**PEOPLE FILE**

**MEDICAL SLEUTH**

TO PROSECUTORS, IT WAS CHILD ABUSE—AN AMISH BABY COVERED IN BRUISES. BUT DR. D. HOLMES MORTON HAD OTHER IDEAS  **BY TOM SHACHTMAN**

It was every parent’s nightmare: a few days before Christmas 1999, Elizabeth and Samuel Glick, Old Order Amish dairy farmers in rural Dornsife, Pennsylvania, an hour’s drive north of Harrisburg, found their youngest child, 4-month-old Sara Lynn, gravely ill. They rushed her to a local hospital, from where she was soon transferred to the larger Geisinger Medical Center in the next county. There, a doctor noted a hemorrhage in her right eye and extensive bruising on her body, and suspected that her injuries were caused by child abuse.

Alerted to the doctor’s suspicion, the police and officials from the Northumberland County Children and Youth Services descended on the Glicks’ farm during the evening milking, and took away the couple’s seven other children, all boys, ranging in age from 5 to 15. The boys were separated and placed in non-Amish foster homes. Sara died the next day, and...
when the county coroner found blood in her brain, he declared her death a homicide.

At Sara’s funeral, on Christmas Eve, Elizabeth and Samuel were not permitted to speak privately with their sons. By that time Samuel had already contacted the Clinic for Special Children in Lancaster County, and pleaded with its director, pediatrician D. Holmes Morton—the world’s leading authority on genetic-based diseases of the Amish and Mennonite peoples—to find the cause of his daughter’s death.

THE AMISH are Anabaptists, Protestants whose forefathers were invited by William Penn himself to settle in Pennsylvania. Today there are almost 200,000 Amish in the United States, of whom 25,000 live in Lancaster County, in southeastern Pennsylvania between Philadelphia and Harrisburg. Some of their customs and religious values have changed little over the past century.

Most people know that the Amish wear conservative clothing, travel mainly by horse and buggy, eschew most modern technologies, and refuse to use electricity from the common grid. The Amish also remove their children from formal schooling after the eighth grade, do not participate in Social Security or Medicare, and in many other ways maintain their sect’s separateness from mainstream America.

But most people don’t know that the Amish, and their spiritual cousins the Mennonites, experience an inordinately high incidence of certain genetic-based diseases, most of which affect very young children. Many of these afflictions are fatal or disabling, but some, if diagnosed and properly treated in time, can be managed, enabling the children to survive and lead productive lives.

That possibility—of proper diagnosis and intervention to save children’s lives—was what intrigued Morton, then a recently minted M.D. on a postdoctoral fellowship. A colleague at Children’s Hospital in Philadelphia asked him one evening in 1988 to analyze a urine sample from a 6-year-old Amish boy, Danny Lapp, who was mentally alert but wheelchair-bound because he had no control over his limbs—perhaps from cerebral palsy.

But when Morton analyzed the urine, he saw no evidence of cerebral palsy. Rather, in a diagnosis that must have seemed to others like the amazing deductions of Sherlock Holmes, he recognized the footprint of a genetic-based disease so rare that it had been identified in only eight cases in the world, none of them in Lancaster County. Morton’s was an educated guess: he was able to recognize the disease, a metabolic disorder known as glutaric aciduria type 1, or GA-1, because it fit the pattern of diseases he had been studying for almost four years, those that lay dormant in a child’s body until triggered into action.

Typically, a child with GA-1 shows no sign of the disorder until he or she comes down with an ordinary childhood respiratory infection. Then, perhaps prompted by the body’s immune response, the GA-1 flares up, making the child unable to properly metabolize protein-building amino acids, which in turn causes a buildup in the brain of glutarate, a toxic chemical compound that affects the basal ganglia, the part of the brain that controls the tone and position of the limbs. The result, permanent paralysis of the arms and legs, can resemble cerebral palsy.

Sensing that there might be other GA-1 children in the deeply inbred Amish community—some of them, perhaps, treatable—Morton visited Danny Lapp and his family at their Lancaster County home. Indeed, the Lapps told him of other Amish families with similarly disabled children.

“The Amish called them ‘God’s special children,’ and said they had been sent by God to teach us how to love,” says Morton. “That idea deeply affected me.”

In the following months, Morton and his fellowship supervisor, Dr. Richard I. Kelley of Johns Hopkins University, visited the other families with afflicted children and collected from them enough urine and blood samples to identify a cluster of GA-1 cases among the Amish. “We very quickly were able to add to the world’s knowledge base about GA-1,” Richard Kelley recalls. “For a geneticist, that’s exciting.”

Rebecca Smoker, an Amish former schoolteacher who had lost nieces and nephews to GA-1 and now works for Morton’s Clinic for Special Children, vividly remembers the sense of relief that began to spread through the close-knit Amish community. Previous doctors, Smoker recalls, had been “unable to tell parents why their children were dying,” but Morton was able to identify the disease. That was comforting. “If you can say, ‘my baby has this,’ or ‘my baby has that,’ even if it’s an awful thing, you can feel better about it,” says Smoker.

Later in 1987, Morton began driving out from Philadelphia to Lancaster County to manage the care of children with GA-1. Many of the patients who had been previously diagnosed with cerebral palsy were paralyzed beyond repair, but there were some with less advanced paralysis whom Morton was able to help with a new treatment: regimen including a restricted-protein diet and, when needed, hospital care. He also learned, through testing, that some of the affected children’s younger siblings—who had not yet suffered paralysis—had the gene mutation and biochemical abnormalities. If he could manage these children through their earliest years, when they were particularly vulnerable to the effects of GA-1, he believed, as he says now, that he could “alter the likely devastating course of the disease.”

Several of the children came down with respiratory infections in the months that followed. Morton’s strategy—immediately getting them to a hospital, giving them IV glucose and fluids, anticonvulsants, and reducing their protein intake to get them past the crisis points—worked, and they escaped without severe injury to their basal ganglia. Morton had gone beyond giving the horror its proper name; he had found ways for Amish parents to help save their other children from the ravages of the disease.

NOW, NEARLY A DECADE LATER, Sara Lynn Glick’s death presented Morton with a new challenge. He was determined to figure out what had killed her, to exonerate Elizabeth and
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Samuel Glick, and to help them retrieve their seven sons from non-Amish foster homes.

Morton’s first clue to what had actually happened to Sara came in a conversation with her mother. “Liz Glick told me that she had to put socks on Sara’s hands, because Sara had been scratching her own face,” Morton says. Such scratching, he knew, was a likely sign of an underlying liver disease. Another clue was that Sara had been born at home, where a midwife had not given her a vitamin K shot—standard procedure for hospital-born babies, who are given the shot to ensure that their blood will clot properly.

Morton concluded that Sara’s death was due not to child abuse but to a combination of genetic disorders: a vitamin K deficiency, coupled with a bile-salt transporter disorder that he had previously found in 14 other Amish children and some of Sara’s cousins.

Convincing the authorities, however, wouldn’t be easy. So Morton called a friend, Philadelphia lawyer Charles P. Hehmeyer. “You’re always looking for good pro bono cases,” Morton remembers telling Hehmeyer. “Well, here’s a doozy.”

Together, they went to see the Glicks in Dornsife, where they sat in a candlelit kitchen, long after dark, as Liz Glick asked through tears if she would be going to jail.

Sure of his diagnosis, Morton went—uninvited—to a meeting between doctors and the district attorney’s office at Geisinger Medical Center, hoping to point out that the hospital’s own records would conclusively demonstrate that Sara’s injuries had not come from child abuse. He was shown the door.

The Clinic for Special Children in Strasburg, Pennsylvania, lies only a few hundred miles from Morton’s childhood home in Fayetteville, West Virginia. But for him the journey was long and full of unexpected turns. The second youngest of a coal miner’s four sons, Holmes flunked all of his science classes in high school, sank to the bottom of his class and withdrew before graduation. “I was never an easy person to teach,” he admits. “I was always doubting, questioning, arguing.” He took a job in an engine and boiler room of a freighter on the Great Lakes—“my first encounter,” he says, “with people who were very intelligent but had little higher education.”

Focusing on practical shipboard problems and doing plenty of physical labor were a spur to developing his mind within a few years he passed an examination for a commercial license to operate the boilers, and, then completed his high-school equivalency degree.

Drafted in 1970, Morton spent four years “working the Navy’s boilers”; off duty he read about, and then took correspondence courses in, neurology, math, physics and psychology. After the Navy, he enrolled at Trinity College in Hartford, Connecticut, volunteered at a children’s hospital and set his sights on a medical degree.

At Harvard Medical School Morton developed an interest in what he calls “biochemical disorders that cause episodic illnesses.” Like a sudden storm troubling a ship on the Great Lakes, these disorders disrupt in a seemingly static environment and do great damage—maybe irrevocable damage. But afterward everything is calm again. As a resi-
With their intermarriage, careful record-keeping and isolation from the mainstream, the Amish are "a geneticist's dream."

dent at Boston Children's Hospital in 1984, Morton met a child who had been diagnosed by the admitting physician as having Reye's syndrome, a buildup of pressure in the brain and an accumulation of fat in the liver and other organs that often occurs during a viral infection such as the flu or chicken pox. Morton thought the diagnosis mistaken, substituted his own—a metabolic disorder—and accordingly changed the child's diet and treatment regimen. The child recovered and now lives a normal life, and the case gave Morton the confidence, three years later, to discount the cerebral palsy diagnosis for Danny Lapp and diagnose him with GA-1 instead.

ANOTHER SUCH "EPISODIC" disease, this one not found among the Amish but among the much larger Mennonite community, had piqued his interest in the late 1980s. Like the Amish, the Mennonites are Anabaptists. But they use some modern technologies, such as internal-combustion engines, electricity and telephones in the home.

Enos and Anna Mae Hoover, Mennonite organic dairy farmers in Lancaster County, lost three of their ten children, and had a fourth suffer permanent brain damage, before Morton arrived on the scene. Their ordeal began in 1970 with the birth of their second child. When the child became ill, refusing the bottle and going into spasms, "the doctors had no idea what was wrong," Enos recalls in a low, even voice. When the boy was 6 days old he fell into a coma, and he died a week later at a local hospital. Four years later, when an infant daughter refused to nurse, the Hoovers took her to a larger hospital, where a sweet smell in her diaper finally alerted doctors to what was afflicting her and had killed her brother: Maple Syrup Urine Disease, or MSUD, which prevents the body from properly processing proteins in food. By then, however, the little girl had already suffered irreparable brain injuries. "Even with a later baby, it took three to four days to get a proper diagnosis," Enos says. "We missed the crucial days where better treatment could have made a difference. Then a doctor asked us if we'd like to meet a Doctor Morton. We said yes, and we were amazed when he came to our house. No other doctor had ever come to see us or our babies."

Around the time of Morton's first visits with Enos and Anna Mae Hoover, he was realizing, as he would later write, that the "economic and academic goals of university hospitals" seemed to be "at odds with the care of children with interesting illnesses." He concluded from his work with GA-1 and MSUD children that the best place to study and care for them was not in a laboratory or a teaching hospital but in the field, from a base in the area where they lived. With his wife, Caroline, a fellow West Virginian who holds a master's degree in education and public policy from Harvard and had worked with rural communities and schools, Morton envisioned a free-standing clinic for Amish and Mennonite children who have rare genetic diseases.

Enos Hoover helped raise some money for the Mortons' dream within the Mennonite community, and Jacob Stoltz-
foos, grandfather of a child with GA-1 saved by Morton’s intervention, did the same among the Amish. Stoltzfoos also donated farmland in the small town of Strasburg for a clinic. Both Hoover and Stoltzfoos eventually accepted invitations to serve on the board of the as-yet-unbuilt clinic, where they joined sociologist Dr. J. A. Hostetler, whose pioneering 1963 book, *Amish Society*, first drew medical researchers’ attention to potential clusters of genetic disorders among Pennsylvania’s rural Anabaptists.

As Hostetler’s book makes clear, says Dr. Victor A. McKusick of Johns Hopkins University, the founding father of medical genetics, the Amish “keep excellent records, live in a restricted area and intermarry. It’s a geneticist’s dream.” In 1978, McKusick published his own compilation, *Medical Genetic Studies of the Amish*, identifying more than 30 genetic-based diseases found among the Amish, ranging from congenital deafness and cataracts to fatal brain swellings and muscular degeneration. Some had never been known before at all, while others had been identified only in isolated, non-Amish cases. “The diseases are hard to identify in the general population because there are too few cases, or the cases don’t occur in conjunction with one another, or the records to trace them back are incomplete,” McKusick explains. He adds that Morton, by identifying new diseases and by developing treatment profiles for diseases like GA-1 and MSUD, is not only building on the foundation that McKusick and Hostetler laid: he’s been able to create treatment protocols that doctors around the world can use to care for patients with the same disorders.

But back in 1980, despite the efforts of Hoover, Stoltzfoos, Hostetler, and Lancaster County’s Amish and Mennonite communities, there was still not enough money to build the free-standing clinic the Mortons wanted. Then Frank Allen, a staff reporter for the *Wall Street Journal*, wrote a front-page article about accompanying Morton on house calls to Amish patients, mentioning that Holmes and Caroline were prepared to place a second mortgage on their home to build the clinic and to buy a particularly critical piece of laboratory equipment made by Hewlett-Packard. Company founder David Packard read the article and immediately donated the machine; other *Journal* readers sent in money, and the clinic was on its way.

There was still no building, but the money and machinery were put to use in rented quarters, allowing the screening of newborns for GA-1 and MSUD. And then, on a rainy Saturday in November 1990, dozens of Amish and Mennonite woodworkers, construction experts and farmers erected the barnlike structure of the Clinic for Special Children, stopping only for lunch served by a battalion of Amish and Mennonite women.

**Early in the Year 2000**, pressure from Hehmeyer, Morton and local legislators—and from a public alerted by newspaper stories—pushed the Children and Youth Services to move the seven Glick children from non-Amish foster homes into Amish homes near their farm. In late February the boys were returned to their parents. But Samuel and Elizabeth remained under investigation for child abuse in connection with Sara’s death. A week later, the Northumberland District Attorney’s office turned over the most important piece of evidence—Sara’s brain—to outside investigators. At the Philadelphia Medical Examiner’s Office, Dr. Lucy B. Rorke, chief pathologist of Children’s Hospital in Philadelphia and an expert on the pathology of child abuse, examined it during a teaching session with other doctors and students, and quickly concluded that Sara had not died of trauma or abuse.

A few weeks later, the Glicks, who had never been formally charged, were entirely cleared of suspicion. The family was relieved, and Morton was inspired: he accelerated his efforts to find the precise genetic locus of the bile-salt transporter disease so the clinic could better identify and treat it. Most newborns in Lancaster County were already being screened for a handful of the diseases that afflict Amish and Mennonite children. Morton wanted to add to the list the disease that took Sara Lynn Glick’s life.

“We don’t pick problems to research,” says the Clinic for Special Children’s Dr. Kevin Strauss. “The problems choose us. Families come in with questions—‘Why isn’t my child developing properly?’ ‘Why is this happening?’ ‘What causes that?’—and we look for the answers.” Strauss, a Harvard-trained pediatrician, joined the clinic because he agreed with its operating philosophy: “If you want to understand medicine, you have to study living human beings,” he says. “It’s the only way to translate advances in molecular research into practical clinical interventions. You can’t really comprehend a disease like MSUD, and treat it properly, without involving biology, infections, diet, amino acid transport, brain chemistry, tissues and a lot more.”

When Morton began his work among the Amish and Mennonites, fewer than three dozen recessive genetic disorders had been identified in the groups; today, mostly as a result of the clinic’s work, some five dozen are known. Cases of GA-1 have come to light in Chile, Ireland and Israel, and of MSUD in India, Iran and Canada.

The clues come from anywhere: working with one Amish family, Morton learned that a 14-year-old girl had kept a diary while caring for a terminally ill sister. Using information from the diary and other patients, the clinic was able to help map
the gene mutation for a syndrome responsible for the crib deaths of 20 infants in nine Amish families— with implications, perhaps, for progress in solving SIDS (Sudden Infant Death Syndrome), which kills thousands of children each year in the larger population.

And at a Mennonite wedding two summers ago, family members rolled up their sleeves to have their blood drawn by Morton, Strauss and a clinic nurse. The team was trying to pinpoint a genetic defect that made the males of the family susceptible to a form of meningitis that had killed two of them. The tests revealed that of the 63 people whose blood was drawn at the wedding, a dozen males were at high risk, and 14 of the women were carriers. The men were put on penicillin, vaccinated and given stashes of antibiotic to take if they became ill. Shortly after the wedding, the combination of antibiotics and immediate hospital care prevented one man from succumbing to a meningitis attack, possibly saving his life. “Genetics in action,” Morton comments.

But Morton’s approach to identifying and treating a disease is more than mere genetics. On an average morning, the clinic’s waiting room looks like any pedestrian’s office— albeit with most adults in traditional Amish and Mennonite dress—

“Most of the kids here have genetic diseases that can kill them,” says one doctor at the Clinic for Special Children.

with children crawling about on the floor, playing with toys or sitting as their mothers read them books. The appearance of normality is actually deceiving, says Kevin Strauss. “Most of the kids here today have genetic diseases that, left untreated, can kill them or lead to permanent neurological disability.” Parents have brought their children, some from as far away as India, not only for the clinic’s renowned research capabilities but for its treatment. Donald B. Krabill, one of the foremost scholars of the Amish, and the Senior Fellow of Elizabethtown College’s Young Center for Anabaptist and Pietist Studies, praises Morton’s “culturally sensitive manner,” which he says has won Morton the “admiration, support and unqualified blessing of the Old Order communities.”

The communities’ support is expressed, in part, through an annual series of auctions to benefit the clinic that are held by the Amish and Mennonites across Pennsylvania. These auctions raise several hundred thousand dollars of the clinic’s annual $1 million budget. Another chunk of the budget is covered by outside contributors, and the remainder comes from the clinic’s modest fees— “$50 for a lab test that a university hospital has to charge $450 for,” notes Enos Hoover.

About two years after Sara Glick’s death, Morton, Strauss, clinic lab director Erik Puffenberger, who holds a doctorate in genetics, and researcher Vicky Carlson from the University of California at San Francisco located the precise genetic site of the bile-salt transporter disorder, and devised a test that
could tell doctors whether an infant might have it. If the test is done at birth, or at the first sign of a problem, no family will ever have to repeat the Glicks’ ordeal.

Or perhaps, any other ordeal caused by diseases passed on genetically in the Amish and Mennonite communities. Morton and his colleagues believe that they’re within a few years of realizing a long-term dream: placing, on a single microchip, fragments of all the known genetic diseases of the Amish and Mennonites, so that when a child is born, it will be possible to learn— from comparing a small blood sample from the child with the DNA information on the microchip— whether he or she may be affected by any of a hundred different conditions, thus allowing doctors to take immediate treatment steps and prevent harm from coming to the child.

The clinic’s use of genetic information as the basis of diagnosis and the individualized treatment of patients makes it “the best primary care facility of its type that exists anywhere,” says G. Terry Sharrer, curator of the Smithsonian’s Division of Science, Medicine and Society. And he suggests an analogy: over a hundred years ago, when Louis Pasteur’s germ theory of disease replaced the four humors theory, it took decades for a majority of doctors to understand and adopt the new approach. “Most of the switching didn’t occur until the next generation came out of medical school. Something similar is happening now with gene-specific diagnoses and treatment, as the aging baby-boom generation demands more effective medicine.

The Clinic for Special Children shows that health care can be reasonably priced, highly tailored to patients and conducted in simply managed circumstances.”

If Sharrer is right, the clinic may be a model for the future of medicine. Even if it’s not, Morton’s contribution has not gone unnoticed. Three years after the clinic opened its doors, he received the Albert Schweitzer Prize for Humanitarianism, given by Johns Hopkins University on behalf of the Alexander von Humboldt Foundation. On being notified of the prize, Morton began to read about Schweitzer and found that the great German physician also came to medicine late, after a distinguished career in music and theology— and that he had established his famed hospital in Gabon at age 38, the same age Morton was when he began the clinic in Strasburg. In a speech accepting the award, Morton said that Schweitzer would have understood why the Clinic for Special Children is in the middle of Lancaster County— because that “is where it is needed . . . built and supported by people whose children need the care that the clinic provides.” After winning the award, partially in homage to Schweitzer and his love of Bach, Morton took up playing the violin.

TOM SHACHTMAN’S Rumspringa: To Be or Not to Be Amish, will be published in June. This is his first article for Smithsonian.