

**Gastroparesis and Dysmotilities  
Association  
GPDA**

[www.digestivedistress.com](http://www.digestivedistress.com)

**Press Release**

**Jeanne Keith-Ferris, RN,  
BScN President/Founder**

**FOR IMMEDIATE RELEASE: March 23, 2003**

**Calgary, AB**

The distance: 100 kilometers on April 5, and 60 more kilometers through the rest of the week. Maybe snow, maybe rain, but it has to be done. How else can we fire up hope where for too long there has been none?

There is a population of patients who have all heard the hopeless and dismissive line from their doctors: “Sorry, you’ll just have to learn to live with it; there is nothing more we can do for you.”

These patients don’t have a celebrity to carry the fundraising banner. They don’t even have an illness that is easy to say; nor did they, until recently, have a non-profit organization to signal the charge.

And so, they are told to “just live with it”. Thanks, they think, we already knew that, for this is what we do day in and day out. Every day they live with nausea, vomiting, abdominal pain/discomfort, and bloating. Imagine living with bad stomach flu for the rest of your life. You might be lucky to be “just” debilitated by daily nausea, for those who suffer the worst from this illness experience years of constant vomiting and require tubes surgically implanted to bypass their non-working stomachs.

The illness in question is called gastroparesis, “gastro” meaning “stomach” and “paresis” meaning “weakness” or “paralysis”. Gastroparesis is a problem of altered motility, or movement of food through the system. Doctors, when they hear the term, think of diabetics, and indeed, many diabetics suffer from this stomach problem. What is not known is that many people who develop this illness — in fact, the largest group in the patient population — do so for no known reason. A stomach is an important organ. Yet, for this illness, little has been done to develop medications or to focus research on finding answers.

Jenny is a Grade 8 student and looks healthy and happy. Yet, each and every day Jenny struggles with the ever-constant presence of nausea. If she follows her diet, takes her medications and does not try to be overly active, she can generally keep the nausea in the background and try to force it out of her awareness. But frequently, the nausea rears up like a six-foot wave to knock her down. Pale as the snow, Jenny starts to hyperventilate; perspiration beads up on her forehead as she leans her face into a bucket. The nausea has her in its grasp again. Not even sleep brings relief as Jenny's dreams are often punctuated by monsters making her vomit in the dream world.

Like the ring bearer in Lord of the Rings, this illness has its own power to drag down the bearer. It can be unrelenting and frightening. One must struggle mightily against its power to sap the spirit and drain hope away.

Our Jenny is that Grade 8 student. It took nearly two years to get a diagnosis for her. So often doctors told her that she was exaggerating her symptoms, that she just wanted to avoid school, or that she was overly anxious. Soon you learn that this is the way doctors speak when they don't know what is wrong or when they are powerless to stop the suffering and cannot offer any help.

From birth Jenny was always in the middle of the growth chart. But when she was in Grade 3 and illness—the result of a stomach infection—her growth started to take a slow slide. Then her sick days, of feeling like she had the stomach flu, started to accumulate. Her days of feeling well became fewer and fewer to the point that now she has forgotten what it is like to feel “normal.” When the stomach infection ended and her gastroparesis began, we cannot tell. One illness just faded into the other.

Those who have this illness to a severe degree, in order to arrest starvation, must rely upon a tube implanted into their heart, like a large intravenous line, to pump a special liquid nutrition into their blood. When they do try to eat, they are unable to keep any food down.

We need to bring hope back for our future, and that has led us to start the Gastroparesis and Dysmotilities Association, the only non-profit organization with a research focus for this illness. We have met some amazingly strong people who fight this illness daily, their suffering invisible to others. They are charged up now, and hope is seeping back into their futures.

Things have developed quickly as GPDA organizes its first International Scientific Task Force on Gastroparesis to be held May 17<sup>th</sup> in Orlando, Florida: [www.gp-workshop.com](http://www.gp-workshop.com).

So my rusty bike will set out down the road to raise funds and awareness for this illness. If this were your daughter, you'd ride a Million Miles for Motility and that is our hope as we initiate our first North American fundraiser, April 5, through the 12.