

The Gastroparesis and Dysmotilities Association (GPDA): Political Action Fax!



Jessica used to run and play with her friends, just like any other 6-year-old kid—until she could no longer eat.

JESSICA'S STOMACH IS PARTIALLY PARALYZED.

Her life is filled with endless bouts of:

**nausea, vomiting, bloating, fullness,
heartburn, and stomach pain.**

Fast-forward ten years...

Jessica still cannot eat normally. For more times than she cares to remember, she has spent birthdays in a hospital bed, family vacations locked in a bathroom vomiting, and endless hours on a couch curled up in pain.

"It's like living with a stomach flu that never goes away."

And, she is not alone; over the past decade, Jessica and **5 million others like her** have little to cheer about because:

- Access to their medications have been pulled from the market or greatly curtailed,
- No new medications are available,
- Access to an implantable medical device called gastric electrical stimulation (GES), which helps reduce symptoms of nausea and vomiting for many like Jessica, is difficult due to limited insurance coverage and treatment centers.

Who gets gastroparesis?

People suffering from: **AIDS, Parkinson's disease, diabetes, scleroderma, chronic kidney failure, chronic fatigue syndrome**, are particularly vulnerable to gastroparesis.

But, for Jessica and countless young women like herself, their cause for this digestive illness remains a medical mystery.



This is not an eating disorder...Jessica's illness has a name!

Called: Gastroparesis (GAS-tro-par-ee-sis), it adds-up to a weak and slow emptying stomach. It is a nerve (neuro) muscular disorder affecting the stomach.

Gastroparesis, in its worst form, represents stomach organ failure. Eighty percent of those affected are young to middle-aged women!

In 2005, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) established the Gastroparesis Clinical Research Consortium (GpCRC). Funding is secure until 2011.

The NIDDK, in their wisdom, took this bold step in order to begin a concerted effort to build the basic elements needed to understand and reverse the abysmal lack of treatments for gastroparesis. This research consortium is a future lifeline for long suffering patients.

Dear Senator / Congressman: Please urge the National Institutes of Health (NIH) Diabetes to renew their funding support for the Gastroparesis Clinical Research Consortium (GpCRC) beyond 2011. Lives literally depend upon it! Thank you.

Digestive motility is the name given for the gut's muscular: mashing, mixing and pumping action, needed for digestion and waste elimination. The nervous system inside the gut is responsible for the coordination of digestive muscular function and motility. When gut-nerves falter, spastic through paralyzed motility can occur causing digestive symptoms.

Just another oddball disease that doesn't touch my life...

Think again! As many as one in five people suffer from dyspepsia (dis-PEP-sia)—a term literally meaning “bad digestion”—which produces the common digestive symptoms of: persistent abdominal pain/discomfort, bloating, a feeling of fullness, filling up after just a few bites of food, and nausea.

Sound familiar?

Easily a quarter of these dyspeptic folks have delayed emptying of their stomachs—a milder form of a stomach motility problem like gastroparesis. There is no hard and fast dividing line between dyspepsia and gastroparesis—same symptoms, just different degrees of intensity—it is very confusing.

Kids like Jessica just represent the top of the pyramid of the worst cases. In North America we are awash in a modern-day epidemic of dysmotility (bad motility)/dyspepsia.

No, not everyone will end up like Jessica. As many as a third of those who suffer from troublesome, non-specific, dyspeptic symptoms may slowly progress over the years to a more severe state. Generally speaking, young to middle-aged females make up the largest group that will move on to a more severe state, for which no known medical cause can be identified.

Your stomach is a vital organ just like your kidneys and heart.

Gastroparesis in its worse form represents digestive failure. Individuals in this state can no longer eat normally and may need to depend on surgically placed feeding tubes, which despite providing nourishment, often offer little help quelling constant digestive symptoms.

Yet there is not one medical treatment currently on the market, which was specifically designed, from the lab to the marketplace, for our patients. All available medical treatments are borrowed from other areas of medicine. Furthermore, over the last nine years, access to three medications vital to our patients was drastically curtailed, leaving these patients reliant upon very old drugs with significant side effects. Finally, an implantable medical device that significantly reduces nausea and vomiting in gastroparetic patients is not easily available to all who need it.

We have a big problem.

In the 21st century, this area of digestive motility (functional) medicine remains ill-defined; patients continue to get diagnosed based primarily upon symptoms (example, dyspepsia); these are not rare conditions, in fact are very common; and funding for this area of research remains anemic compared to other areas of medicine representing both rare and common diseases.

Fast Facts and Figures

- 5 million Americans suffer from gastroparesis (National Institutes of Health, U.S. Federal Government statistics).
- About 1.5 million diabetics have severe gastroparesis. Just as many young women are suffering but no medical cause can be found.
- 20% of North Americans suffer from dyspepsia.
- Medical costs for a severely affected gastroparesis patients costs approximately \$7,000/month per patient.
- Gastroparesis patients can remain in the hospital for 6 or more months due to uncontrollable vomiting and abdominal pain.
- In a recent study following 228 gastroparesis patients, about 70% reported their illness affected their daily activities and 11% were disabled.

If you have a loved one suffering from gastroparesis, or unexplained nausea and vomiting, you need to act now! Please call your elected official: Capitol switchboard at: 202-224-3121 and/or fax this form to your senator / congressman to urge the NIH to fund GpCRC beyond 2011. For more information, visit: www.digestivedistress.com