

**Gastroparesis and Dysmotilities
Association
GPDA**

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June 28, 2003

Gastroparesis in Children, An information sheet

The current medical knowledge about gastroparesis in children is wholly inadequate. There are huge gaps in knowledge and much disagreement among specialists as to the diagnosis, delineation of mild to severe forms, and how to manage the illness once diagnosed.

Understanding of gut motility and the disorder's neurological basis is still in its infancy as is evidenced by the fact that precious few treatment options exist to help combat the disabling symptoms of gastroparesis.

Some groups have recognized this paucity of scientific information and have started to delve into the mysteries of gastrointestinal (GI) motility disorders. The European Society for Pediatric Gastroenterology Hepatology and Nutrition has held their second European meeting on Pediatric GI Motility/Functional Disorders. Even at this venue, the topic of gastroparesis will be a footnote. Why? Because there is very little funding for research into this stomach motility disorder. Yet, delayed gastric emptying (gastroparesis) is at the root of nearly half of all gastroesophageal reflux disease (GERD) and the cause of nearly half of all complaints of dyspepsia (nausea, vomiting, fullness, abdominal pain and bloating). The latter two problems receive far more attention and research dollars.

Gastroparesis is a neuromuscular disorder. Minimizing patients' symptom complaints and telling kids with gastroparesis to "just get on with it" are analogous to removing the ambulatory aids of a child with spastic legs and telling them to "just walk".

Children with gastroparesis — especially the milder forms where vomiting spells are minimal but nausea is the main complaint — suffer invisibly. They can experience intractable and debilitating nausea and other upper GI symptoms of dyspepsia, yet appear healthy and thus, their suffering is dismissed. They have few to champion their plight.

Gastroparesis carries disability statistics. Adults who miss time from work are taken seriously by doctors and society. Unfortunately, small children with underdeveloped communication skills, and even older kids who are able to express themselves, are not taken seriously when school attendance falls off.

Rather, the physician may adopt psychological reasons as the root of the problem. Family doctors and many GI doctors don't know what to do with this group of kids. Often their advice to parents is poor since the underlying source of such advice is the doctor's own frustration.

Medical research on pediatric gastroparesis, upon which the doctor must rely for making clinical decisions, is scarce! Little funding or energy has been devoted to this area of research. Often the GI pediatric medical community must rely upon a trickle-down effect from adult GI research into gastroparesis; then pediatricians have to figure out how to apply what pertains to adults to kids. The end result is little consensus or uniformity of care.

Once diagnosed, even conscientious doctors have very little to offer their patients to help combat the symptoms. You can count on one hand the number of drug choices (prokinetics) available to treat gastroparesis, none of which were specifically formulated for this severe neuromuscular disorder of the stomach.

Like adults who suffer with GP, kids, too, experience debilitating symptoms and yet they appear to be healthy. It is not uncommon for it to take a year or longer for families to get a diagnosis of gastroparesis.

Gastric emptying studies in adults report statistics correlated with healthy individuals. Statistics on normal and abnormal rates of gastric emptying are defined. None exist in the pediatric community.

Therefore, getting a proper diagnosis of gastroparesis in children really rests in the hands of the specialist and his/her personal clinical experience, that is, the number of gastroparetic patients previously seen by the specialist.

The problems grow even greater for the subset of kids who experience functional dyspepsia, since their tests — even gastric emptying — all come back as normal; yet the suffering of these children is real. There are as yet no good diagnostic tools to understand or define abnormal motility patterns in the various regions of the stomach (fundus, antrum) or the significance of abnormal rhythms (tachygastric dysrhythms) in this organ.

Imagine feeling horribly nauseated all the time and no one believes you, or worse, everyone is forcing you to do things because you “look fine.” These suffering children and their families need our compassion and support. They need to realize that there is little medically to offer them at this time. And they need hope instilled by knowing that medical leadership will step up to the plate and get research going to help find answers.

But until then, woe to the child who is afflicted by mild to moderate gastroparesis; he/she will continue to pass under the radar. The life of this child will be one without a lot of support until the medical and larger communities become educated regarding this illness.

GPDA is a non-profit association supporting research, public awareness and education to patients — and families — suffering with gastroparesis and related digestive motility disorders.

GPDA,

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