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SPECIAL ARTICLES

Through My Window—Remarks at the 125th Year Celebration of Children's Hospital of Boston

D. Holmes Morton, MD

Editor's Note:

Once a decade you might hear a really good talk. This was such a talk. I found it moving and thought-provoking. I asked Dr Morton to send it to *Pediatrics* so that we could publish it as a Special Article. Read it and think. It's not your usual journal article.

The Editor

ABBREVIATIONS. MCADD, medium chain acyl dehydrogenase deficiency; MSUD, maple syrup urine disease; GA1, glutaric aciduria type 1.

Ten years ago, when I was a second-year resident here, I was paged by a nurse who said that Dr Aubrey Katz had admitted a 2-year-old boy to the intensive care unit with a diagnosis of Reye syndrome. The nurses in the intensive care unit knew of my interest in the disorder. Through work with Fred Lovejoy I became interested in the mechanism of intoxication in Reye syndrome. I wanted to understand the biochemical basis of the illness and learn how to control and reverse the abnormal metabolic state. After the association between salicylate, varicella, and Reye was recognized, we saw few cases of true Reye syndrome and became more aware of the biochemical disorders that were commonly mistaken for Reye syndrome. When paged that night I was roaming the hospital as a night float. I needed something interesting to keep me awake. A metabolic disorder misdiagnosed as Reye syndrome and a friendly argument with Dr Katz was perfect. I immediately went to the intensive care unit, reviewed the chart, examined the child, and wrote a *rare* legible note stating that this was not Reye syndrome but was

medium chain acyl dehydrogenase deficiency (MCADD). I was right. Aubrey Katz lost our wager, but, still owes me a Chinese dinner. After some minor changes in therapy Eric rapidly recovered and has not been ill again. I get a Christmas card from the family each year to report his continued good health and to repeat their thanks for my help.

Through this case I came to know Richard Kelley who for 10 years has been my friend and mentor. Dr Kelley at that time was at Children's Hospital in Philadelphia and was one of the first clinicians to understand the intoxication of MCADD as a maladaptation to fasts. He recognized the disorder's association with Reye and sudden infant death syndromes and worked with Dan Hale and Charlie Stanley to formulate an effective approach to managing the episodes of intoxication.

Now I am a pediatrician in Lancaster County, Pennsylvania. From Richard Kelley I acquired some skills as a biochemist that I use to diagnose, treat, and study inherited disorders of metabolism similar to the disorder that Eric has. Most of my patients are children of the Amish and Mennonite people of Pennsylvania.

I remain especially interested in biochemical disorders that cause episodic illnesses and masquerade as Reye syndrome, cerebral palsy, sudden infant death syndrome, cyclic vomiting, and culture negative sepsis. The natural history of these disorders reveals that they are treatable. Affected patients may be asymptomatic for months or years between episodes of illness. We need only to learn what adaptations allow tolerance of the biochemical defect dur-

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ing periods of stability and what factors trigger acute biochemical intoxication. Then, often with relatively simple principles of care, we can prevent serious illness, limit hospitalizations, and improve outcome. No gene repair is required, just an understanding of the metabolic adaptations to fasts and illnesses, applied biochemistry, an educated parent and patient, and ready access to care during the common illnesses that provoke metabolic crisis.

USEFUL WORK

This is not the time to explain the biochemistry of such disorders, but I want to tell you that what we learn and do in Lancaster is medically useful.

Two years ago I found the first case of MCADD in the Mennonite population of Lancaster County. The patient is an adolescent 16 years of age who was seen intermittently for many years at a regional medical center for idiopathic cyclic vomiting. Her older sister died suddenly at 6 months of age, her case was signed out after autopsy as Reye syndrome. The next three cases of MCADD I saw in Lancaster were all asymptomatic neonates sent to me by Dr Naylor at Magee Women's Hospital in Pittsburgh through his innovative supplementary neonatal screening program that uses fast atom bombardment mass spectrometry to look for a pathological carnitine ester of octanoate in filter paper blood samples. The third neonate Dr Naylor referred to me shows the importance of screening for MCADD. When first seen the neonate was 10 days old and had no signs of an underlying disorder. His sibling, just 13 months before, had died at age 6 months, 12 hours after her third diphtheria-pertussis-tetanus vaccine and just 3 months before Dr Naylor added the test for MCADD to his routine screens of neonates born at Lancaster General Hospital. Her death was at the time attributed to sudden infant death syndrome but was in fact metabolic death provoked by immunization and an overnight fast in a neonate with a disorder of fatty acid oxidation. Dr Naylor confirmed the deficiency in this neonate by retrieving her filter paper specimen from storage. A fatty liver was described in the original autopsy findings but was not recognized as a sign of metabolic illness. In the first 55 000 neonates screened by Dr Naylor from the general population of Pennsylvania, 12 cases of MCADD were found, for a prevalence of $\frac{1}{5000}$ that is twice to three times more common than phenylketonuria. At the Clinic for Special Children we can diagnose and monitor MCADD through urine and blood analysis by gas chromatography/mass spectrometry and provide comprehensive follow-up care and carrier testing.

Maple syrup urine disease (MSUD) is another recessive disorder commonly found in the Mennonite population of Lancaster County. Our approach to the care of affected neonates and children, combined with what we have learned at the Clinic about the control of protein synthesis and catabolism, has changed the course of this disease in Lancaster County. Ten years ago when Charlie Scriver reviewed the experience of managing nine cases of classical MSUD in Canada, he reported that the average length of hospitalization for the neonate diag-

nosed with MSUD was 2 months and the average rate of admission to hospital because of metabolic illness was 19 days per patient per year of follow-up. We manage 32 children with classical MSUD at the Clinic, 14 are under 3 years of age. More than half of these children were diagnosed and managed out of hospital as neonates. The average length of hospitalization in the others was 4 days with a range from 1 to 7 days. Our rate of hospitalization from a population of 32 is <1 day per patient per year of follow-up. I saw a 7-year-old Mennonite girl in clinic this week who is in all respects normal. She is first in her class in school. Our entire yearly budget can be justified by the services we provide, and reduced hospital costs for just 32 children with MSUD.

Glutaric aciduria type 1 (GA1) is an important biochemical disorder to efforts at my Clinic and elsewhere to understand mechanisms of brain injury that result in selective damage to the basal ganglia and cause cerebral palsy, Parkinsons disease, and Huntington's chorea. The mechanism of brain injury in infants with GA1 is very different from that seen in MCADD and MSUD. The biochemical injury of GA1 is provoked by fasts and catabolism but is influenced by the age of the patient. Between ages 6 months and 2 years the brain of a child with GA1 is especially vulnerable to injury. The biochemical injury to the caudate nucleus is almost certainly mediated by glutamate receptors that are present in high concentrations in the membranes of neurons in the caudate of an infant. I think GA1 will be one of the first metabolic disorders to be controlled by pharmacology rather than diet.

The natural history of glutaric aciduria indicates that treatment of the disorder will only be effective if the asymptomatic neonate is recognized, treated prospectively, and has immediate access to skilled care during metabolic crisis. Once injury to the brain has occurred in neonates with GA1, the injury cannot be reversed. For this reason 4 years ago we established a voluntary neonatal testing program at the Clinic and screen 95% of all Amish neonates in Lancaster County for GA1. In part because of our preliminary work in Lancaster with Amish children, Ed Naylor has recently added GA1 to the neonatal screens done through his supplemental screening program and has found 3 cases in 55 000 screened, 1 Amish and 2 non-Amish infants. At the Clinic we also provide general medical care for neonates with GA1 and provide care in hospital for managing acute metabolic crisis. I have had >25 successful admissions to Lancaster General Hospital to control metabolic intoxication and prevent brain injury in affected children. Four of 6 infants diagnosed prospectively remain unaffected by the disorder. There is much more to learn before I can approach the care of these infants with the same level of understanding that I have for MSUD and MCADD but the progress is real. The results of research and improved care are tangible.

A state-supported medical center near my Clinic does not participate in Dr Naylor's screening program and is little involved in the care of children with the three disorders discussed above. Why? Institutional policies and politics, long-standing divi-

sions between research and clinical work, changing research paradigms with the current disinterest in biochemical disorders? I am told someone there decided Naylor's program would not be cost-effective for a university hospital. I would like to see that cost analysis; I am sure there is some mistake. I also would like a doctor who agrees with this policy to explain to parents of the infants who died from unrecognized MCADD the economics that makes a neonatal screen for MCADD, and 25 other disorders, that costs only \$15, too costly. I cannot answer for those who made this decision or those who must work under the influence of such institutional policies, but, I can tell you that none of that should be important. When you know these diseases as I know them; when you have seen and felt failure, grief, and then hope; when you know the suffering of these children and their families and know relief of suffering and have been thanked for your help; then, you learn that none of that matters. None of that justifies the loss of even one healthy child. I believe this. A physician who does not understand this belief will not understand my work.

THROUGH THE EYES OF PARENTS

In Lancaster County I began to see illnesses from a different point of view. I saw university-based specialty care from a different perspective—that of the family who has a child with complex health care problems that worsen with each cold, ear infection, or bout of diarrhea. Until the Clinic for Special Children was established in Lancaster, a child with MCADD, MSUD, or GA1 who developed a common infectious illness and acute metabolic intoxication did not have access to appropriate care. Obtaining such care was geographically, economically, and culturally difficult. Many children with these and similar treatable metabolic disorders became disabled or died because of difficult access to care.

In 1988, just as my work with glutaric aciduria began in Lancaster County, an 8-year-old Mennonite girl with MSUD died at a community hospital in Lancaster. She had been diagnosed at 48 hours of age, neonatal intoxication was prevented, and her subsequent growth and development were normal. Before her admission she had been ill at home with a cold for several days and was admitted with pneumonia. The physicians at the local hospital talked daily with a doctor from the metabolic group in Philadelphia. The girl appeared stable but on the third hospital day she suddenly deteriorated and died from herniation of the brain.

I was a fellow in metabolic diseases at Children's Hospital in Philadelphia then. I will not forget the meeting in our division about her death. Blame was placed on the doctors in Lancaster. There was much discussion about the possible origins of cerebral edema in patients with MSUD and the need for intensive care for any ill child with the disorder, and, of course, the possibility of grant money to study the problem.

There was no discussion of the fact that for more than a week this girl had been ill at home and amino acid levels were not measured, the urine DNPH reaction was not monitored, her calorie, protein, and

amino acid intake were unknown to us and were not discussed. No significant changes were made in her management to prevent worsening intoxication before hospitalization. What if diabetes mellitus were managed only by intensive care of ketoacidotic episodes without regard to daily control of glucose and sick days? Wouldn't we expect a poor outcome? At our division meeting there were no questions about what simple interventions could have been made early in the course of her illness to prevent intoxication. The conclusion was that any child with MSUD who had a respiratory tract infection, diarrhea, or another such illness that would be likely to provoke protein catabolism must be evaluated and hospitalized in Philadelphia. All suggested changes in care were in terms of Children's Hospital services.

In fact, little was known about how to manage MSUD on sick-days in the outpatient setting, during hospitalization for a common infection, or after immunizations, injury, or minor surgery. Grants to study MSUD in our division had always emphasized management in the university hospital setting. Because of this the doctors in Lancaster were given poor advice. When I reviewed the patient's hospital record recently, I found that the day before she died the glucose infusion rate, used to limit endogenous protein catabolism, was $<1/2$ of her basal metabolic rate, $1/4$ of what would have been needed. Her protein intake from the amino acid mixture in her special formula, needed to support protein synthesis thereby to lower serum leucine, was $<1/4$ g/kg-24 hours, $<1/8$ of what would have been needed.

No one at our meeting asked why appropriate therapy was not available in Lancaster. There were few economic or academic incentives for regional university hospitals to establish a local clinic and hospital service in Lancaster County that would make their own specialty services less necessary, make the shortcomings of those services so apparent, and make children with MSUD and other *interesting* genetic diseases, less available as subjects for grant proposals. In this sense the economic and academic goals of university hospitals can be at odds with the care of children with *interesting* illnesses. Control of speciality services and goals of research at times take precedent over the general health care and quality of life of the children with genetic-metabolic disorders. Research too often emphasizes use of university services and new technology over practical questions about daily care. I know that studies of the genetic diseases of the Amish and Mennonite people have provided important knowledge, but, I also know that some of the work with the Amish and Mennonite people of Lancaster County, done by teams of people from universities, has amounted to little more than *medical tourism*. Too often these teams of physicians, students, and blood drawers were disinterested in the health care needs of those whose genetic diseases were studied. This is a harsh judgment, but it is true, and the Plain people know this.

THE CLINIC

The policies and politics of grants makes it impossible to support our work at the Clinic for Special

Children by grants. *Who supports us?* you ask. *Who sees the benefit of our work?* I ask. *Who knows the value of a healthy child?* Parents. Those who love their children and call children with disabilities or unusual illnesses special children. Those who see these children as people who need our help and believe that these children will show us the value of our caring and our work. That is who supports us.

In the spring of 1989 my wife Caroline and I established a nonprofit organization called the Clinic for Special Children. Establishment of a nonprofit organization is essentially a legal procedure. Organization by-laws are written in a standard legal format. Application for nonprofit tax status is a well-defined process that is simply slow and tedious. The Internal Revenue Service uses frustration as a primary screen for organizations like ours. Caroline persisted, got help from a neighbor of ours (a lawyer), established a bank account, learned accounting, recruited, and organized a board.

I am the only full-time physician. I provide general outpatient care, admit acutely ill children to hospital, operate and maintain our mass spectrometer and amino acid analyzer, give two to four lectures per month, write two to four long letters per month, and, when Jake and the boys get behind, I mow grass, take out the trash, use the scythe and weed eater, and plant flowers. We have low indirect costs. Richard Kelley is on the board of the Clinic. He comes to the Clinic weekly from the Kennedy Institute in Baltimore to work on special projects, see difficult cases with me, and he covers the Clinic when I am gone for a lecture such as this. Debbie Kennedy is a part-time nurse practitioner who does well-baby exams for several of the local midwives, does house calls to follow worrisome Clinic cases, and runs our busy immunization clinic—\$5 per child per visit. Debbie also happens to be National Woman's Endurance Rider Champion for 1993, which means that she and her horse, Stoney, regularly win 100-mile horse races. Rebecca Huyard is an unmarried Amish woman who taught in a one-room school for 15 years. She had five nieces and nephews with glutaric aciduria. Before the Clinic was founded two of these children died, the other three have significant disabilities. Rebecca runs the office, does our genealogical searches, and takes young Amish fathers and mothers by the ear, many of them her former students, to make sure they understand the importance of screens for genetic disorders, immunizations, and general health care. We test on a voluntary basis >95% of Amish neonates in Lancaster County for glutaric aciduria. Without a doubt the success of this screening is due to Rebecca and other members of her family. Caroline administers the nonprofit organization, prepares budget reports and agenda for board meetings, and organizes family meetings and professional conferences. She also tries to organize me, tries to keep the telephone and the curious away from me, balances the demands of the Clinic against the demands of our three children, and, when Jake and the boys and I get behind, she mows grass, takes out the trash, and plants flowers.

The Clinic for Special Children is in a timber frame building with a slate roof salvaged from an 140-year-

old barn. The building contributes to the idea that the work being done at the Clinic will last. 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 where it is—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 regions 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.

THROUGH MY WINDOW

As 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 bluebirds, 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 work in the field. Jake farmed 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 and 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 when 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.

LYDIA

One morning in March, David called at 6:30 after milking was finished. He doesn't say hello. He says, "Morton do you know who this is?"

"Yes," I say immediately, "Is Lydia sick?"

"No," he says, "we want to come to visit tonight. Lydia hasn't been sick so often and we don't get to see you. If it suits we'll come to your house at 7 o'clock, your time." They came to visit—David, Barbara, and six children under 8 years old, with an ice cream maker full of cream packed with snow ready to turn, homemade pretzels ready to bake, and fresh cookies.

My patient Lydia will be 5 years old this summer. She does not have a genetic disease. Group B streptococcus destroyed her pituitary and visual system, and damaged other regions of her brain. She has many of the peculiar and interesting mannerisms of a brain-injured child. Her small dark sightless eyes and the way she moves about a room on all fours in search of the familiar and the new reminds me of a raccoon. She is unusually responsive to sounds and quickly repeats words and phrases. Barbara says something then, Lydia says it. *Lydia likes to repeat what she hears.*

Music, as we know it, is not part of Amish culture. When I recall this visit I will always see Lydia, sitting quietly on my lap on the floor, rocking gently, with one hand slowly exploring the front of a speaker, as we listened to a violin concerto of Mozart.

David first came to see me 5 years ago. "We have a sick baby," he said. "She just came home from hospital. She had a brain infection and can't hold her water. Can you handle that here? We don't want to go back to that medical center."

"Why?" I asked.

"Can't tell who your doctor is and costs too much, he said. Will you take care of her?"

"I would need to study her record," I said. "What medicines does she take?"

"I don't know," he said. "My wife understands that, ask her."

Then he handed me a 65-page itemized bill, totaling \$53 235.59. "I can't understand this," he said. "All that money just to keep the baby from dying. To keep the baby from going to heaven. Now they tell us she won't be able to do much."

"Could they have done all these tests? Does a baby have this much blood? I've got to talk to dad about how we can pay this. Will you let me know if this is an honest bill? At the hospital they know the Amish pay their bills and I hear they add extra to make up for those who don't pay."

We must all answer David's question. Every medical student, every resident, every attending, and every politician should study a bill like Lydia's. The bill was not an honest bill.

Diabetes insipidus can be a difficult problem and

is unusual in the neonate, but, what I found in Lydia's record were simply the mistakes of the inexperienced. Her urine output increased, her weight fell, the intravenous fluids over 12 hours carried 24 mEq/kg of sodium, eight times the daily requirement for sodium. Her serum sodium increased to 165 mEq/L and seizures began. Careless use of antidiuretic hormone followed, her weight increased, serum sodium fell to 119 mEq/L, her seizures worsened. She remained on a ventilator, her stay in intensive care was lengthened by water intoxication. Hundreds of blood and urine chemistries were done, but, in the physician notes in her medical record not one mention of her weight—the most important and least expensive measure of water balance.

David was billed \$3780 for the antidiuretic hormone that caused the water intoxication. Had intranasal form of the same medicine been used at the appropriate dose, the bill would have been \$16. Instead 1 unit out of a 250-unit, \$300 vial, of the hormone was used and the rest was discarded. Shelf life of this medicine at room temperature is 3 months. The mark-up is 110%. Residents did not know that if you want a serum sodium stat but send a chemistry 7 instead, the family is billed for seven stat chemistries—\$18 each. As many as six blood urea nitrogen and creatinines were billed in 1 day, all useless tests. Twenty serum and 18 urine calciums were done, most Stat, \$36 each, all normal, all useless. Urine chemistries, \$3498, yet, not one note discussing the significance of a single urine chemistry and I can tell you those urine chemistries were not useful, then or in retrospect. As many as 5 stat hematocrits in one day, 38 hematocrits in 20 days. More than \$15 000 in laboratory tests, most without value to her care.

The attending pediatrician told David and me, "Lydia was an interesting and difficult case. She is lucky to be alive. Holmes, you did an interesting analysis of the case, easier in retrospect I can tell you. July is a bad time to have diabetes insipidus, new housestaff you know, but the residents did a good job. When I attend I think it is important that they have the freedom to make decisions. We know they send some extra tests but that is part of the cost of care at a teaching institution."

I said, "Lydia was your case. You did not notice her weight. You gave antidiuretic hormone in excess. You threw out \$3584 worth of antidiuretic hormone. You sent \$3498 of useless urine chemistries. You must answer David's question. I think David was right, in your hospital you can't tell who your doctor is and it costs too much."

I am naive, you think. We would all like to change such things but we cannot.

Over the past 5 years Lydia has been admitted by me to Lancaster General Hospital five or six times for management of dehydration and adrenal crisis. Her stays were usually 12 to 48 hours. No such mistakes, no such waste. The family practice residents at Lancaster General Hospital learn to manage diabetes insipidus. They also learn not to send unnecessary tests. They learn that their mistakes are my mistakes and I do not well tolerate mistakes with my patients.

Why did I trouble myself about Lydia? Because I thought I should help them. When I reviewed Lydia's record and bill I saw a kind of dishonesty that

will destroy our university medical centers. A kind of dishonesty that increasingly makes medical care unaffordable, not only for my Amish patients but for all of us, and, tragically, undermines the trust that we all must have in medical institutions where we seek help. Dishonest care is destructive in many ways to the people who use and support the clinic. The Plain people are not allowed to have bad debts. They self-insure by collecting alms and do not accept welfare. Farms and livestock are sold to pay bills such as Lydia's. To pay such bills others in a family will go without dental care, immunizations, and visits to a doctor for a sore throat, ear, or stomach pain. There will be more cases of heart disease caused by untreated streptococcus, more deafness because of untreated ear infections, long hospitalizations for appendicitis diagnosed too late, and more infants with rubella syndrome or tetanus. Because of such dishonesty Plain families are slow to seek and accept help from medical centers for congenital heart defects, malignancies, extreme prematurity, and other conditions where the expertise gathered in such institutions is truly needed and helpful. We all must understand that such bills have many high, unrecognized costs and we all must trouble ourselves about them. We all must answer David's question.

DEATH AND LIFE

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 milk-

ing 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 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.

A NEW SENSE OF PLACE

Not long ago I rode an airplane to Boston to lecture here at Children's Hospital. The Old Order Amish have a rule that members 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, "*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 opportu-*

nities 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. Others soon took my place in Boston; here, I would have been missed."

CONCLUSION

Today we celebrate the 125th year of The Children's Hospital. We celebrate the medical care, the research, and the teaching of the men and women whose efforts made this hospital great. At this time let us also remember the children for whom they cared. This hospital, the knowledge gained here, the work done here, and the inspiration for the life-work of these great people, all of these, were gifts from children. Children who were sick and suffered much to give such gifts. The Plain people call them *God's Special Children* and value them, love them, care for them, and remember them when they are gone. So should we.

ANNOUNCEMENT

**American Academy of Pediatrics
1995 Medical Education Awards
Sponsored by Ross Products Division of Abbott Laboratories**

The American Academy of Pediatrics (AAP) is pleased to announce that nominations are now being accepted for the 1995 Medical Education Awards. Nominations must be submitted by January 27, 1995. The awards will be presented at the Academy's Annual Meeting in San Francisco, California, October 14–18, 1995.

The AAP Medical Education Awards, sponsored by Ross Products Division of Abbott Laboratories, annually recognize excellence in pediatric education, and are offered in three categories: the Professional Education Award for innovative and effective programs in the education of medical students, residents, nurses, and pediatricians; the Lay Education Award for programs that educate parents, teachers, children, and others in aspects of child health; and the Lifetime Achievement Award for lifetime achievements in pediatric medical education.

The 1994 Award Recipients are: Neil A. Izenberg, MD, Director, Nemours Center for Biomedical Communications, Alfred I. duPont Institute—winner of the Lay Education Award for his production of two videos: "It Wasn't Supposed To Happen" and "Baby Talk"; Avroy Fanaroff, MD, Professor of Pediatrics, Rainbow Babies & Children's Hospital (Cleveland)—winner of the Professional Education Award for his development of educational materials in neonatal/perinatal medicine; Waldo E. Nelson, MD, Emeritus Professor of Pediatrics, Temple University—one of the winners of the Lifetime Achievement Award for his outstanding teaching qualities and as editor of *The Textbook of Pediatrics*; and Maria Delivoria-Papadopoulos, MD, Professor of Pediatrics, Obstetrics and Gynecology, and Physiology, Hospital of the University of Pennsylvania—also a winner of the Lifetime Achievement Award for her outstanding research and clinical practice skills.

CRITERIA FOR AWARDS: Selection of awards will be based on originality, educational quality, program/project effectiveness, and the potential for utilization in other programs or practices. Nominees are restricted to pediatricians who are members of the Academy. Nominees for professional or lay medical education awards should be actively involved in the program for which they are being considered, and the program should have come to fruition within the last two to three years. Previous nominees may be resubmitted for consideration.

For additional information, or to obtain nomination forms, contact: Linda Wetzel, Program Coordinator, AAP Department of Education, 141 Northwest Point Blvd, PO Box 927, Elk Grove Village, IL 60009-0927, 800/433-9016, ext 6793.

Through My Window—Remarks at the 125th Year Celebration of Children's Hospital of Boston

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