



October 20, 2005

National Digestive Motility Awareness Month

May 2006

The National Institutes of Health has determined that 5 million Americans suffer from a severe form of a poorly understood stomach disorder called gastroparesis. Gastroparesis, also known as delayed gastric emptying, represents a puzzling disorder of upper digestive motor function that can extend from weakened ability through the spectrum to complete organ failure.

Gastroparesis, being the most common of all severe digestive motor disturbances, will serve as our representative to a family of digestive motility problems.

Digestive motility problems can affect any region of the digestive tract. This diverse, complex group of gut spastic/paralytic digestive problems is impartial to age, sex, ethnic background and economic status, easily affecting about 30% of North Americans and as many worldwide. Our severely affected patient population merely represents the top of a pyramid. We are awash in a modern-day epidemic of dysmotility, which is costing our society dearly.

What is digestive motility?

Gastrointestinal **motility** refers to the overall muscular action of the gut that is needed to mechanically mash, mix, and propel food along the digestive tract. Disruption of gut muscular function and coordination can lead to disabling digestive symptoms.

What are digestive (gastrointestinal) motility diseases/disorders?

- They represent abnormalities in the gut (enteric) nervous system with evidence of neuroendocrine/neuroelectrical abnormalities, and/or abnormalities of the enteric (gastrointestinal) smooth muscle tissue — hence, enteric “neuro-muscular” dysfunction;
- They are a complex, multifactor, chronic, digestive disease state with possible genetic, physiological, social, immune, psychological, and environmental interplays;
- They can affect any region of the digestive tract, including ancillary digestive organs of the pancreas and gall bladder;
- They are impairments of enteric sensory nerves, and/or mechanical motor function of the esophagus, stomach, and intestines, which, when severe, can interfere with digestion, absorption, nutrition, and waste elimination;
- At the severe end of the disease spectrum, they represent digestive organ failure with mortality; and,
- They most commonly occur for unknown, unexplained medical reasons with females over-represented. They can also occur as a secondary problem to metabolic diseases like diabetes or chronic metabolic states like kidney disease or liver disease; neurological

problems like Parkinson's disease, collagen diseases like scleroderma; or post-surgically as in stomach ulcer surgery or heart/lung transplants, to name a few.

These motility problems present as a spectrum from mild through to severe. Although each affected region has its own diagnostic term, all share a weakened to flaccid, discordant function of motility. As many as a third of those who suffer for years from troublesome, non-specific, digestive symptoms may slowly progress to a more severe state. Generally speaking, young to middle-aged females make up the largest group to move on to a more severe state, for which no known cause can be identified. This unknown cause is labeled *idiopathic*. These idiopathic forms show a variable course over the years, with symptom flare-ups followed by periods of quiescence. As well, many individuals affected with an enteric infection (whether bacterial, parasitic, or viral) can then develop a post-infection dysmotility, which may slowly resolve (over a period of from two to five years), but in the interim, can significantly impact quality of life to a disabling degree.

The severe end of faltering motility is represented by digestive diseases with unfamiliar names. Some examples: gastroparesis, achalasia, chronic intestinal pseudo-obstruction, and slow transit constipation, to name a few. Less severe motility problems are better recognized by the more familiar names of: functional dyspepsia, non-ulcer dyspepsia, functional abdominal pain, irritable bowel syndrome and others.

In patients, disordered sensory nerves and motility usually involves various segments of the gut. These digestive motility problems are not rare and represent a continuum of various degrees of malfunction.

No one can image what it is like...

to suffer with endless nausea, vomiting, bloating, abdominal pain, and constipation. These symptoms constantly claw away at one's spirit, draining one's energy. The suffering is further compounded by lack of medical guidance, misunderstanding and waning support from significant others, as well as by the inability to gain treatment options and to have disability claims recognized.

Further, this patient population often finds itself in the unique situation of being blamed by their doctors for their own failing digestive function. Many patients must frequently run the gauntlet of ascribed psychological labels that are given to explain their digestive suffering.

Once a proper diagnosis is made, depression takes hold of the patient who is faced with a lack of effective treatment options and an endless future of suffering and no hope of major medical advancements.

We are facing a crisis

Many new medical advancements and innovative diagnostic tools have been made in the field of gastroenterology for a variety of common and not-so-common digestive disorders and diseases, renewing hope and improving quality of life for those afflicted.

However, despite these successes, one entire field of gastroenterology remains under-recognized, under-funded and under-appreciated by the medical profession, policy-makers, and the wider community; this neglected area is that of the gastrointestinal (digestive) motility diseases/disorders.

In the 21st century, this area of gastrointestinal motility medicine remains ill-defined and lacks the basics enjoyed by better known and less common digestive disorders; further, clinical research in this area of digestive motility lags far behind.

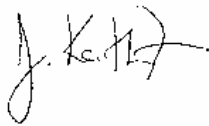
To date, no medical treatment has ever been brought to the market specifically for the treatment of stomach motor problems that is: functional dyspepsia/gastroparesis. No national tissue bank exists to begin the search for the underlying gut patho-biology in the severe sub-set of patients. No national treatment guidelines exist. No agreement exists on a definition or diagnoses for the various digestive

motility dysfunctions. No database or registry currently exists to track the prevalence and incidence of these motility problems. Sadly, disabled patients are diagnosed primarily on the subjective findings of symptoms alone.

Lack of awareness surrounding the ubiquity and seriousness of these digestive motility problems remains our biggest challenge to advancing the vital search for effective treatment options.

Please join us by accepting our proclamation to enact a resolution recognizing the month of May as Digestive Motility Awareness Month.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Keith-Ferris". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

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