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FAMILY HISTORIES - TONY IS GREATLY MISSED

Details

Written by Donna Casey

Published: 17 July 2009

We were in Pennsylvania for the holidays when we received word that Tony Casey had passed away. It was such a shock. We like to think that persons with MSUD have passed through the critical period of their lives by the time they are in their late teens or surely by young adulthood. Tony was born on Nov. 1, 1973 and turned 20 just two months before he died on the morning of the 31st of Dec., 1993.

The Casey family had shared their history in our Feb. '85 issue of the Newsletter. Of their nine children, one son and three daughters died of undiagnosed MSUD. When her youngest son Tony was born, Donna became uneasy by the 5th day. Tony was not feeding well, just as the other four siblings had acted. Because of her concern, the doctors admitted him to the hospital. He was diagnosed at nine days of age.

In Donna's earlier account, she relates what she said when Dr. Ampola told her about MSUD. "I have learned something that I figured I would not know until I stood before our Lord and could ask him, 'What was wrong with all our babies?'"

Tony had the benefit of current health care and did well. He was a highly motivated young man and well liked by those who knew him. Following is an account of his sudden decline and death written by his mother on Feb. 7. We extend our deepest sympathy to the Casey family who has suffered so much. May their faith in the Lord continue to strengthen them.

I have had a very difficult time expressing my feelings on paper. We are still trying to grasp the reality of Tony's death. We miss him so much. He was our life. Everything seemed to surround him. He kept us on the go and thinking young.

Tony graduated from high school last June and was enrolled as a carpentry student at a vocational school in Augusta. He loved school and never missed unless he was sick, which wasn't often. He also loved country music and knew all the songs and the stars. He was very outgoing and friendly and everyone commented about his smile.

He belonged to the youth group at our church and was to have gone to Long Beach, California on Dec. 27. The youth group went to a gigantic youth rally there. They had worked hard all year to raise money to go. We knew the week before that he could not go as he wasn't feeling well.

On Sunday, Dec. 19, Tony was in an accident with his brother-in-law. He was shook up and complained of a stiff neck. Otherwise, he was fine. On Monday, he ran a fever. I took him to the doctor that evening, who checked him and thought he had the flu. On Tuesday, he was no better, so they ordered an antibiotic. By Wednesday, he was over the fever, but still didn't feel good. He refused to eat or drink much and vomited after eating.

On Thursday evening he wasn't much better, so we returned to the doctor. We just got in the office when he started to hallucinate. This was the first time he realized that he was hallucinating and he started to cry÷something he never did before when he hallucinated. I told him to hug me and it would soon go away. He did, and it did for awhile. They immediately put him in the hospital and started an IV. He got upset with me once and pulled it out. So they sedated him and put it back in. By the next morning he was much better, and that evening, being Christmas Eve, they let him come home. He vomited the French fries he had eaten.

By Tuesday of the next week, he was still not feeling much better, so I called Dr. Ampola, our doctor in Boston. She advised me to take him back to be checked and have blood work done again. After checking him the doctors were sure it was sinusitis and gave him a new antibiotic. He was complaining of a headache. (He had problems with frequent headaches and sinusitis.) All tests were normal.

Wednesday evening, Tony asked if I were going to take him to the hospital. I guess he thought he should go back. Thursday, my husband was admitted to the hospital with flu and fever. While I was at the hospital, the pediatrician's office called and asked how Tony was doing. I called them back and expressed my concern. They decided to check him again.

He took a bath and I helped him get dressed. As I patted his hair dry he complained that the top of his head hurt. His right eye looked droopy to me. He was dehydrated and they put him in the hospital again. He walked into the hospital and signed his own papers. They put in an IV, and he went to sleep. I left him and came home. (My heart aches to write this because, I wish I could have been with him when the Lord took him. But I guess the Lord knows how much we can handle.)

They told me later Tony continued to complain about his head, and they put ice on it. His belly also hurt. At 2:00 a.m. they called the doctor and told him that Tony was complaining about his head and he ordered Tylenol with codeine. Then he went to sleep. The nurse checked on him at about 5:30 and found he was in trouble, (they didn't go into detail with me about it), and they called a code. It was too late. He died as they worked on him. One nurse who was with him and knew him personally took it so very hard.

My husband came home from the hospital Saturday. He really wasn't ready, but the doctor knew he needed to come home. They performed an autopsy on Tony and we donated his eyes, heart valves, and some of his bones. It was a very hard thing to do, but we know he no longer needed them. He has a perfect, whole body now, and of course, we always say÷now he can have his hamburgers. The autopsy showed there was brain swelling and his lungs were full of blood.

On Monday, we had a beautiful service for Tony. I have two sons-in-law who are ministers. One of them spoke of his qualities, and the other read a letter that the nurse who was with him had written. It was very touching. Our pastor talked to the people about Tony and their need to get right with the Lord. A wonderful Christian lady friend sang two songs, "How Great Thou Art" and "Because He Lives."

As I write, I am trying to recall how often Tony was in the hospital. His first time, after his initial stay at Boston, was when he was 13 months old. He had an eye infection, and they put him in the hospital as a precaution. He was fine. When he was about 3 years old, he had a bad illness. He didn't know us and he couldn't sit up. After about two days on IVs, he bounced back fine. This happened again when he was about 9 or 10. He had his appendix out when he was about 8 years old. He came through that with flying colors. Then he was in the hospital when he was 15, because he had stepped on a nail. He had no problems with that either. All in all he was very healthy.

We are still having a very hard time÷missing Tony. As our pastors put it, we are experiencing a double whammy; not only are we grieving but experiencing the "Empty Nest Syndrome" also. I guess they are right. Tony was still very dependent on us.

He was such a normal, good boy that we are having a hard time understanding why our precious Lord chose to take him home at this time. But we also know the Lord has all wisdom and can see further down the road and what might have been in store for him there.

FAMILY HISTORIES - BROCK'S STORY

Details

Written by Celeste C. Wiles-Battle

Published: 17 July 2009

As I finished reading "Nick's Story" in the Dec. '93 issue of the Newsletter, I felt compelled to write for the first time since Brock was born.

Brock Douglas Wiles was born April 21, 1979 in Jamestown, NY. I'd had my new son home for less than 24 hours when the doctor's office telephoned me. There is no need to explain

the shock, disbelief and pain I faced that day, as all of you parents have felt the same.

Children's Hospital in Buffalo, New York was our home for the next three months. Feeling at home (in the hospital) was difficult. I had a 13 month old at home with Grandma from whom I hated to be separated. Three months was like three years!

Brock has classic MSUD, strictly limited to 750 mg of leucine per day. What a challenge! (I needed the insight to buy into a McDonalds 14 years ago; I'd be wealthy today!) His diet is potatoes, potatoes, and more potatoes, fruit, cereals and Egg-free Raisin Bread from Ener-G-Foods. Brock dislikes vegetables, except corn. His formula is Maxamum MSUD mixed with fruit punch and water to yield 12 ounces per day. He drinks 4 ounces three times a day, followed with a glass of water, as this mixture is very concentrated.

Brock's most recent hospitalization was this past Christmas. He caught the flu complete with vomiting and diarrhea, leading to rapid dehydration. Brock begins to suffer from hallucinations and difficulty with his sight when he becomes ill. IV fluids are generally the ticket to prompt recovery. Fortunately, hospital stays are far less frequent than when Brock was younger.

Like Nick, Brock suffers from tendon tightness and cramping. He remains small at 95 pounds and 5 feet even. He suffers from frequent cold sores and sores that crack at each corner of his mouth. He has many hangnails and his finger cuticles are generally red and cracked. He has an excess of ear wax which needs to be cleaned out frequently as it drains. Ear flushes are completed two or three times per year.

Brock has ADHD along with a few other learning disabilities. He (again like Nick) is not highly motivated, could care less about homework, assignments due, or tests. To study at home is a major task. MTV, Nintendo and music are his favorites. He can whip anyone at any video game, knows the words to most rap songs, and can describe any music video in detail. No trouble with motivation there! He, too, loves sports, but energy levels are depleted too rapidly to participate much. Basketball seems the sport best tolerated by him. I wish school grades were as high as his memory of football plays! He remains in the 7th grade (mainstreamed) with 45 minutes of Resource Room per day. Organizational skills are poor, which is very frustrating for the person who is organized; patience is not one of my virtues.

We are not yet worried about the future; we concentrate on weight gain, school grades, and controlling the sassy mouth that is common of most 14 year olds. (This story was written before his 15th birthday.) His poor impulse control and vivid story telling make it difficult for Brock to make lasting friendships.

He is looking for new friends, especially those that can relate to this illness. He loves to write letters and would love to write to anyone who takes the time to write him. He sent out a few letters in the past month attempting to reach out. (He sent one to Nick just a week prior to receiving the Newsletter with Nick's story).

Brock is a truly special young man. He requires firm limits and constant guidance, enjoys testing those limits and resists guidance, but at the end of the day he's the first one to kiss you good night, give you a hug and express his love in front of anyone present! A true gift from God!

A LETTER FROM SCOTLAND

Details

Written by Nicky Guthrie

Published: 17 July 2009

With permission from Nicky Guthrie, I am reprinting most of a letter she sent to me. Nicky and her family live in Scotland; thousands of miles in distance from many of us, but close in heart and experience. I think most families can identify with her candid account in some aspect of our own relationship with others. She also gives sound advice which applies to any of our relationships.

I find the MSUD Newsletter a **lifeline**! I have never met anybody with children with MSUD, or indeed any other metabolic disease, and the information and experiences shared in the Newsletter, I find absolutely invaluable!

I have been trying to think of some way I could contribute something to the Newsletter, but I am not really sure that I can be of any help. It seems that our situation is just so different from most of the other people that read the Newsletter, that I'm not sure our experiences would be relevant to them. We have two children with MSUD; Laura, aged five, and Catherine, aged three. Laura, interestingly enough, has an almost identical early history to the boy, Nick Lovrin, featured in the last Newsletter. She was diagnosed late, at 14 months, and really should not have survived, as blood and skin tests showed her to be very severely affected indeed. She was badly delayed mentally and physically at the time of diagnosis, and we were told that she would be permanently brain damaged; but, miraculously, she had closed the gap between her and her peers by the age of three years, and is now above average intellectually. Catherine was diagnosed antenatally, and, despite many hospital admissions to correct metabolic imbalances (nine in seven months last year), is so far developing normally.

As you know, there are many different aspects to caring for a child with MSUD, and the area I have been pondering over lately has been relationships with other people; friends and the extended family. This is where we perhaps do not have much in common with most of your readers. Geographically we are very different, and perhaps the people involved are rather different. Perhaps I have a false view of Americans, and I know it **must** be wrong to lump all Americans together, but it does seem that you guys are generally more "open" people than we Scots, who are probably too private by half!

Anyway, I have found that we have felt a great deal of support from our friends, but that things have not always been so easy with the wider family. I thought it might be interesting to write about this. I have never heard anybody say this, and yet I am **sure** that other people must have experienced it too. It can make you feel so isolated and hurt, despite all the support you feel flooding through from your friends.

The first, and by far the most obvious area I have felt this, is from my sister-in-law, my brother's wife. (I write this knowing that they will never read it, and with the feeling that to share this experience may be helpful to other people who may find themselves in a similar position.)

I feel difficulties have arisen between our family and theirs for several reasons. The most important one is that their eldest child is nine months younger than our eldest child and their second child is four months younger than our second child. Because our children are just slightly older, and have a potentially very serious disorder, I think my sister-in-law must have felt, subconsciously, that all the attention (of relatives) was going to be focused on our children, and that theirs would be neglected. Of course, "normal" babies and very small children can be very stressful to look after, and parents of "normal" children have many worries too. I think that my sister-in-law felt that nobody would pay any attention to her worries and difficulties. We live only ten miles from them, but I had to spend so much time coaxing the children to take their special diets when they were tiny, I could not spend as much time with my brother's family as I would have liked.

As all parents with MSUD have done, we have been through some very difficult times. When our first child, Laura, was eighteen months old (not an easy age), and I had just been told that the child I was then carrying was also affected with MSUD (devastating news), I started getting messages from my sister-in-law to the effect that I cared about nobody but myself and my problems; I didn't care at all about her and her child. At the time this felt like the straw that would break the donkey's back. I was desperately hurt and upset by it, as I **do** care for them **so** much, and I spent many sleepless nights because of it.

The point I need to make here is that my sister-in-law is by no means a nasty person. She is a very kind, loving, generous person, who makes friends easily and is generally an open, welcoming sort of person. But she is also impulsive, and very subjective. She is not an objective person. What I now think must have happened is that she had started to resent the fact that we had a "special" child. She felt that her child should be considered "special" too, but was only ordinary. This was, and is, absolutely untrue, but as all our other relatives live a long way away from us, it was possible for this illusion to grow. When we were told our second child would be a "special" child, this may have, subconsciously, seemed even worse for her. Of course my brother, to whom I had previously been pretty close, spent a lot of time with his own family and very little with us. His wife's feelings towards us began to spread to him, though by no means to the same extent.

Again, I found this wildly hurtful, and felt powerless to dispel these illusions. The isolation and loneliness I felt when dealing with my two children with MSUD was greatly heightened because of it.

All four children are older now, and life is that much easier for all of us. Our relationship with their family is better than it was, but not ideal, and we lead pretty separate lives. I do not know if they know exactly what MSUD is.

If anyone else finds themselves in a similar position to this, I think there is only one course to take. **Do not let any resentment build up** within yourself against the other people. It will destroy you. You may find yourself hurt, but do not let yourself resent them. Even if the other people's feelings **are** subjective and untrue, you can understand why they have

arisen, and if you can continue to show them care and love, then, hopefully, in time, their resentment will be dispelled. There is nothing to be gained by animosity, except more stress. You are too vulnerable.

I was four months pregnant when we were told that our second child had MSUD too. I phoned to tell my mother-in-law, who was on holiday in the States at the time, and to tell her we were keeping the child. She thought we should terminate, and her immediate reaction was, "Well, it's your child, and your decision!"

True enough, but it was the way she said it! She had told me previously that she thought we should not have another child with MSUD. She said she would like her son to have the experience of bringing up a "normal" child. That was her immediate reaction, but she phoned us a couple of days later to say that, of course, she would support us to the full, whatever our decision. I must say that she has.

Having a "special" child within the family network is not an easy business for so many different reasons. Perhaps it is more difficult for the "in-laws" because they feel slightly on the outskirts of that particular family. The same expectations are perhaps not the same with friends, which is possibly why difficulties do not arise so often with them.

TESTIMONIALS ABOUT THE USE OF TPN

Details

Written by Joyce Brubacher

Published: 17 July 2009

Sandy Bulcher, Ohio

Last month was a trying, yet educational time for our family. Jordan our 4¸ year old son with MSUD was sick from a viral infection. I was in contact with Jordan's dietician, Julie Jacobson and Dr. Allen from the University of Michigan Hospital and was hopeful that his levels wouldn't elevate significantly. Unfortunately, he awoke the following Sunday morning irritable, ataxic, and with slurred speech. He was admitted to our local Children's Hospital and it soon became obvious that his condition was deteriorating. The medical staff communicated frequently with Dr. Allen and it was decided that Jordan needed TPN.

TPN is the abbreviation for total parenteral nutrition and is an effective means of lowering the leucine level. It is an IV solution that provides adequate nutrition and calories without the branched-chain amino acids. After some research, the staff located a 3 day supply at Children's Hospital of Philadelphia. The solution was sent to us via plane and Jordan was started on the TPN.

To our amazement, Jordan became more responsive, less ataxic, and spoke more clearly

within hours. Since this incident, the pharmacy staff at our local hospital has gathered data about the TPN, so they can obtain it as quickly as possible if needed in the future.

This was our first experience with TPN and clearly Jordan's recovery time was shortened. I feel a sense of comfort knowing that it is available and very effective if Jordan should need it again. I would encourage everyone to discuss TPN with their doctor and educate themselves also.

Leon & Dianne Kennedy, Michigan

Joyce asked for a paragraph on our experience with MSUD TPN. Actually we have had to use it twice for Lewis, and I would highly recommend it when an MSUD child gets sick with vomiting and is not responding to the usual treatment.

Both times we have used it for Lewis, he was very ill. The first illness was apparently triggered by an infection, during the second one he just started falling asleep at his desk at school. By the time I picked him up and got him home, he was vomiting. We took him to our local hospital (after contacting Dr. Allen). We got the usual run-around there as they always want to wait and see if the child will quit vomiting on his own. I think maybe they feel it is just the flu or something.

Anyway by seven o'clock in the evening, Lewis could not walk, sit, or hardly hold his head up. The hospital had started an IV which wasn't doing a thing. Dr. Allen told them how to get the TPN (or ordered it for them). It took about 24 hours to get it. Within eight or ten hours on the TPN, Lewis was sitting up watching cartoons. The doctor in ICU called it "miracle juice."

Carl & Sandy Kiel, Michigan

We had two experiences where we used the MSUD TPN for Jenna. The first was as a newborn. Although Jenna was caught by newborn screening, she was suffering severe signs, such as loss of sucking reflex, very fussy and irritable. By 10 days of age she had a slight seizure and was near comatose. She began on the TPN at 10 days of age at the University of Michigan Hospital. They had the TPN available there because the Kennedy's Lewis had used it two weeks prior. After two to three days on TPN, Jenna was responding much better and we were able to come home after only one week!

The second time was when Jenna was almost three years. She contacted the flu. She had vomited Monday, and I fought hard to keep her drinking well so she would not become dehydrated. She seemed better some days, but by Friday she just lay around very quiet, not playing or talking, just sleeping. Dr. Allen arranged to have the TPN shipped to our local hospital. It took 24 hours after we checked into the hospital for it to arrive and Jenna to start receiving it. Within 24 hours on TPN she was once again talking, sitting and by 48 hours was back to normal.

WHAT IS TPN?

Details

Written by Joyce Brubacher

Published: 17 July 2009

I had already started this Newsletter when I talked on the phone with Cliff Webster, the Grandfather of a child with MSUD. I mentioned that Jessica, Peter Shaffer's daughter, had been hospitalized for vomiting which did not respond to IVs. I mentioned the good response to a specially modified Total Parenteral Nutrition (TPN) treatment for MSUD that she and other children have experienced. He encouraged me to print more about this treatment in the Newsletter in laymen's language.

In the April '91 Newsletter under Resources we listed the paper titled "Branched-Chain Amino Acid-Free Parenteral Nutrition in the Treatment of Acute Metabolic Decompensation in Patients with Maple Syrup Urine Disease" by Gerard T. Berry, M.D., et.al. from the Children's Hospital in Philadelphia (CHOP) and reprinted from the New England Journal of Medicine 324:175-179 (January 17, 1991).

That column in our '91 issue was submitted by Alice Mazur, R.N., P.N.P. from CHOP. The description of the paper is given thus. "This report explains the treatment of acutely ill children using a new intravenous nutritional therapy. It involves nine episodes of illness in five patients with MSUD at CHOP. A mixture of complete nutrients, except the branched chain amino acids is administered intravenously. This proved effective in reducing the plasma branched chain amino acid (BCAA) levels when patients were not eating or were vomiting."

Dr. Morton mentioned the use of this type of hyperalimentation (more than normal nourishing) in his article, "MSUD News From the Clinic for Special Children," in the Dec '92 issue of the Newsletter. In the Dec. '93 issue, Glenda Groff told how the TPN was instrumental in helping her son, Jordan, recover from a severe illness. In the same issue, Dr. Richard Allen (from the University Hospitals in Ann Arbor, Michigan) called TPN a great advance in treatment, avoiding the need for dialysis that had previously been used during acute bouts of illness. Dr. Allen, Dr. Morton and CHOP have used this treatment very successfully on newborns with elevated levels of BCAA. I do not know how many other medical centers are using this treatment at this time.

Rather than reprint a technical article on TPN for MSUD, I decided some personal testimonies from parents may help to verify the importance of this apparently lifesaving treatment. It is very important that you and your doctor are familiar with TPN and have a plan for its use **before** it is needed.

I called three families who had children treated with TPN. I asked them to write a short account of their experience and fax it to me as soon as possible. All three faxes arrived within twelve hours. I call that real support! Hopefully these reports will help this treatment receive the recognition it deserves.

A MODERN DR. SCHWEITZER

Details

Written by Joyce Brubacher

Published: 17 July 2009

In the last Newsletter (Dec. 1993) we printed a newspaper account of Dr. Morton receiving the Albert Schweitzer Award. His acceptance speech has since been printed in the Clinic for Special Children Newsletter. Many were impressed with his speech,and especially his philosophy, which is the foundation of his work in this unique clinic. Since he is one of our professional contact persons, and probably serves the largest number of children with MSUD of any medical center in the North America, we think both families and professionals in our organization will find his acceptance speech interesting and touching. With permission, it is reprinted here from the Clinic's newsletter.

Dr. Morton Wins Albert Schweitzer Prize for Humanitarianism for 1993

Dr. Holmes Morton, founder of the Clinic for Special Children, is the recipient of the 1993 Albert Schweitzer Prize for Humanitarianism. Given in Baltimore, Maryland on October 27 by The Johns Hopkins University on behalf of the Alexander von Humboldt Foundation, the prize recognizes Dr. Morton for his dedicated and effective work at the Clinic for Special Children. Previous recipients include former President Jimmy Carter, Marian Wright Edelman, Norman Cousins, and former Surgeon General Dr. C. Everett Koop. The Prize includes an award of $10,000 to Dr. Morton which he will donate to the Clinic.

The work recognized by the Schweitzer Prize is made possible through the support of many who helped raise the Clinic from frustration and hope since the need became public through the Wall Street Journal in the fall of 1989. In a sense the prize also belongs to many of you who have made the work at the Clinic possible and to many of the families who come here. In his acceptance speech, Dr. Morton spoke of why children within the Amish and Mennonite cultures, born with genetic disorders, who have complex medical problems, are thought of as Special Children; how they are accepted as a gift rather than as a burden, and why these children inspire his work. Many who heard his speech in Baltimore asked for a copy. We decided to print his remarks in this newsletter as one way to share his thoughts about his work and say thank you to all who have made it possible.

"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 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 Lamberene 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 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 over-shadowed 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 stars, and the elderly and children 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 of these children 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.

I recently thought of you on a November night as I walked out of an Amish farmhouse into cold rain and darkness and 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 weaker, and, toward evening, just faded. He didn't seem to suffer. He had 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 gift. 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 simple words would change the way those children, and I, would remember the life and death of the boy. I understood that 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 child'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 to love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people. And because of them, 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.