

**Gastroparesis and Dysmotilities
Association
GPDA**

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Press Release

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GPDA: Our Fall Fundraiser

Some things you just don't want to remember — or, you are no longer able to sketch the details. The memories blur; they are not worth hanging onto. They can be called forth, but it takes energy and courage to re-examine the past.

Over 5 years ago, while on a family ski trip, we thought nothing of drinking the water at the local ski hill. The Rocky Mountain water was clear and refreshing — or so we thought. Unbeknownst to us, the water we were drinking was untreated surface water, which led to an infection called giardia or beaver fever.

That is where our tale began, but unfortunately it seems not to have an end. Many who contract giardia may have a rough ride with symptoms that are usually taken care of with a two-week course of antibiotics.

For us, the giardia seemed to lead to far greater problems: an unrelenting cycle of nausea, periodic vomiting, abdominal bloating, loss of appetite, and heartburn. We took endless treatments and, the giardia was definitely gone. My own symptoms faded slowly over a year, but as for my two children, their symptoms persisted and even escalated. Soon, they refused to eat and were wilting under the non-stop nausea.

They described a “nausea monster” who would visit them in their sleep and make them vomit in their dreams; then they would wake up and do just that.

One day became like the previous day: two children on a couch, complaining of horrible nausea, and lacking the energy to run, jump, play or even squabble. Gradually they began to lose weight. My son's pants hung from his waist; my daughter's face was pale and thin. Soon we were counting the missed school days in weeks and then months.

Some doctors thought their symptoms were caused by anxiety. Others blamed the symptoms on a “dysmotility” or cyclic vomiting syndrome or functional abdominal pain (despite the fact that the children never complained of pain). Labels, labels and more

labels. All we wanted was symptom relief.

After two long years, the kids finally received a diagnostic test that came back abnormal — their stomach emptying time was very delayed. Food sat unprocessed in their tummies for hours and then was vomited up undigested hours after eating. What a relief to finally have a name for what they had been suffering from for all of these years!

The disease is called gastroparesis. “Gastro” means “stomach” and “paresis” means “weakness” or “paralysis”. It is a neuromuscular problem of the stomach that can affect other segments of the digestive tract. It is a problem of abnormal motility (motility being the word to describe the propulsive and digestive action of the gastrointestinal tract).

In the early stages of this chronic illness, we felt that if we could only discover what was wrong with the kids, we could find the right answers and treatments. Then the kids could return to the world of the healthy and back to playing with their friends whom they were dearly missing while housebound with symptoms.

Yes, we were able to start medications that helped to stabilize the kids’ weight loss. However, it seemed that nothing we did or tried — diets, alternative medicine, experimental treatments, and consultations with doctors from coast to coast — could completely beat back the kids’ symptoms, especially the nausea monster that never left them.

There were no answers to be found. The realization that precious little research has been devoted to these digestive motility diseases focused our search on finding the non-profit association that was leading the charge into uncovering the answers. Sadly, it too did not exist.

We have since founded the Gastroparesis and Dysmotilities Association (GPDA), a federally registered charity and the only North American non-profit association actively supporting research, increasing awareness and providing information to patients and their families about this disabling group of digestive diseases.

Outreach volunteers provide on-line support in chat rooms to help patients cope with their struggle with chronic illness, feeding tubes, isolation and ensuing depression.

Some people who suffer from gastroparesis do get better, while others face a slow deterioration over the years, which can lead to death. Very little is known about these diseases — however, gastroparesis is not rare. About 10 % of diabetics as well as people with scleroderma, Parkinson’s disease, muscular dystrophy, AIDS and liver disease can develop these digestive motility disorders to a devastating degree.

By far, the largest group to be hit is comprised of women between 18 and 50 years of age, and since no known cause exists for this group’s predilection to these disorders, these patients are often misdiagnosed and provided with little information.

GPDA will host its first major, local fundraiser, Music for Motility at the University of Calgary, Rosza Centre on September 20th. Charles Foreman, professor of Piano Performance at U of C, and Kathleen van Mourik, who along with Professor Freeman is a musical director of Mountain View Connection, will anchor an evening of classical and vocal jazz music. Silent auction items will help to raise funds for research and patient education materials.

Tickets are available at the U of C campus ticket office, on-line at www.gpda.net or by calling 247-3215.