

Family Wrestles with Genetic Illnesses, Supports Benefit

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RONKS (Lancaster Co.) — The sounds of children's laughter, computer beeps, and cheers permeate the home of Ralph and Barbara Atkinson.

It's a sound expected to be heard in any home with children. What isn't expected are the wheelchairs, the feeding tubes, the walker, and even the dolls who wear casts and are equipped with feeding tubes in their stomachs.

These serve as grim reminders that the lives of nine-year-old Timmy and his five-year-old sister Sarah are quite different than those of most children.

Over the years, a myriad of blood tests, MRI's, spinal taps, muscle probes, nerve biopsies, and EKG's have failed to reveal any cause for Timmy's and Sarah's progressive neurological disorder.

Knowing the pain of watching their children suffer inspires the Atkinsens to help others.

"Whatever we can do to keep this from happening to other children, we want to do," Ralph said.

For this reason the Atkinsens are part of a team of parents who are planning the third benefit auction to support The Clinic for Special Children.

The clinic is a non profit medical, research and diagnostic service

for children with inherited disorders.

The clinic was started as a result of Dr. Holmes Morton, who diagnosed a genetic disorder, glutaric aciduria, that appears primarily within Mennonite and Amish circles.

Since then he has identified Maple Syrup Urine Disease and about 30 other genetic diseases or syndromes that may leave a child severely brain damaged if not detected in time.

Morton discovered that a simple urine test can identify infants who are at risk and through a controlled diet, brain damage, which happens within a matter of hours, can be averted.

Morton's work has been so successful that the Amish and Mennonite community have rallied to support his work by building a clinic in Strasburg in 1991, and by holding an annual benefit sale to raise funds that enable the clinic's expenses to be kept at a minimum.

These savings are passed on to the clients.

Caroline Morton, the doctor's wife, said that clients only pay about one-tenth the amount that the same services would cost in Philadelphia or New York.

She said that in the past two years, 10 infants have been diagnosed with Maple Syrup Disease;



The Atkinson family are delighted with their move from New Jersey to Ronks where, for the first time in their lives, they have been able to raise a garden and meet other families with children who have neurological disorders. Ralph and Barbara with children Timmy and Sarah.

seven of the 10 were diagnosed and treated at the clinic, with an average cost of \$500 to \$1,500 each. Compare this with the three infants diagnosed at a major medical center with a combined cost of \$200,000.

The clinic had not been in operation when Timmy began having problems. The Atkinsens consulted with children's hospitals in many cities and were assured that although Timmy's disorder was not diagnosed, it was not hereditary. That diagnosis proved wrong when Sarah was born.

The parents watched as their seemingly healthy infants learned to sit, crawl, and walk and then regressed to the point where Timmy no longer has the muscle tone to hold up his head without support or even swallow his food. They watch helplessly as Sarah, so full of energy and spunk, finds it increasingly difficult to run and must resort to a wheelchair more and more each day.

While the children's mobility decreases, their intelligence con-

tinues to progress. Although Timmy's vocal chords have restricted his conversation, he easily comprehends conversations of those around him. His eyes remain alert and expressive and he has perfect vision.

Sarah is the verbal one. She tests above grade level in mental abilities, but her parents foresee signs of physical deterioration in her body — the same that preceded those of her brother before his speech became garbled.

"It's been a roller coaster existence for us," Ralph said.

At first, Timmy was diagnosed as having cerebral palsy, but later that was ruled out. At one point, Timmy was suspected of having dystonia, which could have been halted by enzyme treatment.

The Atkinsens were ecstatic when they talked with a family whose son had identical symptoms and who within a few weeks of treatment progressed to almost normal muscular ability.

But tests determined that Timmy's disease was not the same and that the enzyme treatment would be useless.

After contacting many research hospitals and enduring painful tests for Timmy, the Atkinsens found that they were no closer to a diagnosis or, more importantly, to a cure than before.

"I said, 'This is enough. We will accept it (the debilitating effects of the disease). No more trying to change it. No more putting Timmy through the cruel pain of spinal taps and blood tests,'" Barbara said. "They can take blood out of me, but not out of my son."

The couple focused on acceptance, on enjoying the moments, however limited, with their children.

At that time, the family lived in New Jersey. They needed to move because their home was not wheelchair accessible. Because they often vacationed in Lancaster County, the Atkinsens decided that the purer county air would be a better environment in which to live. When they purchased a home in Ronks, the Atkinsens were delighted to find other parents with whom they can empathize and it was here that they learned about Morton and the work he is doing for children with genetic diseases.

Both Timmy and Sarah were tested at the clinic, but Morton was unable to identify the disease. That does not deter the Atkinsens from being supportive of his work.

"Dr. Morton has the superb ability to sort out facts and come up with solutions," Ralph said.

It's an attribute echoed again and again by parents of the clients that the doctor sees.

Ralph said, "I consider it a privilege to raise funds to help other families. We are grateful that something is being done to keep children from suffering needlessly. Morton continues to search for clues that the Atkinsens hope will someday bring a cure.

The money raised at the auction does not go to Dr. Morton, but for equipment and upkeep.

The Atkinsens do not know what the future holds for their children. The children may outgrow the disorder or the results of the disease may level off or their life span may be shortened. Each time one of the children lose a skill that they once had attained, Barbara admits that she goes through a mourning period.

"I had a stomachache for months

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Timmy and Sarah spend hours playing computer games together. Timmy, now too weak to push buttons, is still able to operate the mouse while Sarah pushes the buttons.



Ralph, who designs computer software for insurance companies, finds pleasure in inventing things that make life for his children as normal as possible. He built a special hitch so that Timmy can use his electric wheelchair to pull Sarah in her express wagon.

Homestead Notes