

College professor runs Marine Corps Marathon for his children

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But, at 3-1/2 years old, Sydney was diagnosed with a hearing disorder and, eventually, a group of eye diseases that the Moffs were told could lead to blindness.

Although Sydney has patchy hair and light skin, she led a fairly normal life up until the age of 7.

"Things started surfacing when she was put into an academic setting," Moff said. "Up until then, she was integrated with normal kids and went to birthday parties."

Eventually, when her friends began to progress normally and Sydney had reached her plateau of development, she began to receive less and less calls to attend social engagements.

Today, Sydney is 4 feet 6 inches tall and functions at a second grade level. For the last year-and-a-half, she has experienced vision, hearing and balance loss, signs that she has already started her downhill descent. Until that point, she seemed to be progressing, so this recent downhill shift has been very difficult for the Moffs to accept.

According to Moff, Sydney knows that she is different from other children, but is not aware that her disorder is fatal.

Hunter, 11, who has a more severe case of the disorder, did not walk or talk until after the age of 2. Even today, he still only has a single word vocabulary. He tends to be in his own little world and can become fixated on something for months at a time. With symptoms like speech difficulties, hyperactivity and a talent for getting into things, he was initially diagnosed with attention deficit hyperactivity disorder, pervasive development disorder and autism.

Stefan, 12, is the Moffs' middle child, and is a perfectly normal prepubescent boy.

Two out of three children have problems

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A Loyalsock Township man's goal is to raise \$25,000 for the Children's Medical Research Foundation, a non-profit organization that raises money for research to help find a cure for Sanfilippo syndrome. Pictured in the inset is James Moff, father of Hunter Moff, left, and his sister Sydney, who suffer from the fatal disease.

326 Washington Blvd., but must attend at different times because of Hunter's hyperactivity.

"For us, believing in God and Jesus has really helped," Moff said.

Planning for the future

The Moffs have built a new house, one which is handicap accessible, for when the disorder forces their children into wheelchairs. With first-floor living, hardwood floors and a bathroom downstairs, Moff said the new house is "all the future planning I

you begin to look for the next mile marker. Up until that point you meet a lot of nice people in the race who you just start talking to while your running."

Master of endurance

With the stress of his daily life and his outlet for that stress being running, Moff is obviously a master of endurance. It is his perseverance to carry out his love and obligation for his children, and his perseverance to finish the marathon for the children of others, which is truly inspiring.

"I've never quit anything in my life and I never will," Moff said. "I'm going to finish the race or die trying. My son Stefan thinks I'm nuts. He can't even ride his bike that far."

Moff trains with a local group called Team in Training, directed by Lee Laughlin. Team in Training trains people to run marathons, usually in support of leukemia research. Laughlin makes the courses ahead of time and sets up water stops at every two-mile marker.

Team in Training inspired Moff to run this year's marathon in support of Sanfilippo Syndrome. What Moff has gained with training with the group is a sense of camaraderie, and knowledge of the passion it takes to run for the cause of loved ones.

Next summer, the Moffs have planned to take Sydney to Austria to see the land of her favorite movie, "The Sound of Music."

Hunter will continue to swing at baseballs with all his heart has to offer, and Steven, Theresa and Stefan will continue be a strong family support system for their loved ones.

Most people will never know what the Moffs go through on a daily basis. Most will never know the love and courage it takes to look your child in the eyes, knowing that your eyes will be around far after theirs have peacefully closed. Yet what will remain, is the bright light of their souls, shining through their eyes, long after they have blessed this world with their unique presence.

Moff may be supported in the Marine Corps Marathon by sending donations to Brad and Sue Wilson, The Children's Medical Research Foundation, P.O. Box 70, Western Springs, Illinois 60558 or by donating online at www.curekirby.org/donation.htm.

- Farr may be reached at sfarr@sungazette.com.

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Two out of three children have problems

"We were two parents with no familial backgrounds of problems," Moff said. "And two out of our three children had problems, we knew there was some way that they had to be connected."

It wasn't until the Moffs took both their children to Geisinger Medical Center in Danville that pediatric neurologist Scott Myers diagnosed the disorder through urine, blood and skin graft samples. By this time, at 10 years of age, it was the fourth diagnosis that Sydney had received, but at last, it was the correct one.

"It's a pretty devastating diagnosis," Moff said. "You live through a blur for the first six months. There is no cure and no way to stop it or slow it down — that's the hard part."

Everyday, the Moffs must live with the knowledge that two of their children will probably die within their parents' lifetime. But beyond that lurking nightmare are the everyday challenges they must face in raising two children with such a disorder.

Both children tend to be very needy, cannot play alone and require six different types of medication a day. When coloring, Sydney must ask someone what color every part of the picture should be and Hunter seems to be in a constant state of motion.

"They are two very different children," said Moff. "If you want to make one happy, you can't make the other happy."

The Moffs are members of the St. Boniface Catholic Church,



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But for the children of tomorrow who will be diagnosed with Sanfilippo syndrome, Moff is running the Marine Corps Marathon, Oct. 31 in Washington, D.C.

He has a goal of raising \$25,000 for the Children's Medical Research Foundation, a non-profit organization that raises money for research to help find a cure of Sanfilippo syndrome and related disorders. The organization was started by the Wilson family of Chicago whose daughter, Kirby, was diagnosed with Sanfilippo syndrome at the age of 4.

"We are not naive," Moff said. "We realize that any money raised will most likely not benefit Sydney and Hunter, as research is slow and it may be too late for them by the time a solution is discovered. However, we hope that the money raised will help the researchers find a solution so that other children and their families do not have to endure the tragedy of Sanfilippo Syndrome."

Moff, who ran the marathon for himself in 1989 and 2003, is a serious triathlete who considers running therapeutic. He was a hockey player in college who began to take running seriously in law school because he needed some kind of mental break.

"In my opinion the race starts at mile 17," he said. "That's when

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College professor to run Marine Corps Marathon for his children

By STEPHANIE FARR
Sun-Gazette Staff

For some people, Sanfilippo may sound like a gorgeous island vista off the coast of Argentina, but for Steven and Theresa Moff of Loyalsock Township, Sanfilippo is something they struggle to cope with every day.

Sanfilippo Syndrome is one of seven Mucopolysaccharide disorders in which children are missing an essential enzyme that breaks down a complex body sugar called heparin sulfate.

Eventually, this sugar backs up in the brain

and halts the normal progression of mental functions. Children reach a plateau of development and then gradually decline to a complete neurological breakdown. The average life expectancy for a child with Sanfilippo Syndrome is between 12 and 15 years of age.

It is a rare inherited genetic disorder that only about 200 youngsters in the United States are born with each year. It is only passed on to children if both parents carry the recessive trait, and even then, there is only a 25 percent chance that the child will develop the disorder.

For the Moffs, their chances were not so good.

Two out of their three children, ages 11 to 15, are afflicted with the disorder. But, Sanfilippo is such a rare disease, that it took the family 11 years before they received a correct diagnosis.

Loyalsock Township graduate

Steven Moff is a 1975 graduate of Loyalsock Township High School and his wife, Theresa, was raised in Tampa, Fla. After both attended the University of Pennsylvania in Philadelphia, where he pursued his master's degree in business administration and she pursued her master's in primary care, they moved to Will-

iamsport.

Steven is an assistant professor of business law and marketing at Pennsylvania College of Technology and Theresa is a nurse practitioner at Susquehanna Pediatrics.

Their first born, Sydney, 15, was a normal child, who even started talking at nine months of age. She was 15 months old when her parents attended the University of Pennsylvania for graduate school. She would shoot basketballs with the guys at her parents favorite hang-out, and was an incredibly social child for her age.

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