M.D. ’79, MacArthur Fellow
Reads Not Taken: Reflections About an Education, Difficult Learning, and Meaningful Work
The Goodwin Theater, Austin Arts Center
Remarks in the Trinity Chapel before a Concert for solo guitar by Paul Morton, and solo cello by Matt Haimovit.

The First MacArthur Lecture November 11, 2007

This Chapel is an extraordinary Place to play the Cello. When I come here I start by playing single notes. Sound fills the Place, as light from a candle does. Sustained sound of strings and wood is echoed, shadowed, and shaped by these walls of old stone. This Place gives any Cello a Voice unique, heard only here. As a player I become immersed in the sound. I enjoy that thought.

Two years ago I played a Cello made in 1697 by the great Antonio Stradivarius. The Voice of the old cellos made by this master is each unique, is each different from one another. To some extent the differences can be explained by variations in size, shape and materials. The Castelbarco Cello I played has a back and sides made of Italian Willow, rather than maple, and it is one of the largest cellos that Stradivarius made.

I was inspired by the experience of playing that Cello to ask a young French instrument maker, named Pierre Moisy, who now works in Philadelphia, to make a cello patterned after the Castelbarco. This new cello and its maker Pierre Moisy are here today. The “Morton Cello” was carved by Pierre using the same type of simple hand-tools that were used by Stradivarius, and the same woods. My Cello was made like a fine sculpture being carved from a block of marble. The scroll of the head is pear wood; the tuning pegs are of box-wood, and the neck is maple with a finger board of black teak. The back was carved from a single piece of thick, old Italian Willow. The sides are thin strips of the same Willow-wood curved into ribs and reinforced, inside, with pieces of linen - the same technique that Stradivarius used to help assure the ribs of the Castelbarco would last, and, they have lasted for more than 300 years. The top of the cello is wide-grained European white-spruce. Each small region of the top and back were slowly shaved to measured thicknesses, again, similar those of the old cello.

We are going to study the Voice of this new cello, and learn how its acoustics are similar to, and different from, the old Castelbarco. But, Pierre and I know the Voice of a Cello is an elusive thing. That Voice changes in time. A new cello is changed by being played; within the fine deep structure of joined woods the structure of resonance is slowly shaped by sound itself. In a sense, over time, a fine cello remembers the music played on it, and the people who have played it. The 8 months of work by Pierre Moisy is embodied in the substance of a fine Cello.
that will last and be played long after my lifetime. The Voice of the Cello is also defined by the Places it is played, by perception of the player, and by the listeners, which brings me back to this Chapel, and the Concert we are about to hear.

In recent years a few Students have happen by this Chapel, by chance, and found me here, alone, playing a cello. Playing the cello is for me largely a solitary activity. I am not a performer; the only listeners to my concerts are evesdroppers. I was aware that each student paused, listened, and then went on their way. One girl from a distance said That was really beautiful. I had played the Sarabande of the 5th Cello Suite as she listened, which by the end of the day you will all know and remember. I have always imagined that she might have been Inspired by that chance encounter to learn to play the cello.

We have experiences and make choices every day that determine the course of our lives. The significance of many small, but important, events and choices becomes apparent over time - remembered from a distant place and time. So the poet Robert Frost writes:

Two roads diverged in a wood, and I.
I took the one less traveled by,
And that has made all the difference.

Today, and tomorrow, I will talk about, remember, some of the choices I have made and some of the extraordinary people who have influenced my life and work. Many of those people are here. For many of you the Concert & the Lecture is my acknowledgement; is my expression of appreciation for your friendship and help.

For the students who listen to this Concert and my Lectures - the music, the stories, and the gathering of people is intended to make you think about the experiences you will have, here at Trinity College and else-where, and the choices you will make as a result of those experiences, that will take your lives in new directions, often unexpected. How you think about, make and learn from these Choices is finally, I think, the essence of an Education, and becomes the substance of Living too.
The Pennsylvania Academy of Music was founded at the about same time as our Clinic; it is also a small non-profit that has thrived. Between 1991 and today the Academy of Music has enriched the lives of thousands of students, parents, teachers of music, and the citizens of this Community called Lancaster County.

In February of 1991, the Pennsylvania Academy of Music opened its doors to its first 50 students, offering courses in instrumental performance and music theory.

Our mission is to provide a thorough training of the highest order in every aspect of musical principle, technique, interpretation, and expression, thus creating a platform on which students and faculty can practice and perform.
The Academy’s work has also included the institution of an international program in cooperation with area high schools, the Bravo Program to foster the talents of inner city youth, and the all scholarship Summer String Institute.

For my family and me the presence of this Academy of Music has been unusually important.

In 1994, in recognition of the Clinic’s Albert Schweitzer Prize for Humanitarianism, the Academy hosted at the Fulton Opera House a Johann Sebastian Bach Concert to recognize Dr. Schweitzer’s integration of music and medicine into a life shaped by a humanitarian purpose. Schweitzer’s essays on the organ music of Bach remain important essays on the history and performance of Bach’s work for organ. Throughout his life Albert Schweitzer studied this music. At his Clinic in Lambaréne Africa he had a specially made “pedal piano” where he practiced daily. His trips back to Europe from the Schweitzer Clinic always included fund raising concerts. In 1996 Caroline and I traveled to Strasbourg France, for which our town of Strasburg Pennsylvania was named. We attended a Concert of Bach’s Prelude and Fugue in F Minor in St. Thomas Church. The Concert was played on the Silbermann Organ that Schweitzer had helped construct as a young man, and that he played throughout his life, often to raise money for his medical work in Africa. His last concert at St. Thomas Church was played at age 80 on July 28, 1954 to commemorate the death of Bach.

My enjoyment of Bach’s Cello music, and this event tonight, is in a sense the result of the Albert Schweitzer Prize in 1993, the Schweitzer Concert here in Lancaster, and the presence of the Academy of Music.

More personal, it was through the Academy that our son Paul met Ernesto Tamayo, who has remained for Paul an influential teacher of classical guitar, a role-model as a performer, and a good friend.

Daughter Sarah and I tortured Michael Jamanis Jr. with our early studies of the violin. Despite Sarah’s resistance to Michael’s instruction, she went on to play in the violin section of Mennonite High School. Listening to Sarah and her class-mates play and sing Handel’s Messiah in its entirety has been a fine memory for me.

Paul and I also took turns with lessons on Cello from Sara Male, Michael’s wife. I think Sara and Paul mostly talked about baseball; he soon moved on to an electric guitar and left the cello to me.

I taught Sara about the challengers of teaching an independent, older student. Matt Herren, a Juilliard Trained Cellist originally from Lancaster County, traveled from New York City to give lessons at the Academy. Matt patiently worked with me for over a year at the Academy before moving to the Midwest. Now, Christine Watts is gradually over-coming some bad practice and playing habits that I acquired through 2 years of self-instruction. Christine
recently told Sara Male, You know Holmes is actually improving! I have not, you might gather, turned-out to be an Adult Prodigy on the Cello. Nor was I given a MacArthur Fellowship in recognition of my promise as a musician. I progress slowly with the same stubborn effort, driven by a deep interest in, and lasting enjoyment of, music that has marked all of my efforts to study complex subjects.

My favorite image of the Jamanis’ Academy of Music comes from walking from the far end of the long hallway of the Armstrong Building, where my cello lessons are given. Dozens of students of all ages are scattered on benches and on the floors tuning instruments, practicing sequences of bowing and fingerings, and talking in small groups. Some smile, look at the cello that I carry and at me with puzzlement, Teacher or Student? Parents are often along the hallway too, talking in different groups, reading, waiting for lessons to start or end. Some nervously await the start of a recital. From each room along that hallway comes Music in Progress: the Bach Violin Partitas, Massenet’s Meditations, a piece of the Bach’s Suites for Solo Cello, Etudes, Scales - phrases started, stopped, played again, with some small refinement in bowing or an improved shift; scales on a piano, then suddenly fragments of Chopin, Rochmaninov, or Gershwin. The booming operatic voices of John Darrenkamp and Amy Yovanovich burst through any closed door and fill the hallway with voice. Another room has a circle of Ernesto Tamayo’s guitar students, each playing a finished piece for others in the circle, then taking about what they intended to play or heard, or didn’t hear, and between sets some rebellious boy rips through a fragment of a song of Bob Dylan or Jimi Hendrix. From another room comes a chorus of young voices that rise, stop suddenly, then the director’s voice No, No, let’s do that again, and again and again....

The hallway is filled with this cacophony of musical learning, practice, the beginnings of music of all kinds - beginnings too of friendships, careers, and Lives shaped, inspired by music. This is An Academy of Music in the best sense. This was the Spirit in the old Bank Building on Prince Street where the Academy started. The Spirit is everywhere along the hallway of the Armstrong Building on West Liberty Street, and, this Spirit of An Academy of Music will move into a new Place on June 11, 2008 - students and teachers, moving forward in Time as long as the Place, Memories, and the Spirit endure - enriching lives, making lives - of the younger and older, performers and listeners.
The Scroll was carved from Pear, the Tuning Pegs are Boxwood.

Pierre Miley’s Cello
The Still, Mass Morning
oil on canvas 48x36" 2008
INTRODUCTION: The day Vicki Modell telephoned our Clinic to ask me to give this talk we had
gotten a letter from a Deputy Editor of the NEJM to say that our Case Report about an infant
with Omenn Syndrome, named Edna, would not be published in the Journal. The usual
phrase is: The editors did not think the report was of general scientific significance, and would
not be of interest to the general readership of the Journal...

I was disappointed, but I was not surprised. The Case Study, and the care of an individual
patient which such studies report about, is not considered the important work of Physician-
Scientists in modern university medical centers.

At the same time, my friends Francis Collins and Alan Guttmacher tell us in their lectures, and
in their commentaries about Genomic Medicine in the NEJM, that the Human Genome Project
will finally bring to a revolution to medical practice - Individualized Genomic Medicine based
upon an understanding of the genetic pre-dispositions toward disease in the individual.

I simply cannot imagine what Genomic Medicine will be if not the kind of work that was done
to save the life of Edna.

That thought motivated me to write a letter to the deputy editor to explain why I thought the
work reported in Edna’s Case Report was of general scientific significance and should be of
great interest to the readership of the Journal. He replied: Your paper was returned by me
because it lacked originality. It revealed no new principle, and no novel idea was presented.... Contrary to your belief, the paper was not of general scientific interest.

I also decided I would talk this evening to this distinguished gathering about Edna’s Case. Vicki and Fred Modell know the story of Edna. They know Edna and her parents too, Daniel and Rebecca. They share a common bond with Edna’s parents; both have lost children from illnesses caused by primary immune deficiencies.

When Erik Puffenberger, Kevin Strauss, Nick Rider, or I have discussed Edna’s case with Clinicians at Children’s Hospital of Philadelphia, Hershey Medical Center, the Genetics Department at Johns Hopkins, and elsewhere, physicians at these University Medical Centers are surprised that the technology, which is present in the Research Labs of each of these Medical Centers, could be used in such a remarkable way to uncover the cause of, and direct the medical care of, a single infant. Physicians were quick to say “we would never have done that work here.....”

Why not? Why is the Translation of Genetic Knowledge into patient care difficult?

I am an interested observer of Big Medicine and Big Science, from a distance now, but, I did train within the Harvard, Penn, and Johns Hopkins medical systems. Almost 20 years ago I decided that for me the practice of medicine should involve “caring for patients” as a general Pediatrician. But I was a Physician who found myself caring for children in a rural area whose routine medical care required an understanding, and monitoring, of their underlying genetic disorders, I found it important not only to take some Science and Technology with me to my Pediatric practice, but to continue to learn about the effects of these disorders through my daily work.

Can any of us imagine an NIH Grant prefaced with the often-quoted phrase of Dr. Francis Peabody, The secret of caring for the patient, is in caring for the patient...?

A recent editorial in the Journal of Clinical Investigation indicates that research support in the past 20 years has overwhelmingly directed Physician-Scientists to the laboratory and away from patients - 97% of Physician-Scientist who received the Howard Hughes Clinical Research Awards elected to do research that did not involve patients (Goldstein JL 1997). Less than 3% of money NIH and Hughes Foundation support research of the sort that requires the doctor to shake the hands of those who have the disease to be studied.

I also cannot imagine being funded by NIH to provide the kind of care we provided for Edna,
which is why very little of my time in the past 18 years has been spent writing grants to support the work at the Clinic for Special Children.

I work in a different Place, where Dr. Peabody’s statement “The secret of caring for the patient, is in caring for the patient” is familiar and finds its way routinely into lectures and papers, and constantly influences our daily work. Where we shake the hand of every patient, parents, grandparents, and where we think of Health Care and Translational Medicine in terms of individual children, their families, and a Community of people. Because of our personal involvement in the care of patients like Edna, much of the support for our work comes directly from the Communities of Amish and Mennonite that we serve. Approximately 30% of our $1.5 million dollar budget at the Clinic for Special Children, which is a non-profit organization, comes from Community Benefit Auctions. Quilts, furniture, tools, farm supplies, and food are made, donated, and auctioned by people from these Communities, and the income is given to the Clinic for Special Children to underwrite our work. Clinic and laboratory fees provide only 20% of the income needed, and these fees are paid in cash - more than 95% of those we serve are uninsured. Although the lack of medical insurance is in part by choice, in reality the Plain families we work with, who are at high risk for inherited disorders, are uninsurable. Another 5% of our budget is generated by a Research and Education Endowment Fund that Caroline and I started 18 years ago, which has grown slowly over the 19 years to $1.8 million and generates approximately $75,000 for Clinical Research and Education directly related to our work. We hope to increase this Endowment Fund to $10 million over the next 5 years. The remainder of our support comes as gifts from individuals and foundations that have a particular interest in our medical work, or are interested in the Plain Communities and the different form of modern life they have chosen.

You should understand that our approach to medical care also has scientific reasoning behind it too. We not only believe the Care of the Patient is important to our success as doctors; we think our understanding of the biology of disease in the individual, and within a these populations, also depends fundamentally upon Case Studies like Edna’s.

In a paper about our work at the Clinic published in the American Journal of Medical Genetics in 2003 I wrote - Physician-Scientists who work as doctors and care several patients with the same genetic disorder over long periods of time will develop a different understanding of genetic disease than scientists who study disease mechanisms only in the laboratory…. Our experiences at the Clinic over the past (19) years suggests many important aspects of genetic disease will only become apparent to Physician-Scientists who care for individual patients over long periods of time and who are interested in individual patients,
pathophysiology, and biology in the most general sense. (Morton DH, Morton CS, Strauss KA, Puffenberger EG, Robinson DL, Hendrickson CT, Kelley RI. (2003) Pediatric Medicine and the Amish & Mennonite People of Pennsylvania. Am J Med Genetics (Seminars in Medical Genetics) 121C:5-17.)

Many of us here tonight knew Dr. Fred Rosen. We remember his dedication to patients as their physician. And, we understand that one reason we are here tonight is because Dr. Rosen's Cared for a boy named Jeffrey Modell.

EDNA
I first met Daniel and Rebecca in 1993, shortly after their first-born child Anna Ruth died at 3 months of age of an immune disorder and an overwhelming infection. She had been sent home from Hershey Medical Center. Her parents were told that little was known about the cause of Omenn Syndrome, and, that nothing could be done.

I saw each of Daniel and Rebecca's next 7 children - 3 developed severe eczema-like skin lesions with high eosinophil counts and high IgE levels. But, in each of these children all classes of immune globulins were present, and their problems resolved after being started on low-allergenic formula, and one or more short courses of corticosteroids. All seven children remain healthy today. (I suppose it is remarkable enough for a Pediatrician to be able to say he has known a family with 7 children over a 15-year period.)

When Edna was born she was different than the other children. She had diffuse erythema, alopecia, hepato-splenomegally, an eosinophil count of 17,000, and undetectable IgE, IgM, and IgA.

Remarkably, her skin condition improved, and her eosinophil count decreased rapidly, on a hypoallergenic diet and a brief course of steroids, but all classes of immune globulins remained low. Subsequently, low cytometry showed near absence of B-cells, and, in vitro, her lymphocytes responded poorly to mitogen stimulation.

By the time the results of these laboratory studies were completed, Edna had developed diffuse adenopathy, a hemolytic anemia, then, staphylococcal sepsis. Her father, Daniel, is an unusual Amishman; he is curious about science and medicine - all that fancy equipment and big words used at the Clinic. After his first daughter died he read extensively about Omenn syndrome. He telephoned and wrote to families all around the United States and Canada to find out about cases similar to Anna Ruth's. He learned that other Amish children had had a similar immune
disorders, and they, like Anna Ruth, died. Daniel and Rebecca were resigned to her impending death. Daniel also knew enough about the cost and complexity of bone marrow transplants to be skeptical. He told me several times that Rebecca and he did want to do what they could for Edna, but that they would probably not agree to an experimental therapy.

I told them much has changed since 1993. We should treat her infection, learn what we could, and then decide what can, and cannot, be done for her. Kevin Strauss and I admitted her to an isolation room on the Pediatric Floor of our local hospital Lancaster General Hospital. Fortunately, she responded to antibiotics, stabilized, and gave us time to study her problem.

NEW SCIENCE
I will describe briefly the remarkable range of Knowledge of molecular disease mechanisms, Bioinformatics, Technologies, which were used to study Edna. (Dr. Nick Rider has a Poster at this meeting that presents the data which I will briefly describe. Our paper about Edna is being reviewed for publication.)

National Center for Biotechnology Information Data Bases: It is interesting to realize that between the death of Daniel and Rebecca’s first child and the birth of Edna, the data-bases from the Human Genome Project came into existence. After hearing Edna’s story, Dr. Victor McKusick told me that he recalled sitting before Congress about the time Anna Ruth died asking for funding for the Human Genome Project. He said he had on the table in front of him six volumes Mendelian Inheritance in Man, the McKusick Catalogue of Human Genetic Disorders. The books were placed there to impress members of Congress with how much was known by then, and to convince them of the need for funding the National Center for Biotechnical Information Data Bases. Today, we cannot imagine that the massive amounts of information in these data bases could even exist in printed form.

What is also very remarkable about this Information is that it is accessible, to all of us - parents, students, and doctors - even to doctors who work from a field in the middle of Jake Stoltzufoos’ farm, which is where our Clinic is located. Francis Collins, Alan Guttmacher, and many others at NIH had much to do with keeping this information public and freely accessible. Today, the Medical Community takes this fact for granted, but, we should not. Access to this Information could easily have been prevented by corporate ownership of genomic information, patents, or high access fees to these data bases.

NEW PEOPLE AT THE CLINIC
Another important change between the death of Daniel and Rebecca’s first child and the birth
of their last child - Erik Puffenberger and Kevin Strauss came to work at the Clinic for Special Children.

Erik Puffenberger a Ph.D. came to the Clinic for Special Children in 1998 as a Population Geneticists/Molecular Biologist. Erik came to the Clinic from Case Western University where his PhD work was done with Aravenda Charkavardi. His thesis focused upon several recessive genetic disorders of the Mennonites populations of the United States and Canada. Erik, like Kevin Strauss, could work at any University Research Lab, but chooses to work at the Clinic. Most of the new insights into the population genetics and molecular biology that I will summarize today reflect Erik’s work. Edna’s Case Study also describes an unusual direct collaboration between a PhD and Clinicians - Erik, Kevin Strauss, now Nick Rider, and myself.

Kevin Strauss came to the Clinic as a Pediatrician in 2001. He got his MD from Harvard Medical School, during his senior year he found his way to the Clinic and stayed 4 months. He then did a Pediatric Residency at Boston Children’s Hospital. I have been told more than once by Sam Lux, Fred Lovejoy, Bob Masland and others that Kevin Strauss was among the best residents who trained at Children’s - Ever. The year he finished he won all of the major awards for teaching, research, and clinical work. I am told there were Departmental meetings at Children’s to figure out how to keep him in Boston.

The transformation of the Clinic from a pediatric medical clinic that was focused largely upon biochemical genetic disorders, into a place where immunologic problems like Edna’s can be routinely diagnosed and studied using molecular techniques came about because of knowledge brought to the Clinic by Erik Puffenberger, Kevin Strauss, and, more recently by Nick Rider. Caroline and I enjoy the thought that we have provided these talented people with an interesting place to work, a range of unsolved problems to study, and a Place where children like Edna inspire us, and teach us, everyday.

RESULTS

1) Affymetrix 10,000 SNP Microarrays were first used to find the locus of the candidate genes. Erik made 10,000 SNP marker genotypes on all 8 living child and the parents. Then ask, where is Edna autozygous for a cluster of SNPs and genes, and where is she specifically different from her 7 siblings and parents. He uses an Excel spread sheet to ask such questions. A single such region was found, bounded by SNPs rs496623 & rs603648, which contained 366 known or putative genes. A quick review of this list revealed 2 genes known to be associated with a SCID-Omenn phenotype RAG1&2.
2) Our daughter Mary Morton was working with Erik in our lab at the time. She was in transition from an undergraduate studies in Biology and Geology at Franklin & Marshall College and on her way to a Graduate Science-Journalism Program at Johns Hopkins. Mary pulled-up the structure of the RAG1&2 genes from the NCBI Data Base called Gene. She designed and ordered primers on-line, using a link to the program Primer. Mary sequenced both genes in less than 1 week, and a cost of about $400. (We all recall when PhD candidates would spend a year to do such work.) Mary and Erik found the sequence of RAG2 was normal, matched the Consensus Sequence shown in Gene. The disease-causing mutation for Edna’s variant of Omenn Syndrome was found in RAG1. Daniel and Rebecca, and 6 of 7 of Edna’s siblings were carriers of this mutation.

3) We also obtained the paraffin block from a skin biopsy that was done on the sister Anna Ruth just before she died in 1993. The paraffin was dissolved using a solvent, and DNA was extracted from the tissue. We confirmed that Anna Ruth was homozygous for the same mutation in RAG1.

This is of course an interesting method in itself...Paraffin blocks from biopsies and autopsies, along with the Case Studies themselves, are an important, often forgotten, archive of previously unrecognized genetic disorders. Erik says he can probably do whole genome amplification from this DNA to generate full SNP genotypes, in addition to the kind of targeted mutation detection that was done in Edna’s case.

4) By this time, Edna was well appearing. Her infection was controlled. She was gaining weight, but it was also apparent that the only effective therapy would be bone marrow transplant. Did she have a possible donor? How much would it cost to find out?

We knew something about that too - a few years ago we had send another SCID case to Children’s in Philadelphia for a bone marrow transplant. Just to learn that none of Raymond’s 4 siblings were HLA matched cost this Amish family $68,000. Ultimately, Raymond was transplanted with marrow from a HLA matched donor, but there was an Rh antigen mis-match. He died of a hemolytic anemia caused donor antibodies, which always seemed to us an avoidable problem. It is a small Community, Daniel knew Raymonds story. The high costs and fatal outcome contributed to his skepticism. The cost to do HLA mapping for Edna’s 7 siblings would be about $120,000, and, these studies would take weeks to do.

I asked Erik, Can’t you use the SNP genotypes at the HLA loci and find which of Edna’s siblings are likely to match? He did. The SNP genotypes of the siblings were already done, at a cost of about $100 each. The SNPs within the introns of HLA loci on chromosome 6 are inherited in clusters in association with HLA genes. Erik found on the 10,000 SNP arrays that the HLA region was well saturated with SNPs.
The manner in which he displayed this complex data is the kind of data an older Pediatrician likes to see - the match among the 7 siblings was obvious to me at a glance. Only 1 of 7 siblings shared all SNPs with Edna - her sister Mary. Erik also looked at the SNPs clustered around ABO & Rh determinants and found sister Mary was matched there too. Of course, we also imagined it might be an advantage that the matched sibling was female, so the donor cells would not shed immune-irritating antigens from a Y chromosome.

(Studying the variations within the family's HLA-SNP genotypes was in itself an interesting study in the maintenance of genetic diversity. Recombinants created by crossovers within chromosome 6 during meiosis created a remarkable variety of HLA genotypes even within this family.)

Of course, those who run the HLA-matching laboratory at Children's in Philadelphia did not take Erik's report for granted. However, they did do HLA serological & molecular typing on only 1 sibling, sister-Mary, who was a perfect match HLA, ABO, and Rh - as Erik predicted she would be.

5) Population Genetics & Implications:

a) Daniel and I had learned of a few other cases of Omenn syndrome in the Amish Communities of the Midwest & Canada, similar to Anna Ruth. But in the early 1990's there was no opportunity to use micro arrays and sequencing. Mapping studies using 300-400 micro-satellite markers that were being done in the early 1990s required large numbers of affected patients and their parents. These DNA samples were not available. Again, times have changed. Many of the new disorders we have discovered in the Plain populations in the past 5 years were mapped using only 2 or 3 affected patients.

b) Mary Morton also looked for the RAG1 mutation in 100 randomly selected DNA samples from Lancaster County: 5/100 were carriers, 1/20, the predicted disease frequency would be 1/1,600 in this population - about 1 new case per year. Within Daniel and Rebecca's immediate family, the disease risk will be higher, but we can now be determined accurately by carrier testing for the mutation, and by selective testing of high-risk infants, rather than by guess work based upon probabilities.

c) In June 2007 Drs. Kevin Strauss and Nick Rider traveled to Indiana to meet with Amish and Mennonite families who have had children with SCID syndromes. Between 1978-2007, 30 children with SCID syndromes had been born within the families they met - 12/30 (40%) were undiagnosed, 4/30 probably had Edna's variant of Omenn syndrome, but the mutation was not known. Of the 30 patients, 26 had died.

Unfortunately, we expect these families represent a small sample of the total immune
deficiency disease prevalence. Most infants in the Plain populations probably die of infection and their primary immune disorder remains unrecognized.

d) The major determinant of outcome in this group of patients will be age at diagnosis and treatment, as clearly reported by Rebecca Buckley, whom I have enjoyed meeting here. The experiences of her transplant team at Duke University show that the prognosis of neonates with SCID undergoing BMT under 2 months of age is excellent, 95% success, using either a matched sibling or the infant's mother as a donor. Edna was transplanted at 62 days of age, using her 2 year old sister Mary as a donor.

e) With the help of Franklin & Marshall College, Lancaster General Hospital, and some MacArthur Funds, we recently acquired another piece of new technology at the Clinic, the Light-Cycler. The first clinical sample run on this instrument was to rule-out Omenn Syndrome in an Amish newborn in Wisconsin, whose ill sibling we found had the same RAG1 mutation as Edna. Start-to-finish, extracting DNA from whole cord-blood to mutation detection took 2 hours. We can now run 96 to 380 samples simultaneously, for multiple mutations. This Real-Time PCR method allows large families studies, real population genetics, and rapid testing of high-risk infants, at an actual cost of less than $20 per sample.

f) The ability of see HLA matches using SNP genotypes will also provide an inexpensive mechanism for looking for donors within a family, rapidly and at low cost. Also, the accumulated SNP genotype data-base generated though our work with 105 different inherited disorders, and many mapping studies, will provide an opportunity to scan through genotypes to look for HLA matches within extended families, quickly, inexpensively. It seems more likely that we will find HLA matches for our patients within the closed Plain populations than within the general population of the US.

g) It is true that Autozygosity Mapping Studies, like the one done in Edna's family, are easier in the Plain populations than in a more ethnically diverse population, where a patient's ethnic backgound may be mixed. In such population heterozygous mutations are more common, and larger patient groups and linkage studies are needed to map a gene locus. Using the genotypes of Edna's siblings it was possible for Erik to focus Mary's search upon RAG1&2. However, for a distinctive disorder like Omenn Syndrome, the list of causative genes is finite, and candidate gene sequencing based upon a molecular differential diagnosis can be done when mapping is not successful.

h) Finally, it very important to understand that the use of SNP microarray genotypes to screen for HLA matches within a family is not limited to the Amish or Mennonite populations. The same information can be generated with 10,000 SNP genotypes within any family or any ethnic backgorund. In the United States approximately 15,000 bone marrow transplants are done each year. (http://www.marrow.org) For each transplant, several relatives, 40,000-60,000 people per year, are studied by HLA typing as potential donors. You can do the math - $100
The success of Edna’s bone marrow transplant represents another kind remarkable technological progress. She was the youngest infant ever transplanted at Children’s Hospital of Philadelphia. The transplant was done at no cost to the family through funds in CHOP’s Endowment Fund. The Amish Community wanting contribute something for Edna’s care, took up a collection and donated the money to the CHOP to help support other charitable work there. We have established a good working relationship with the immunology and transplant group to facilitate neonate transplants for infants diagnosed with Omenn Syndrome and other Primary Immune Disorders at the Clinic.

The Amish and Mennonite people are interest not because they are different than us, rather they are us. The disease-causing gene mutations we see in these populations only came from Europe 300 years ago. Gene mutations in these populations are similar to, not different from, the disease causing mutations in the US & European populations.

The distribution of European disease causing mutations within the closed Amish and Mennonite populations range from low (B12 deficiency cause by a mutation in amnionless 2 case over 19 years) (MCADD in Mennonite 1/15,000), or absent (CF Amish & Mennonite, and MCADD in Amish) to high (GA1 and MSUD).

Random genetic drift within a small rapidly expanding population, rather than inbreeding, or natural selection, is the primary cause of high frequency, and low frequency, disorders. These human populations are typical, not different from, all human population throughout history. Genetic predispositions to illness are common, not rare.

SIGNIFICANCE

It would be a mistake to let you think that the Significance of Edna’s case should only be discussed in terms of Science, Technology, and Population Genetics. The application of this technology and knowledge was all the more remarkable because it was done to provide care for Edna as a single case. And, the work could be done at a small Clinic in an Amishman’s cornfield. The next frontier of Genomic Medicine is the everyday practice of medicine. (dhm 2007) I simply cannot imagine what Genomic Medicine will be if not the kind of work that was done to save the life of Edna.

1) Edna as a successful case in this small Community. For the families who have such children, Edna’s story provides Hope. The success of her treatment is known throughout the
Amish & Mennonite Communities in the United states and Canada - as is the message that timely diagnosis and treatment is possible, and is important to successfully treating these disorders. Late diagnosis, after infection with CMV, EBV, chronic malnutrition, invariably results in disastrous illnesses, high costs, and poor outcomes. Call it Newborn Screening, or call it selective testing of high-risk infants within families at risk, the message is the same. Starting with a healthy infant is better that attempting to rescue severely ill infants.

2) Victor McKusick and Genetics Rounds: A couple weeks after I visited Victor McKusick and told him about Edna’s case, I got a letter asking us to present her case at Genetics Rounds at Johns Hopkins. Apparently, Dr. McKusick thought her case was of general scientific interest. I will always remember Dr. Mckusick at age 86 sitting on the front row of the lecture hall, as he always does, taking notes into one of those small “Nurses' Record” notebooks, as he always has, while Kevin Strauss and Erik Puffenberger presented Edna’s Case. After the Lecture Dr. McKusick smiled, shook his head and said, Remarkable! I wish The deputy editor at the NEJM had heard that review.

3) After we transferred Edna to the care of Drs. Nancy Bunin and Jordan Orange at CHOP - complete with her diagnosis & a HLA-matched sibling donor - several car loads of people came from CHOP to Clinic for a seminar to find out how we had done that. I also got a call from the purchasing office of Children’s to find out what equipment we had used to do these studies on Edna’s family. To their surprise, they had all the equipment, it had just had never been used to do a Case Study like Edna’s. Kevin Strauss and Erik Puffenberger will present Pediatric Grand Rounds at CHOP in December about Edna, and other Case Studies representative of an array of 105 disorders among the 800 children that we care for, and learn from, at the Clinic. The next frontier of Genomic Medicine is the everyday practice of medicine.

4) Dr. Nick Rider has a Poster at this meeting about Edna’s case. Dr. Rider is newly boarded in Pediatrics and Internal Medicine, and was Chief Resident at the Penn State Hershey Medical Center. He is finishing a 2 year Fellowship in Immunology and Allergy. Most of Dr. Rider’s Research during Fellowship has been done at the Clinic for Special Children. Edna’s case, and studies of children with several other immune disorders, have not only provided Nick with interesting work during his Fellowship training, Case Studies and Data for many presentations at several National Immunology meetings, but these children have captured his interest as a Doctor. He likes practice model of the Clinic and plans to work with is starting next year - a decision that will change the lives of many children not yet with us. Dr. Rider will experience first-hand how Knowledge is Translated into patient care.
5) The RAG1 mutation, and several other disease causing mutations, were found by our daughter Mary Morton who last year was working with Erik as a lab technician. Mary is now in a Graduate Science-Journalism program at Johns Hopkins. Part of her thesis will be about the science, and sociology, of Edna’s case.

6) Finally, Vicki & Fred Modell understand the significance of Edna’s story in a way that few here can. Their efforts over a 21 year period to be helpful to families and children with disorders of the immune system similar to Jeffrey’s, is exactly why we are here this evening and why the new laboratory is named for their son Jeffrey.

CONCLUDING THOUGHTS

I have been told that special children are gifts from God.
I have been told that special children are punishments from God.

I have heard scientists and doctors refer to these children only in terms of their genetic defects, aloof and with no human insight, as though the life of a child can be reduced to such terms.

My experiences have made me think in a different way about these children and their short, often difficult, lives.

I cannot say why these children come and go upon the Earth but I do know that they change the lives of those who know them.

Such children have been my most important teachers. I have learned more from them than I did from many instructors in Harvard Medical School, who were by reputation great teachers. These children have reshaped time and again the way I practice medicine, both the science and the art of it.

I have heard sermons by ministers about compassion, I have heard fine lectures about ethics and medicine, but no sermon or lecture has taught me as much as a single special child. These little children can change whole Communities of people in ways that last far beyond their brief lives.

They are not merely the focus of compassion but often are compassion’s very source. Special children enrich the world in ways that many who are blessed with longer lives do not. They have much to give us, to teach us, about themselves and about ourselves. (from the story Croquet, dhm 1996)
I won’t be working in the nice building called the Jeffrey Modell Immunology Center at Harvard Medical School. My Place, as Wallace Stegner uses the word Place, is in a small Pediatric Clinic in a field in Lancaster County Pennsylvania. But I understand the purpose of the Modell’s Building; I don’t underestimate the importance of the work that will be done here.

However, my challenge to those who will work in the Building named for Jeffrey Modell is to understand that the care of an individual child, The Case Study, is in many respects, the most important work that we Physician-Scientists do. The secret of caring for the patient, is in caring for the patient. Caring is the important work of a Doctor. Our motivations for learning and working often arise from the individual acts of Caring, and, in my experience, the Science of Medicine often begins and ends with the Case Study. Translational Medicine, Genomic Medicine, whatever term you like, must finally care for children like Jeffrey Modell and Edna Stoltz fus.

I don’t know what to do about the New England Journal of Medicine except write an occasional letter to the Editors, and publish elsewhere, work elsewhere. Twenty years ago I found Meaningful Work in a Place called Lancaster County, away from frenzied academic centers where success and failure is too often defined only by Grant Scores and by counting publications. At the Clinic for Special Children we define our successes and failures in human terms – the successful Care of Edna was important.

We should all again thank Vicki and Fred Modell for bringing us together tonight. I thank them for the opportunity to speak this evening to this remarkable gathering. dhm Boston 11 17 2007
The Mirror and the Martyr
oil on canvas 48x80" 2008
Haverford is a College historically, and currently, associated with the Quaker Church. I enjoyed the traditional pre-graduation service in the old Quaker meeting house and the remarks about the long history social and humanitarian activities of the members of the Haverford College Community. The President of Haverford is Dr. Stephen Emerson, a physician and molecular biologist, who not only reminded students of the College’s tradition of service and philanthropy, he has made a commitment to reduce the debt of graduates to allow career choices that are not constrained by debt. My remarks were influenced by discussions with students and faculty at Haverford in the day before graduation. Much of the talk was written during the Quaker meeting. (dhm May 18, 2008)

If the miseries of the poor be caused not by laws of Nature, but by our Institutions, then great is our Sin. Charles Darwin, Voyage of the Beagle, Notes On Slavery from 1832-1835. For the purpose of my remarks, it is interesting that, as Charles Darwin implies, Enslavement often involves the poor. Impoverished people are easily enslaved.

What is Slavery? The Microsoft Dictionary defines Slavery four different ways:

1) In past times - the condition of being forced to work for somebody else...

In our Time, who are the Slave owners? We are so enlightened, so modern, so advanced, that no such Inhumane Institution could exist within our Society. Isn’t that what we think?

2) A system based on using the enforced labor of other people...

3) Hard work, especially for low pay and under bad conditions...
We think of Enforced Labor in terms of physical enforcement by overseers on a Plantation or guard of a roadside prison workforce. But, if Enforcement is by Society’s Powerful Economic & Legal Institutions, and the Labor is an ordinary job that provides no opportunity for betterment or independence, and, if the Labor is a Job doing undesirable work at low pay because of fear of losing health insurance, a car, or home, are these modern limitations of personal freedom less real? Are Economic Dependencies, which are so common in our Time, Unreal or Unimportant?

Is the Entrapment by Debt a modern equivalent of Slavery? Educational Debts, Mortgage Loans, Insurance and Car Payments, Credit Card Debt, Medical Debt, all collectively limit our choices, restrict our freedoms, and force dependency in our day to day work and lives. It is not difficult to understand how an Economy of Debts prevents the young, You, from pursuing dreams or searching for what I have called Meaningful Work. A young physician I know wants to work with us at the Clinic for Special Children. But, he has an Education Debt for College and Medical School of $190,000. If he stays within a University Medical System, which is heavily financed by NIH Funding, then he can apply to have $1/2 of this debt paid by NIH as long as he progresses toward being an Independent NIH Researcher. Another choice is for him to join a lucrative private practice as a specialist in Immunology and Allergy or Internal Medicine. But, if he works for a small non-profit Philanthropic Institution called the Clinic for Special Children, he must repay these loans in full. Does his Educational Debt limit his freedom? Yes.

The Clinic will pay $25,000 per year for 4 years so this physician can work where he wants to work - freedom at a price, Meaningful Work at a price. Think about that before you rush off to buy that BMW, get a mortgage on a big new house, and as you consider a costly graduation celebration financed by your new American Express Card.

4. Slavery - a state of being completely dominated by another...

We should remind ourselves of two other definitions:

phil·an·throp·ic

1. showing kindness, charitable concern, and generosity toward other people...
2. devoted to helping other people, especially through giving charitable aid...

pred·a·to·ry adj

1. greedily eager to steal from or destroy others for gain...
2. extremely aggressive, determined, or persistent...
Medical Dependency and the Practice of Predatory Billing by Once Philanthropic Organizations:

In the 1980s, as Human Genetics emerged as a paradigm for scientific medicine, medical care in the United States, and Lancaster County, underwent Transformation. Local Medical Clinics and Community Hospitals, often founded as non-profits with a humanitarian mission to provide health care, were absorbed into Scientific Medical Centers, which transformed into corporate enterprises, influenced more by principles of politics, law, and business than by humanitarian goals, but, none-the-less, most have continued to operate under an IRS Non-Profit Status.

The emergence of corporate enterprise in health services is part of two broad currents in the political economy of contemporary societies. The older of these two movements is the steady expansion of the corporation into sectors of the economy traditionally occupied by self-employed small businessmen or family enterprises. In this respect, the growth of corporate medical care is similar to the growth of corporate agriculture.

The second and more recent movement is the transfer of public services to the administrative control or ownership of private corporations...

In contrast, influenced by the needs and beliefs of the Plain Communities, the Clinic for Special Children has remained for almost 20 years a small, independent, not-for-profit local clinic, whose mission is Humanitarian, and where the remarkable knowledge of modern genetics is routinely translated into better medical care.

We work within a Community of people, who have a deep sense of responsibility to provide care for those who are disabled by age, by misfortune, by mental infirmity, and by complex, chronic illnesses that arise from genetic predispositions to disease. They not only accept this responsibility, but also accept individuals with such problems as important members of their families and communities. They consider the work to care for them important and often interesting. The people, for whom we work - ill children, their families, and the Plain Communities, have constantly influenced our work at Clinic for Special Children. Our meaningful work, and the science and the art that arises from that work, is considered a Gift from our patients to all of us. The understanding, the acceptance, that many common illnesses arise from genetic predispositions and are nonetheless treatable, may finally be the most important contribution of the Plain People to modern medicine.

Improvements in patient care begins with a commitment to care for the patient - as an individual. An individual who is not merely an example of this or that “mutation” but as a person who has varied and complex medical problems and has ask for our help. Frances Peabody in an address to Harvard Medical Students in 1927 summarized this commitment. One of the essential
qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.

The Plain Communities Against a Background of Social Change and an Emerging Industry of Medical Research:

Byler’s Horses - Public Law 761 went into effect on January 1, 1955 and extended Social Security Taxes to farmers, including the Amish. Citing scripture “if any provideth not for those of his own house, he had denied the Faith and is worse than an infidel.” The Amish elders petitioned Congress to be exempt. “To pay SS Tax was to admit that government had responsibility of the Aged Amish Members and to admit this was to deny the Faith.” (Hostetler Amish Society 4th edition 1993, page 270) In 1963 an Amishman named Valentine Byler was working in his field, plowing with three horses when two men from the IRS walked into the field, removed his horses from the harness, then took the horses to a sale barn where they were sold for collection of Byler’s Self-Employment Tax.

The story made its way into the national press and caused widespread public outrage; by this time about 30 horses had been confiscated by the IRS. The publicity about Byler’s story led to a moratorium on IRS “Horse Collections” and, ultimately, led to an exemption in the Medicare Section of the Social Security Act of 1965. Subsection 1402h that allows self-employed individuals to apply for exemption, IRS Form 4029, if they are members of a religious body that is opposed to Social Security Benefits, and the group makes reasonable provisions for its own dependent members.

Two older systems of Christian giving currently exits:

Alms - originally collected to help the elderly who have no income and no, or poor, children. Some Churches like Jesse’s still collect Alms for payment of medical bills. If the local church members cannot provide sufficient funds, then other churches will be asked to donate and multiple collections will be made. The process is slow, and depends upon the effort of church deacons, not the family with the bill. Because the process is slow, time dependent discounts may be lost and bill collection agencies call the family asking for payment but the family is fully dependent upon the good will and resources of the Community and the efforts of their Deacon. By custom, the family may not ask the Deacon to help with the bill. It is fully the Deacon’s responsibility to recognize the need and make the collections for the family.

Good Will Offerings and Collections are still used by the Groffdale Mennonite Church to help dependent members. Quarterly collections are made from about 3500 families distributed throughout the United States. In recent years these collections have increased to $3.6 million per year and most of the money is used to pay for medical bills.
Amish Aid & Mennonite Aid are two self insurance programs that families can join, which are specifically programs for major medical hospital coverage. No family or individual is excluded because of pre-existing condition and fees are the same regardless of medical needs. Approximately ½ of the Old Order Families pay into the Fund. A family pays one $4000 deductible per year for hospital care, and a 20% co-pay for hospital bills. The current the Amish rate is $125 per adult, which includes children under age 18. Last year in Lancaster County Amish Aid paid $9.5 million in hospital bills, an increase from $5 million in 2004-005. This organized effort to pay medical bills has given the Plain businessmen who run the program, who administer the fund without drawing salaries, some leverage to negotiate for discounted payment rates, which are typically 15-25% reduction for payment of the agreed amount in less than 30 days. Rarely, a large bill (>500,000) will be discounted by 50%; Medicare pays about 40% of the billed rate, Medicaid about 20%, which is inflated to compensate for the fixed payment rates. Discount rates for BlueCross-BlueShield, and other private insurers, are secretive agreements. The actual payment rates vary widely among policies because reimbursement schemes are negotiated carefully by businesses and providers, and payment rates are affected by payment exceptions, deductions, and self-pay plans of group and individual policies.

Many failings of modern scientific medicine arise from the disconnection of medical research, medical knowledge, and patient care. A recent editorial in the *Journal of Clinical Investigation* indicates that research support in the past 20 years has overwhelmingly directed physician-scientists to the laboratory and away from patients - 97% of physician scientist who received the Howard Hughes Clinical Research Awards elected to do research that did not involve patients (Goldstein JL 1997). *Less than 3% of money NIH and Hughes Foundation support research of the sort that requires the doctor to shake the hands of those who have the disease to be studied.*

**Stories of Patients and Families are often overlooked or misunderstood within large, modern Medical World:**

Last year, after the Nickel Mine shooting victims and an Amish infant with severe combined immune deficiency were given free care at Children’s Hospital of Philadelphia, the Community took up collections and donated the money to Children’s Hospital, because their families and Community felt unworthy of free care. They believed that other children needed hospital charity more than the Amish children did.

*Willi:*
Because of extraordinary medical costs, pressure from aggressive bill collectors, and with the help from Hospital Social Workers, some families have found loopholes in the Social Security agreement and have applied for Medicaid. One Amish infant diagnosed with a form of sever combined immune deficiency was enrolled in research protocol to prove the efficacy of a new drug called PEG-ADA. Once this Orphan-Drug was approved by the FDA, the cost of continuing the Willi’s treatment PEG-ADA was $35,000 per month. The family was forced into the Medicaid System because the Amish Church could not pay for the drug. At age 19 years, the boy no longer qualifies for Medicaid, and Medicare has refused to pay for the drug. Over the past 19 years many other families have chosen not to start the drug; their infants with ADA deficiency have either gone untreated and died, or have undergone bone marrow transplants, which have a very high failure rate for this disease. PEG-ADA was one of the first “successful” Biotech spin offs from NIH Funded Research by a Non-profit Duke University Research Group. The drug has no competition. Approximately, 200 people are being treated at a cost of $450,000 per year, $90,000,000 per year, almost $1 billion per 10 year period. Those who need the drug are desperate because of a severe illness, and there is not alternative treatment. Is this an example of Predatory Billing? Why does this drug, and others like it, cost so much? I have always wondered what Vitamin B12 would cost were it discovered today. B12 is truly complex and wonderful molecule that cures deadly diseases of the blood and brain. (I was told recently by the VP of a Biotect firm, it would now cost $500 million to $1 billion dollars to market vitamin B12.) Predatory Billing? Unsustainable Economics?

Jesse’s Children:

There are families who do not look for loopholes in the Medicaid Laws and do not join medical insurance programs, but who try to pay extraordinary medical bills with their own resources and Alms. Jesse happens to have 9 children affected by recessive disorders - all treatable, but costly. Although Jesse and his wife have passed on an unusual number of recessive problems, the medical problems within their family is not as unusual as it first appears. The more we learn about the genetic basis of common diseases, the more apparent it is that the majority of disorders like heart disease, diabetes, joint degeneration, mental illnesses of all kinds, and degenerative diseases of the elderly are health problems arising from genetic determinants not unlike those in Jesse’s family that will affect many members of the same family. It is likely that in a family of 4 or 6, most children and adults have health problems that arise from Genetic Predispositions to Disease. The understanding, the acceptance, that many common illnesses arise from genetic predispositions and are nonetheless treatable, may finally be the most important contribution of the Plain People to modern medicine.
You know Jesse. He is a farmer. He works at a difficult job so we can all live easily - we neither labor for food nor worry about hunger. He sells produce at the Leola Auction House in Lancaster County that is bought for grocery stores of Philadelphia and the Main Line and is served by this College and Bryn Mawr Hospital too.

He also sells tobacco for cash to pay the taxes on his farmland, which supports schools that his children do not go to. If you, or your children, went to the Public Schools of Pennsylvania then you benefit from his labor as a tobacco farmer and his property tax.

He and his brothers and neighbors tear down old barns and salvage the chestnut logs and old pine boards for the antique paneling found in some nice houses of the Main Line. This is difficult and dangerous work. When I first met Jesse he told me about a father and son who recently fell and were killed while they were helping him tear down an old timber-frame barn. The house Jesse, his wife, and 10 children live in was built with his own labor, using salvaged lumber from barns and from stones turned up by his plough in his fields.

Jesse trains some of the carriage horses that you may have seen, or enjoyed a ride with, in Central Park of New York City.

Jesse and his family are Impoverished - by his honesty, by their inherited misfortunes, and by the medical bills sent from over 18 years from three different Non-Profit Medical Centers of Pennsylvania. He recently explained to me that in all the years I have cared for his children his family has not been able to use money to buy clothes. His neighbors give them cast off clothes and extra pieces of clothe and his wife makes the clothes wearable again. His family does not have money to buy fancy food like oranges - any the citrus fruit they eat is given to them by neighbors. His cash income, all his savings and his assets were long ago sold, to pay medical bills. Jesse says, “We want to do our part. We try to pay half. We think that’s fair. I know that’s more than some others pay for the same care.”

But half was not enough, 50% of a recent $160,000 bill was not enough. Why would a non-profit Hospital, founded by a family with a Mennonite name, bother to file a law suite to collect $160,000 from someone as poor as Jesse? He has paid more than $500,000 to the hospitals of Pennsylvania - About 20% of this money was his and his family’s, the rest was collected as Alms or Good Will offerings within the Mennonite Church. He offered to pay 1/2 of this bill, but the Hospital refused to negotiate with him. Why? In part, someone in the business and collection offices of the Hospital probably does not like Jesse - has no respect for Jesse and his way of life. I expect some who work at the Hospital hope that as a result of the law suite that Jesse won’t come back to their hospital with his children’s problems. But someone there also knows that Jesse owns valuable land and they believe it is their Legal Right to collect on the value of the land. As a young man, before he was married, Jesse bought his farm for $200,000. He paid off the loan in 8 years, before he was married, and before he and Esther had children. His land is clear of debt and it is valuable - for real-estate for
development, and as farmland. The farm land is Jesse's only remaining asset, and his only means of feeding his family, but the Medical Center wants it, and has a legal right to it, because of the illnesses of his children. Is this a Philatrophic Hospital? Or should this be called this Predatory Billing?

phil·an·thropic
1. showing kindness, charitable concern, and generosity toward other people...
2. devoted to helping other people, especially through giving charitable aid...

pred·a·to·ry adj
1. greedily eager to steal from or destroy others for gain...
2. extremely aggressive, determined, or persistent...

FINIS:

If the miseries of Children with Illnesses, or sufferings of the Elderly or the Mentally Ill is caused, not by laws of Nature, but by our Institutions, then great is our Sin.

If the miseries of Children with Inherited Illnesses, or sufferings of the Elderly or the Mentally Ill, are caused not by the diseases themselves, or by inadequate knowledge, but by Prejudice or Indifference or by Greed within our System of Medicine, then great is our Sin.

Many of you here today will soon become part of this System of Modern Medical Care. Remember Jesse’s story. Remember too the words that Dr. Peabody said to the students of Harvard Medical School in 1929:

One of the essential qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.

Thank you for allowing me to be part of this day.

D. Holmes Morton MD
Gradduations Remembered
&
Thoughts About Your Future Work as Doctors
University of Pittsburgh
May 23, 2011
D. Holmes Morton M.D.

Congratulations, to the graduates, to their families, to those on the faculty who have shaped the lives of these young Doctors. Thank you for allowing me to be part of your celebration.

GRADUATION TALKS

I don’t remember what George Will said when I graduated from Trinity College, which I am sure was more of a reflection on my state-of-mind on that day than Mr. Will’s message.

In 2007 I was ask by the President of Trinity College James Jones to write a letter to the incoming class of Trinity, the class of 2011, which is a tradition started by Dr. Jones. I noticed that Georg Will had written the letter the year before. I read it, thought the letter was brief, professional, and the message was predictable. I spent about 4 weeks working on my “Letter to a Student.” It is 7,511 words, 61 paragraphs, 11 pages – it was a serious essay and was difficult for me to write. This Letter to a Student, written in 2007, is your graduation talk. I’ll summarize the Letter for today, and, tell you how to get a copy of it.

The shortest talk Graduation talk I have given lasted 3 ½ minutes, which as I recall was the length of Lincoln’s Gettysburg Address. My wife & I traveled to the Medical College of Ohio in response to a friendly offer of an honorary degree and a weekend away at a busy time in our lives.

As the Dean showed us the campus, he introduced me as an honorary degree recipient & the graduation speaker, to two groups of students. The first time I didn’t say anything. As we walked away from second group of students I said, “ I didn’t know I was the graduation speaker.” He said, with little hesitation, “I know. We find that if we don’t tell them until they get here they give shorter talks.” I did give a short talk. I said “Learn to Care” I used the idea of Dr. Francis Peabody, spoken to Harvard Medical Students in 1927. One of the essential qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.

I admitted to that graduating class that I was not by nature a friendly or caring person. That I found that caring-for-a-patient required effort, thought, but that I had found that if I made learning about the life of the person being cared-for part of my work that the work of medicine became a rich human experience. The work of Learning-to-Care for the patient helped me value of those I cared for and gave me a sense that my work was Meaningful.
Lewis Thomas spoke at a graduation while I was at Harvard Medical School. This was a memorable talk. Dr. Thomas spoke as eloquently as he could write. He was a pediatrician, a pathologist, was by then President of Sloan-Kettering Cancer Institute, and was a writer. His essays *Notes of a Biology Watcher* appeared in the New England Journal with some regularity when I was a medical student. The text of his talk from the graduation found its way into his final book *The Fragile Species*, published in 1992 near the time of his death.

He spoke, and wrote, about the progress in understanding disease over the 50 since he had graduated from medical school and said that he imagined this new knowledge would help us as physicians. In a similar way in *your Letter to a Student* I write about the remarkable new form of knowledge that is contained in the National Center Biotechnical Information Data-Bases. The Human Genome Project and the vast repository of information found online by searching “NCBI” has become essential to my daily work of caring for patients. Such deep and useful knowledge was not even imagined when I finished medical school in 1983. You too will see a remarkable growth of knowledge too over your professional lifetimes. The need to learn will be for you, as it is for all Doctors, unremitting. Most of the knowledge I use in my daily practice of medicine was learned long after lectures stopped, and, when my most important teachers had become the children I care for. *Active learning is a fundamental part of the job.*

Lewis Thomas made a remark that stuck with me and years later provided the theme for another memorable graduation talk in 2008. Dr. Thomas said his father had told him that when people mention the word ETHICS they were talking about MONEY. I was reminded of that idea as I sat in a traditional Quaker Meeting just before giving the graduation talk at Haverford College in 2008. I began my talk to these undergraduates by quoting Charles Darwin. From his Notes On Slavery 1832-35.

*If the miseries of the poor be caused not by laws of Nature, but by our Institutions, then great is our Sin.*
Charles Darwin, *Voyage of the Beagle*, Notes *On Slavery* from 1832-1835. Darwin was suggesting that enslavement of the endogenous people of South America by the Spanish and other Europeans was the result of flawed human laws and greed, rather than being a lesion in *Survival-of-the-Fittest* or a *Divine-Right* that was imagined by some to allow one group of wealthy and powerful people to own and use another. Charles Darwin noted that *Enslavement* often involves the poor. Impoverished people were easily “enslaved” today too.

*If the miseries of children with illnesses, or sufferings of the elderly or the mentally ill are caused, not by laws of Nature, but by our Institutions, then great is our Sin.*

*If the miseries of Children with inherited illnesses, or sufferings of the elderly or the mentally ill, are caused not by the diseases themselves, or by inadequate knowledge, but by prejudice or indifference or greed within our System of Medicine, then great is our Sin.*

And that phrase was spoken there too: *One of the essential qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.*
You might imagine how these phrases evolved as I sat in the Quaker Meeting before the commencement ceremony thinking about children and families I care for whom have become impoverished, enslaved, by complex genetic illness and modern medical costs.

The talk was later published in the Haverford College News about graduation and found its way into the hands of Max Muenke, who regularly attends Quaker Meeting in that area of the Main-Line-Philadelphia. Max and I were fellows together in 1986. He has done much fundamental work in brain mal-development of holo-prosencephaly, and over 20 years has maintained a lab at University of Pennsylvania and NIH and for 17 years has directed the fellowship programs of NIH. Our children and the Muenke’s were the same age. Our families got together for birthday parties. Anyway Max’s wife read the essay then sent a copy to their son Nikolas. In response, Nikolas wrote me a long and thoughtful letter saying he wasn’t sure he wanted to be a doctor; he knew he wanted to do something different from his father. He found my essay interesting and he said he would like to work at the Clinic for a while. He came and stayed two years, worked in our lab, then married our daughter Sarah. They live in Freiburg Germany now – she is a painter and can work anywhere; he will attend medical school at the University of Freiburg in the Fall. So, you never know about the tangled consequences of graduation talks.

THOUGHTS ABOUT BEING A DOCTOR NAMED HOLMES MORTON - FAMILY & WORK

A few months ago I spoke with a physician at Children’s Hospital who told me she had just interviewed a student from this class at Children’s Hospital of Pittsburgh who when ask about his goals said, “I want to be Holmes Morton.”

Apparently, they didn’t hold this notion against him, and offered him a residency position in Pediatrics.

A few weeks later the same student sent me an email asking me to give his class’s graduation talk.

I decided I should talk briefly with you about a subject I can discuss with some confidence – being Holmes Morton. Also about Value – which is a commonly used word in medical essays today. How do I, and the families I serve, “Value” the work of caring?

Midnight, January, 15, 1997 - Half asleep, I am waiting for amino acids to finish running. A blood sample was brought in by a hired driver from a hundred miles away. A sample from a new baby who I find does have maple syrup urine disease. He is not ill, and because of timely diagnosis, he can be easily treated. His sister will be happy to have a brother to share her special diet and formula with. He is the fourth child for these young parents, their first son, the second of their children with the disease. His mother is 25 years old and has four children, two with this disease. How much of the next 20 years of her life will be given to this child and his trouble? How many hours of my life will he claim? I always think of that as I examine a newborn with maple syrup disease or glutaric aciduria or Crigler-Najjar disease - each child takes, needs, defines another piece of my life, a few more hours from nights and holidays, a few less hours of needed rest or reading or writing or playing the cello. Meaningful work? Yes. No doubt what I know, what I learn helps these children - interesting life, interesting work too. Exile too? Yes. Child by child, hour by hour as I am needed, my future is taken, decided, shaped. Yours too? Unaware, have these children
already begun to take your time, your life? Was that part of the cost of coming here, searching for, seeing, meaningful work? Was that the ultimate cost of looking into the eyes of such children? Will you give them that much? (From a letter to a medical student)

In my office hangs a large oil painting 6-9 feet that was painted by Sarah McRae Morton, our daughter. In the history of painting large canvases like this were reserved for kings & queens, General Washington, and Christ figures. This painting was done as part of a series of large figures and landscapes depicting common places, people and events that shaped the lives of my family. The paintings are allegorical. Her violation of the Rule-of-Largeness, replacing Royalty with the Commonplace in a painting of large size, was intentional. This particular painting was based upon a photograph taken by wife’s Uncle Bill in 1939. He was standing on the mine-face above the entrance to deep-mine as coal-cars emerged carrying bodies of miners. A crowd of people from the small town of Raleigh West Virginia crowd along the tracks. In the last mine-car, prominent in the foreground of the large painting, are two men – my wife’s Father & Grandfather – Bill’s Father & Brother-in-Law. They were doctors in the Community of Raleigh West Virginia in 1939 and had gone into the mine to help bring out injured miners and the dead.

Caroline’s father practiced in that area of West Virginia for 45 years. Her grandfather practiced in the same small town of Raleigh for 65 years, into his 80s. The manner in which they worked and lived within a Community was not unlike our work at the Clinic. The effects of their work upon the lives of their families and families they served was similar to ours. The work of medicine was a way of life, not only for the doctor but also for the family. My wife has said that one reason we were able to start the Clinic For Special Children and work as we do was because she knew what the life of a doctor was like, and it was not easy.

Caroline and I were married just before I started medical school. We had children born during medical school, residency, and during fellowship. There is much I do not remember about the first years of our children’s lives. I was gone, often on-call, always distracted by work, and as I recall when I was off I was weary. After those 10 years of medical school, residency and fellowship, we left the university medical centers for Lancaster County and founded the Clinic. Our children were immersed in our work too – for 10 years I was the only Pediatrician at the Clinic. There were no family vacations and few real days-off. There were many missed ballgames, interrupted holidays, late dinners and I was often gone before breakfast too. My wife ran the business of our small non-profit clinic – she help design the building, picked-out paint-colors, door-knobs and lights, paid bills and pay-roll, handled audits, insurance, fund-raising-newsletters and events, and wrote those all important thank-you letters to donors. While we worked our three children were at times left to run around Amish farms, sometimes we found Mary and Sarah in Amish dresses with their hair rolled and tied into a bun. They went on house-calls too, often hours away.

The work took its toll. I recall daughter Sarah, the painter, as a teenager, saying more than once, “Clinic-Clinic-Clinic that is all we ever talk about! Tonight at supper for once we are not going to talk about that. We are going to talk about something else.” Sarah’s paintings have many complex and interwoven messages, but *Banks & Smith in Raleigh 1939, The Death of Enos, Amos’ Child, American Cannon, The Allgyers at Prayer* were painted large because the people, events, and landscapes depicted in her work shaped the lives of all of us and provided a foundation for her as a person and painter. *The work of medicine was for us a way of life, not only for the doctor but also for the family too.* (To see the paintings mentioned in this essay visit <mcraemorton.com> or search on-line for Sarah McRae Morton, a Fine Painter.)
My wife and I are at a time in our lives when we see in our children the influence of our choices, and our work. None of our children has decided to become a physician. They found other work to do. Our son Paul is a classical guitarist. He plays the Bach Cello Suites on a classical guitar with musical skill and an ease that I can only dream of. He looks for his music in the complex compositions for guitar by Heitor Villa-Lobos, and Augustine Barrios. Sarah’s ability to translate experiences and words into paintings came, in part, from years of study to develop technical skills with lines, shadows, composition, and color. But, her art has a restless quality too. She is watching for an instant, an image, that expresses the idea of the physician-writer Carlos Williams who said, “We catch a glimpse of something, from time to time, which shows us that a presence has just brushed past us, some rare thing .... For a moment we are dazzled.” Her artistic search seems familiar to me. It is a search for “Meaningful Work.” The oldest, named Mary after both of our Mothers, for a while moved quickly around a laboratory sequencing genes of people, or trout, with ease, but, as a biologist she felt more at home along a mountain stream than in a laboratory. She sees falling water with the eye of a geologist too. She knows the ancient records of mountain building and erosion. She can name exposed strata and predict the forms of fossils found in each ledge. As a biologist she can think about the consequence of interrupted migrations of trout from the Atlantic into inland fresh water streams. Streams that ever-so-slowly rose with mountain-tops, and finally held a but few of the ancient progenitors of today’s Brook Trout. Separated from the ancients by not only by Place but by adaptations within a finely woven net of sunlight, dark and seasons, ranges of weather and temperature, water, dissolved minerals, and cycles of forests and insects. Linked to the ancients by continuous life and by a fine thread of genes to be read by Mary’s generation like the Rosetta stone. She took her knowledge of Biology, Geology, and Genetics to graduate school in journalism where she learned to write about scientific problems, as a professional, as her father never did.

TIME & INSIGHT

My friend Leon Eisenberg, who was a child psychiatrist & Chairman of the Department of Social Medicine at Harvard Medical School, wrote that “Time is the Currency of Pediatric Care.” Pediatrics 102, 1998. Time to listen. Time to make diagnoses and sort out therapeutic alternatives; Time is not measured simply by the length of visits, but by the multiple visits needed to provide continuity and establish lasting ties….. He suggested that Time is important to the humanistic task of caring for a patient.

I agree with Leon, but I would add that Time is also fundamental for gaining knowledge, gaining an understanding of the disease natural history, pathophysiology, and management. This is as true for Translational Medicine as it was for medical care based upon pathophysiological models. Time is a fundamental unit of discovery, learning, sustained memory, and that essential component of actionable knowledge called Insight.

Each summer for the past 26 years I have given a Lecture at the National Youth Science Camp in West Virginia. The lecture is often about the disorder Glutaric Aciduria and begins with the passage from a story of mine called Amos’ Child.

His mother said, We hoped he was not like our others. He seemed all right. He sat-up and walked when he should have. But then it happened. He was 18 months old. He had a cold and a fever. He seemed tired, so, I put him
down for a nap after lunch. When I checked on him two hours later he was helpless. He couldn’t hold-up his head
or swallow, he couldn’t sit, no strength was left. We knew then he was like the others, there was no other reason for
it.

Amos and I just sat together and cried for a long time before we took him to the doctor. We knew the doctor
would send us to the hospital. But, we knew that after all the pain and tests and money there wouldn’t be any
answers. Nothing could be done for him either. (The mother of an Amish infant with Glutaric aciduria in 1988,
From the story Amos’ Child)

My lecture will be about infants who have an inherited disorder of biochemistry called Glutaric aciduria,
type 1. Glutaric acid is a five carbon dicarboxylic acid, which accumulates within the brain and other organs, and
derives from the deficiency of a dehydrogenase enzyme in the degradation pathway of two essential amino acids,
Lysine and Tryptophan. The genetic disease is characterized by sudden, stroke-like injuries within a region of the
brain called the basal ganglia that leaves infants helpless. Injury of the basal ganglia occurs before 18 months of
age, older children who have escaped injury are normal.

I will describe my work as a physician to provide medical care for these children, understand the disease,
and translate that understanding into a new therapy to prevent brain injury. The lecture presents information from
molecular biology and biochemistry, neuroanatomy and neurochemistry, which is used to develop a complex
pathophysiologial model of the disorder. It is a complicated lecture, not unlike I would give to experienced
physicians and neurobiologists. I expect the students at the Camp to feel a little overwhelmed by the difficulty of
the problem. I explain that I have studied this disorder for 17 years. My medical career has been consumed by the
effort. I tell them about the simple clinical observations that led me 17 years ago to believe that the injury should be
preventable. I explain that medical care has improved over 17 years – 80% of children now escape injury, but, still
in 20%, treatment fails.

I always start this lecture by playing a piece from the Bach cello suites, the Sarabande of the 5th Cello Suite,
and then I say to these intelligent young men and women -

If I would ask you to listen to a recording of the Bach Cello Suites and become familiar enough with the
music to name the number and key of one of the Preludes or a Sarabande that kind of learning would present little
difficulty. Such learning is typical of most school-work. In contrast, if I ask you to learn to play this same music,
well, and from memory, with an appreciation for the complexity of the music and with the kind of controlled
expression that makes the cello playing of Pablo Casal’s distinctively different from the playing of Mstilav
Rosropovich, you would find this a difficult assignment, regardless of your musical aptitude. My message to you is
that the most significant learning that you will do over your lifetime is similar to learning to play the Bach’s Cello
Suites. Significant learning takes Time - sustained effort, sustained interest, tolerance of frustration, and tolerance
of failure. I do not have much musical aptitude. I have a poor ear for music, yet, my sustained interest, my stubborn
determination to learn, my willingness to practice day after day, the great value I assign to the task of learning the
cello, allows me to develop skills over time. The talented student who has no interest, makes no effort, assigns no
value to the task of learning to use his or her talent, will never play the Cello Suites.
The difficult problems we face in translating knowledge into effective medical care require sustained effort, tolerance of uncertainty, and an acceptance that the reward of hard work is as often failure. Over the past 20 years, I have spent more than 20,000 hours of my life working to understand the effects of maple syrup urine disease and glutaric aciduria upon the brain. Working to develop methods of diagnosis and treatment that will rescue patients from the metabolic crisis that cause coma, brain edema, strokes, mental retardation, and a lifetime of disability. Medical treatment of these problems is now available, but success comes at a high cost in terms of effort, time, and money. However, we must never forget that the costs of failure are much higher – in terms of effort, time, money, and human suffering too. (dhm, Notes from a lecture at the National Youth Science Camp, The Cello and the Brain.)

In 2011, for the first time, I will be able to describe our greater than 95% success in treating infants with this disorder. We will publish a paper this summer describing improved outcomes over a 5-year period – the result of careful observations by Kevin Strauss - that show an important predictor of brain intoxication with glutaryl-CoA is the plasma lysine-to-arginine concentration ratio. Keeping this value less than 1 – that is, the arginine concentration greater than the lysine concentration, limits the transport of lysine into the brain via the (y+) transport system by 50% and results in a significant reduction in basal ganglial strokes in affected infants under 2-years of age. In 1988, when I first went to Lancaster county, 95% of infants were disabled. By 1995, 50% of infants were successfully treated. Between 1996-2005, successful treatment outcomes increased to 67%. Over the past 5 years, 12 of 12 infants have been kept healthy. A real sense, this was Kevin Strauss’ discovery, he made the statistical observation. He understood the theoretical interaction between arginine and lysine at the blood-brain-barrier, but much more important, he was able to show that this variable could be controlled in patients, well and ill, over a critical period of time in brain development and the statistical difference made a difference in their young lives. My contribution to the work was that I doubted that those variables were important and that control was possible and gave him the opportunity to prove me wrong. More important, my wife & I, 21 years ago started a unique place, created a paradigm of medical care, where Kevin Strauss could work, and this specific observation could be made.

Scientists who work as physicians and care for many patients with the same genetic disorder over long periods of time develop a different understanding of genetic disease than scientists who study disease mechanisms in cell cultures in the laboratory. It is often through the daily work of a physician caring for a patient that new opportunities for treatment are realized.

The every day practice of medicine is a frontier of Translational Genetics. The medical care of a child with a genetic disorder is no different than the care of a child with other complex medical problems - diabetes mellitus, depressive illness, rheumatoid arthritis, seizures, and many other chronic troubles come to mind. As with the majority of diseases treated by physicians, there are few perfectly treatable genetic disorders. Nonetheless, improved understanding of disease mechanisms, combined with accessible and effective medical care can often decrease suffering, improve function, reduce dependency upon others, and otherwise limit the effect of disease, genetic and acquired, upon the life of a patient.
The understanding, the acceptance of the fact, that many common illnesses arise from genetic predispositions, but are nonetheless treatable, may ultimately be the most important contribution of the Plain Communities and our Clinic for Special Children to Translational Genomic Medicine. (DH Morton, The Doctor in the Time of Genomics 2010; and, Morton DH et al. (2003) Pediatric Medicine and the Amish & Mennonite People of Pennsylvania. Am J Med Genetics (Seminars in Medical Genetics) 121C:5-17.)

SMALLNESS AND THE PRACTICE OF MEDICINE – A DIFFERENT PARADIGM

The Sociologist, John Hostetler, who as a boy lived within the Amish Society that he later wrote about, said that a fundamental feature of the Amish Community is smallness - there are usually 10 families within a Church District. Every other Sunday these 10 families travel by horse and buggies, or walk, to one of the 10 homes to attend Church. The size of the district is limited by the travel time of a horse and by the size of the typical Amish home. John also said that the Amish people should not be considered backward or archaic, but they were Modern People who have chosen to live in the modern world in a way different from us.

The Clinic for Special Children is similar to the Amish Community in these two ways. We are a small medical practice, by design. We choose to work within the field of medicine in modern-times, but have not adopted the Modern Medical System as a model - either as a scientific model or a business model. We use modern technology, but with a different focus, for a different purpose. We are biologist, pathophysologists, and molecular biologists who happen to make our living caring for children who have genetic predispositions to disease. We do what we call Small Science - Basic Research on a small scale. The fundamental unit of our work is the Case Study. Translational Medicine is in our Clinic practiced everyday, involves the care of the individual child and her family.

A SENSE OF PLACE

Not long ago I rode an airplane to Boston to lecture at Children’s Hospital. The Amish have a rule that members of the Old Order must stay in touch with the earth, which is why the wheel rims of buggies, farm-wagons, and ploughs are steel and why the Amish are forbidden to travel in airplanes. Leaving Boston, as I was pulled into the night sky and watched the city below become motionless and silent, day and place diminished and I thought, the Amish are right, we should stay in touch with the earth. Having thought of this, it seemed fitting to me that I went back to Boston by airplane to give my lecture. In the school and hospital where I was for seven important years, where many friends and teachers remain and welcomed my return, I was out of place. My sense of place, to use the phrase as Wallace Stegner does, is in Lancaster County in a small clinic surrounded by a field worked with mules.

I recently wrote to David Nathan, a teacher of mine in Boston, I cannot be sure that what I learn in Lancaster will be of any lasting medical or scientific significance, but, I do know that my work here has lessened the misery of the children and families who depend on the Clinic and me. That is for me sufficient reward and justification for whatever opportunities were lost when I decided to leave Boston. Many of us who trained at Children’s hoped to stay in university hospitals, few from such hospitals have valued these children or this work in
Lancaster County as I do. In Boston, others soon took my place, here I would have been missed. (Morton DH: (1994) Through My Window - Remarks at the 125th Year Celebration of Children's Hospital of Boston. Pediatrics 94, 785-791.)

FINAL THOUGHTS

My Letter to a Student written in 2007 is your graduation talk. Most of the readings in this talk were drawn from that essay. If you write to me I’ll send you your copy - <dholmesmorton@gmail.com>. Mike Fox also has my address.

Holmes Morton is a pediatrician. I also have some skills as a biochemist that I use to diagnose, treat, and study inherited disorders of metabolism. Most of the children I provide care for have illnesses with a genetic basis. Some of these genetic disorders are quite treatable; the children grow and develop normally. Some of the disorders are lethal, affected infants and children live only a few days or a few years. My work as a doctor and biochemist is fairly ordinary, such work is done by doctors and technicians elsewhere. But to the Community of people served by the Clinic for Special Children, for the individual child in need of such care, the work at the Clinic is extraordinary. I have found what my friend Wendell Berry calls Meaningful Work.

Throughout your lives as Doctors search for Meaningful Work. There is much to be done.


QUOTE FOR THE PITT MAGAZINE: HOW WOULD I SUMMARIZE THE TALK?

“Learn to Care.” In the sense of Dr. Francis Peabody’s famous talk to Harvard Medical Students in 1926 titled “The Care of the Patient.” One of the essential qualities of the Clinician is interest in humanity, for the secret of caring for the patient is in caring for the patient.

I understand that I am not by nature a friendly or caring person. For me caring-for-a-patient requires effort, thought. If I make learning about the life of the person being cared-for part of my daily work that the work of medicine becomes a rich human experience. Learning-to-Care for the patient helps me value of those I care for, and, adds to my sense that my work is Meaningful.

Learning-to-Care requires that you spend Time with those you care-for. Time is a fundamental unit of discovery, learning, sustained memory, and that most important kind of knowledge called Insight.

Scientists who work as physicians and care for many patients with the same genetic disorder over long periods of time develop a different understanding of genetic disease than scientists who study disease mechanisms in cell cultures in the laboratory. It is often through the daily work of a physician caring for a patient that new opportunities for treatment are realized.

The every day practice of medicine is a frontier of Translational Genetics. The medical care of a child with a genetic disorder is no different than the care of a child with other complex medical problems - diabetes mellitus, depressive illness, rheumatoid arthritis, seizures, and many other chronic troubles come to mind. As with the majority of diseases treated by physicians, there are few perfectly treatable genetic disorders. Nonetheless, improved understanding of disease mechanisms, combined with accessible and effective medical care can often
decrease suffering, improve function, reduce dependency upon others, and otherwise limit the effect of disease, genetic and acquired, upon the life of a patient.

The understanding, the acceptance of the fact, that many common illnesses arise from genetic predispositions, but are nonetheless treatable, may ultimately be the most important contribution of the Plain Communities and our Clinic for Special Children to Translational Genomic Medicine. (DH Morton, The Doctor in the Time of Genomics 2010; and, Morton DH et al. (2003) Pediatric Medicine and the Amish & Mennonite People of Pennsylvania. Am J Med Genetics (Seminars in Medical Genetics) 121C:5-17.)

NOTE: The JAMA article derived from a talk given by FW Peabody to the students at the Harvard Medical School at Boston City Hospital on October 21, 1926 – “The Care of the Patient.” Peabody’s wife remembered him saying, “I am absolutely sure that this little lecture will be remembered long after anything of a scientific nature I have written has been forgotten.”
Auction Remarks Lancaster County
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September 20, 2008
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PRELUDE TO THE BENEFIT AUCTION
On Wednesday September 17, 2008 I took Tom Beeman, the CEO of Lancaster General Hospital, to the home of Jesse and Esther Martin. Jesse and his wife Esther, and 9 of their 11 children were there to meet Mr. Beeman. Henry and his brother were working in the tobacco field near the house. Jesse’s father and three of his brothers were also at the meeting. Jesse told his story of an 18 year history of medical bills that included three surgeries for Hirschsprung’s disease, two bone marrow transplants, a long hospital stay for acute renal failure caused by hemolytic uremic syndrome for one otherwise healthy son, two farm accidents requiring trauma surgeries and long recoveries, and recurrent hospital stays for each of five of his children with maple syrup urine disease, including the twins who were premature and had maple syrup urine disease. He had paid over $400,000 from his own earnings and the Church Community had helped as it could, but his bill at Lancaster General Hospital remained over $196,000. He said with all these bills he had offer to pay ½ of the total, which he knew was more 10% than Medicare pays and 200% of what Medicaid pays. Regardless of these complex problems as Tom Beeman met the children of Jesse and Esther, he saw healthy and happy children.

The bill was settled, marked paid in full. Mr. Beeman commented that he is a religious person, he is a devout Catholic educated by Jesuits. He said he shared with Jesse and his Community a belief that medical care is not a share obligation. That he, and the hospital he worked for, had respect for the Plain communities, was there to serve these Communities, and had no intention to take land or equity from the land in payment for bills, or otherwise impoverish families who accidents or illnesses. He told Jesse and Esther that they, their children, and others in the Community were always welcome at Lancaster General Hospital.

After our visit I sent Mr. Beeman a note to remind him of the history of the Catholic Church and the Anabaptists. I said that Jesse and his family may be aware of the irony of receiving help and reassurance from a Jesuit Catholic through their reading of Martyrs Mirror. Perhaps the help the family received should be seen as Atonement for long-past trouble.

Dear Tom there are others who know the history of the conflicts between the Anabaptist & Catholic Churches better than I do, but when we were at Jesse Martin’s home I was sensitive to the irony of your reference to your Catholic faith being, in part, the basis for empathy with Jesse’s
problem, and for your interest in finding solutions to high health care costs so that medical bankruptcy does not continue to threaten land ownership and the Anabaptist way of life.

Within the Anabaptist Community Martyrs Mirror is a traditional wedding gift, and is constantly used in church services to preserve the memories of the Martyrs. It was the religious tolerance of William Penn, and the good farmland, that attracted these people to Lancaster County. I am sure the historians Amos Hoover, a friend who owns several of the earliest copies of Martyr’s Mirror, and Don Kraybill will be very interested to know that the fate of the Plain Community may be significantly influenced by a person educated by the Jesuits. This effort might even be perceived as a kind of atonement.

Best,

Holmes

FOR YOUR INTEREST THE ONLINE VERSION OF MARTYR’S MIRROR CAN BE FOUND AT:

http://www.homecomers.org/mirror/intro.htm

MARTYRS MIRROR of the DEFENSELESS CHRISTIANS

INTRODUCTION TO MARTYRS MIRROR

We admire those willing to die for what they believe, and we pay attention to the last words of those we admire. The book Martyrs Mirror consists primarily of final messages from Christians in jail, joyfully waiting to die for their faith. Most of Martyrs Mirror describes the persecution and execution of thousands of Anabaptists in the Low Countries between 1524 and 1660 (plus Germans, Swiss, Austrians and other Europeans). Martyrs Mirror contains their final testament to the world.

Though based on earlier works, the present Martyrs Mirror was first published in 1660, a hundred years after the worst persecutions, by Thieleman J. van Braght, a Dutch Mennonite pastor. By the 17th century, his native Holland was one of the most prosperous nations on earth, and van Braght saw that his fellow Anabaptists were sinking back into the complacency their spiritual forefathers had left. In this sense, his day greatly resembles our own. Today his book is a traditional Mennonite or Amish wedding gift.
Martyr’s Mirror is about Christians who discovered God wanted more for His people than they had ever imagined. Because their transformed lives set them apart, they were criticized and even persecuted, meeting in secret, anticipating arrest, but often winning the respect of their neighbors, even winning converts from those who watched their patient executions. The people memorialized in this book wanted to restore the glory of God’s original plan for His Church, and often testified they saw at least a glimpse of it. They laid the plumb line of the Gospel to their lives, and as best they could, sought to adjust their lives to match Christ’s example, instead of reinterpreting Christ’s example to fit their lives. They did not serve a weak God.

Living 450 years ago, and called Anabaptists by their enemies because they insisted only believers could be truly baptized, these people typified the "Radical Reformation" which questioned literally every human tradition that had propped up the state church for a millennium and a half. Refusing to defend themselves with political or military power, this people’s influence spread even under persecution and foreign occupation. Perhaps one-tenth of the inhabitants of the Low Countries (now Holland and Belgium) came to believe as the Anabaptists did, despite mass tortures and executions under the Inquisition of their Spanish rulers.

Once the Spaniards were driven out of the Low Countries by Protestant patriots in the later 16th century, the executions and tortures stopped. But persecution continued in Europe, causing some of the most earnest followers of the Anabaptist dream to immigrate to North America in the 18th and 19th centuries. The largest group, the Mennonites, includes members, missionaries and relief workers throughout the world, of all races. The largest Mennonite groups are in North America and Africa. In Germany, most Mennonites are from the former Soviet Union. The Hutterites still live in farming communes in the Great Plains and Prairie Provinces of the United States and Canada. Though the conservative Amish disappeared entirely from Europe by the 1930’s, their numbers are increasing in North America with each generation. Today many other seekers, without affiliating themselves directly with these older groups, have aligned with the Anabaptist vision.

Jan Luykens created the original etchings for the second edition of Martyrs Mirror, some of which were later discovered in a box that had survived World War II Germany. Most of the original plates are still lost. Luykens, like van Braght, was a 17th century Dutch Anabaptist pastor and writer who also illustrated a classic edition of Pilgrim’s Progress.
Though most of the persecution described in Martyrs Mirror was directed by a single international religious organization under state authority, the greatest danger to our souls today is not any particular denomination, but any religious tradition that intertwines itself with the world system and relies on state support. The complete book, which is in the public domain, is available from Herald Press (Scottdale, PA and Waterloo, ON). Convinced that we desperately need to drag ourselves from a slumber which rapidly looks more and more like death, Martyrs Mirror has been placed online for the glory of God.

ABOUT ONE HUNDRED PERSONS CALLED WAL DENSES, BURNT FOR THE FAITH, AT STRASBURG; THIRTY-NINE AT BINGEN; AND EIGHTEEN AT MENTZ, A. D. 1212

A. D. 1212, the true doctrine of the Gospel began to manifest itself to a great extent in Alsace, among the Waldenses, who were one people and of the same faith with the Albigenses. But the prince of darkness, unable to endure this great light, exerted every means to extinguish it, so that in said year, in Strasburg alone, about a hundred persons, men as well as women, were burnt alive on the
same day, for this confession, by the servants of antichrist, particularly through the bishop of that city.

Concerning this, the papistic writer H. Mutius writes, ‘A. D. 1212 a heresy arose in Alsace, by which noble and ignoble were led astray. They maintained that it was lawful to eat flesh every day throughout the whole year, and that there is as much excess in the immoderate eating of fish, as of any kind of flesh.’ Again, ‘That they do very wrong who forbid marriage; since God has created all things, and everything may be used in a holy manner, with thanksgiving.’, ‘This, their opinion,’ he writes, ‘they maintained very firmly, and many believed them. Moreover, they did not hesitate (hear how the papists speak) to revile the most holy lord, the pope, because he prohibited ecclesiastical persons from marrying, and bade them abstain on certain forbidden days from some kinds of food. The pope of Rome therefore commanded that these people should be made away with and put to death. Hence, about a hundred were burnt together on the same day, by the bishop of Strasburg. H. Mut., Chron. lib. 19. (From the English-On-line Version of Martyr’s Mirror)
Henry gave me a simple bird-house. It was made of scrapes of wood, a patch of metal roofing, nails, and in his free time after a day of hard farm work. There are about 16 small new nails, the other nails along the roof are old, reused. The peg for the bird to stand on is a hand-made square nail made by a blacksmith probably more than 100 years ago. The cost to make this house is less than 10 cents, but I ask you “What is its value?”

The house is made of weathered wood, sheltered by a curved corrugated metal roof, and is sturdy. It will last through many generations of wrens or gold-finches or bluebirds. From each family that nests here will come many more birds. Imagine an endless unfolding small birds whose lives began and were sheltered by this simple, safe place that Henry made. “What is the value of song birds in the fields and wood near your home?”

“Here,” Henry said, “This is for your Auction.”

It was not many years ago that almost half of the children with his disease died long before the age of 17, and many of those that did survive could not work on a farm, as he does, or make a bird-house. We should be thankful just for his ability to make the house. We should always remember, Such is the final purpose of our work as doctors. Not just money, not just research or publications, not how many visits per year to a doctor or hospital, the final purpose of our work is the quiet continuation of the ordinary work and events in the life of a person like Henry.

This bird-house is also like the house Henry grew up in. When I first knew the family of Jesse, at the time Henry was born, they lived in an old and small log and board structure that was on the property when Jesse bought the farm. Part of the work of Jesse and his brothers is to tear down old barns and houses and salvage logs and lumber that are reused, often in fine new homes along the Main Line west of Philadelphia. From such salvaged materials Jesse and his brothers built a sturdy, warm and dry house for a family of 13. Their house, just like Henry’s bird-house, was made from material saved and refashioned into a home that will last for many generations. All of us, who live in world where so much is thrown away, wasted, undervalued - could learn something from the example Jesse, Henry and his family.

Here, Henry said, this is for your Auction. The bird house is a gift from Henry himself to help others. He knows that is part of his place in his family and in this Community. This auction, the quilts and furniture and food and auctioneers all the hard work of this day come from people shared this sense of Community purpose. Each item sold here today is a gift and each has its story of how it came to be here. Henry has learned this - feels this. The bird-house takes its value from this purpose too.

The day Henry gave this house I had gone out to the home to arrange a meeting with
Tom Beeman, the CEO of Lancaster General Hospital, who wanted to meet with the Martins in their home and work out a way to help with their medical bills. We had this meeting. Having gone to the home, seen the children we care for, and heard Jesse’s story, he understood their need. He helped solve their problem.

After we had settled the bill for Lancaster General Hospital, Jesse remarked that he still had a bill at the Clinic of almost $9000. I said, “We’ll talk about the bill at the Clinic after we see what Henry’s bird-house brings at the Auction.” I heard Lena, Henry’s younger sister, snicker about that bird-house. She didn’t know how valuable, how important, Henry’s gift was. Lena and Henry are here today. I thought it would be good for them to learn what a gift can bring....

There is a story I enjoy about an auctioneer who tried to sell an old fiddle. At first there was no interest, no offers were made. A Master of the instrument stepped forward and played the violin. From the weathered and worn violin came the beautiful old music of Bach. Everyone then knew its value, and it sold for a high price. I have told you about the Meaning of Henry’s Gift. And, it is a good bird-house too.

NOTE: The bird-house was sold for $6,200 to an Amishman, he is a young man that has a good business, and a child we care for at the Clinic. Henry, Lena, and all of us learned something about how some ordinary thing became Meaningful, and about Giving, and about how fortunate we all are to live in such a Community such as this. dhm 9/21/2008
Remarks at the 16th Clinic for Special Children Benefit Auction.

Held at the Leola Produce Auction on Brethren Church Road
September 16, 2006

Prayers are said, and prayers are answered, in many ways.

I am often asked what I think about when I stand before this crowd. I remember an evening in August 1989, 17 years ago. I was driving from Baltimore to our home in Saint Davids. I stopped along the highway to think about what to do. By then I knew there would not be grant money from National institutes of Health or Johns Hopkins to support my studies of glutaric aciduria. By then I knew my research fellowship at the Kennedy Institute would soon end, and there would be no job from there. By then too I was supporting our family entirely by working nights and weekends in the newborn intensive care units of Bryn Mawr and Harrisburg Hospitals, which was difficult work and would not help the Amish families with glutaric aciduria. I had on that day decided to come to Lancaster to work as a pediatrician, but I had no idea how to start a practice, set up the laboratory I would need, or build a Clinic. My former teachers in Boston at Harvard Medical School and Children’s Hospital told me the move to Lancaster County would end a promising career in academic medicine. My wife, Richard Kelley, and my father were supportive, but were understandably worried. A few Amish and Mennonite families knew about the idea of Caroline and me to start the Clinic, but they were understandably skeptical that such a Clinic could be supported by them, and were doubtful that the other members of the Plain communities would help. On that rainy day in August, the Clinic for Special Children, as we know it today, seemed an unlikely dream.

I cannot say how long I sat by the road that day, or what new ideas I may have found. I remember at one point there were tears of frustration and disappointment in my eyes. I said to myself out loud, “If this ever works out, I hope you will always remember this day. I hope you remember how difficult this time really was.” Every year for 16 years, as I have looked out over this crowd, I do remember that Time.

Most of you know about the writer Frank Allen and how his story about the effort of Caroline and me to start our Clinic appeared on the front page of the Wall Street Journal on September 19, 1989. His writing changed our lives, and the lives of all who are here today. The Benefit auctions for the Clinic for Special Children started in September 1991. This is the 16th year this gathering has taken place to support our work. Whatever new ideas were found that
gray day along the highway from Baltimore are long forgotten. The solution to the problems we faced were unimaginable.

**Prayers are said, prayers are answered, in many ways.**

Each quilt, each piece of furniture, the pictures, the music boxes, the work of those who help with this auction in so many ways - each has a story. I always imagine the conversations, the memories, and at times the sadness, at times the thankfulness, that inspires the work of this day.

Last year the Postage-Stamp quilt was bought by a family from Florida who in the winter of 2005 brought their child to the Lancaster General Hospital, severely ill from Maple Syrup Disease. They left the large medical centers of Florida and came to Lancaster County for help. Not just because of Dr. Strauss and me, but because a whole community of people over many years have worked to care for children with this difficult disease. We all know that the lessons were often difficult.

In the early years, 1966-1986, death and sadness often were the inspiration for the Mennonite community to look for new and better ways to care for these children. Before the Clinic was started in 1989, 40% of children born with Maple Syrup Disease died of brain edema before their 10th birthday. Among those who survived mental retardation, difficulty walking, and other disabilities were a common problems. Today, that has changed. From 1989 until now there have been no deaths from cerebral edema, children learn to walk, ride bicycles, and they go to school with their friends. But the transformation did not come easily.

In the first years of the Clinic when I worked alone there many difficult problems to solve. I found that one advantage of working by myself back then was that when a decision did not give the result I expected, that I didn’t need to waste time thinking about who made the wrong decision - it was me. I could move right along to the task of solving the problem. The little girl from Florida survived because of the community of people that are here today. When I look at the Postage Stamp quilt, and I know that the same person has made this same quilt for this auction year after year. I know that in her husband’s sister’s family three children died of Maple Syrup Disease, and the one girl who survived was badly crippled before the Clinic started. I imagine that each piece of the quilt has a story, a remembrance. It is a quilt that was inspired both by sadness and by hope.

**Prayers are said, Prayers are answered, in many ways.**

I am often asked what about the Clinic after you can no longer work. Does it have a future? The Future of the clinic is all around you. The future of the Clinic for Special Children is a gift from God’s Special Children, not only to others children like them who need our help,
but to all of us. They make us better people. They make this a better community. They make this a better world.

In 1993 I was given an award called the Albert Schweitzer Prize. It was a great honor, which I did not think I deserved. The Prize was named after Dr. Albert Schweitzer, whom many of you will remember. I knew of him when I was young as a famous writer, theologian, musician, and physician. By age 30 he was one of the most famous men in Europe. At age 30 he decided to go to medical school and by age 40 he began his work in Africa as a medical missionary. To those who did not understand this change in his life, he explained that he had transformed the expression of his faith from written words and music into the daily work of providing medical care for those most in need.

**Prayers are said in many ways.**

The Clinic had just started in 1993. It was not apparent that it would be successful or endure. I did not feel worthy of a prize in the name of Dr. Schweitzer. I accepted the award with the perspective that it was not reward for work done, but for work that would be done to honor of the great man Albert Schweitzer. The Schweitzer prize has had many influences upon my life and the work at the Clinic, but one of the most important influences was through a collection of essays written in 1993 and 1994 called “Through my Window.” The essays began as an acceptance letter to Dr. William Richardson, then President of Johns Hopkins, and to the family of Alfred Toepfer, a German grain merchant, an environmentalist, and a friend of Dr. Schweitzer, who established the prize in his honor. In my letter to Dr. Richardson I remarked that the prize gave me an opportunity to think about why Special Children are important to the Amish and Mennonite communities, to my work, and to all of us. That idea was the theme of my acceptance talk at Johns Hopkins, was the focus of a lecture I gave at the Children’s Hospital of Boston in the Spring 1994, and was the essence of a collection of stories and essays published in Pediatrics in December of 1994, called Through my Window. The article was eventually translated into 36 languages and has been required reading for students in many medical students around the world. Over the years I have had many letters from students and physicians that say that the ideas in the essays changed the way they practice medicine. One student who read the article is here today - Dr. Kevin Strauss. Another was Dr. Heng Wang, who is the director of a clinic for special children in Ohio, which is modeled after our Clinic in Lancaster County.

As you walk though this crowd and see the work that makes this auction possible, understand that all the work of this auction, the knowledge gained at the Clinic, which changes the lives of many children, here and elsewhere around the world, are Gifts from Special Children to us. Today we thank them in many different ways.
Prayers are said, and prayers are answered, in many ways.

A few weeks ago I learned about a new baby in a family I know well. The baby was not gaining weight normally. It worried me that her parents had not called the Clinic. I drove to their house, walked in, sat by the mother and said, “I heard the baby is not gaining weight. Do you think she is alright?” She said, “We are praying about her.” I asked, “What answer to your prayers do you expect?”

As I drove from the Clinic to this house, I already knew what the problem with the baby was. She was like some of the couple’s other children. I recalled a telephone call in 1990 from Doctor Stanley Ulick. His voice was feeble from age and an illness. Although we collaborated, he could not travel, we did not meet. He called me from a medical center in New York City to say he had read a paper in the New England Journal of Medicine in 1980 about an Amish family with an unusual disorder of aldosterone biosynthesis. The father and grandfather of the baby I was going to see had this same disorder and were, in fact, part of that medical study. Dr. Ulick did research about this particular rare disorder, he wanted to find the gene mutation that caused the problem. He asked if I thought I could get blood and urine samples from the family to help him with his work. I did. He sent DNA from their blood to Japan. After 3 years, Dr. Mitsuchi, a medical researcher in Japan, published the information about the genetic basis of the disease with many other coworkers, Dr. Ulick and me. This was the second scientific paper from the Clinic. Dr. Ulick has since died, I enjoyed remembering him that day.

That day too I remembered studying the genealogy of another Amish family in the Fisher Book, which records the deaths of many infants with this disorder. In one family, three infants died in a row. Back then, 50 years ago, the mothers were likely told that babies died because “their milk was no good.” How do you think those mothers felt to hear that explanation? What would those mothers have thought if I had come into their homes and explained, “This is not a problem with your milk. The baby has a mutation in the gene needed to make a simple hormone called aldosterone. For this baby, aldosterone is like a vitamin - it is an essential biochemical that the baby cannot make, but it can be added to your milk to prevent the wasting illness of infancy caused by aldosterone deficiency. Here is the medicine the baby needs. Dissolve it a teaspoon of your milk. Give the baby 1/10 milligram each day, and she will be fine.” Fifty years ago this would have been considered a miracle, an answer to prayers. Today, because of the work of Dr. Stanley Ulick and others, we now have a simple answer to this once deadly problem.

I asked the young mother “What answer to your prayers do you expect?” “A doctor, a friend too, has walked into your house, will use a few drops of blood to do an inexpensive test to detect the gene mutation which explains your baby’s illness, and he will offer you a simple treatment, which costs only pennies each day. From my point of view, that is a good answer to
a prayer. Knowledge like this, the ability to understand and treat the genetic basis of disease, should be accepted as an answer to prayers.

Prayers are said, and prayers are answered, in many ways.

These are my thoughts as I look upon the crowd.
All of us at the Clinic thank you for making our work possible.
All of us especially thank the Special Children. They ask for our help, and through our efforts to help them, they make us better people. (dhm September 19, 2006)

Publications:


Remembering Dr. Avery
D. Holmes Morton MD
February 4, 2012

Much of what we learned as students about to practice of pediatrics has changed over the past 30 years. What do I remember about knowing Mel Avery that seems to have been important to me?

THE ROTCH PROFESSOR OF PEDIATRICS COULD BE BLUNT

When I was a 3rd year Harvard Medical Student Dr. Avery was the attending physician on the infant ward. Our Team presented physical findings suggestive of child abuse. She listened then asked, What are you missing? What else could this be?

She said, Frankly I understand how a parent can become frustrated and angry trying to care for an irritable infant. What do you understand about this? Did her parents tell you what happened? Are the parents poor, exhausted, or ill, physically, mentally? What can we do as pediatricians about problems that cause such anger? Her remarks left a lasting impression.

A VISIT TO THE CLINIC

The last conversation I had with Mel was in the late 1990s. She came to Hershey Medical Center to give a lecture about surfactant. After her talk, she rode with me 40 miles to the Clinic for Special Children. She remarked, “I am tired of giving that lecture.” Then she quoted Virchow Knowledge is first ignored, then evokes hostility, and finally it is said, “We’ve known this all along.” She said “Tell me about what are you doing here that is interesting.”

The remainder of the afternoon we talked about our interest in the care of newborns in places where NICUs do not exist. After being unburdened of her responsibilities as Physician in Chief, she enjoyed being Dr. Mary Ellen Avery The Harvard Medical School Thomas Morgan Rotch Professor of Pediatrics. From that vantage she talked about disparities in medical care – in South & Central Americas, Africa, but she also spoke, often bluntly, about the disparities in the United States. That day Mel and I talked about disparities of care within the shadows cast upon the farmland and cultural landscape around Hershey Medical Center. I work in those shadows, as described in an essay “Through My Window.”

May 1994 Dr. Avery invited Caroline and me to come to the 125th-Year celebration of Children’s. “Take 10 minutes to talk about what you two are doing in Lancaster County.” When I arrived Mel said, “The Surgeon General canceled, you can fill-in his time.” That talk became Through My Window, printed in Pediatrics 1994. The essay explained why I work in rural Lancaster County, instead of Boston or Philadelphia.

A PLACE OF GREAT NEED, A PLACE TO WORK

On June 19, 1988 I drove from Philadelphia to Lancaster County to examine an Amish boy with cerebral palsy - a term that even today for many pediatricians suggests only “birth asphyxia.” Glutaric Aciduria Type I had disabled Danny and 16 other Amish children that I examined that summer. The disorder, untreated, causes strokes
within the basal ganglia and a movement disorder often called athetoid cerebral palsy. Today routine newborn screening for GA1, worldwide, allows disabilities like Danny’s to be prevented. This interesting biochemical disorder of the mitochondria of the brain also causes cerebral venous hypertension, cerebral spinal fluid accumulation in dural and subarachnoid spaces, and a poorly understood risk for intracranial and retinal hemorrhages after minor head injuries – like falling from a bed or rocking horse. In the early 1990s I realized that children with GA1 were also being misdiagnosed as “Shaken Baby Syndrome.” I received a letter from Denver Colorado pleading for my help. A father had been accused of abuse. Months later the parents learned their infant girl had GA1. I wrote an opinion that helped them. The hostility followed - How could I suggest that cerebral palsy and child abuse have genetic causes? I remembered Dr. Avery asking - What are you missing? and Virchow’s quotation.

In 1999 an Amish infant died with extensive intracranial and retinal hemorrhages. Sara was the 7th child born into a family of only boys. Amish women often say about such families, “Lazy man gets help first.” Sara was her mother’s joy – a few minutes talking with her mother revealed this, yet, pediatricians of killing her infant accused Liz. Accused of shaking Sara violently to death. Collectively, the pediatricians at Geisinger Medical Center believed that retinal hemorrhages were “pathognomonic” of Shaken Baby Syndrome.

This mother knew in her own way why Sara died. She needed to be asked the right questions. Sara had pruritus, worse after nursing, Liz routinely covered her hands with socks for when sharp fingernails made a scratch on her face it bled and-bleed. Sara’s brother Daniel had the same problem in infancy. Liz knew other Amish families came to our Clinic because of a liver problem. No pediatrician asked and this mother was accused of murder. An unfriendly gathering of prosecutors and doctors at the medical center heard me ask, What are you missing?

Sara died of late-presenting-hemorrhagic-disease of the newborn. Vitamin K deficiency had caused the large venous intra-cerebral hemorrhage. Laboratory data from her hospital record, including a rapid response to vitamin K, supported the diagnosis. Later the diagnosis was supported by high serum bile acids and a markedly increased PIVKA – Protein Induced by Vitamin K Absence, non-carboxylated Prothrombin-II. Sara’s retinal hemorrhages were on the side of her fatal intracerebral hemorrhage. Retinal hemorrhages have a differential diagnosis too; these hemorrhages in the eye were not diagnostic of Shaken Baby Syndrome.

I suggested that the pediatricians that in their investigation of this unfortunate mother, “Be kind. Think of what you will say to her when you learn that you are wrong.” The hostility known by Virchow followed.

Sara’s case was resolved with the help of a Neuropathologist named Dr. Lucy Rorke. Within the next year Sara’s underlying genetic risk was found. Sara and her brother inherited a recessive disorder that is common in the Amish Community. Their risk of vitamin K deficiency arises from a polymorphism in the gene TJP2. My Amish friends quietly paid their $47,000 bill and forgave those involved in the mistake, which is the way of the Amish people. Their names faded from the national News. They had another child, a boy. Sadly, Sara was not replaced. I was invited to join the Attorney General’s Advisory Board on Child Abuse, which I have been a member of for 10 years. Similar experiences within and outside the Plain Communities caused me to write case studies and lectures about Preventing Injustice In the Time of Genomics: Genetic Disorders & Mistaken Diagnoses of Child Abuse, Neglect, or SIDS.

In all populations genetic disorders masquerade under old medical names. Genetic problems are mistaken
for child abuse with tragic medical and legal consequences. Today our Clinic For Special Children provides general medical care for more than 2000 Amish and Mennonite children with 115 different inherited disorders. More than 20 of these disorders cause signs of disease too often mistaken for abuse, neglect, or SIDS. The medical-genetic problems of the Plain People are not unique to them, as is often believed, but arise from gene mutations carried during migrations out of Europe to the Americas and elsewhere. In this *Time of Genomic Medicine* testing to uncover disorders that mimic abuse must become routine.

The Rotch Professor would have been interested in the genomic differential diagnoses of conditions familiar to her as cerebral palsy, mental retardation, autism, SIDS, lethal infection, seizures, strokes, hemorrhages, asphyxia, and child abuse. The answers to her question *What are you missing?* are much different in 2012 than in 1982 when we stood beside a crib on the infant ward of Boston Children’s.

*I cannot be sure that what I learn in Lancaster will be of any lasting medical or scientific significance, but I do know that my work here has lessened the misery of the children and families who depend on the Clinic and me. That is for me sufficient reward and justification for whatever opportunities were lost when I decided to leave Boston. Many of us who trained at Children’s hoped to stay in university hospitals, few from such hospitals have valued these children or this work in Lancaster County as I do. In Boston, others soon took my place; here I would have been missed.* From “Through My Window” Remarks at the 125th Year Celebration of Children's Hospital of Boston. Pediatrics 94, 785-791.

The stories and ideas in “Through My Window” will be remembered long after the few scientific facts I have reported are forgotten. I re-dedicate my essay to Mel Avery.

A MARY ELLEN AVERY FELLOWSHIP AT THE CLINIC FOR SPECIAL CHILDREN

At Franklin & Marshall College Kevin Strauss, Erik Puffenberger, and I teach a seminar called “Plain People & Modern Medicine.” We also give lectures in courses in Public Health, Ethics, Medical Anthropology, and The Physician & Literature. A few interested undergraduates become involved in research at the Clinic. We want students to learn about our manner of working as doctors before they are influenced by university-based health care.

The Clinic for Special Children has established a Mary Ellen Avery Fellowship. Our Avery Fellows will learn about disparities in rural health care, the education and work of midwives, the culture of the Plain Communities, and they will learn how the *Clinics for Special Children* could bring *Genomic Medicine* to the everyday work of doctors outside university hospitals.

THE DECLINE OF MEL AVERY

I did not go see Dr. Avery during her last years. I once asked Fred Lovejoy if I should. He said, “Holmes she might not remember you.” I was seldom in Boston, but, there was another reason I didn’t go see Mel - I knew the nature of her illness too well.

When we moved my mother from West Virginia to Lancaster County I imagined that my relationship with her during her declining years would be something like *Tuesdays with Morrie*, a best selling book about wisdom gleaned by a writer who spends Tuesdays with an elderly, dying teacher. In reality, the 7-years caring for Mary
Stansbury Morton during her decline were more similar to a journey through *Dante’s Inferno* than *Tuesdays with Morrie*. Her last years were difficult, as we all know Mel Avery’s were too.

Before the end of her life Mary Morton’s depression, paranoia, and anger drove away all but a few. Most of the time I did not feel my mother was angry with *me*, rather, she was angry about being old, ill, fearful, lost, and, finally, about living on-and-on far beyond her desire to be alive.

_How frozen and how faint I now became,_
_Ask me not reader, for all language here_
_Would not make words enough for me to tell._
_I did not die, nor yet remain alive:_
_If genius flowers in you, now imagine_
_What I became, deprived of life and death._

_Dante. The Divine Comedy, The Inferno, canto XXXIV_

So, I didn’t go see Mel Avery in her last years. I had had enough of such illnesses. I mention this final, sad time in Mel’s life because in this gathering of her medical friends from Harvard and elsewhere there is an extraordinary capacity to understand such diseases. Someday we will prevent the underlying problem that caused the final declines of Mel Avery & Mary Stansbury Morton - if we keep asking *What are we missing?*
*Water & Time - Cutting the Rock*
Dear Mary,

Your mother went to West Virginia yesterday. I could not go. I have a sick baby in the hospital, Luque (pronounced Luke), the new infant with glutaric aciduria. Also, because of my few days off last week, I have unfinished lab work, unanswered mail, phone calls to return, as well as, grass to mow, a garden to tend, and animals to care for - your dog, mice, frog, rabbits, and a cat in the barn that may or may not be yours but seems to stay. I decided to alternate working in the yard today with writing my yearly camp letter to you. As I told you last year, my father seldom wrote letters. I knew he worked long days at the coal mine and I did not really expect letters from him. But, because I remember that he did not write, and, because I again want to let you know that I think of you when you are away, another letter.

Before I started this letter I looked through our house to find the three pieces of limestone that contain fossils of seashells. For some time I have wanted to write about those stones.

My summer camp was beside the Greenbrier River at Caldwell West Virginia. From the river valley a mountain rose more than 1000 feet above the camp. The river ran south past camp against the western edge of the mountain. Howard’s Creek ran west from White Sulfur Springs, cut the mountain range, and at Caldwell flowed into the river. The mountainous region north of Howard’s Creek and east of the Greenbrier River was wilderness. When I was boy I often walked or rode horses into that wilderness. It is a place I have not forgotten. Our stones with fossils of seashells came from there.

I last crossed through that region a day in early spring of 1966 when I was 15 years old. I walked northwest across the mountain range from the valley of Howard’s Creek to the Valley of Greenbrier River. I went into the woods behind Mountain Home which then was still surrounded by farmland, although its builder, a blind horseman named Hunter, had died. Hunter raised horses and ran the stables for the Greenbrier Hotel in White Sulfur Springs. He was blinded by an accident, maybe during the war, I can’t remember, but afterward he continued to lead trail rides for guests at the hotel into the mountains above his home. It was said that he and his horses knew the trails there so well that his work was little affected by his loss of sight. It was almost 30 years ago that I crossed through Hunter’s pasture. His horses were sold by then, the pasture was overgrown, the rail fences and his house were neglected. No one saw me cross the pasture that day and disappear at its edge into the woods. I remember the trees were just budding and snow remained on shaded slopes of the mountain.
morning air was cool but sunlight was high in the blue-white air and washed over the top of
the mountain as sunlight always has at that time of year and that time of day in that place.

There was no trail where I climbed; my progress upward was slow and difficult. At the
edge of each strata of sandstone, shale, or limestone, rocks are broken off by weather, weight,
and time. Rocks with sharp edges fall below the strata along the mountain slope at the angle of
repose. Soil is thin over loose sharp rocks and footing is always unsure. After the first hour of
climbing the day seemed warm, my face and shirt were wet with sweat although the sunlight
was still far above me. By late morning I had to rest every few minutes because of cramped leg
muscles and an ache in my side from hours of hard breathing. Near the top, in the full sunlight
of noon, I climbed a stratum of limestone. When I rested on the upper edge of this strata I saw
that the limestone was laced with fossils of seashells.

I don’t remember that I thought long about the seashells that day. I didn’t collect our
three pieces of stone at that time, but those limestone shells became part of the place.
Remembered and as familiar to me as the smooth stones on the bottom of streams, as the
smell and sounds of water in mountain streams, as the wild bright silver and red trout there,
as the deer, raccoons, mountain sheep, black bear, and hawks and owls that came into sight
briefly then went into shadows. Remembered and as familiar as the sounds of the dark forest
beyond the light from a campfire, as the sound and smell of rain in deep woods on hot days, as
the cold and silence of snow in winter woods. Remembered and as familiar as the sunlight that
washes across those mountains at dawn, then by midday descends into valleys, then toward
evening rises again, reddens, and fades from the high limbs old trees then fades finally from
the blue air as sunlight always has there, as sunlight always will there, until the mountains
have fallen. All of these are the collected memories and mysteries of an unforgotten wilderness
place.

I went back to find our three pieces of limestone on a November day 25 years later. I
was in White Sulfur Springs to give a talk, not a medical lecture, but a talk about education.
Hunter’s pasture I found covered by parking lots, trailers, a truck stop, a filling station, a
MacDonald’s Restaurant, and trash. Few who work in those businesses would have heard of
the blind horseman. I started my climb in early afternoon and found the limestone strata late
in the day. By the time I had gathered three stones with fossils and was rested and ready to
leave the mountain, the valley of Howard’s Creek was darkening. In a notebook I carried that
day I wrote, the moon is small, high, and white to the southeast as sunlight fades from
westward ridges, from the upper limbs of trees, and at last from high clouds. Trees above me
are black against the autumn sky. Silence is broken by my steps on dry leaves then suddenly
by a solitary deer running. The rocks, leaves, and trunks of fallen trees along the ridge that is
my downward path and deep woods beyond are washed in a gray light. When I stop, I can hear
far below me the sound of water falling stone to stone toward Howard’s Creek. That night I saw the light of the moon in ribbons of silver in the water of a stream running down to the sea. dhm
November 15, 1991

The strata of limestone that held our fossils of seashells was formed beneath a sea now gone and then was pushed upward within those mountains by great imperceptible forces over a span of time far beyond our sense of time. Our presence compared to such events seems small, insignificant, unlikely, but, in the same sense that the mountains were an inevitable result of great forces in a long course of time, so are we. The mountain falls by forces we can perceive and, in part, falls in the span of our time. The mountain falls to the sea as mineral in water, as dust in rain in snow in winds, as stones in mountain streams that roll downward in the fast water of spring and with fall of rock on rock edges break to form smooth round stones and with each click of pebble on stone some weight of sand is thrown into the downward rush of water. We are able to know that the mountain falls back to the sea where those shells of limestone become shells again.

Who was I to meddle with such a grand design? Who was I to go back to the mountain and carry away those stones to be seen and held by children? Who was I to ask that fossils of seashells in stones have some other purpose, or some other meaning, than to fall back to the sea and become shells again? The forces within and around us that shape such questions are as immediate and perceptible to us, and are as much part of our nature, as the slow fall of the mountain is part of its nature. The mysteries of solitary and wild places are revealed by our perceptions and questions and make our brief time here more rich and significant. I know that for you now, at only 12 years of age, this letter may be as the fossils I saw in limestone 25 years ago that I first passed with little thought. Only recently did I go back to collect three stones so that my children too could begin to wonder at the presence of seashells high on a mountain far from a sea.

The first planting of corn is ripe. Tomatoes are red. Melons are on vines. Our sunflowers are 12 feet high and heavy with new seeds. The hollyhocks are taller than I and sing with voices of color in each breeze. The finch nest in the flower basket by our front door is empty now, the young birds have grown and gone. Summer runs by like falling water. You are missed here, summer and I cannot wait for you, come home soon.

To quote you, how is that for a thoughtful letter? (#21 10/16/94)

Love.

Your Dad, Holmes
Since this letter was written Mary and I have climbed this mountain many times to collect fossils. In college she majored in Evolutionary Biology. She studies Science Journalism at Johns Hopkins and is now a free lance writer and photographer. In December 2007 Mary, Sarah, Paul, two “grand-dogs” and I climbed Mary’s Mountain.

Mary’s Mountain, On Top. December 2007
Butterflies
For Mary Christmas 1997

In meadows
beautiful, fragile, ephemeral.

To watch them tossed about by breezes
and dance from flower to flower
I would think they will go no where.

I am told
they endure storms of summer
and winter too
and that finally they go far.

Where?
To the south, to Mexico I’ve heard
but I can’t believe this.

If You dare
to ask where
follow them yourself.

Beautiful, enduring, travelers -

Butterflies in meadows
remind me of children.
The Deep End of the Yard from the Studio
Oil on canvas 30X40"
**Paul Morton, My Father**

**FROM A LETTER WRITTEN TO DAD’S FRIEND GASTON CAPERTON IN 2007:**

Gaston as you know, there was much about the course of my education that concerned my Father. Much that he did not understand, including my decision to study medicine at Harvard Medical School. He always encouraged me, but said more than once that he did not see how I got from one-place-to-the-next in my education. But, in the Spring of 1989 when I told him about the decision of Caroline and me to set-up the non-profit organization called the Clinic for Special Children, and that I had decided to move Lancaster County and work as a doctor within the Amish and Mennonite Communities, Paul said simply, “I think that will be worthwhile.” In 1993, after I was given the Albert Schweitzer Prize for Humanitarianism for work at the Clinic, he wrote a letter to me that said - For many years I worried about you. I was uncertain about what kind of work you would find to do. So much of what you were interested in I didn’t understand. But now I understand what you do. I am writing to say that I am going to stop worrying about you.

Paul enjoyed visiting Lancaster County, and meeting the people that we work for - farmers, builders, wood workers, craftsmen, hard working people of all kinds. He particularly enjoyed watching 80 men gather together on a cold November day in 1990 to build the Clinic as a Community Clinic-Raising; he also enjoyed watching their wives serve a hot meal for more than 100 people in Jake and Naomi Stoltzfoos’ farmhouse, which is on the farm where the Clinic stands.

A few times I took Dad on house calls with me. I remember particularly in 1996, at the time of the Auction, he was here and I took him with me to an Amish home to see a newborn that was having seizures. I was working many hours each day at the hospital and in the Clinic laboratory to try to understand the cause of the seizures, and to find a way to control them. This was the second infant the couple had had with early onset, severe seizures. Their first baby had died of uncontrolled seizures a few years before the Clinic was started. They knew what they were facing.

The day Dad and I went to see John and Rachel’s baby one of John’s prize workhorses had fallen into an old barn foundation, was injured badly, and had to be destroyed. I remember Rachel saying several times I’ve told John it was just a horse. We have a sick baby. That’s more important. It was just a horse. But, we do still care about him. Despite their problems John and Rachel welcomed Dad’s visit. They introduced him to all of their children, and to John’s
parents who lived on the farm with them. They ask about his life and work and where he lived now. They told him was special to have Dr. Morton’s Father visit them and asked him to sign their guest book as we left. He never forgot that visit, and how, despite their own worries, how interested and kind they were to him.

A few weeks after his visit he asked me about the infant I told him the baby died, regardless of my best efforts. I think it was the first time Dad felt the difficulty of my work and realized how often I face limits of medical knowledge. After that, when I talked about the Research we do at the Clinic, and the importance of new discoveries about the causes of inherited illnesses, he understood. In his Will he left about $25,000 in City Holding Stock to be used at the Clinic as needed. Caroline and I have decided to place this money in the Research and Education Endowment Fund. In Dad’s memory and in memory of those children like John and Rachel’s, whose illnesses we have yet to understand.

A TRIP TO THE METROPOLITAN OPERA: Gaston if you had been standing on Columbus Avenue in front of The College Board building at 4:20 PM on Saturday December 1st you would have seen a black limousine pass. Seated in the back seat were Caroline and I with a distinguished, white-haired lady. She is a Patron of the Metropolitan Opera. She had invited Caroline and me to her home in Moorestown New Jersey for the weekend, to join her at The Met to see Gluck’s Iphigenie en Tauride. As is her monthly routine, we were picked up at her home at 10 AM, traveled by limousine to The Met, had lunch in the Patron Dining Room, and enjoyed the afternoon performance from very nice seats. When we passed the door of the College Board we were on the way to the library of J.P. Morgan. Afterward, we had dinner in Greenwich Village, and then returned to Moorestown. Seated in the opulent unreality that Is the Metropolitan Opera, surrounded by thousands of people who live and work daily within such unreality, and listening to the extraordinary music and voices, I thought of Paul Morton and, oddly enough, of Governor Gaston Caperton.

In our home in Fayetteville we had a surprisingly large collection of LP Recordings of Operas. As a boy I listened to them, not often, but I was always curious about what they were. In my boy’s recollections I always assumed the records were Mom’s - she was, of course, the Artist of the family. I was surprised to learn years later that they were Dad’s, and that as a young man he had collected, and enjoyed listening to, these operas. Seated in The Met I wondered if on one of his business trips to New York, he had come there.

As I looked around The Met, I knew I was Out-of-Place, and I remembered your story about leaving the Governor’s Mansion in West Virginia, and spending the first night on the floor of the small, cold apartment provided by Harvard College, where you had gone to start teaching at the Kennedy School of Government. You told Caroline and me that you said to yourself on that night, this is a long way from the Governor’s Mansion. As I looked around The
The white-haired lady who took us to the *Met* is the world-renowned Neuropathologist, Dr. Lucy Rorke-Adams. She was for many, many years the Chief of Neuropathology at Children’s Hospital in Philadelphia, and at age 77 still works there regularly. We have become good friends though our common interests in the studies of the brain, and music. As we rode back and forth to the New York, Caroline, Lucy and I talked of many things; a wedding Lucy had recently attended in Thailand as the guest of honor of the bride’s father, a former student of hers; Lucy told us about her house in Moorestown that she and her second husband had designed and built after they were married, but, which he did not live to see finished; we discussed the Opera we were about to see - Lucy explained that as a 16 year old girl she had a beautiful voice and wanted to sing in the opera, but, fate gradually directed her to the study of Medicine instead. I told her about the design and voice of my new cello, patterned after the Castelbarco Cello made by Antonio Stradivarius in 1697, a cello that I had played at the Library of Congress in the Spring of 2006. We talked about the ideas that fostered my Letter to a Student and the Concert at Trinity College by Paul Morton and Matt Haimovitz at Trinity College, and how those ideas were woven into my Lecture on that evening. And, of course, at times our conversation turned back around to the realities of our daily work. I told her on the trip about the infants of Dad’s friends, John and Rachel - four of their children have died now. In the past year we have found two other Amish families in another settlement near State College who have had children with similar seizures. New technology and other advances in Molecular Genetics have allowed us to locate the abnormal gene within a region of chromosome 7; we are now sequencing through a list of candidate genes in the region to find the disease causing mutation. One of the new Amish families has recently allowed us to examine the brain of their infant girl after she died. Dr. Rorke offered to help study the slides of the brain. She suggested we carefully section and stain a region called the thalamus. *In my experience*, she said, *infants who have malformations of the thalamus can have such problems*... In our busy lives, Art and Science never are far apart.......
Paul Morton, Winnifrede, West Virginia 1945
Mary Stansbury Morton Dies

ONE OF THE STANSBURY’S OF MORGANTOWN, WEST VIRGINIA; PROMINENT IN
WOMEN’S AMATEUR GOLF; AN ARTIST.

D. Holmes Morton M.D.

August 2008
Mary Stansbury Morton died in Quarryville in the Presbyterian Retirement Community on July 9, 2008. She was 88 years old. A celebration of her life took place with family and friends in Fayetteville, West Virginia at the Presbyterian Church, and at the Morton Home at 212 Maple Avenue. A private graveside service was held at the End of the Trail Cemetery at Sam Blacks Church in Greenbrier County later that same day. Her friend and minister, the Reverend Paul O’Gorek from Harrisonburg Virginia, and Reverend Catherine George, the Church’s current minister, officiated over her services.

She was preceded in death by her husband Paul Morton, by five brothers Bill, Harry, Bud, Bunk, and Sam, and an adopted brother Fred. Her younger sister Pat died on August 15, 2008. Mary is survived by a brother Jim Stansbury of Buckhannon, and by her four sons and her grandchildren; Paul Wailes Morton and his wife Carolee, son Ben and daughter Emily of East Greenwich RI; Charles Stansbury Morton and his wife Sharon, sons Chris and Adam and daughter Elizabeth of Fayetteville and Myrtle Beach SC; D Holmes Morton MD and his wife Caroline daughters Mary and Sarah and son Paul of Strasburg, PA, and Frank Hurxthal Morton and his wife Karen, sons Taj and Kit of Philamouth OR.

SOME EARLY FAMILY HISTORY: Mary’s Father Harry Adams Stansbury (HAS) was born on December 9, 1891 in Marshes, West Virginia. His Father, Mary’s Grandfather, was Charles Stansbury from Baltimore. Her Grandmother was Ella Callaway, who was a native of the Raleigh County West Virginia and was said to be a descendent of the legendary leader of the Hatfield family, Devil Anse Hatfield. The Callaway family owned land and timber around Marshes, and Ella’s parents offered room and board to travelers, in part, because her father enjoyed having conversation with interesting people. Charles Stansbury came to Marshes in 1885 from Baltimore and stayed at the Callaway home. He was an interesting guest.

The Stansbury family had been in the Baltimore area since the mid 1600s, all descendents of Darius Stansbury from Amsterdam in the Netherlands. Much of their early family history is told in a book by Archibald Hawkins (1766-1851): The life and times of Hon. Elijah Stansbury b 1791, an "old defender" and ex-mayor of Baltimore; together with early reminiscences, dating from 1662, and embracing a period of 212 years. Charles was educated and a land surveyor, others in his family were bankers. He had traveled by train from Baltimore to the railroad town of Prince, West Virginia, on New River, then rode a horse 40 miles westward to Marsh Fork to find land to buy. By 1889 Charles Stansbury had purchased more than 1000 acres of timber, coal rights, farmland, and marshes, and he had fallen in love with the young, beautiful Ella Callaway. She was 15 years old when they married, 18 when her third son Harry Adams was born, and by age 22 she was widowed. Charles Stansbury contracted typhoid fever during a trip to Baltimore and died in Raleigh County in the fall of 1895. One of HAS’ earliest memories was riding all day in a wagon to the train station in Prince
to pick-up the marble headstone for his father’s grave.

Charles’ young wife, Ella, remained for the rest of her life on the land called Stansbury Farm in Glen Daniel, West Virginia. There Mary and her siblings spent long summers working for “Grannie.” Mary was very close to her Grandmother Ella, admired her, and told stories about her often. Ella Callaway Stansbury died at the farm in the summer of 1943. When Mary and Paul Morton married in 1944, Mary wore Ella Stansbury’s wedding dress.

Mary Stansbury’s mother was Ada George Stansbury, the daughter of Taylor and Dora George of Philippi West Virginia. Ada George’s mother, Mary’s grandmother, died in the 1918 influenza epidemic, 2 years before Mary’s birth. Mary’s Grandfather Taylor George practiced law in Philippi more than 60 years and was a member of the West Virginia House of Delegates. He was a notoriously successful defense lawyer, accepting many cases other lawyers refused, and, in his 80s, argued a case before the West Virginia Supreme Court. Mary liked to stay in Philippi with her Grandfather. She told stories about going to the court to listen to him argue cases. Taylor George found in Mary a willing and able student of cards - bridge, rummy, and poker. In a letter to her parents, Mary, age 12, wrote “Taylor doesn't like it when I beat him in card games.”

WESLEYAN: Ella Stansbury sent her three sons to a Methodist School in Buckhannon, West Virginia, now Wesleyan College. HAS was 12 years old when he started school at Wesleyan. With exception of a year at home to run her sawmill at age 18, he stayed at Wesleyan until 1917.

In 1912 HA Stansbury was the quarterback and captain of the first undefeated Wesleyan football team. He was also a star pitcher for the baseball teams with a 10 wins and 2 losses in 1912 and, when the baseball teams wasn’t traveling, he was a pole-vaulter for the Wesleyan track team. After graduation he stayed at the school as its first Athletic Director.

In those early days of college athletics there was great rivalry between Wesleyan and West Virginia University (WVU). Between 1907-1914 HAS had contributed directly to many of the Wesleyan victories over WVU teams as a quarterback and running back of the football team and as an outstanding pitcher on successful baseball teams. When he interviewed for the job as Athletic Director in Morgantown by “about a dozen leading citizens” he learned that his appointment was “opposed unanimously.” His highly publicized hiring was announced by a headline in the Morgantown newspaper, “Stansbury to Come Anyhow.”

MORGANTOWN DAYS: In 1917, at age 26, HAS was hired to be Athletic Director of WVU. Over his 21 years at WVU he became one of the early organizers of inter-collegiate athletics in the United States. He raised $400,000 in private donations and directed the construction of one of the first large university stadiums with seating for 33,000 fans. Mountaineer Stadium was
completed in the summer of 1924. The student body and faculty voted to name the stadium “Stansbury Stadium,” but HAS was opposed, stating that he didn’t believe in memorials to living people. He was 33 years old when the football stadium opened. He immediately began raising money for an indoor track and field house, which was completed in 1929, held 6,800 people, which today is still in use at WVU and is called Stansbury Hall. He was elected to the West Virginia Hall of Fame in 1953.

Mary Stansbury’s father is also remembered because of the “Javelin Story,” which can be found in Ripley’s Believe It or Not, and, every few years, an account of the event reappears in a Morgantown or Charleston newspaper. On March 17, 1920, as he absent-mindedly walked across an athletic field during track practice, a javelin thrown by a student named Gaines, pieced his neck. He was knocked to the ground, but was able to regain his footing, held the javelin upward, and he walked from the athletic field to the University Infirmary. As HAS told the story to his grandchildren, he walked down the middle of the street along several city blocks of Morgantown, holding the javelin steadily. He led a crowd of people made up the entire track team, and a mixture of friends and enemies from the town – the former hoped he would survive the wound, the latter hoped that he would not. He said when he arrived at the Infirmary the nurse on duty fainted, and the javelin was finally pulled out of his neck by the track coach. The year of 1920 was a time before antibiotics, tetanus shots, or malpractice suits. His wound was soaked with iodine, wrapped with gauze, and he went home to work in his vegetable garden before dinner, as was his routine. Mary Elizabeth, the third Stansbury child, was born 2 months later on May 20 1920.

The Stansbury home in Morgantown must have seemed as much part of the university, and as much a boarding house, as private home. There were finally 9 Stansbury children, including an adopted cousin, Dr. Fred Stansbury. Especially during the depression years after 1929, many of the student athletes that HAS recruited for WVU sports teams were told they were welcome at the Stansbury table for meals. The home was also filled with guests for ball games, prospective student athletes and coaches, HAS’ golf partners, who were usually potential donors to support building the football stadium and field-house, and Morgantown friends who came to play in the infamous Stansbury bridge games, which often lasted until early morning hours. As teenagers Mary and her sister Pat kept house, cared for younger siblings, cooked and served meals for “just who-ever showed up.” Dr. William Morgan, an Otologist, who cared for Mary’s unusual ear problems throughout her life, never billed her for his medical care. He explained that as a University student he ate so many meals at the Stansbury’s table, many of which Mary prepared, that would be ashamed to charge her.

Mary and her oldest brother Harry Jr. were outstanding students in the Morgantown Public Schools and, because of their father’s job, they had free access to classes at the University. Harry majored in Chemistry at WVU, obtained a PhD in Organic Chemistry at Yale,
and worked throughout his life as a research chemist for Union Carbide. Mary majored in Mathematics and Psychology at the University and graduated in 1942. Before she finished college and during the early years of World War II, she worked for duPont. As the United States became more involved in the war, several of her friends and coworkers traveled westward to become part of the secret *Manhattan Project*. Two of her brothers became wartime fighter pilots, her younger sister Pat joined the Red Cross and followed the war westward. By the end of the war Pat was in Japan. In later years, Mary remarked that she wished she had done something different with her mind and education. She remembered her job at duPont as her opportunity for a different life, as her “Road Not Taken.”

[Image of a family photograph showing the Stansburys of Morgantown in 1932.]

**The Stansburys of Morgantown in 1932.**
Mary top center, age 12
Bunk, Pat, Mary, Bill, Jim
Harry Jr., Sam, Bud

TRANSITIONS: Mary Stansbury moved quickly from childhood to adulthood. Although little discussed in her mother’s nostalgic writings about the life of the Stansburys of Morgantown, *May Our Tribe Increase*, life during the Depression was difficult. Her parents were often away from home at WVU athletic events and on fund raising trips. The feeding and supervision of the younger Stansbury children was as much her responsibility as her mother’s. Her brother Bill, 6 years younger, had a troubled childhood and was finally sent to Greenbrier Military School to get him away from problems in Morgantown. Bill was killed by a pistol shot to the chest at age
14 on May 8 1940, Mary’s 20th birthday. His death was officially ruled accidental, but Mary always believed his death was suicide, to end a troubled and unhappy life. The family never openly discussed Bill’s death. Her parents did not celebrate Mary’s birthday after Bill’s death. Even at an advanced age she preferred to ignore her birthday, as it reminded her of this lost brother.

Mary Elizabeth Stansbury, Morgantown Country Club Women’s Champion
1932, Age 12 years
By the age of 20, progressive deafness from an inherited disorder called otosclerosis had become a significant handicap to her university studies, work, and social life. She was the youngest patient to undergo an experiment surgery called a large fenestration procedure, which was a difficult operation that involved removal of the tympanic membrane and ossicles.
with extensive dissection of the mastoid bone to create a new “window and ear drum” in the wall of the semi-circular canal. In that time before antibiotics, modern dissection microscopes and surgical tools, this was a difficult, and risky, surgery. The operation left her nauseous, dizzy with vertigo, unable to walk for weeks, and, unfortunately, did little to restore her hearing.

Her father resigned his University job in 1938, and began working for the Chamber of Commerce in Charleston, but his wife and children remained in Morgantown through the time of Bill’s death in 1940 and Mary’s graduation from WVU in 1942. The Stansbury family finally moved to Holly Road in Charleston in the winter of 1943. This was a fateful move for Mary; a new neighbor on Holly Road was David Holmes Morton, her future husband’s uncle. She met Paul Morton, in the Summer of 1944, they were married in December of the same year.

At the time of their marriage, Paul was 30 and was the general superintendent of a coalmine on New River at Ames, West Virginia. Their first home was at the end of a narrow “red-dog” road in the bottom of the New River Gorge, a few hundred yards from the mine face and coal tipple, and a few feet from the C&O Railroad. Coal was mined day and night and constantly moved in the trains from Ames, and many other mines along the New River Gorge, to steel mills - all part of the great war effort in support of WW2. Mary’s father visited her home at the Ames Mine only once. At the end of his visit, he said to her he didn’t know why she would choose to live in such a god-forsaken place - other than for Love. Although a hard place to live and start a family, some of Mary and Paul closest friends came from the days at the Ames Mine. Many miners moved from job-to-job with Paul and worked with him throughout their lives.

Paul Wailes was born in 1946, Charles Stansbury in 1948, and David Holmes in 1950. The son’s all have a photograph of Dad standing in front of the Ames’ mine-face with a crew of night-shift miners in 1950. He was 36 years old and was the mine-boss. By 1952 the Morton family had moved from the Ames mine to new jobs and homes: First, we moved to a home on top of Ames mountain, then to Landisburg, and, finally, to the Morton Home at 212 Maple Avenue in Fayetteville, where the family would remain for 20 years. By 1952 Paul Morton had become President of Cannelton Coal Company, a small West Virginia mine operated by a Canadian Steel Company, Algoma Steel. He worked at Cannelton until his retirement at age 70. By 1972 the Morton sons had scattered widely around the United States, Mary and Paul Morton moved and lived several different places, but the house at 212 Maple Avenue, and the small town of Fayetteville, was always considered home. Morton Home, a frame cottage build in 1865, was recently bought and restored to a fine condition by Charles Morton.

ILLNESS & RECOVERY: The last Morton son, Frank Hurxthal, was born in 1954. He was healthy but his birth was followed for Mary by a long, severe depressive illness. She was
resistant to therapy and was hospitalized for months. She began to make a slow recovery only after electroconvulsive therapy. The illness would haunt her, and her family, for the remainder of her life. Depressive illness, intermixed with periods of mania or paranoia, was a problem she shared with her mother’s father Taylor George and his son William. Mary’s troubled brother Bill Stansbury was likely an unrecognized young victim of the disease. Her youngest brother Sam, once a star athlete at WVU, was manic-depressive too. On the manic side of his illness Sam was a compulsive gambler and alcoholic. In middle age Sam moved away from West Virginia, westward, leaving a trail of debts, a destroyed marriage, and lost friendships, including his sister Mary’s. At the time of Sam’s death in 2007, she had refused to speak to him for many years. Over the months before he died Sam lived in his old car near the gambling casino’s of Reno Nevada. A waitress at a road-side diner and his brother Jim loaned Sam money for food, as he gambled away each Social Security Check. When Mary was told that Sam had died, while trying to drive back to West Virginia, she said, “I am glad that is over for him, death, and life too, I know how miserable Sam was.”

Mary Morton’s recovery from her first depressive illness was made possible by medical care, a supportive husband and family, and by many understanding, helpful friends. Relief from the isolation of deafness was also probably important. In the late 1950s she underwent a remarkably simple and successful surgery called a stapendectomy - an ossicle of left ear was replaced by a small metal post. The repair provided near perfect hearing for the remainder of her life. She also recovered by teaching her sons to play the game of golf and by returning to competitive amateur golf.

GOLF: Many days of Mary’s life were spent on golf courses. Her father was a fine amateur player. He taught himself the game while he was Athletic Director because the golf course seemed to him a good place to raise money for WVU Athletics. He likely played golf with every individual in West Virginia who might have money to donate to the University Athletic programs. The Stansbury home was across from the old Morgantown Country Club and a family membership came with her father’s university job. Mary learned the game the age of 9 from a Bert Spencer, a Scottish Golf Professional. Like her father, and all of the Stansbury children, she was a natural athlete. She won her first Club Championship at age 12. She was an Amateur Golfer in the tradition of her friend Bill Campbell, whom she greatly admired, a West Virginian who was the 1964 United States Amateur Champion and remains today one of the worlds respected, famous amateur sportsmen. One of her closest friends was Sue Everett the West Virginia Amateur Champion in 1929. Mary was the Women’s Champion at White Oak Country Club in Oak Hill West Virginia 5 times; 1963-65, 1969, and 1971. A highlight of her last Championship match at White Oak was a hole-in-one on #6, her first after 42 years of playing golf. She competed in the West Virginia Woman’s Amateur regularly. Although she
never won this tournament, she was for many years Chairman of the Tournament Rules Committee and otherwise ran the tournament. She traveled throughout West Virginia rating golf courses and developing a standardize handicap system that allowed women from private and public courses to compete in the Amateur Tournaments throughout West Virginia and the United States. In this sense, she did for Women’s Amateur Golf what her father had done for University Athletics. A letter written by her to all members of the West Virginia Women’s Golf Association about implementation of the new system of course rating and handicap states her perspective on the rules of the game. “The handicap is the great equalizer in the game of golf, the thing that allows the new golfer to compete against the seasoned player… One thing which should be discussed along with handicaps and course ratings is this THING of “winter rules!” (which means moving the ball to a good lie to make it easier to hit.) The basic rule for the game of golf is PLAY THE BALL AS YOU FIND IT…..Handicaps done on scores played under winter rules are not true handicaps..”

A REMEMBRANCE: On July 20, 2008 I stopped at The Homestead in Hot Springs Virginia, played golf, and began to write my Rememberances of Mary Morton. The writing of letters, essays, lectures, scientific papers, has always been something I valued. Writing is a way to refine thoughts, gain insight, outline facts, the course of events, create a history. The effort transforms feelings or thoughts, some of which cause sleepless nights, into an understanding, or at least an explanation.

Mom and I had first played golf on The Old Course at the Homestead and the Upper Cascades when I was 8-10 years old, almost 50 years ago. On July 20, I walked the old familiar course alone, carrying my bag, which we always believed was the best way to play. I played the back tees, no Mulligans, played the ball as it lay, finished all putts, and made no second practice shots or putts. The round took 3 hours and 50 minutes. Mary Morton would say the game was played as it should be played.

It was a round of golf that indicated the player knew the rules of the game and once could play the game pretty well, but was out-of-practice, or, perhaps became tired or distracted as the round progressed. I had 6 pars, 4 birdies, the par 5s were played 1-under-par, 4 bogies, and 4 double bogies, two of which resulted from putting errors - a 4 putt caused by a careless downhill second putt, and a three putt from a distance of only 10 feet, which never should happen. There were 17 putts on the front 9, and 14 on the back, 31 putts for 18, an average of 1.73 putts per hole. The longest birdie putt was 33 feet and the shortest was 6 inches. I hit 7 of 12 fairways with the driver, and 4 wood, and 3 of 6 greens on par the threes. Drives with my #1 metal club that hit the fairway ranged from 271 to 315 yards, an average drive length for 5 well hit drives of 295 yards. Two 4-woods, hit on shorter par 4s, were 244 and 264 yards in length. Fairways missed with the driver were always missed in the left rough. One such poor drive was
under a spruce tree, was unplayable, and added a penalty stroke. My score on the front nine was 40, on the back 39, total 79, and the game was played as it should be played. The next day I played the Upper Cascades - the Championship Course designed by William Flynn in 1923. A 70 year old caddie named Willi walked the course, he retired from the paper mill in Covington and carries bags because this allows him to play the Cascades Course without charge on slow days. Willi and I walked the course in 3 hours and 10 minutes. I played the back tees, no Mulligans, played the ball as it lay, sunk all putts, and made no second practice shots or putts. The Upper Cascades is a classic mountain course and an unforgiving championship course. Par is 70, the yardage 6679, but the rating is 73. My score was 89, with 6 penalty strokes that contributed to 3 double and 2 triple bogies. I had only 3 pars and 2 birdies. Those drives pulled to the left on the Old Course were in the rough, but playable, but on the Cascades such drives were in creek beds or woods. I hit 7 of 13 fairways with drives, which ranged in length from 254-301 yards. I hit none of the 5 par 3s in regulation, no pars, and on two of these found creek-beds for penalty strokes. I had only one 3 putt green, but only three 1-putt greens, for a total of 34 putts, 1.9 putts per hole. The difference in the scores on the two courses was accounted for by penalty shots from pulled drives, and missed putts. So the game goes.

Mary Morton once said of her four sons, and her work as a mother, Other than teaching them the rules of golf, I didn’t have much to do with how they grew-up and turned-out. They could all learn - at least when and what they wanted to. They all worked hard, like their father. Each of our sons was able to leave home at an early age and become independent of us. I once remarked to a friend that I considered that my having a smooth golf swing was something like being skilled with a pool-stick - both skills were signs of a misspent youth. When she learned about this remark, it provoked a lengthy letter from her to me about the virtues of the game of golf, its rules, and the fine people she had known in the world of amateur golf.

Mary with her Sons in Strasburg, 2005
DEAFNESS: The need for studies of deafness has always been in the Amish and Mennonite Communities. There are churches and schools for the deaf in both Communities. Little is known about the causes hearing loss in these Communities, even less is known about the opportunities for prevention. But hearing loss is a common problem for all of us; in the general population, 1 in 1000 infants will have significant hearing loss and most congenital deafness has a genetic basis. The genetic causes of loss in the Plain populations is, as is true of all of their inherited disorders, are similar in all people of European origins. What the Plain People teach us about deafness, as is true of all of their inherited disorders, will be helpful to everyone in the United States and Europe with similar genetic ancestries.

INTERWOVEN STORIES AND INTERESTS: My personal interest in hearing and deafness arises from loosely interconnected experiences and memories, including undergraduate work 30 years ago at Trinity College that focused upon language development and perception. Studies of the acoustics and perception of the human voice and the cello are not very different subjects. The cello I played at Mary’s Memorial service is a copy of a Stradivarius Cello called the Caselbarco; the original was made in 1697 and is owned by the Library of Congress. I played this Cello two years ago. Afterward, a fine instrument maker named Pierre Moisy made a copy of the 1697 Cello for me. It took Pierre almost a year to make my Cello, using the same simple hand tools that were used by Stradivarius and all the old instrument makers of Cremona. The Cello was made like a fine sculpture being carved from a block of marble. The back was carved from a single piece of old Italian willow. The sides are thin strips of the same willow-wood curved into ribs and reinforced, inside, with pieces of varnished linen - the same technique that Stradivarius used to help assure the ribs of the Castelbarco would last, and they have lasted for more than 300 years. The top of the cello is wide-grained European spruce. Each small region of the top and back were slowly shaved to measured thicknesses similar those of the old Cello. The scroll of the head is pear wood; the tuning pegs are boxwood, the neck is maple, and the fingerboard of black teak. I am interested in studying the similarities and differences in the voices of these two Cellos.

The voice of a Cello is an elusive thing. Beyond the delicate substance and form produced by Pierre’s art, a new Cello is made by being played. The voice changes over Time as within joined woods the structure of resonance is slowly shaped by the sound itself. In a sense, a fine Cello remembers the music played on it, and the people who have played it. The hands and tools of a maker sculptured it once, and then it is shaped again by age and the gentle forces of music.
The voice of the Cello is also defined by the Places it is played, by listeners and especially by the perception of the player. My Cello has been played in Chapels and Cathedrals with lime-stone walls, vaulted Gothic ceilings and stained glass; in an old barn and at the Clinic where the Cello’s voice is changed again by old wood and sunlight; and I have played the Cello in dappled light of deep woods beside a mountain stream where I tried to play a melody using the complex rhythms of water falling on ancient stones - ever aware that I was playing in a Place where such a voice had never been heard, and playing melodies that had never been played.

Always when I play my solitary concerts I remember my Father, Paul Morton, who told me near the end of his life that, as a young man, he had dreamed of playing the violin. Somehow this completely surprised me. It was only then that I realized that our family’s large collection of recordings of classical music and opera were his, not my mother’s. I had never thought about the dreams of my Father’s youth, which were ended by the Depression and World War II. My memories of him were made 20 or 30 years after his young hopes were gone. I knew him as a coal miner, a mining engineer, remembered by others, and me, for a lifetime of hard work at a difficult job. He was known too for his honesty and concern for others in a business where both traits are often lacking. I recall hearing that miners moved from job-to-job just to be able to work with Paul Morton. I played the cello at his funeral, and though many years have passed, I never play the Cello without thinking of him. No doubt part of my enjoyment of the voice of the cello is in these remembrances.

My mother was deaf by the age of 19. I knew little about her problem until 2001 when I became involved in her medical care and studied a CT scan of her middle ears that revealed her old surgeries. She and four of her brothers had an inherited form of deafness called otosclerosis. Her maternal grandmother’s name was Dora Brown Howell. The Browns and Howells were from the central region of Pennsylvania. Traveling westward in the late 1800 her husband stopped at an Inn run by Dora’s Pennsylvania Dutch family. He stayed at the Inn long enough to convince one of the daughters, Dora our great grandmother, to go westward with him. One of them likely carried with them a gene mutation for otosclerosis.

At age 19 Mary Morton underwent an experimental surgery called a large fenestration procedure. The surgery was done by Dr. Day in Pittsburgh in the early 1940s, before modern microscopic surgical instruments, long before CT or MRI imagines were imagined, and before modern antibiotics. Remarkably, after a long recovery, which included learning to walk again, some of her hearing was restored; I recently saw her use that “bad right ear” to talk on the telephone. By 1960, advances in microscopic middle ear surgery allowed replacement of the
sclerotic stapes in her left ear with a small post of wire; her hearing in that ear was instantly and almost completely restored and remained undiminished for the remainder of her life.

A year ago a Mennonite family from central Pennsylvania came to the Clinic with the same inherited form of otosclerosis as my Mother, possibly the same gene mutation, since the genetic heritage of my great grandmother would be the same. I was surprised to learn that the genetic basis of this form of otosclerosis is not known, and that none of the members of this Mennonite family had benefited from the kind of care my mother had received. Why not? At the Clinic we can find this gene mutation, understand the disease process, and help assure that the children and the elderly benefit from modern medical care - a new unexpected purpose.

My enjoyment of Bach's music for Solo Cello is in a sense the result of the Clinic's Albert Schweitzer Prize for Humanitarianism Prize in 1993. As I learned about Dr. Schweitzer I became interested in his writings about the music of J. S. Bach. Schweitzer's essays about the organ music of Bach remain today important discussions about the history and performance of Bach's work. Throughout his life Albert Schweitzer studied this music. At his Clinic in Lambarene Africa he had a specially made “pedal piano” where he practiced daily. His trips back to Europe from the Schweitzer Clinic always included fund raising concerts. In 1996 Caroline and I traveled to Strasbourg France, which our town of Strasburg Pennsylvania was named after. There we attended a Concert of Bach's Prelude and Fugue in F Minor in St. Thomas Church. The Concert was played on the Silbermann Organ that Schweitzer had helped construct as a young man, and that he played throughout his life, often to raise money for his medical work in Africa. His last concert at St. Thomas Church was played at age 80 on July 28, 1954. This was a concert to commemorate the day of the death of Bach, July 28, 1750.

One purpose of the scientific study of causes of deafness is new understanding of disease mechanism, the development of a simple gene-test that provides a diagnosis and leads to treatment, or better, the prevention of deafness. Such discovery is the everyday work of the Clinic Staff. However, the greater purpose of our work, which other physicians and scientists should remember and value, is the hope that our work finally and simply allow an infant to learn to talk, a child to sing, and the elderly to hear and tell the stories of their lives in an ordinary human voice. And, the work will allow an infant, a child, and the elderly to hear the old music of Bach or Dvorak played on a Cello.

CELLO MUSIC PLAYED AT THE SERVICE OF MARY MORTON BY HOLMES:

Variation of the Prelude of the V Cello Suite & The Sarabande of V
Simple Gifts
Going Home
WRITING & ART: In winter, and in the later years of her life, Mary Morton was known for writing long letters, keeping scrap-books of family records, for fine needle-point work and paintings. Her letters to her children and friends were clearly written, precise, thoughtful, and she wrote often. Writing was a Stansbury trait. Her father had letter-writing contests for his grandchildren, with $1 prizes, and he returned our letters complete with red marks and grades. Mary’s Mother was also a habitual writer and diary keeper. A selection of writings from Ada Stansbury’s diaries was printed privately as a manuscript about the Stansbury’s of Morgantown, entitled *May Our Tribe Increase*, a title borrowed from one of her husband’s letters.

Mary Morton also had an unusual, natural sense about the use color and design in needlework and painting. She particularly enjoyed the study of Chinese art design and brush techniques. Her finest paintings are watercolors of mountain landscapes, birds and flowers in the style of ancient Chinese masters. Many of her paintings were shown and sold in art galleries in southern West Virginia. On her desk she kept a copy of a poem that a friend had
written about her and her paintings. She assigned great significance to the poem. She believed it said something true about her art-work that few people knew.

Mary with a ball, about 1923.

[Image of Mary with a ball, about 1923.]
Mary in the wedding dress of Ella Callaway Stansbury, 1944
Needle work on a footstool, c. 1968
EYNDE: Mary Morton played golf well into her 70s, but an inflammatory muscle disease gradually made her too weak to play. By 1998, age 78, her game was gone. Her golf clubs leaning against her dresser were, she said, a statement about her life. Later, she said the memories of the game were just another heartache. She hated being old and weak.

There is no greater sorrow
Than to be mindful of the happy time
In misery.
Dante. The Divine Comedy, The Inferno canto V

After her husband Paul’s death in October 1999, her letters, paintings and needlework gradually stopped, and the old paranoid depression, the illness we all feared, returned. So began her long slow decline.

When we moved her from Harrisonburg Virginia to Lancaster County I imagined that my relationship with her would be something like Tuesdays with Morrie, a best selling book about the wisdom gleaned by a writer who spends Tuesdays with an elderly, dying teacher. In truth, the years caring for Mary Morton during her decline were more like Dante’s Inferno than Tuesdays with Morrie. Her last years were difficult. Most of the time, I did not feel she was angry with me, rather, she was angry about being old, ill, and, finally, about living on-and-on well beyond her desire to be alive. In 2002, she fell and broke her hip. After that, weakness, and fear of falling, required a walker. Whether loss of will or loss of strength came first, the end was the same. Being confined to a wheelchair was the kind of dependence she wouldn’t have imagined that she could accept.

How frozen and how faint I now became,
Ask me not reader, for all language here
Would not make words enough for me to tell.
I did not die, nor yet remain alive:
If genius flowers in you, now imagine
What I became, deprived of life and death.
Dante. The Divine Comedy, The Inferno, canto XXXIV

In rare lucid moments she asked where she was, and how she came to be in Quarryville, then would say “Holmes, I am lost. I am just completely lost.” Rarely, her old dry wit would appear. Once I found her sitting alone in a dark corner across room from a group of residents who were watching a rerun of The Lawrence Welk Show. I ask her “Would you have to pay extra to sit near the TV?” Without hesitation she said, “I have to pay extra to sit back here.”
I would stop at her room to say goodnight on my way home from work, but often during those visits she was mute. Not long before she died, anticipating her silence, I took my cello. At 7 PM she was in bed, her room was dark, but I thought she was awake. I said nothing, entered her dark room and played the cello for 20 minutes, then stood up and simply said good-night. She finally spoke, “I wondered if that was you playing that music. You are getting a little better.” Sadly, her waking hours were often filled with unimaginable fear and despair, which is the nature of the illness called paranoid depression. I wondered how her sleep was. I hoped that at least her sleep was restful, peaceful. Medicines provided some relief, but her memory faded, parkinsonism and other problems came. By the end, I believed she had lost all awareness. So it goes at the end of a life too long. In the evening of July 9, 2008 the life of Mary Stansbury Morton passed.

Her room held a collection of prized paintings, samples of needle-work, photographs, scrapbooks, her custom fitted golf clubs, and that single poem from a friend. After her death I at first imagined I could describe her life as a single winding path, fixed in time, possibilities now gone. I looked through her old photographs, letters, yellowed grade-cards and score-cards, recalled her stories - searching for the people, places, and events that set her life along one course, rather than another. I soon understood that all of these were just fragments of larger histories, which quickly spread outward into Time like ripples on a pool. I realized too that much of her life remains among us - remembered person-by-person, child-by-child, story-by-story across generations - newly unfolding backward and forward. In this sense, The Past is never dead. It is not even past. (William Faulkner)

In the last years, Mary Stansbury Morton was fortunate to have the care of many fine people in the Memory Support Unit and the Skilled Nursing Floor of the Presbyterian Retirement Community in Quarryville. She also benefited from the care of two kind and skilled physicians, Drs. Andy Warren and John Schmitt. The Morton Family is grateful for this compassionate care. We are also thankful to the Reverend Paul O’Gorek who remembered her, enjoyed her independent spirit, spoke at her memorial service, and said a fine prayer over her grave.

In memory of Mary Stansbury Morton her family suggests donations to The Clinic for Special Children to support research to better understand and treat inherited causes of deafness and depressive illnesses. Donations may be sent to the attention of Holmes & Caroline Morton, The Clinic for Special Children P.O. Box 128, 535 Bunker Hill Road, Strasburg, PA 17579. The Clinic is a non-profit 501- (c) organization.
I am a pediatrician whose practice provides medical care for children with inherited disorders. In 1989, I was cofounder, with my wife Caroline, of the Clinic for Special Children in Strasburg Pennsylvania. The Clinic is a nonprofit organization that is supported by the Amish and Mennonite families of Lancaster County Pennsylvania. In the early years much of our support came from families who had children with maple syrup disease and glutaric aciduria. However, since 1989 patients with more than 80 other genetic disorders have come to the Clinic in Strasburg from 27 of the United States, Canada, and from as far as Iran, The Netherlands, England, Brazil, and India. The Clinic has grown from a solo practice to a current staff of nine including two pediatricians, a pediatric nurse practitioner, a registered pediatric nurse, and a lab director with a Ph.D. in molecular biology and population genetics. The Clinic’s laboratory is CLIA certified for complex testing and routinely uses biochemical and molecular methods to diagnose and manage genetic disorders. Publications from the Clinic are available at the website: <clinicforspecialchildren.org>.

I was from a town of two thousand people named Fayetteville in the coal region of southern West Virginia. The town had two stop lights and two pool halls, each just before and after the Court House, at the start and end of main street, and, the town had one of just about
everything else required to make a town, including one policeman, an ex heavy weight boxer whose career ended in coma, after a professional fight with a young, quick, black boxer from Kentucky named Cassius Clay.

For high school I was sent Greenbrier Military School, which didn’t suite me for a variety of reasons, and left me with a deep aversion for marching in step and military routines. After two years I asked to transfer to Virginia Episcopal School, which was more civil, but I found the course work difficult and, except for literature, uninteresting. I did not graduate, I left school to work, travel, and write. I worked for six years as boiler man and engineman in the Merchant Marine and US Navy, obtained a General Education Diploma, completed several college correspondence courses in mathematics and the sciences, read constantly, but, wrote little.

After discharge from the Navy in 1975, I applied to an independent degree program at Trinity College in Hartford Connecticut. My application essay described papers and books that I had read about neurobiology and early childhood development and stated that I planned to build upon these interests while at Trinity. I graduated from Trinity College in 1979 with Honors in Developmental Psychology and Biology. I earned an M.D. from Harvard Medical School, did a three year residency in Pediatric Medicine at Children’s Hospital of Boston, and three years of fellowship work with Dr. Richard I. Kelley in Biochemical Genetics at Children’s of Philadelphia and Kennedy Krieger Institute at Johns Hopkins.

My work in Lancaster County Pennsylvania began, unexpectedly, in June 1988 with a drive from Philadelphia to an Amish home to examine a boy with a inherited disorder called glutaric aciduria type 1. Glutaric aciduria was then believed to be a rare metabolic disorder. None of the physicians at Children’s had diagnosed or seen a child with the condition. The Amish boy’s parents told me that there were many children similar to Danny in the Amish community. Most, like their son, appeared to be normal at birth, but between six and eighteen months of age were suddenly stricken with a form of paralysis, which was later often called by physicians “cerebral palsy.” The boy’s parents gave me names of these children, and I began to regularly visit Amish farms in Lancaster County to find the children with glutaric aciduria, and learn more about the biochemical basis of the quick and lasting brain injury that it caused. My early clinical impressions about the natural history of glutaric aciduria suggested the disorder might be treatable. But, as is true for many similar inherited biochemical disorders, the success of any treatment ultimately depends upon finding, and caring for, asymptotic newborns. My preliminary studies in Lancaster County led to an invitation from Hugo Moser and Richard Kelley to spend a research year at Kennedy Krieger in Baltimore. In the Spring of 1989, after learning that my proposed research about glutaric aciduria would not be supported
by NIH or Johns Hopkins, Caroline and I founded the non-profit organization called Clinic for Special Children, and we began to work in Lancaster County full time in December of 1989.

Caroline and I have three children. Mary, 24, who studied Biology and Geology, and works on my brother's organic seed farm in Oregon. Sarah, 22, who studies painting at the Pennsylvania Academy of Fine Art in Philadelphia. And, Paul, 19, who found math more interesting than biology, disliked high school as his father did, plays all styles of music well on the guitar, but, now studies classical guitar at the Peabody Conservatory in Baltimore. We live in Strasburg Pennsylvania, a short distance from the Clinic.

I am a member of the American Academy of Pediatrics, The American Society of Human Genetics, the US and European Societies for the Study of Inborn Errors of Metabolism. Beyond biology and medicine, my interests include playing the cello, fishing for brook trout in mountain streams, writing short stories, and playing an occasional game of golf. In recognition of my work as a pediatrician, I have been given seven honorary doctoral degrees, I was featured in Contemporary Pediatrics as an Advocate for Children, and twice, the Clinic for Special Children and I were awarded the Smithsonian Institution Award for Innovations in Technology. In 1993, I was given the Albert Schweitzer Prize for Humanitarianism, a prize given jointly by the Alexander von Humbolt Foundation of Germany and Johns Hopkins University. This prize has influenced my life and work in many ways. Probably most important the award led me to write a collection of essays about my work as a pediatrician in Lancaster County. The essays began in the form of an acceptance letter for the Schweitzer Prize to the President of Johns Hopkins, was expanded first into an acceptance talk for the Prize, then into a lecture at Children's Hospital of Boston, and was finally published in the journal Pediatrics in 1994 as an essay called Through my Window. I am told that students in some medical schools are given the essay to read early in their studies.

In lectures to students about my work, I tell them that I a biologist, with special interest in neurobiology and genetics, who has found an unusual way to make a living as a general pediatrician for children who have difficult problems. And, I am a person with many interests in the sciences and humanities, who set out a age 18 to travel, learn, and write, and who many years later, unexpectedly, found in the work of a doctor remarkable opportunities to learn and to write.
Scientists

The beauty of flowers is suspect.
Oh yes, the splendor of flowers.
Science is concerned to deprive us of illusions.
Though why it is eager to do so is unclear.
The battles among genes, traits that secure success, gains and losses.
My God what language these people speak.
In their white coats. Charles Darwin
At least had pangs of conscience
Making public a theory that was, as he said devilish.
And they? It was, after all, their idea:
To segregate rats into separate cages.
To segregate humans, write off as a genetic loss
Some of their own species and poison them.
“The pride of peacock is the glory of God.”
Wrote William Blake. There was a time
When disinterested beauty by its shear superabundance
Gratified our eyes. What have they left us?
Only the accountancy of a capitalistic enterprise.
I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I -
I took the road less traveled by,
And that has made all the difference.

(from The Road Not Taken by Robert Frost)