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A Gold Medal Performance to Raise Awareness of a Hereditary Disease

GRINNELL, Iowa – August 31, 2008 – In the early hours of Saturday morning, David Paige, 21, carefully slid his thin legs into the Obermiller Pool at Grinnell College and began swimming. Nearly 14 hours later, surrounded by cheering friends and family, Paige emerged from the pool a champion.

Paige's extraordinary feat defied the medical prognosis that was presented to him as an 8-year-old child. He was diagnosed with Charcot-Marie-Tooth, the most commonly inherited neuromuscular disorder, estimated to affect one in every 2,500 people – approximately 2.6 million people worldwide.

Paige's late father, a neuropsychologist, suffered from CMT, as did his paternal grandmother.

CMT is progressive, causing the nerve cells leading to the body's extremities to slowly degenerate, resulting in the loss of normal use of the feet/legs and hands/arms. The disease may also lead to a loss of sensory nerve function and deformities. CMT strikes people of all ages, genders, races and ethnicities.

Doctors told Paige that he wouldn't be able to write his own name or walk on his own by the time he turned 20. After having completed the grueling 26.2 mile marathon swim in the college pool, he proved them wrong.

"I started swimming about the same time that I started walking," said Paige, "and all along, I've been determined not to let CMT victimize me. I wanted to do something to help promote awareness and to show other young people that you don't have to let a disability affect your goals."

CMT is often misdiagnosed and misunderstood. Very little is known about the disease or how to treat it. But the Charcot-Marie-Tooth Association, like David, is working hard to change that.

"One of the most frequent things we hear is that people don't know where to turn when their child, their parent or another loved one is diagnosed with CMT," said Pat Dreibelbis, Director of Program Services at the CMTA, headquartered in Chester, PA. "The CMTA has been a vital provider of information and support to patients, families and the medical community for over 25 years."

According to the CMTA, for many of the most common forms of CMT, if one parent has CMT, there is a 50 percent chance of passing it along to each child. However, the severity of the disorder may vary significantly from patient to patient, even in members of the same family.

David's father recognized his son's symptoms early-on, which led to his quick diagnosis. Often the first signs may be frequent tripping or clumsiness, accompanied by an abnormal burning sensation. As the disease progresses, symptoms may include weakness and loss of function in legs/feet and arms/hands, poor balance and gait abnormalities, deformities, and sensory loss.

The elder Paige encouraged David to get into the pool and to begin swimming. While atrophied muscles cannot be restored, exercising and strengthening the surrounding muscles not affected by the disorder can help patients maintain mobility.

Currently there is no cure for the disease, but through the collaboration of the CMTA, and scientists around the world, researchers are moving closer. The Strategy to Accelerate Research (STAR™) was recently launched by CMTA and aims to develop treatments in the next few years, and even a cure within ten years.

“STAR represents a new and concentrated effort to find therapies and treatments for CMT, and it provides hope for patients and their families,” said Dreibelbis.

Today, 40 specific genes known to cause the disorder have been identified. According to Dr. Michael E. Shy, Director of the CMT Clinic and Co-director of the Neuromuscular Program at Wayne State University, and Chair of the CMTA Medical Advisory Board, “We now are able to replicate this disorder in the laboratory and in doing so, can begin testing new treatments that will ultimately lead to clinical trials in people. In addition, the translational science used in the research could have major implications for the treatment of a host of related genetic disorders.” These disorders include Multiple Sclerosis, Muscular Dystrophy and ALS (Lou Gehrig’s disease).

Paige’s early diagnosis was fortunate. Many live for years believing their problem is something other than CMT. “Many of the patients we see tell us that, in hindsight, they had symptoms as a child but blamed it on their own clumsiness, when in fact, the problem was CMT,” Dr. Shy said.

David Paige’s primary objective of his swim was to help make people aware of CMT. He believes that if just one person concludes that he or she may have CMT, and that it can be treated through exercise and bracing, then he reached his goal.

For more information on Charcot-Marie-Tooth disorder visit www.charcot-marie-tooth.org or call the CMTA at 1-877-4CMTFAQ.

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