

**Gastroparesis and Dysmotilities
Association
GPDA**

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Press Release

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President/Founder**

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“Music for Motility,” a fundraising event for people suffering with a poorly understood stomach illness. Rozsa Centre, University of Calgary; September 20, 2003; Charles Foreman, Piano Performance Professor at the U of C and Kathleen van Mourik, Mountain View Connection.

Imagine a world where food is your enemy; it brings a sense of anxiety and foreboding. “No, this is not an eating disorder, but it is often misdiagnosed as one,” says the president of the Gastroparesis and Dysmotilities Association, Jeanne Keith-Ferris, RN.

People with a neuromuscular problem of their digestive tract can suffer for years with bouts of endless nausea and vomiting. These symptoms are often found in association with other upper digestive symptoms. Symptoms of heartburn, abdominal bloating, nausea and a feeling of fullness after a few bites of food are very common complaints.

Dr. Tougas, Associate Professor of Medicine, Division of Gastroenterology at McMaster University in Hamilton, Ontario helped to co-author a study looking for the prevalence of upper digestive tract symptoms in the general Canadian population. The study, “Digest”, sponsored by Janssen-Ortho Inc. of Canada, set out to interview people randomly selected from twelve of the largest Canadian cities covering the five major regions. In all, 1,036 individuals participated. The final tally concluded that upper gastrointestinal symptoms are very prevalent in the general population and substantially affect quality of life, ability to work and the psychological well-being of individuals. Chronic nausea was found to be associated with everyone who complained of upper GI distress, and it was determined that the rate of chronic nausea experienced by the entire group interviewed was 4.6%.

“Our patient population certainly knows all about the symptoms of nausea, vomiting and abdominal pain,” says Ms. Keith-Ferris. Gastroparesis represents a much more severe form of these upper digestive complaints. This paralytic problem of the stomach leads to non-stop vomiting for some patients and carries a 5 to 10% mortality rate. “Gastro”

means “stomach” and “paresis” means “weakness” or “paralysis”. Gastroparesis 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 used to describe the propulsive and digestive action of the gastrointestinal tract). People with this illness lose their ability to get proper nutrition and slowly waste away.

Often gastroparetic disorders are misdiagnosed as irritable bowel disease, or worse, dismissed; yet, for the person suffering, life becomes a struggle. The joy of food is replaced by anxiety since a meal can really crank up symptoms an hour or two later. “And high fibre (often recommended for irritable bowel) is about the worse thing you can eat,” say Ms. Keith-Ferris. Anyone who has suffered a bout of stomach flu or has had motion sickness completely understands the debilitating effects of nausea and vomiting.

Yet, many patients who have digestive motility diseases live years with the symptoms. And since there are so few treatment options and very little research into these disorders, the best advice many doctors can give is “just learn to live with it.”

Currently, medications on the market for these lethal GI diseases have been borrowed from other medical uses; not one medication is available that has been specifically designed for gastroparesis.

Ms. Keith-Ferris points out that not everyone who develops these diseases has a bad outcome. Some can develop these dysmotilities as the result of a gut infection and they will slowly heal over time. Others do respond to the medications and manage okay; but sadly, some patients deteriorate and require the implantation of feeding tubes in order to fight their ensuing malnutrition.

Most patients are worn down by the symptoms, which interfere with outings, physical activity, work or even just the eating of a simple meal.

Diabetics are often thought of in association with gastroparesis; however, the largest group of this patient population is comprised of women for whom no known underlying cause of the illness can be found. Parkinson’s disease, scleroderma, AIDS and some types of cancers can all lead to this devastating weakening of the digestive tract.

These are perplexing digestive diseases that have received little attention. “Telling patients to ‘just get on with it’ is unacceptable. Nausea, vomiting, and abdominal pain are some of the worst symptoms known, so as a patient group we need answers,” states Ms. Keith-Ferris.

The Gastroparesis and Dysmotilities Association (GPDA) will host its fall fundraiser, “Music for Motility”, at the Rosza Centre, University of Calgary campus. Charles Foreman, professor of Piano Performance at the U of C, and Kathleen van Mourik, who along with Professor Foreman is a musical director of the Mountain View Connection, will anchor an evening of classical music and vocal jazz. Silent auction items will help to

raise funds for research and patient-education publications.

GPDA is a federally registered charity and does not receive government or United Way funding “so for us to make a difference for these individuals, we have to be very resourceful,” says Ms. Keith-Ferris. The GPDA Web site has developed into a resource for both patients and physicians who wish to learn more about these diseases. Outreach volunteers across North America help with on-line chat sites for patient support. GPDA has just celebrated its first anniversary and has already organized the first International Scientific Task Force on Gastroparesis.

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