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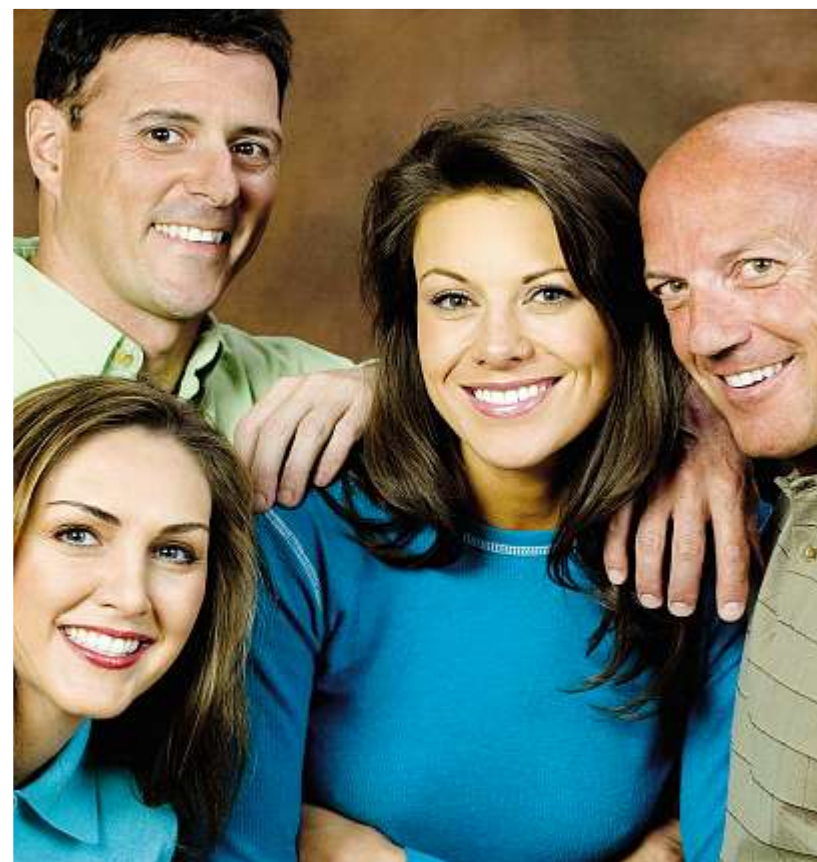


If you, or a loved one, suffer from distressing digestive problems of nausea, heartburn, bloating, abdominal pain, constipation and other digestive symptoms, we invite you to learn more.

The Gastroparesis and Dysmotilities Association, a federally registered charity, has sponsored this insert especially for you.



*May is
Digestive
Motility
Awareness
Month*



Gastroparesis & Dysmotilities Association
www.digestivedistress.com



Digestive Motility Awareness Month

Poor digestion affects millions, but few understand why

Stories by Alex Frazer-Harrison

The ability to digest food and remove waste from our bodies is a fundamental necessity — so when these systems malfunction or stop altogether, the consequences



Jeanne Keith-Ferris

can range from uncomfortable to life-threatening. Yet gastrointestinal (GI) motility disorders remain a mystery to many people — including many physicians. In an undertaking that may go a long way toward raising the profile of these disorders among the public and the medical community, Calgary is

now home to Canada's first centre of excellence dedicated to studying the many conditions that fall under the GI motility disorders banner.

The centre's goal is to find better methods of diagnosis and treatment.

While relatively few people experience the more severe forms of GI motility disorders such as gastroparesis — which affects the body's ability to digest food and the stomach's ability to empty — large numbers suffer from milder forms.

Some of these milder forms include dyspepsia; symptoms of nausea, fullness, bloating and abdominal discomfort after a meal; gastroesophageal reflux disease, persistent heartburn and stomach-acid wash; and chronic constipation.

Many may suffer with constant linger-

ing digestive symptoms, frustrated in their attempts to get a diagnosis.

"Across Canada, there are millions of people suffering from some form of digestive motility disorder symptoms," says Jeanne Keith-Ferris, who established the Gastroparesis & Dysmotilities Association (GPDA) when she discovered the lack of support available when her own children, Jenn and Thomas, developed gastroparesis.

"Often these people can't get good relief from medication, and what's unknown to them is that these disorders are often related to a problem we call poor digestive motility."

Motility is the muscle-pumping action that operates from the esophagus through to the bowel. It is essential for the intake and digestion of food, the absorption of nutrients and

the elimination of waste.

But the nerves involved can malfunction, compromising motility.

The ailment can have far-reaching effects on the body's systems, Keith-Ferris says.

"Many who suffer from scleroderma, lupus, chronic liver failure, HIV, MS and other diseases may have their illness extend into the working of the digestive tract, affecting the digestive nerves' and muscles' ability to digest a meal. The resulting digestive symptoms can be enormously challenging to control."

Doctors have different names for conditions involving GI motility disorders, depending on the area affected.

"But it's the same story — and for some people, the entire digestive system is affected," Keith-Ferris says.

CONTINUED, NEXT PAGE

EVERYTHING'S HARDER WHEN YOUR BODY TURNS AGAINST YOU.

The Parkinson's Society of Southern Alberta

The Parkinson's Society of Southern Alberta

Parkinson Society Canada
Société Parkinson Canada

Learn more at parkinsons.ca

The Parkinson's Society of Southern Alberta recognizes that May is Digestive Motility Awareness Month.

If you have Parkinson's, you may experience digestive motility issues.

The Parkinson's Society of Southern Alberta sends their congratulations for the new Digestive Motility Centre at the Foothills Hospital.

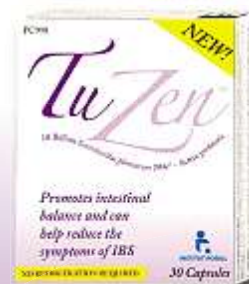
PSSA is dedicated to helping people and families of Southern Alberta who live with Parkinson's and related disorders. Our core services include individual and family counseling, support groups for people with Parkinson's and their caregivers, Parkinson's specific physical therapy support and speech therapy. Community education and public awareness programs are also offered by PSSA.

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Digestive Motility Awareness Month



The best-known of the more common conditions is probably irritable bowel syndrome (IBS), a fairly common ailment, says Dr. Keith Sharkey, a professor in the departments of Medicine and Physiology & Biophysics at the University of Calgary, and a leading researcher into gastrointestinal disorders.

IBS affects 10 to 15 per cent of Canadians, predominantly women.

"These disorders can be relatively mild, where there's a degree of abnormal motility — perhaps either slowing down or speeding up the passage of food," he says. "The most severe are the ones where motility is too slow — where the stomach fails to empty. And if you can't move food through the gut, you in effect end up with an obstruction of the gut, which we call a pseudo-obstruction."

However, unlike a true intestinal obstruction, in pseudo-obstruction sur-

gery does not fix the problem, and for some may actually hasten further obstructive episodes.

Symptoms of a GI motility disorder can include bloating, distention, pain and frequent vomiting and diarrhea, Sharkey says, adding it often takes complex diagnostic procedures to actually identify what's wrong, as standard blood tests and other assessments don't always indicate that a problem exists.

"Most physicians aren't trained to do these procedures, or to expect this condition to be there," he says.

Gastroparesis, considered one of the more severe forms of dysmotility, is frequently associated with diabetes, though it can be triggered by other conditions, such as when Keith-Ferris's children contracted an infection during a family ski trip a decade ago which led to them developing the ailment.

CONTINUED, PAGE 7



Wil Andruschak

From left, Dr. Martin Mintchev, Jeanne Keith-Ferris, Dr. Chris Andrews, Dr. Keith Sharkey and Don Ferris at the University of Calgary Medical Building.

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Digestive Motility Awareness Month

'I know, underneath, the things I'm dealing with'

Jaime Thomas was 27 when she was diagnosed with a gastrointestinal motility disorder — but by then, it had already changed her life.

"I had an intestinal infection which affected the nerves in part of the intestine," Thomas says.

"Sometimes the nerves would overwork and sometimes they would underwork."

Like many with moderate to severe motility disorders, many of the day-to-day things we take for granted were difficult.

"It's been three years... It's interfered with sleeping, and certain foods aggravate it. It starts to interfere with your life; you start to think, 'What am I eating that's aggravating it? Why can't I eat?'"

Gastrointestinal motility disorders can take many forms, and dozens of different names have been associated with conditions related to dysmotility.

Symptoms can range from heartburn to difficulty swallowing, to in more severe cases nausea and frequent vomiting, as the muscular contractions that are supposed to move food through the gut malfunction.

Thomas delved into holistic medicine and travelled to clinics from Switzerland to the United States in order to find treatments for her condition.

"I've done a lot of experimenting with diet," she says. "In some cases, I've made myself worse, and at other times I've made myself better."

Thomas says she often has difficulty getting people to understand her situation because, like many with motility disorders, she often doesn't look ill.

"I look very healthy to the average person, but I know, underneath, the things I'm dealing with," she says.

In 2005, Dr. Catherine McKay lost her mother, Brenda, to a chain of events that started when she was diagnosed with an intestinal pseudo-obstruction, another form of GI motility disorder.

"She was about 40 and she started having profuse vomiting and lots of abdominal pain," recalls McKay. "She



Don Molyneaux

Thomas Ferris, 16, and sister Jenn, 18, have been able to resume normal lives thanks to special electronic implants that help maintain digestive motility.

went to the doctor because she was a nurse herself. She was told she was crazy, and this went on for six years until she was diagnosed."

McKay saw her mom visit some 60 physicians in Ontario and elsewhere, enduring surgery that ultimately resulted in her losing her large intestine.

Then, Brenda went to the Mayo Clinic.

"She was told she had a problem with her autonomic nervous system," says McKay. "The sad thing was at that time there was not enough research and she was told this was going to be her life. By this time it was affecting her stomach and small intestine."

By 2004, Brenda had lost most of her small intestine and required intravenous feeding (called TPN, or total parenteral nutrition) to stay alive, and her only hope was a multi-organ transplant, which was conducted in April 2005 and was initially successful. But she succumbed to an infection that August at the age of 48.

"People don't want to talk about

bowel problems — it's embarrassing for them," says McKay, who says most research and fundraising publicity tends to focus on issues like cancer, heart disease and other gastrointestinal conditions such as ulcerative colitis and Crohn's disease. "Yet more people are affected by this than by Crohn's."

McKay was inspired to undertake a PhD at McMaster University on gastrointestinal motility disorders — in particular studying the interstitial cell of Cajal (named for Nobel laureate Santiago Ramón y Cajal, a Spanish pathologist), a cell that acts to trigger the reactions of the intestinal tract — in order to promote more research into her mom's condition.

And she has a personal urgency to see increased research into causes and treatments of GI motility disorders.

"I have bad migraines, and my mom had them as well," she says. "There is some concern I might be paralleling her condition."

But there is hope for those with GI motility disorders. Until a few years ago, Jenn Ferris, 18, was unable to go to school regularly due to severe gas-

troplepsia, a motility disorder that affects the body's ability to digest food and empty the stomach.

Ferris and her brother, Thomas, developed the condition after contracting an infection on a family ski trip. For the siblings, continual nausea and frequent vomiting became a fact of life.

"The difficult thing about the nausea is it saps your energy," Ferris said in a 2007 interview. "It's really difficult to function when you're consumed by the nausea, and you wake up feeling sick and go to bed feeling sick."

Ferris's dream is to act onstage, but the disorder prevented her from getting roles in school plays because she couldn't predict her condition from day to day. But after being implanted in 2004 with a groundbreaking gastric electrical stimulation device, Ferris's life has turned around.

Her symptoms began to decrease, and she was able to go to school full time, and finally pursue her dream of being a performer. Today, she attends the American Musical and Dramatic Academy in New York City, with her eyes set on Broadway.

"I feel great — the things the implant has done for my quality of life have been amazing," she says. "There's a little metal box under my skin, so I have to be careful with activities like dance classes. But it's helped me so much, I want other people to have that kind of help."

"I went from housebound, without much hope at all, to New York City."

Ferris says she's excited that a centre for excellence has been established in Calgary, so local people who have GI motility disorders don't have to travel to seek the latest treatments.

Adds Thomas: "There definitely needs to be patient-doctor communication and learning to be done."

As for McKay, she hopes the new Canadian Centre for Digestive Motility will be able to attract the best and brightest researchers and physicians to work together to discover ways to better diagnose and treat GI motility disorders.

"What am I eating that's aggravating it? Why can't I eat?"

Digestive Motility Awareness Month



Treatment options slowly gaining ground on disorder

Compared to other conditions, the study of gastrointestinal motility disorders is still relatively in its infancy, with researchers still exploring ways of best treating the many conditions that fall under its umbrella.



Dr. Christopher Andrews

But thanks to state-of-the-art implants and more traditional methods, there is hope for many that it's possible to restore some normality.

"Once the diagnosis has been made, the vast majority of treatments are going to be related to lifestyle changes and medication," says Dr. Christopher N. Andrews, an assis-

tant professor of gastroenterology at the University of Calgary's Faculty of Medicine who specializes in GI motility disorders.

"For example, we often find that for people with GI motility disorders, certain foods are harder to digest than others, so we recommend smaller meals spaced out throughout the day.

"Simple things like that can make a difference."

Medications exist to help with the nausea associated with GI motility disorders, and to help the stomach empty faster, Andrews says, adding the long-term effects of the drugs can be variable.

"We're always hoping for the idea of finding a drug that works well and has no side effects," he says.

"And some patients will get some

efficacy from a medication for a while, and then it'll stop working for them."

For people with more severe forms of GI motility disorders, such as gastroparesis, a relatively new surgical implant option has the potential to significantly reduce the symptoms of the disorder. In the early 1990s, Dr. Thomas Abell of the University of Mississippi Medical Center in Jackson developed gastric electrical stimulation (GES), using a device that helps improve or restore the involuntary nerve impulses necessary to move food through the gut as it digests.

"The device I have implanted in my stomach has little leads into the stomach wall, and they send electrical impulses every five seconds ... that pretty much allows me to live," says

Jenn Ferris, 18, a Calgarian who along with her brother was implanted by Abell several years ago to address her gastroparesis.

"It really changed my life."

Ferris's story is an example of a best-case outcome for the GES implant, says Abell.

"Of the people who responded to treatment, 80 per cent of them have a pretty good response, with at least a 50 per cent reduction of symptoms," he says. "And with this condition, a 50 per cent reduction is worth having."

Even better, half of those who experience this significant level of relief achieve a reduction of 80 per cent.

"They feel like they've gone to heaven," Abell says, noting that Ferris falls into this category.

CONTINUED, NEXT PAGE

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Digestive Motility Awareness Month



GPDA in the spotlight

Above: A tribute to Dr. Thomas Abell.
Top left: Awareness night at Shea Stadium, New York.
Top right: Former NFL star Archie Manning.
Bottom left: Volunteers in Dalhousie, northwest Calgary.
Bottom right: Calgary Stampede Parade.

FROM PAGE 5

Abell has spent the last 30 years working in the area of GI motility disorders, and about 20 years ago started to work on a way to stimulate the gut electrically. He implanted his first patient with GES in January 1992; since then, he estimates about 2,000 people have been implanted worldwide.

Andrews' team recently performed the first Calgary GES implantation on a diabetic (gastroparesis is a potential complication for those with diabetes).

"The patient seems to be doing quite well," reports Andrews. "She's in her

30s ... people can get gastroparesis at virtually any age."

GES doesn't work the same for everyone. Ferris's brother Thomas, for example, was implanted at the same time, and while he also experienced improvement to his gastroparesis-related symptoms, it wasn't to the same degree as his sister. Abell says he's working on developing a way to endoscopically (non-surgically) test the effectiveness of GES on a patient before committing to surgery.

Meanwhile, Dr. Martin Mintchev, director of the Biomedical

Instrumentation Laboratory and professor at the U of C, is developing the next generation of implantable, micro-processor-controlled neuro-electrical stimulators to treat GI motility disorders.

"The idea is to practically recreate the motility of a given organ of the GI tract," he explains, "in much the same way a pacemaker gives the electrical rhythm and the heart itself does the mechanical action — here, we practically recreate the motility."

Mintchev has also developed a device similar to an electrocardiograph, called

an electrogastrograph, that is used to non-invasively measure electrical activity within the GI tract, providing better assessment of GI motility disorders.

"This multichannel system measures the electrical activity of the stomach which is of very low-amplitude and difficult to interpret. It is in use in Edmonton already, and I would like to see it utilized here as well."

Mintchev says the new Canadian Centre for Digestive Motility will provide an ideal venue for developing and testing new homegrown technology such as this.

Digestive Motility Awareness Month



7

FROM PAGE 3

Dr. Christopher Andrews, an assistant professor of gastroenterology at the U of C's Faculty of Medicine, is another Calgary-based GI motility disorder researcher. He says at least 52 disorders related to the nerves of the gut have so far been identified.

This makes correct diagnosis a challenge.

"We're very good at diagnosing inflammation or ulcers or cancers or blockages," he says. "But we don't have a lot of tests that show us a malfunction in the nervous system. It's a software problem as opposed to a hardware problem.

"We're understanding more about how it works, but as it stands now, compared to other aspects of the gut, we're very far behind in terms of having reliable tests to see if there are

nerve problems or muscle problems," Andrews says.

"And there's a big lack of awareness among the medical profession, through no fault of their own."

Until recently, those seeking answers about GI motility disorders — and advanced treatments such as gastric electrical stimulation (GES) implants — had to leave Alberta, and even Canada.

But through the support of the GPDA, the U of C and others, the new centre of excellence, dubbed the Canadian Centre for Digestive Motility, aims to bring together expertise in gastrointestinal issues for research and patient treatment, while at the same time inspiring medical professionals and students to specialize in the field.

For more information on GI motility disorders and the Canadian Centre for Digestive Motility, visit the GPDA website at www.digestivedistress.com or call 247-3215.

"The centre will become a nucleus where we can accomplish treatment goals and research goals for these disorders," says Sharkey, who, along with Andrews and others, will be part of the knowledge pool in the endeavour.

"There is no similar centre for this in Canada. We're very excited because it allows Calgary to really focus on these disorders as a centre for training, absolutely."

Dr. Martin Mintchev, professor and director of the U of C's Biomedical Instrumentation Laboratory, who has been working on several engineering-based tools for diagnosing and treating GI motility disorders, says the centre has the potential to put Calgary "in the forefront of this research worldwide. The frontiers of contemporary medi-

cine will be pushed by this amalgamation of technology, clinical research and basic science research."

Mayo Clinic-trained Andrews, who was part of the team that performed the first local implantation of a GES system into a diabetic patient, says he's hopeful the centre will allow researchers to more easily follow the progress of patients.

Keith-Ferris's family made one of the centre's major startup donations.

"We want people to understand that these symptoms are really common. For those folks whose doctor can't put a finger on what's wrong, and they're struggling to find help ... they now have hope and a place to go," she says.

A free forum on GI motility disorders is scheduled for June 14 at the Libin Lecture Theatre in the Health Sciences Centre by Foothills Hospital.

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The mission of the Scleroderma Society of Canada is to promote awareness of scleroderma, to support research toward finding a cure and to provide support and information to those affected by the disease.

The Scleroderma Society of Southern Alberta joins the Gastroparesis and Dysmotilities Association (GPDA) in recognizing May as Digestive Motility Awareness Month and extends best wishes to the GPDA on their patient support meeting and public forum.

Digestive motility is a common problem for those who suffer from scleroderma, a progressive disease of the vascular and immune systems in which the overproduction of collagen results in the thickening, hardening and scarring of the skin and other organs.

Although scleroderma is considered to be a rare disease, as many people are affected by scleroderma as are affected by multiple sclerosis. There is no known cause and no known cure.

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