

Sykesville mom prays for son's cure of rare disease

Aimee Murray can deal with carrying her 31-pound, 4-year-old son. She can handle putting a 1.5-inch feeding tube into a hole in his belly and inflating a small balloon inside his abdomen to keep it in place. She can even endure exhausting hours of constantly checking on her boy to monitor his breathing and comfort him when he has muscle spasms.

What's really tough for the St. Joseph, Sykesville, parishioner is the knowledge that little Cormac "Mac" Murray will never get better. Metachromatic leukodystrophy (MLD), a rare genetic disease that is slowly robbing him of everyday functions, will one day claim his life unless there is a miracle.

"It's all hard," said the 35-year-old stay-at-home mom, "but the physical challenges have nothing on the mental challenges. Just knowing what he's lost is very difficult. There are times when you don't want to face the day because it's so depressing. We try to live each day to the fullest times 1,000."

Mrs. Murray and her husband, Brian, first became concerned about Mac when at 18 months he had only taken a few steps. He was misdiagnosed with mild cerebral palsy before an MRI, blood and urine tests finally confirmed more than a year later that he had MLD.

The debilitating disease occurs in only 1 in 40,000 births and is caused by a deficiency of the enzyme Arylsulfatase A. MLD impairs the development of the myelin sheath, a fatty covering that acts as an insulator around nerve fibers.

Without a properly functioning myelin sheath, the communication between nerves and the brain is weakened. Patients suffer loss of mobility, paralysis, seizures and other physical disabilities.

When Mrs. Murray first heard the diagnosis, she admitted being angry with God. As she cares for her son, the devoted mother now finds strength in her faith.

“God has carried us when we needed to be carried,” she said. “We wouldn’t be good parents without God in our lives.”

Calling Mac a “gift from God,” Mrs. Murray said her son has taught her to love every moment of life.

“We take nothing for granted,” she said. “We don’t stop believing in miracles, and we pray all the time – for a cure and for comfort for Mac.”

While bone marrow transplants may delay the progression of the disease in some cases, Mrs. Murray said Mac is not eligible for the procedure because the development of the disease is too far progressed.

The Murrays and their friends have formed a group called “Mac’s Team,” which is devoted to raising awareness about MLD. Mac’s Team held a bull roast and benefit auction in 2007 and 2008 to raise money for the Murray family. Many fellow parishioners supported the cause, Mrs. Murray said.

Mac currently has no mobility and is suffering from a bout with pneumonia, but when he’s excited he still pumps a fist in the air. It’s a gesture Mrs. Murray treasures – a symbol of an indomitable spirit. Praying with Mac, her husband and their other son, Colin, is also a joyous moment for the entire family, she said.

“Those quiet moments with Mac mean so much,” Mrs. Murray said. “It’s such a blessing.”

For more information, visit www.macsteam.org.