

Irrepressible personalities drive fundraising and hope for ALS research and treatment.

LONDON, Ont. - Amyotrophic Lateral Sclerosis, also known as ALS, and sometimes called Lou Gehrig's disease in North America (after the New York Yankees baseball icon who was diagnosed with the illness in 1939) may place limits on people's physical abilities, but for some, it cannot suppress their will and hope to defeat this condition.

Ayr resident Heather Snell was diagnosed with ALS in 2006. Heather has lost her ability to speak and play the piano, but it has not stopped her from communicating through sign language and a keyboard. Nor have they stopped her from continuing to be both an inspiration and the driving force in an annual fundraiser called "Heather's Hootenanny for Hope", or "the Hoot" for short.

Heather says that the Hoot is "a celebration of all things good." The event raised close to \$90,000 in its first two years. This year the Hoot added another \$70,000. An additional \$22,000 was raised by an ALS snowmobile ride in February, and monies raised at events like bake sales, pond hockey, and concerts held by former students and friends of Heather bring the total amount to well over \$200,000 in just a few years.

The donations go towards the work of Heather's physician, Dr. Michael Strong, who is Chief of Neurology at London Health Sciences Centre. Dr. Strong runs an ALS clinic within LHSC's Clinical Neurological Sciences program along with Dr. Christen Shoesmith. He also conducts ALS research at the Robarts Research Institute in London. Dr. Strong is always quick to point out that both the research and the clinical practice are a team effort.

"I don't know if hope fuels research or research fuels hope," Snell writes, "but I think they work together like Dr. Strong and his team who contribute to this important research."

Heather, like many others has developed a close and true friendship with Dr. Strong and the caregivers at the hospital.

The other driving force in Heather's life is her family. Her husband Bob and her three children Meg, Stuart and Ben fuel her positive and determined attitude.

"If we're together and surround ourselves with a caring community, we'll be better, stronger people with some truly great memories and lifelong friendships," says Snell.

Like Heather's friends and family, the Barber family from St Thomas and the community have rallied around Steve Barber since his diagnosis 5-1/2 years ago. Barber was working for the City of St. Thomas public works department and a landscaping company in London when his ALS appeared. He first lost the grip in his hands and had some difficulty with balance. Now unable to use his hands, he has trouble walking.

"It's a bit frustrating, but it is better to focus on being positive and living normally as much as possible," says Barber, who turned 31 in September.

According to Dr. Strong, the disease usually targets patients over 50, but about a third are under the age of 45.

In 2004, a London fundraising walk for ALS included a 150-strong “Team Believe” comprised of the Barber family, friends and supporters, and outfitted in shirts supplied by Steve’s childhood friend and NHL star Joe Thornton. The team pulled in \$32,000 for the cause. Over the years they raised about \$100,000 for the London walk before raising another \$38,000 in the first annual “St. Thomas Walk for Lou Gehrig’s Disease” last year.

The new event was organized because the Barbers wanted to directly support Dr. Strong’s efforts. This year’s walk held on Sept. 26, a golf tournament called “Believe in a Cure” and an event called “Meg Barber and Friends Music in the Park” has resulted in close to \$40,000 more directed towards Dr. Strong’s work.

Both groups of fundraisers were on hand at Robarts Research Institute today to present cheques from this year’s fundraisers to London Health Sciences Foundation.

“We are tremendously grateful for the support of these events,” says Dr. Strong. “People often under estimate the impact of such support. In the case of our research program, many of the critical ideas that we have pursued in developing novel approaches to ALS would never have seen the light of day in the absence of this support. Indeed, new concepts in the causation of ALS that reflect changes in our fundamental understanding of the disease, take their origin directly from research performed here in London and supported by our ALS community.”

Dr. Strong’s research and his clinical practice garner accolades from patients and peers alike. He is the only Canadian to have earned both international awards given for ALS research, and the ALS clinic has become an international referral centre, seeing Canadian patients from Alberta to Newfoundland and others from as far away as Europe and Asia.

“The ALS clinic, and indeed the entire CNS program, continues to build on the heritage of its founders with leading edge treatment, research and innovation,” says Dr. Strong. “There’s no other institution like ours.”

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London Health Sciences Foundation is a Better Business Bureau accredited charity, linking our community and health care experts—including physicians, allied professionals, researchers, staff and educators—together in pursuit of medical excellence at London Health Sciences Centre. Established to strengthen London Health Sciences Centre's ability to provide the highest quality health care for patients in Southwestern Ontario and beyond, we offer opportunities to support discovery and innovation in research, education and patient care at our hospital. To see how donations create positive moments changing the lives of patients, their families and friends, and to see how you can support patient care and innovation at London Health Sciences Centre, visit www.lhsf.ca.

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