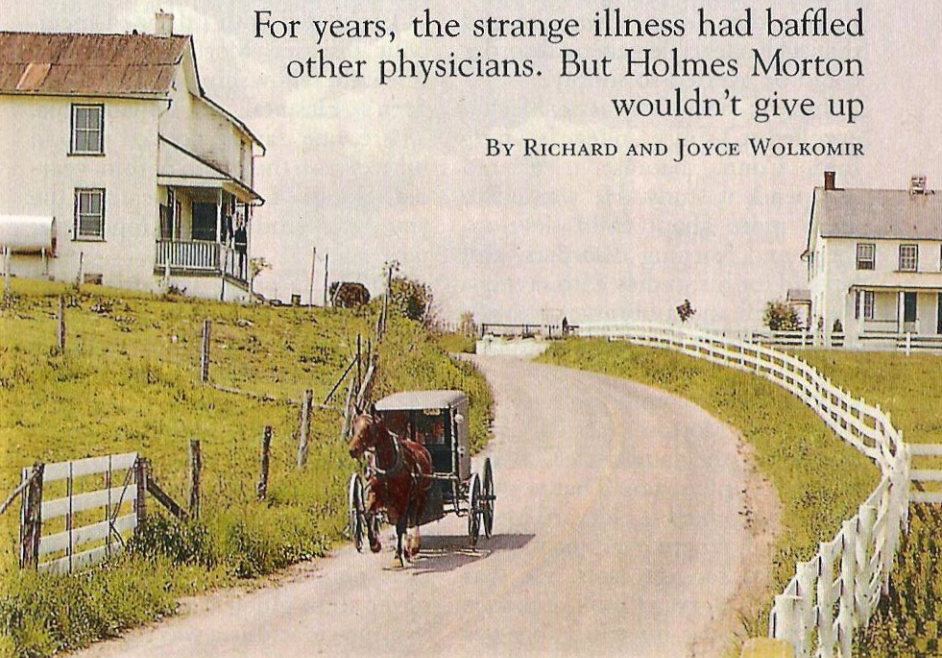


# The Doctor Who Conquered a Killer

For years, the strange illness had baffled other physicians. But Holmes Morton wouldn't give up

BY RICHARD AND JOYCE WOLKOMIR



**T**EACHERS IN Lynchburg, Va., didn't always understand Holmes Morton. He never studied. Regular schoolwork bored him. Yet he would spend weeks in the library on his own, mesmerized by philosophy or the novels of William Faulkner.

When it became clear Morton would not graduate, he dropped out to work as a boiler tender on a

Great Lakes freighter. In his spare time, he took correspondence courses in physics, mathematics, whatever interested him, earning a high-school-equivalency degree and a year of college credits.

Reading a scientific journal amid the clangor and heat of the engine room one day, he became fascinated with an article about a genetic disorder, phenylketonuria, or



PKU. Afflicted children cannot break down one of the amino acids, which are the building blocks of proteins. Toxins then accumulate in the child's body and attack the brain, causing severe retardation. But newborns are routinely screened for the disease and given a low-protein diet. Morton was amazed that such a terrible genetic disorder could be averted so simply.

In 1975, when he was 24, Morton enrolled at Trinity College in Hartford, Conn., because it offered independent study. He wanted to learn more about child development and learning disorders, and he paid for his studies with savings, the GI bill and a library job. Morton also worked with handicapped kids at a hospital and began to contemplate becoming a physician.

In 1979, Morton married Caroline Smith, the daughter of a Beckley, W.Va., physician. That year he also was accepted at Harvard Medical School, where over 4000 applicants vied for 166 slots. He was convinced Harvard took a chance on him because his education was so peculiar. Being a high-school dropout, he would say, gave him an unfair advantage. In medical school, Morton walked out on dull lectures. Nevertheless, he graduated with flying colors and went on to specialize in pediatrics and biochemical disorders.

Morton did his residency at Children's Hospital, Boston. Pediatrician and biochemical geneticist Harvey Levy, one of his supervi-

sors, described his diagnostic ability as "superb, and in some cases astounding." He admired Morton's peculiarities, too, saying with a laugh: "Holmes Morton is an iconoclast if God ever made an iconoclast—he never accepts anything just on authority."

Fascinated with inherited metabolic diseases, Morton accepted a research fellowship at The Children's Hospital of Philadelphia. There, one day he noticed an odd upstroke on the graph of four-year-old Danny Lapp, indicating the youngster produced too much glutaric acid.

Danny, Morton was told, was Amish and lived with his parents in Lancaster County, Pennsylvania, a center for the Amish and related Mennonite sects. The boy had been healthy until age 14 months, when he suffered a mild bout of diarrhea. A few hours later his body went limp. He never regained control of his muscles. To Morton, the two facts pointed to a disease he had never seen: glutaric aciduria.

Glutaric aciduria was then virtually unknown. It is a genetic disorder in which the body fails to produce enzymes needed to break down two of the 20 amino acids that make up protein. As a result, a toxic byproduct—glutaric acid—builds up. Normally, the kidneys can flush the buildup away, but any illness that leads to dehydration—diarrhea, chicken pox—halts the removal. In a matter of hours, the acid buildup attacks the brain, and

a seemingly healthy child suffers a spastic type of paralysis.

Morton decided to act on a philosophy he had formulated at his career's start: "If you wait for patients to come to you, you lose the opportunity to see and learn things, and to teach them about their disease." He went to see Danny Lapp.

The Amish and the Mennonites are Christians who emigrated from Switzerland in the 1700s. Many reject technology, driving horse-drawn buggies. They value strong families, peacefulness, self-sufficiency and hard work, usually as farmers. In Lancaster County

16,000 Amish are all descended from the original 200 settlers, who married only among themselves. As a result, those first settlers bequeathed to their descendants any defective genes they carried. Since the Amish continued to marry only among themselves, defective genes spread throughout their population.

Morton found Danny sprawled in a wheelchair, his body paralyzed. The child's eyes were intelligent, but he could not speak. His arms and legs writhed. Glutaric acid, the doctor knew, attacks portions of the brain that control these muscles.

It was vital, he told the parents, to make sure Danny's two brothers were not at risk for the disease.

Amish style, the Lapps had no telephone and no car. And so Morton made the three-hour round trip between Philadelphia and the Lapp farm to collect samples. Then he made the drive again to report the

results: Danny's brothers were safe. But Morton was sure other Amish children must carry the gene. The Lapps told him of Amos and Susie Miller, who lived on a farm 30 miles to the south.

AMOS MILLER is a wiry man with a

weathered, expressionless face. It seemed made of stone when Morton knocked on his door and introduced himself.

"We've not heard of that name," Miller said, immovable in the doorway.

"I'm a pediatrician. I may be able to help you," Morton said.

He sat with Amos and Susie Miller at their square, oak kitchen table. The only light in the cavernous kitchen came from the windows. As Old-Order Amish, the Millers eschewed electricity.

Susie Miller, wearing gold wire-rimmed glasses and a long Amish dress, was slender and bright, as



Dr. Holmes Morton



talkative as her husband was taciturn. But Morton could see that she, too, regarded him suspiciously.

Three-year-old Alvin sat on Susie's lap, too paralyzed to sit by himself. Stevie, 11, had one paralyzed leg. Pretty Levina, nine, could barely speak and could not walk. She sat on her hands to keep her arms from writhing. Of the Millers' seven children, five had been paralyzed in varying degrees. It had struck first a decade earlier.

"Our son Sylvan went to sleep in his crib one night and awoke with no control at all, unable to lift his head and look around," Susie explained. The Millers tried doctor after doctor, but none could even name the affliction. Sylvan died at age two. Not long afterward, Levi died of the same paralytic illness. He was six years old.

As their children were stricken, the Millers' life became a grim round of farm chores, caring for incapacitated youngsters and hiring cars for trips to hospitals in Baltimore and Philadelphia. Physicians performed expensive tests, with no results. The Amish have no health insurance or government support for medical costs, but as the bills mounted, some of the Millers' friends offered financial assistance.

Now a physician had come to their door, something that had never happened before. He was sitting at their table, listening. And he promised a diagnosis.

"All I need are urine samples," Morton told them. He wanted no

payment. The Millers agreed to try once more.

FROM THE MILLERS' FARM, MORTON drove back to Philadelphia and ran tests. As he suspected, the Miller children had glutaric aciduria. Susie Miller had sometimes thought her children's paralysis might be a punishment from God. Now she knew it was an understandable disease, with a name. "After all these years," she said when Morton told her, "a doctor has finally given us an answer!"

Morton now began spending evenings and weekends driving from farm to farm, talking to families and running tests. At first the Amish were suspicious. But as word spread, the smallish man who drove a rusty car and wore a frayed bow tie was welcomed. Sometimes he spent the night at a farmer's. Families began to worry about his long hours.

Glutaric aciduria, Morton discovered, was widespread in Lancaster County. He estimated that one Amish person in seven carried the gene. Medical literature said treatment of the disease rarely, if ever, worked. He ignored the literature.

Finally, he began to formulate theories based on laboratory work and clinical observations. A child's first six years were critical, he believed. After that, the brain matured and seemed to become less vulnerable to toxins. If he could just keep glutaric acid levels low during those years, the child

might never become paralyzed.

Morton had never forgotten how the effects of PKU, the metabolic disorder he once read about, could be averted with a low-protein diet. He began planning. First, he would identify at-risk infants at birth. Then he would put them on a low-protein diet. He would have them drink liquids and take doses of baking soda to maximize excretion of glutaric acid by the kidneys.

"Such a horrible disease and that's all it takes to prevent it?" Susie Miller exclaimed when he told her what he had in mind.

For children like Levina Miller, whose brain already was damaged, a cure was impossible. "But we can keep her paralysis from getting worse, and we can prevent episodes of sickness," Morton told Susie. He explained that children like Levina became more agitated, unable to control their limbs, when their glutaric-acid levels rose. He gave Susie a medication much like baking soda for Levina and went over her diet to reduce the amount of protein. He also prescribed the vitamin riboflavin, which helps to reduce buildup of glutaric acid. Before long, Susie noticed that Levina's penmanship and speech were improving. One day, Levina came home glowing from her school for handicapped children. She had won a wheelchair race.

DRIVING HOME late one night, Holmes Morton came to a realization: to treat Amish children prop-

erly, he needed a clinic in Lancaster County. By avoiding a large institution's overhead and minimizing his salary, he could charge \$18 for a screening test that would cost up to \$450 elsewhere. Instead of seeing patients for the usual 15 minutes, he would spend up to two hours examining children and talking with their parents, for which the clinic would charge \$35, instead of the typical hospital charge of \$100-\$200. He would screen all Amish babies in the county at birth and treat at-risk children before the disease struck.

Morton discussed the idea with Caroline. They agreed the only way they could finance the clinic would be to take a second mortgage on their home. But then a bolt of benevolent lightning struck. A *Wall Street Journal* article about the effort to create the nonprofit clinic resulted in an outpouring of donations.

As word of the project spread, Amish and Mennonite craftsmen offered to donate their labor for the construction. Local companies promised building materials. Hewlett-Packard, a major maker of scientific equipment, donated the machine Morton would need most: an \$80,000 mass spectrometer to screen urine samples. Amish farmers Jacob and Naomi Stoltzfoos provided a three-acre pasture near their farmhouse as a clinic site.

At dawn on November 17, 1990, workers began arriving, a few clip-clopping up in their black buggies. Drizzle turned into a



chilly rain as the 50 volunteers hefted wooden posts and beams into place for the clinic's frame. Amos Miller worked all day next to his oldest son, Elmer.

While the men worked outside, Susie Miller prepared lunch with the other women in the Stoltzfoos kitchen. At noon, the men rode a wagon to the farmhouse. They washed up in a pail on the front porch, bowed their heads in silent prayer and then went inside to eat. More than 100 people sat in the big kitchen, spooning soup from bowls in their laps. Each family had brought a dish to pass.

By 4 p.m., the roof frame was up and the clinic's skeleton was erect. As the farmers left for the evening milking, the sun came out, illuminating the newly raised timbers.

In April 1991 the clinic was ready. The final touch was a roof made of slates over 100 years old, recycled from a torn-down barn.

ONE DAY the previous summer Morton received an urgent phone call from John and Lydia Stoltzfoos, the parents of Barbie Ann Stoltzfoos. She was the first new-

born Morton's countywide screening program had identified as having glutaric aciduria. Just after her birth, Barbie Ann's glutaric-acid levels had been the highest Morton had ever seen. He gave her parents instructions for a low-protein diet, which they followed carefully.

But now they had a crisis. They were away on vacation, they told Morton over the phone. Barbie Ann had developed diarrhea. They knew that could lead to dehydration and trigger glutaric aciduria. In addition to other precautions, Morton directed the Stoltzfooses to give Barbie Ann plenty of liquids and doses of baking soda. "And as soon as you get back, bring her here."

Two days later, when Barbie Ann's mother brought the infant in, Morton examined her carefully, tentatively moving her arms and legs and peering into her eyes. Then, slowly, Holmes Morton, the high-school dropout who became a doctor and conquered a killer, stepped back and smiled.

"Barbie Ann looks fine," he said to Lydia Stoltzfoos. "She looks just fine!"

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### Male Call

ON THE LAST DAY of a university course, we attended a lecture given by the millionaire founder of a large company. "I hope you'll have some questions for our visitor," the course director said. "What does one ask a millionaire?"

There was a moment of silence. Then a female voice called out, "Are you married?"

—Contributed by Alan Porter