

Gastroparesis and Dysmotilities
Association
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Press Release

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A fundraiser and drive for a centre of excellence.

Oldest person ever to hike Vancouver Island's West Coast Trail: 85-year-old Ed Keith is planning to turn his historic hike into a campaign to raise money and awareness for a poorly understood stomach disorder.

Considered one of the most stunning hikes in North American, the West Coast Trail — part of Canada's Pacific Rim National park — follows the rugged Pacific coastline near the southwestern end of Vancouver Island. The demanding vertical ladders and slippery rocks that must be negotiated along the 75-kilometre trail, challenge the best and fittest.

As a newer member of the Calgary Outdoor Club, Ed Keith has become a sort of legend among the club's 3,500-strong membership. Standing six foot four, Ed is able, thanks to his long legs, to keep up to hikers decades younger than himself. After noting that Ed had completed just over 50 hikes in one year with the COC, the group's founder, Rhonda Scheurer, felt he might be up for a bigger challenge.

Encouraged by Rhonda to join the small group of club members meeting the demands of the West Coast Trail in August, Ed considered the offer and took it one step further. He has decided to make it a more personal journey.

Eight years ago, Ed's two grandchildren developed unrelenting upper digestive symptoms of dyspepsia commencing in the aftermath of a stomach infection. "Their infection cleared up, but their symptoms never went away," explained Ed. Nausea, frequent vomiting and bloating became the pattern of daily life for Ed's grandchildren, and doctors were unable to find anything wrong. Ed continued, "They just slowly started to lose weight and were no longer able to attend school. My daughter had to start them on a home-schooling program."

It took two years and several trips to the United States for Ed's daughter to finally get a diagnosis for the children.

The illness is called gastroparesis, which literally means “weakened stomach.” It is the most common of the paralytic disorders of the gut. These disorders are characterized by uncoordinated contractions somewhere along the digestive tract, and in severe cases, this altered motility leads to an inability for food to move through the body. Less severe forms of these neuromuscular problems of the gut are very common.

Irritable bowel syndrome (IBS), functional dyspepsia, chronic constipation, and GERD (gastroesophageal reflux disease) are the better-known gastrointestinal tract disorders comprising this same family of digestive diseases. These digestive motility disorders affect as many as one in three Canadians and, compared to other illnesses, are the cause of the highest rates of worker absenteeism and disrupted quality of life.

When doctors hear the term “gastroparesis”, they think of diabetics. Indeed many diabetics suffer from this stomach problem as do individuals with Parkinson’s disease, scleroderma and AIDS, to name a few.

What is not well recognized is the number of people who develop gastroparesis for no known medical reason, or in the case of the Ferris children, who develop it following a stomach infection. Among the vast majority of gastroparetic sufferers who fall into the unknown category, eighty percent are young women. Sadly, many of these women often go years without a diagnosis, or their illness is misdiagnosed as being induced by mental stress or depression or as an eating disorder.

For the very ill, constant vomiting may mean nutritional support via feeding tubes that bypass the poorly working stomach. For others, a special lifelong diet may be required.

Treating gastroparesis is extremely frustrating since there are very few medications approved for the disease and no new drugs exist on the horizon. Also, many people do not respond well to the medications.

A novel approach to treating gastroparesis is gaining popularity across the United States. It is a medical device similar to a heart pacemaker. Implanted on the surface of the stomach, the device delivers small electrical shocks that help to tone up the stomach’s motility. For some implanted patients, the device greatly reduces nausea and vomiting, thus helping to dramatically improve quality of life.

The device is approved by Health Canada as safe and effective, but Alberta Health refuses to cover its \$10,000 cost.

Not one to give up easily, Ed’s daughter, Jeanne Keith-Ferris, began a non-profit association to help advance research initiatives, raise awareness and support families struggling with debilitating digestive motility diseases such as gastroparesis. Says Jeanne, “I guess I got my persistence from my dad.”

Ed joins his daughter’s family every Sunday for dinner. It was on one such occasion that the inspiration took hold to use the West Coast hike as a fundraising/awareness event.

Says Keith-Ferris, “The timing dovetails with our Association’s vision of a Calgary centre of excellence that would provide both research into the more severe forms of mid-gut motility problems as well as access to proper diagnosis and effective treatments for this patient population.

Really, it is appalling that we don’t have one single centre in all of Canada acting as a safe haven of compassionate, multidisciplinary care for these very ill patients. Mid-gut motility diseases can be very frightening illnesses that can even lead to death. Watching loved ones suffer leaves you feeling very powerless.”

Adds Jeanne, “This is not a rare disease. Those who are very ill make up a small number, but it has been determined that five million Americans suffer to some degree from gastroparesis, and in Canada, the number would be proportionate.”

Ed most assuredly must be the oldest person to ever tackle the West Coast Trail. Joined by his daughter, he will hike with a core group of COC members. Jeanne says, “Seeing how our children suffered brings a personal meaning to each and every step we take on that trail. We have dubbed this trek the “Hike of Hope” in the hope that our dreams will turn into practical action to help others.”

Summing up, Jeanne says, “This is grassroots activism at its best. Here we are, a family marshalling a community of people around this cause. My father has been overwhelmed by the support shown to him by members of the Calgary Outdoor Club and the people who know him. Our family and children are touched by Calgary’s spirit of support.”

One hundred percent of all donations will go towards The Dream: Calgary Motility Centre of Excellence.

Individuals or corporations interested in donating may do so on-line at the bottom of any page on the GPDA website, www.digestivedistress.com or, by mailing cheques or money orders to:

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