

TRACKING A KILLER

Why did seemingly healthy Amish babies suddenly sicken, become paralyzed, or die? Dr. Holmes Morton solved this mystery for the anguished parents.

by Ryan Ver Berkmoes

D. Holmes Morton, M.D., cradled 18-month-old LeRoy Stoltzfus in his arms. The infant was limp and lethargic.

"I'm a little bit worried about him," Dr. Morton told LeRoy's parents, John and Sadie. Both sat quietly and listened carefully.

Outside the cozy farmhouse, an ice storm raged on this cold January night. Inside the combination kitchen and family room, a gaslight provided sharp illumination as Dr. Morton drew blood from a now crying LeRoy.

There are no electric lights in the Stoltzfus home. The family is Old Order Amish, dedicated to a lifestyle that eschews modern conveniences. Commonly called "Pennsylvania Dutch," the 15,000 Amish of Lancaster County are all descended from the 200 Swiss Anabaptist farmers who settled here more than 250 years ago. (The term "dutch" is an anglicized misnomer of "deutsche," the dialect the Amish speak among themselves.)

Their closed society, with its well-known images of horse-drawn buggies and simple black clothes, is also known for its hard work and thrift. But in the medical community, the Amish are known for something less bucolic. Generations of in-breeding spawned by the religion's strict prohibition against marriage to outsiders has produced an array of serious genetic disorders.

Little LeRoy has one of them: glutaric aciduria, which afflicts at least one in 200 Amish children in the United States.

Children with the disease show no symptoms at first but usually are stricken within the first year of life. Many die; the survivors, like LeRoy, are left with paralysis similar to cerebral palsy.

The disease went unidentified and untreated here until two years ago.

It was Dr. Morton who diagnosed it, while working as a research fellow at Children's Hospital in Philadelphia,

two hours east of Lancaster County. That discovery changed his life.

The 40-year-old pediatrician has devoted himself to studying and treating the genetic disorders that afflict Amish children and their religious cousins, the Mennonites. Working 16-hour days, six or seven days a week, he has put his concern for his patients above his personal life. Slightly rumped, with a proclivity for bow ties, he yawns a lot. Sometimes the strain puts him in peril. In December, while driving home at the end of a long day, he fell asleep and his car collided with another vehicle. His car was totaled, but no one was hurt.

The night Dr. Morton examined LeRoy came near the end of a typical workday. He made the housecall on his way home to Wayne, an hour's drive from Strasburg. But his concern about the child's condition made him change his plans.

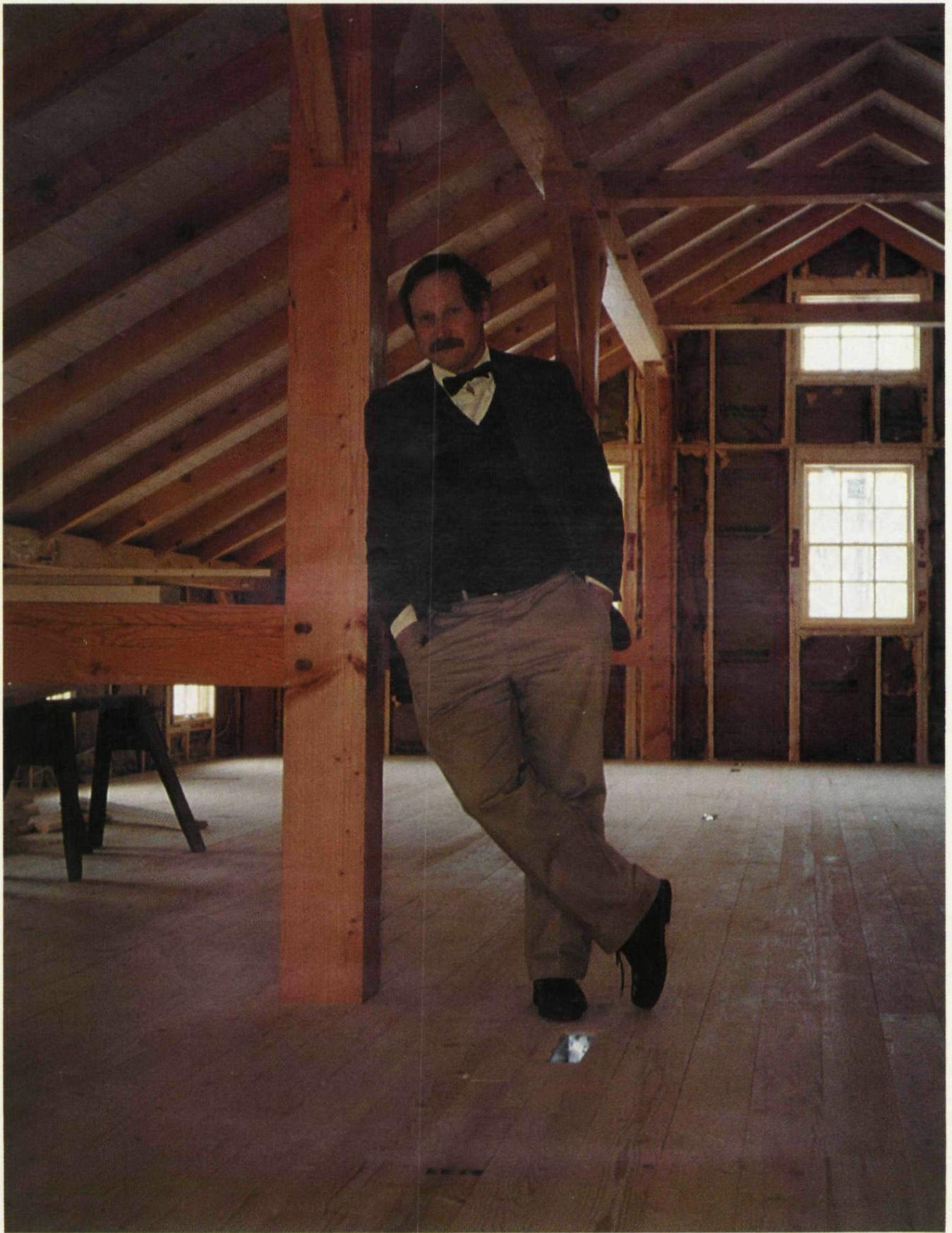
Rather than drive home, Dr. Morton returned to his office to run tests on LeRoy's blood and urine. If the boy did not improve overnight, he would have to be admitted to the hospital. Fearing that icy roads and deteriorating weather would delay his commute the next morning, Dr. Morton decided to sleep at a friend's house near his office. This was the second night in a row that he would not return to his wife and three children.

Such dedication has earned him the respect and acceptance of the Amish and Mennonite communities. Proof of their regard is found on a plot of land situated among the picture-postcard farms in the rolling hills south of Strasburg. At the end of a gravel lane, a pasture had been cleared for a building that is nearly complete. Built in the sturdy and simple style favored by the Amish, it will house Dr. Morton's clinic. Much of the labor and material used in its construction has been donated, as was the land it is built on.

When Dr. Morton moves his prac-



Generations of inbreeding caused by a strict prohibition against marriage to outsiders has led to an array of genetic disorders in Amish children.



Ryan Ver Berkmoes

At his new clinic, Dr. Morton will apply his simple strategy for treating the disease he diagnosed.

tice, which he calls The Clinic For Special Children, into the building next month, it will be an achievement that few would have predicted for the high-school dropout from the small West Virginia coal-mining town of Fayetteville.

Leaving school because he enjoyed learning only on his own terms—"I preferred reading William Faulkner to attending class"—he got a job on the crew of an ore carrier plying Lake Michigan. There, between the hustle of port calls, he studied, taking correspondence courses in subjects such as physics and chemistry.

During the Vietnam War he completed a four-year stint in the Navy that included a one-month leave which he spent alone, reading, on the Mediterranean island of Elba. Two decades later, he recalls that time with a look of youthful joy.

After the Navy, he returned to crewing on ore carriers until he obtained his high school equivalency diploma. He left the lake for Trinity College in Hartford, Connecticut, drawn by the school's policy of self-directed learning, where students pursued knowledge unfettered by classes.

He graduated with honors in biology and psychology.

His next stop was Harvard Medical School, where he found another academic system to his liking. "They grade pass-fail, so rather than waste your time competing for grades, you can spend your time learning." About 15 minutes after his first lecture class began, he decided to learn the material on his own.

He did his residency at Children's Hospital in Boston. "Holmes was a phenomenon," recalls Harvey Levy, M.D., a pediatric neurologist who helped supervise Dr. Morton. "His ability to synthesize everything and make a diagnosis was superb, and in some cases was astounding."

Dr. Levy, who is now director of metabolic disorders for the New England Newborn Screening Program, recalls that Dr. Morton could be found on the ward at all hours. "He was very caring. His patients were his inspiration to science."

Next came the research fellowship at Children's Hospital in Philadelphia. There, in June 1988, he diagnosed glutaric aciduria in a sick Amish boy. There had been only eight cases reported worldwide.

Since then, Dr. Morton has diag-

nosed 27 cases among the Amish.

He had solved a mystery that had been a source of anguish for many parents with seemingly healthy infants.

The first time that children born with glutaric aciduria experience an infection leading to fever and diarrhea, they often lapse into a coma and die within 48 hours.

Under the stress of the infection, their bodies stop metabolizing protein normally. Toxic glutaric acid builds up rapidly in the bloodstream and muscle tissue and attacks the liver, nervous system, and brain. Children who survive the first episode are left with progressive paralysis.

Dr. Morton began driving to Lancaster County from Philadelphia at least one day a week to measure the glutaric acid levels in the urine of infants and children. During endless rounds of house calls, he sought to earn the community's trust while conducting tests that would lead to additional cases.

He enlisted the midwives who deliver most Amish children to help him gather urine samples. He also made an important friend. Rebecca Huyard is Old Order Amish and had spent 15 years as an Amish schoolteacher. Five of her sister's seven children had become mysteriously ill. Two had died and the others were severely physically disabled. Dr. Morton diagnosed their problem.

Huyard decided to go to work for

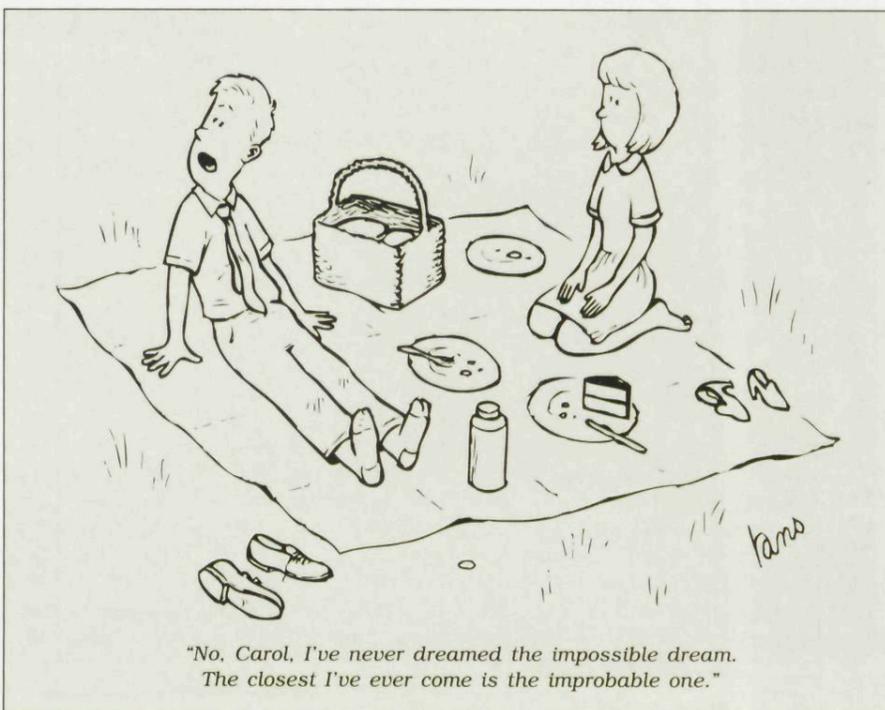
Dr. Morton—the first Amish woman ever to do such a worldly thing. "He was doing work that needed to be done. I figured, let people raise a few eyebrows if I helped him," says Huyard in her lilting accent.

In late 1988, Dr. Morton received an appointment to study glutaric aciduria full time at the Kennedy Institute at Johns Hopkins University in Baltimore. But his life became increasingly hectic. He would spend several days a week collecting information and urine samples in Lancaster County and the rest of the week analyzing the samples two hours away in Baltimore. At nights and on weekends, he worked at a hospital near his Philadelphia-area home to help support his family.

It soon became apparent that this schedule, even for the indefatigable Dr. Morton, was too demanding. With the help of Huyard and his wife, Caroline, he began planning a clinic in the county that would have the necessary lab equipment. He applied for several grants, but was rejected.

In the fall of 1989, Dr. Morton, characteristically, decided to take matters into his own hands. He began arranging for a second mortgage on his house to fund the clinic.

But two days before he was to close on the loan, manna appeared in the form of a front-page story in *The Wall Street Journal*. A reporter had been tipped off to Dr. Morton's dis-



"No, Carol, I've never dreamed the impossible dream. The closest I've ever come is the improbable one."

covery and financial dilemma. Within days, hundreds of letters and checks began arriving.

Dr. Morton continues to be moved by this outpouring, which included an anonymous donation of \$100,000. He got \$3,000 from a childhood friend whom he hadn't seen for more than 20 years; the friend had raised the money by contacting their former school mates.

Hewlett-Packard Co. donated a gas chromatograph and mass spectrometer, worth \$85,000. Construction expertise and materials also were offered. Lancaster General Hospital donated renovated office and lab space for Dr. Morton's use until he could move into his building.

Subsequent publicity and local fund-raising efforts have attracted more donations; in all, Dr. Morton has received more than \$300,000 in money and equipment.

The clinic opened last January in its temporary space. In addition to screening and treating Amish children for glutaric aciduria, it treats Mennonite children who are susceptible to maple syrup urine disease, another genetic disorder that is detectable in newborns and that, without proper treatment, can be fatal within the first 48 hours of life.

Dr. Morton downplays his discovery of glutaric aciduria. Instead, he focuses on his approach to treating his clinic's unique patient population. "I don't think of myself as a specialist who practices in a rural setting. Rather, I consider myself to be a general pediatrician who is aware of particular health care needs of the people who come to me for care."

The Amish and Mennonites do not have health insurance. They tend to accept care from midwives in the home, seeking treatment outside only in the event of serious illness. Dr. Morton and Huyard try to hammer home to them the philosophy of preventive care.

"We are screening about 65% of the at-risk newborns in the county now," Huyard says. "That figure should be 85%, and I would like it to be 100%. But Amish people especially are very suspicious."

Without television or movies for distraction, the Amish community's major form of entertainment is social gatherings. That's where Huyard preaches prevention.

The test for glutaric aciduria costs

\$300 or more if done by a major medical center. When he does it in his own lab, Dr. Morton's cost is less than \$20.

"We tell everyone that payment for testing is optional," he says. "In the long run it works out better because people give more. Somebody won't be able to pay us one time, but the next time they'll give us \$100."

Economics motivated two Mennonite churches to raise \$56,000 for an amino acid analyzer for the clinic. "The machine is vital to diagnosing maple syrup urine disease," Dr. Morton says. "We can do the test for about \$45. Sending out the test costs \$200 to \$400, and can take longer than the 24 to 48 hours after birth during which the disease must be diagnosed to avoid damage.

So far it has worked. Dr. Morton has been able to keep healthy those children who tested positive for the disease at birth. For those who, like LeRoy Stolfus, weren't screened at birth and had been damaged by one bout with the disease before they were diagnosed, he has been able to keep their conditions from worsening.

Richard Kelley, M.D., a geneticist and specialist in metabolic diseases at the Kennedy Institute, has worked with Dr. Morton to set up his laboratory testing methods.

"Much of the Amish and Mennonite's problems with access to health care stem from the problems shared by all rural populations," Dr. Kelley says. "Contrary to popular belief, they will seek out health care, but they have a problem of mobility. It



"One incident where a child ends up sick in a hospital can cost \$70,000. The communities are self-insured with everyone sharing the cost. It was easy for them to see the wisdom of having our own machine for screening."

Dr. Morton has devised a simple strategy for helping children who test positive for glutaric aciduria. "We cut down on their proteins and give them riboflavin, which breaks down glutaric acid. We also keep them well hydrated. It's a simple therapy that mothers can do at home cheaply."

takes a long time to get some place in a horse and buggy. Also, the kind of care the children need is tantamount to intensive medical care. Dr. Morton is in the community to deliver the care and he has the expertise to do it."

Dr. Morton appears to be in his element surrounded by the variety of high-tech equipment in the clinic's lab. He moved with grace to transfer a test tube here, load a sample there. It is where he comes early in the

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Wollypops

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isn't there. If you've ever attended a political convention, or a dedication ceremony, or a testimonial dinner, you may have wondered what all the people were doing. Now you know.

Another time we had guests who brought their little girl with them. Roy came into the room where we were talking and wanted to know where their daughter Amy was. Her mother said she believed she was in the bathroom.

"Well," Roy said, "whereabouts in the bathroom?"

For a child of his age I thought this showed a delicacy of expression and social awareness that was unusual.

And there was Aunt Clara. She became very annoyed one time because the mailman was late. "I was watching by the window," she said, "and he didn't come, and he didn't come, and he didn't come."

• I don't think we ever found out why he was late—probably just birdin' around somewhere.

• This is the sort of thing you have to expect in life. You wait for something you've set your heart on, and it doesn't come, and it doesn't come, and it doesn't come. At such a time it's always comforting to have a few quotations to fall back on.

As a matter of fact, the pathway of life is a rocky one and strewn with pieces of wollypops.

But that's the way it goes. Sometimes you get the cardboard sled and sometimes you don't. ❧

John Falter

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interesting to note that the artist always painted from the south—that is, in viewing a Falter scene, you are always looking north. Falter later described his painting technique. He began with the most distant objects and then traveled with his brush toward himself, filling in the painting as he went.

By the late '40s, Falter began to loosen up, including some of his own at-home experiences as his cover subjects. He especially relished the whimsical, unpredictable crises that families with small children found themselves in all too often.

The boy on the roof of the garage about to trust his life or limb to a

rotar blade was, for example, a recollection from his own childhood. Another was of a boy in his father's U.S. Navy officer's cap cruising his submarine in the family tub, after getting the shower going into disastrous overflow and locking the bathroom door from the inside.

In 1950 Falter painted a cover of President Harry Truman addressing a joint session of Congress. Truman liked it so much that he asked if he might procure it for his personal collection. The artist happily made the journey to the White House for the presentation. Falter later recalled that the President had hunched down in front of the painting, pointed at Mrs. Truman and said, "Yes, sir, that's Bess!" The painting is on display today at the Truman Library.

Falter painted for the *Post* until 1962 when the magazine decided to change from illustrated covers to photographs. After the *Post*, the artist continued to work at a feverish pace on personal projects. These included over 100 paintings of western art, and another 190 canvases of scenes depicting the western migration from the Missouri River to the Rocky Mountains. The quality of his work earned him the position of academician of the National Academy of Western Art. Falter's long list of distinguished accomplishments includes the painting of two U.S. postage stamps. The *Post* was lucky enough to engage the painter one more time in 1971 to paint a cover which featured his daughter and his home in Pennsylvania.

John Falter died in May of 1982. His ashes were cast into the mouth of the Platte River where they would flow down the Missouri—the setting of many of his historical paintings.

Norman Rockwell once remarked that John Falter was "America's most gifted illustrator."

After looking over this retrospective or visiting the Post Hall of Fame, we think you'll agree. ❧

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morning and stays until late at night, taking breaks to make house calls.

He laments that the files he keeps in one computer need to be transferred to another. But he scoffs at the

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idea that someone else could do the work. "It would take me twice as long to teach somebody to do it right than it would take me to do it."

Such independence is no surprise to his old mentor, Dr. Levy. "Holmes' set-up is ideal for him. He doesn't work well in conjunction with others. He likes to do things himself. I think he always has doubts about whether somebody is doing work that meets his standards."

His dedication has strained his home life. After his accident, Caroline told him that if he got home after 8 p.m., he wouldn't be let into the house. "I'm not trying to change his work habits," she says. "I just don't want him to work 20 hours at a stretch and think he needs to drive home. It's better if he stays over with friends."

With the construction of the clinic, the family plans to move to Lancaster County, and put an end to the hour-long commutes. If Dr. Morton has his way, they will live in a house within "walking distance of the new clinic."

The two-story building is built on three acres of land donated by Jacob and Naomi Stoltzfoos, an Amish couple whose granddaughter had been diagnosed with glutaric aciduria. So far, her condition has been monitored carefully and she has been spared the effects of the disease.

The frame of the clinic was built using the post-and-beam technique mastered by the Amish and Mennonites. Last November, nearly 100 local men erected the structure. Since then the interior and exterior walls have been added along with the plumbing and other technical details.

Visiting the site in January, Dr. Morton encountered Jacob Stoltzfoos, who was working that day.

"Looking beautiful," Stoltzfoos said, proudly.

"Our clinic certainly is," Dr. Morton replied.

As he wandered the 2,700-square-foot main floor of the building, Dr. Morton's glee was palpable. Standing in the space that will be his office, he looked out a window that overlooks a creek. "There's trout you can fly-cast for in there," he said, alluding to one of the few pleasures he allows himself outside medicine.

Later, he paused where his lab will be. "This will probably be the only lab in the country with exposed posts and beams," he said with a chuckle. He added, "I know I'll spend the rest of my life working here."

"I believe we can prevent brain injury in the majority of children who have glutaric aciduria. I expect that over the next ten years the fate of 50 or more children will be determined by the success or failure of the clinic. That provokes a frightful sense of responsibility in me. That's what motivates my work."

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