CEDARS-SINAI MEDICAL CENTER NEWS

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B-ROLL IS AVAILABLE

TEEN ATHLETE WITH DEBILITATING DEFORMITIES BACK ON FEET AFTER COMPLEX SURGERY AT CEDARS-SINAI MEDICAL CENTER

LOS ANGELES (August 4, 2008) – After seven years, Ryan Woodward, 16, is getting a new pair of shoes. Not even a new car could elicit the excitement the Canadian teenager feels about this seemingly ordinary purchase, made possible after painstakingly complex surgery at Cedars-Sinai Medical Center's Charcot-Marie-Tooth/Hereditary Neuropathy Center.

Since childhood, Ryan has contended with the debilitating—and initially mystifying—symptoms of Charcot-Marie-Tooth (CMT) disease, a neurological disorder that typically affects the nerves and muscles in the feet, causing varying degrees of pain, deformity and disability.

"Imagine walking on two fists," describes Glenn Pfeffer, M.D., a distinguished foot and ankle surgeon who directs the Cedars-Sinai Charcot-Marie-Tooth/Hereditary Neuropathy Center, one of just two such specialized centers in the U.S.

Now, Ryan can't wait to slip into golf shoes—instead of the clunky sneakers that for so long accommodated his malformed feet.

"Golf is my main sport," explains the 6-foot, 190-pound high school junior, who once ranked near the top of his age group. "The shoes should help me improve my swing, and I'll be able to walk the tournaments now."

When Ryan was 5, Kelly Woodward says "mother's intuition" told her something just wasn't quite right about the way her son walked and the shape of his foot. She took the youngster to the family doctor and a podiatrist in Edmonton, Alberta, but neither offered an explanation.

As time passed, Ryan pursued his love of sports—golf, hockey, soccer, lacrosse and water polo—with increasing difficulty. "It got to a point where he couldn't keep up," remembers his mom, who watched with concern as his feet became more misshapen.

Finally, at age 10, Ryan was referred to a specialist who immediately diagnosed Charcot-Marie-Tooth disease, a hereditary neuropathy that affects one in 2,500 people. CMT causes progressive deterioration of nerves and muscles that control balance and gait and can trigger painful and disfiguring contractions of the feet. In more advanced cases the hips, spine and upper extremity become involved. Even breathing can become difficult in some patients. The condition often appears in childhood, though symptoms are usually subtle, leading to misdiagnosis.

"It was such a relief to know what it was and what we were dealing with," recalls Kelly of the CMT diagnosis, a further shock since neither she nor husband Geoff nor other family members had the disease. "The next challenge was what to do about it."

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After appointments with five different orthopaedic surgeons in Canada, the family explored the Web for a physician with the expertise to tackle the complex case. Through the Hereditary Neuropathy Foundation (www.hnf-cure.org) in the U.S., the Woodwards learned about Pfeffer, who has treated hundreds of patients with CMT over the past 20 years.

Pfeffer first encountered the disorder as a young surgeon, when a vibrant teen patient timidly removed her shoes. "This young girl's feet were twisted and deformed like the limbs of an old oak tree," Pfeffer remembers. "This was the kind of deformity a 90-year-old might develop—not a healthy adolescent. It made quite an impression."

CMT's unique complexity—and latent emotional toll—fueled Pfeffer's keen interest in the disorder and potential therapies. "Adolescence is a very vulnerable period in life," he explains

Though Ryan's classmates were supportive, he admits to feeling "pretty isolated from friends," primarily because CMT sidelined him from the sports he loved. His mother concurs: "There were definitely feelings of frustration. He just couldn't keep up."

Kelly was eager to schedule an appointment with Pfeffer, before her son's naturally upbeat disposition and self-confidence took a downturn.

"Dr. Pfeffer answered our questions the way we'd hoped, and we had total confidence he could do the surgery."

This highly specialized "custom" surgery is actually a compendium of intricate procedures—more than 25 in all—designed to "remodel" the foot by correcting both muscle and bone deformities. Pfeffer likens the surgery to turning a "gnarled oak tree into a beautiful willow."

Unlike the fusion surgery of the past, which left the foot frozen with little movement, surgical advances have enabled "motion sparing" of joints to allow greater range of motion, flexibility and balance.

In 2007, Pfeffer successfully operated on Ryan's first foot—with dramatic results. The teen was eager to return in May 2008 for repair of his second foot. After a six-week recovery in Los Angeles, the family was scheduled to return to Canada—and normal life. Ryan may need additional tune-ups down the line, says Pfeffer, but the major work is behind him.

This likely won't be the Woodwards last visit with Dr. Pfeffer. Their daughter Alexa, 12, also has CMT, though her symptoms have developed more slowly. Ryan plans to be a source of support in the years ahead: "I can tell her what CMT is all about and help her through it."

Pfeffer fears many people with CMT are suffering needlessly, not realizing the dramatic improvements specialists can offer.

"There are a large number of Americans with CMT who sit at home, don't go to high school dances, don't play sports, don't get jobs—all because they don't know what can be done for them," he says.

Pfeffer hears from former patients who, after surgery, are elated to put on "normal" shoes for the first time, to run or stand without pain, to go on dates and to start college .

"When you take away the burden of CMT, these young people finally begin to fly," says Pfeffer.

Ryan's mother has witnessed his transformation first-hand: "I've never seen a happier, more outgoing child."

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