



International Foundation for  
Functional Gastrointestinal Disorders

IFFGD

*Information. Assistance. Support.*

# DigestiveHealth Matters

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**Dear Readers,**

**We are grateful for all of our supporters and dedicated readers of Digestive Health Matters.**

**In this issue you will find information about bloating and distension, the latest research and treatment news, and profiles of our recent Research Award recipients. You will also discover some opportunities to get involved with the digestive health community through advocacy and fundraising.**

**Our collective efforts are making progress toward improving treatments and creating hope for those living with functional GI and motility disorders.**

**Thank you.**

**Your Friends at IFFGD**



# Understanding Bloating and Distension

By: Max Schmulson, M.D., Professor of Medicine, National Autonomous University of Mexico-UNAM, Mexico City, Mexico

**B**loating can be described as the feeling that there is an inflated balloon in the abdomen. It is a commonly reported symptom and is sometimes associated with distension, or the visible increase in the width of the area between your hips and chest (abdominal girth).

Both bloating and distension cause discomfort, and sometimes pain, and have a negative impact on the quality of life for some individuals. The symptoms may be linked with other gas related complaints, such as burping or belching (eructation), swallowing air (aerophagia), and passing intestinal gas (flatulence).

Some people with functional gastrointestinal disorders (FGIDs) and motility disorders frequently experience bloating, distension, or both as symptoms of their conditions. There is also something called functional bloating, which is fullness and or/distension of the abdomen, not associated with changes in bowel movements.

## Causes

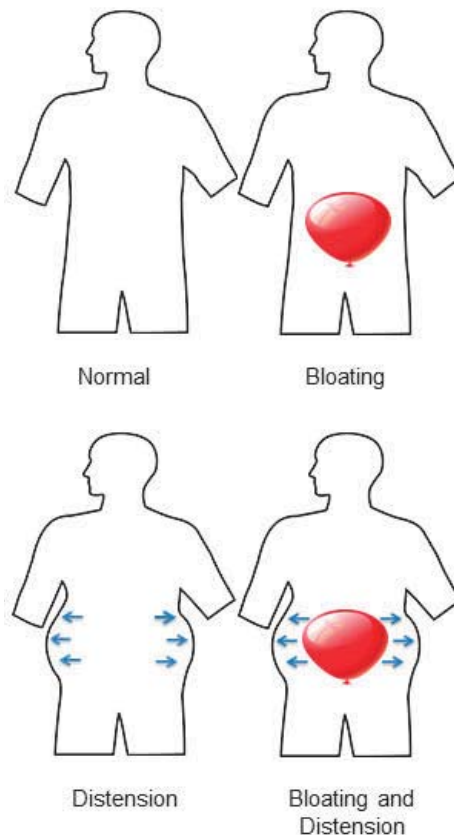
While researchers have proposed several different explanations for bloating and distension, there is no conclusive answer as to why the two symptoms occur.

### Possible reasons for bloating and distension include:

- Too much gas in the intestine
- Abnormal levels of bacteria in the small intestine (small intestinal bacterial overgrowth – SIBO)
- Imbalance of microorganisms that usually live in the bowel (dysbacteriosis); sometimes the result of taking antibiotics
- Food intolerance
- Difficulty absorbing (malabsorption) carbohydrates from food, such as FODMAPs (Fermentable Oligosaccharides, Disaccharides, Monosaccharides, and Polyols)
- Increased perception and sensitivity to what is happening in the digestive tract
- Increased curvature of the lumbar region of the spine (lumbar lordosis), which decreases the capacity of the abdomen to hold gas

## Treatment

There is no universally effective treatment for bloating and distension. Treatment availabilities vary from country to country and there are many underlying possibilities as to what is causing the symptoms. However, despite the fact that there isn't an easy answer for bloating or distension, there are things that people can do with the help of their physicians to try and alleviate the symptoms.



### Frequency of reporting of abdominal bloating in individuals with FGIDs

- IBS: 23%-96%
- Functional dyspepsia: 50%
- Chronic constipation: 56%

## Bloating and Gastroparesis

Gastroparesis is a motility disorder in which the muscle contractions that move food along the digestive tract do not work properly and the stomach empties too slowly.

Reports from highly specialized (tertiary) medical centers that often see people with severe gastroparesis suggest that bloating is a common symptom. Bloating severity appears to be related to the intensity of other gastroparesis symptoms, but is not affected by gastric emptying rates. Antiemetics, probiotics, and antidepressants with significant norepinephrine reuptake inhibitor activity may help.

The main symptom of bacterial overgrowth (SIBO), a condition that sometimes accompanies gastroparesis, is bloating. Careful use of antibiotics and probiotics may be helpful in the management of these symptoms.

Individuals can help their physicians by describing their complaints as accurately and concisely as possible. With regard to bloating and distension, here are some important questions to ask and details to tell your health care provider (keeping track of the things that trigger your symptoms is a good way to discover the answers):

### Things to Ask your Doctor:

- Am I bloated?
- Am I distended?
- Am I both bloated and distended?

### Things to Tell your Doctor:

- Is the symptom located in the upper or lower abdomen? Is it in a concentrated area?
- Is your bloating or distension associated with burping?
- Do you experience nausea or vomiting?
- Is the symptom associated with pain in your abdomen? Upper or lower?
- Does the bloating or distension relate to passing gas or a change in your bowel habits (diarrhea, constipation, or alternation of both)?
- Are your symptoms related to food? Which ones?
- Do they occur right after eating?
- Do your symptoms increase during the day or improve during night hours?

## Working with a Doctor

It is important to speak openly and honestly with your physician to express a clear picture of your experiences and symptoms. FGIDs present special challenges when communicating, specifically because of their vague symptoms and sensitive subject matter.

There isn't a diagnostic test for bloating or distension; however your doctor may run some tests to rule out underlying problems or associated disorders.

### These tests include:

- Stool analysis
- Blood workup
- Abdominal x-rays
- Barium swallow
- Small transit follow through
- Barium enema
- Gastric emptying tests
- Esophageal, antroduodenal, or anorectal manometry
- Colonic transit studies
- Breath test
- Upper endoscopy
- Colonoscopy with biopsies

## Medications and other therapies

Some medications and other treatments have been found to help ease the symptoms of bloating and distension. Your doctor may talk to you about some of these options, depending on your symptoms and other health related considerations.

**Antispasmodics:** These can relax the muscles of the bowel and provide relief. Examples include dicyclomine (Bentyl) and hyoscyamine (Levsin) in the United States and otilonium bromide or pinaverium bromide available in Latin America and some countries in Europe and Asia and a combination of pinaverium bromide with simethicone (Alevian Duo) in some Latin America countries.

**Probiotics:** These dietary supplements contain live bacteria that help balance out the existing bacteria of the intestines. Some that include a relatively low level of probiotic bacteria are available over the counter or in yogurt varieties. Other options include *Bifidobacterium infantis* 35624 for individuals with Irritable Bowel Syndrome (IBS) in general, and *Bifidobacterium animalis* DN-0173 10 for patients with IBS with Constipation (IBS-C).



For specific guidance regarding personal health questions, we advise consultation with a qualified healthcare professional familiar with your particular circumstances. Be sure to thoroughly discuss treatment options and the use of any medications for treatment with your physician. When prescribed a medication, disclose the use of all other drugs or supplements (whether prescription or over-the-counter) with your physician.

**Rifaximin:** This antibiotic is only slightly absorbed and can be used for short periods of time. Usually it is used (off-label) to lessen bloating in people with IBS whose symptoms do not include constipation, or in those with small intestinal bacterial overgrowth.

**Prokinetics:** These are medications that improve the time it takes for food to travel through the digestive tract. Some prokinetics have been shown to improve bloating. A person's age, health and other considerations must be taken into account for these therapies and availabilities vary from country to country.

**Antidepressants:** These drugs affect receptors in the gut and in the brain. Given in lower dosages than what is used to treat depression, they have been shown to help alleviate bloating and distension. For example, citalopram (Celexa), an SSRI (selective serotonin reuptake inhibitor), has been shown to help improve bloating in individuals with IBS. Amitriptyline (Elavil), a tricyclic antidepressant, is commonly used to treat pain and discomfort, as well as diarrhea, and may be helpful for bloating.

**Other options:** Medications that increase fluid content in stools, lubiprostone (Amitiza) or linaclotide (Linzess) for example, may also be used.

**Psychological therapies:** Treatments including hypnotherapy and cognitive-behavioral therapy can be useful and help with symptoms and mood.

#### Did you know that Spanish and some other languages don't have a word for "bloating"?

People use the words "swelling" and "inflammation," or describe it as "feeling pregnant." Using the balloon analogy can be the most helpful. Let your doctor know exactly whether you have the sensation of having a balloon in your abdomen (bloating), the truly visible increase in your abdominal girth (distension), or both.

**Low FODMAP diet:** Working with a doctor or registered dietitian to determine a diet low in FODMAPs is an option for alleviating bloating and distension symptoms. Foods that are rich in FODMAPs include:

- Fruits such as mangoes, apples, pears, avocados, blackberries, and plums
- Dairy products like cow, sheep, and goat milk, as well as yogurt, ice cream, and soft cheeses including cottage cheese, cream cheese and mascarpone
- Honey
- Vegetables and legumes such as asparagus, bell peppers, broccoli, Brussels sprouts, cabbage, cauliflower, eggplant, onion, garlic, baked beans, kidney beans, and lentils
- Sweeteners like sorbitol and maltitol (frequently used in gum and other candies)

#### What are FODMAPs?

FODMAPs are short-chain carbohydrates that are poorly absorbed in the small intestine and rapidly fermented by bacteria in the gut.

#### Conclusion

Bloating and distension are both very common, for the general population and for those with FGIDs and motility disorders. Either of the two may be very bothersome to individuals that are experiencing the symptoms, as well as challenging to those trying to treat them. There is not a conclusive cause for bloating or distension, nor is there a universally effective treatment. With the help of a physician, individuals can find different treatment options that may help alleviate their symptoms.

#### Additional Reading

For more information about GI tests and how to prepare for them, see our website [www.aboutGIMotility.org](http://www.aboutGIMotility.org) or contact IFFGD for publication #219, #111, or #510.

For more on prokinetics (also called promotility agents) see [www.aboutgastroparesis.org/about-gastroparesis/treatments/medication](http://www.aboutgastroparesis.org/about-gastroparesis/treatments/medication).

For more on antispasmodics, see Current Pharmacologic Treatments of Irritable Bowel Syndrome, publication #168 found in the IFFGD Publications Library ([www.iffgd.org/library](http://www.iffgd.org/library)) or by contacting IFFGD.

For more information on FODMAPs see Dietary Triggers for IBS Symptoms: The Low FODMAP Diet Approach, publication #251 found in the IFFGD Publications Library ([www.iffgd.org/library](http://www.iffgd.org/library)) or by contacting IFFGD.



# Report from the 10th International Symposium on Functional Gastrointestinal Disorders

The 10th International Symposium on Functional Gastrointestinal Disorders, jointly sponsored by the University of Wisconsin School of Medicine and Public Health, Office of Continuing Professional Development in Medicine and Public Health, and the International Foundation for Functional Gastrointestinal Disorders (IFFGD), took place in Milwaukee, WI April 12-14.

The biennial symposium brings together professionals in multiple disciplines from around the world to communicate new knowledge in the field of functional gastrointestinal (GI) and motility disorders to those who treat the conditions.

Nearly 400 physicians, psychologists, researchers, fellows, physician assistants, nurse practitioners, nurses and other health professionals – from five of the seven continents – discussed the latest in clinical skills in diagnostics and patient care.

Over three full days, 31 medical education sessions were taught by 87 international experts on topics across the spectrum of these chronic digestive conditions. The first sessions of the symposium, presented by senior researchers in the field, laid out our most current knowledge about functional GI disorders, including:

- What is the currently known about functional GI disorders?
- How widespread are they?
- What is known about their causes and mechanisms?

These talks presented the background for the cutting-edge research that would be presented throughout the symposium.

## WHAT WE KNOW: An integrated understanding of the functional GI disorders

Presented by Douglas Drossman, M.D. (Drossman Gastroenterology; Chapel Hill, NC), this session explained what is known and accepted by the medical community about functional GI disorders, and how best to treat them.

Dr. Drossman emphasized that, despite the fact that functional GI disorders are not defined by tests like x-ray or endoscopy, they are very real medical conditions. While not caused by stress alone, stress does make them worse. Current research

into understanding and treating functional GI disorders uses what is known as the biopsychosocial model. Dr. Drossman demonstrated to the audience how this model encompasses all of the scientific findings into the causes, mechanisms, and triggers for functional GI disorders. He touched on a number of topics that were discussed later in the meeting, including:

- Genetics
- Early life factors
- Communication between nerves, hormones and cells within the body (Nerve, hormonal, and intercellular signaling)
- The role of infection or injury
- Gut flora
- The role of intestinal barrier functions (intestinal permeability)
- Dietary influences
- Neuroplasticity and neurogenesis (change in nerve patterns and connections; and nerve growth)

**“This meeting is a demonstration of the importance and the significance that functional GI and motility disorders have in the field of medicine internationally.”**

*- IFFGD president  
and co-founder Nancy Norton.*



The current standards of diagnosis for functional GI disorders were then discussed, along with the work of the Rome Foundation, a professional organization that provides help for research into these disorders, to develop multi-component diagnostic measures. These consider factors such as severity and physiological function in addition to the currently used symptom-based diagnostic criteria.

Dr. Drossman went on to review current available treatments, as well as new options still being researched. The latest strategy suggests providing different types of treatment depending on disease severity, and focuses much more on how a good relationship between patient and physician is necessary for a good therapeutic outcome.

### GLOBAL EPIDEMIOLOGY: How widespread are they?

Eamonn Quigley, M.D. (Methodist Hospital; Houston, TX) presented an overview of the global status of functional GI disorders, using IBS as an example. He reviewed a tremendous amount of data from around the world studying IBS, looking at symptoms, severity, causes, age, gender, and other factors. With much more international research contributions to these disorders, he says, we are establishing that functional GI disorders are an important global issue.

Scientists across the globe are researching similar topics. The genetics of IBS is being studied in many countries, as are the roles of diet and of infection. Access to healthcare is important for adequate treatments of these disorders and is being studied in many parts of the world.

“This perhaps is the most important advance... that irritable bowel syndrome is common worldwide, and is a healthcare burden for many. And this is because, for some individuals... IBS can be extremely disabling.”

— Eamonn Quigley, M.D.

Dr. Quigley noted that while there is some variation in what these studies have shown, overall the findings are quite similar. This may have implications for understanding the effects of important factors like diet, genetics, and the gut microbiota, which should be somewhat different in different countries and regions. Dr. Quigley suggested that, if IBS appears mostly the same across the world despite these differences, this could help us understand something about the fundamental nature of IBS and other functional GI disorders.

Dr. Quigley concluded with research priorities for global study of these disorders. Among these is making sure that there is consistency in the description of the conditions throughout the international community, and determining if the conditions are truly the same everywhere, and recognizing how local variables such as diet and microbiota are affecting this digestive disorder.

## NEW CONCEPTS IN PATHOPHYSIOLOGY OF FUNCTIONAL GASTROINTESTINAL DISORDERS:

### Causes and mechanisms:

Giovanni Barbara, M.D. (University of Bologna; Italy) discussed the latest research into what cause functional GI disorders and their symptoms.

Bringing together scientists and clinicians around the world, the Rome Foundation works to legitimize and increase the knowledge of functional GI disorders, allowing scientists and researchers to make recommendations for diagnosis and treatment. The Rome Criteria is a system developed to classify functional GI disorders through symptom-based criteria, as they cannot be explained through traditional testing.

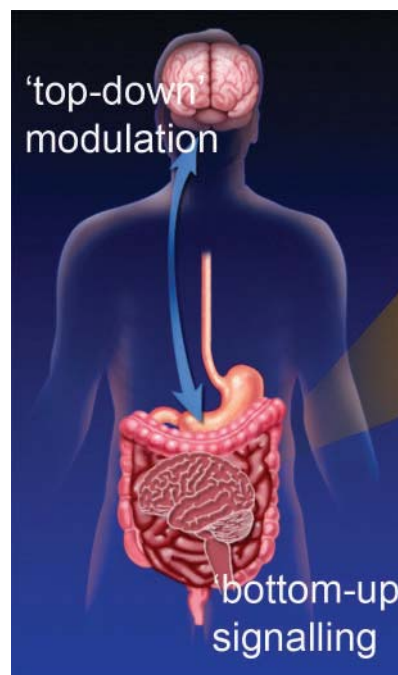
It has been established that changes in the pathways between the brain and the gut involving the central nervous system (CNS) have a “top-down” role in the development and severity of functional GI disorders.

These include the nerve and cellular mechanisms that are the result of psychosocial triggers such as stress and lead to changes in gut motility and secretion; as well as the changes in pain signaling within the brain.

Additionally, Dr. Barbara indicates that research has shown there to be important “bottom-up” mechanisms involved as well. These are often referred to as peripheral mechanisms because rather than the CNS, they are within peripheral nerve pathways located outside the brain and spinal cord or even within the gut itself.

An example would be alterations to the microbiota of the gut or changes in the gut’s behavior in response to foods. Sometimes these changes can activate responses in the gut which eventually leads to stimulation of brain responses such as increased pain perception.

With evidence for both top-down central mechanisms and bottom-up peripheral mechanisms,



it is concluded that communication goes in both directions. Functional GI disorders therefore result from a disturbance in this communication in one or both directions between the brain and the gut. It is hypothesized that differences in which mechanisms, or how much of them, are altered may be associated with differences in how severe a person's functional GI disorder is, or even which of these disorders a person has. Some of these alterations may affect how vulnerable an individual is to developing a functional GI disorder if they are exposed to certain environmental triggers. Others may themselves be the triggers to developing a disorder or symptom. There are also interactions between vulnerability and triggers that are not yet known.

Dr. Barbara concluded his talk by discussing some candidates for future research, which may help find a unifying mechanism underlying both directions of brain-gut dysregulation.

“Functional gastrointestinal disorders are complex... likely with different underlying mechanisms.”

– Giovanni Barbara, M.D.

“I’ve been coming to this meeting since its inception in 1995 and I’m very pleased to say, with the efforts of all you present in the room: our scientists, our basic scientists, our patients, and our patient advocates and advocacy groups, we’ve seen a vast improvement in the overall funding of research in the area of GI and functional disorders. We just want to thank you for all of your efforts that you’ve done behind the scenes in order to make a difference in the lives of so many of our patients.”

– Frank Hamilton, M.D., Chief of the Digestive Disease Branch, Division of Digestive Diseases and Nutrition, National Institute of Diabetes and Digestive and Kidney Diseases at the National Institutes of Health

## Conclusion

These and other topics discussed at the 10th International Symposium on Functional Gastrointestinal Disorders shed new light on potential treatments and understanding of these disorders. There were many more exciting research avenues discussed at the meeting – we will feature these in future issues of this magazine.



Douglas Drossman, M.D. addresses symposium attendees as Frank Hamilton, M.D. looks on





## IFFGD Presents 2013 Research Awards

On April 12, 2013 IFFGD presented eight investigators with our 2013 Research Awards in recognition of their contributions to scientific and clinical advancements in the area of functional gastrointestinal (GI) and motility disorders. The awards support and encourage the participation of clinicians and scientists in multidisciplinary efforts aimed at providing a better understanding of these conditions in adults and in children.

Since 2003, we have presented Research Awards to 38 active investigators. Their work is increasing understanding of these complex digestive conditions so as to better diagnose them and improve treatments.

“We are pleased to recognize these dedicated investigators for their contributions to functional gastrointestinal and motility research,” said Nancy Norton, president and founder of IFFGD.



Award Recipients and Presenters (Left to Right): Muriel Larauche, Ph.D.; Lukas Van Oudenhove, Ph.D.; Jan Tack, M.D.; Douglas Drossman, M.D., Selection Committee Chair; William Norton, IFFGD; Nancy Norton, IFFGD; Enrico Corazziari, M.D.; Niranga Manjuri Devanarayana, M.D.; Frank Hamilton, M.D., National Institutes of Health; L. Ashley Blackshaw, Ph.D.; Gary Mawe, Ph.D.; Carlo Di Lorenzo, M.D.

“Continued scientific advancement will allow us to better understand the complexities of chronic digestive disorders and improve the quality of life for those that are affected by their symptoms.”

– Nancy Norton, president and founder of IFFGD

The eight honorees were recognized at the 10th International Symposium on Functional Gastrointestinal Disorders in Milwaukee, WI. You can read more about the symposium on the previous pages. We invite you to meet the award recipients on the following pages. We congratulate them on their accomplishments and wish them well with their future research.



## 2013 Research Awards

**Enrico Corazziari, M.D., Università La Sapienza in Rome, Italy –**

**Recipient of the award for Senior Investigator in Clinical Science**

Dr. Corazziari's research covers a wide spectrum of functional GI and motility disorders, from the brain to the gut. His work is contributing to the clinical understanding of esophageal disorders such as dysphagia and GERD; upper GI conditions such as dyspepsia; biliary disorders such as sphincter of Oddi and gallbladder dysfunction; and bowel disorders such as IBS and chronic constipation.



Dr. Corazziari is Professor of Gastroenterology in the Dipartimento di Medicina Interna e Specialità Mediche at the Università La Sapienza in Rome.

His research areas of interest span the spectrum of biopsychosocial medicine and neurogastroenterology including gut physiology and motility research, clinical and

epidemiological studies, and the assessment of psychosocial factors in functional GI disorders.

He has had an interest in functional biliary disorders for which he has developed an international reputation. In addition, he has studied patients with inflammatory bowel disease, and the effect of neurological disorders on GI symptoms.

Dr. Corazziari's research includes developing and applying non-invasive techniques for the study of the GI tract, such as ultrasonography to test motility of the small bowel, stomach, and gallbladder. His studies are also providing data that looks at cultural differences to help doctors more effectively personalize medical management of different patients. His genetic studies are increasing the understanding of idiopathic achalasia.

In addition, as a founding member of the Associazione per la NeUroGastroenterologia e la Motilità Gastrointestinale (ANEMGI) and the Rome Foundation, Dr. Corazziari has made countless contributions to the worldwide knowledge of functional gastrointestinal and motility disorders.

**Clinical Science** is the research approach aimed at understanding the diagnosis and treatment of diseases and disorders through studies involving people, usually carried out in clinical settings.

**Jan Tack, M.D., Ph.D., University Hospitals Leuven in Leuven, Belgium –**

**Recipient of the award for Senior Investigator in Clinical Science**

Dr. Tack's research interests include advancing understanding of functional dyspepsia, GERD, IBS, chronic constipation, and gastroparesis, as well as furthering the understanding of the nerves within the digestive tract (enteric nervous system).



Dr. Tack is currently Head of Clinic in the Department of Gastroenterology, Professor in Internal Medicine and Chairman of the Department of Clinical and Experimental Medicine at the University of Leuven, Belgium.

His research lies in the field of neurogastroenterology and motility, and includes diverse topics such as understanding the factors underlying

functional dyspepsia, GERD, and IBS; the control of hunger and food intake; and the physiology and pharmacology of the enteric nervous system, GI hormones, and intestinal inflammation.

His research has also contributed to new treatment approaches for disorders including gastroparesis, reflux disease, IBS, and functional dyspepsia.

Professor Tack is in charge of a large translational research group, addressing various aspects of basic and clinical gastroenterology.

**Lukas Van Oudenhove, Ph.D., University of Leuven in Leuven, Belgium –**

**Recipient of the award for Junior Investigator in Clinical Science**

Dr. Van Oudenhove's research interests include the understanding of interactions between the brain and the digestive tract, the complex factors involved with signaling and sensation, and how these interactions may contribute to symptoms and treatments of functional GI/motility disorders.



Dr. Van Oudenhove is Professor, Translational Research Center for Gastrointestinal Disorders, KU Leuven Department of Clinical and Experimental Medicine, University of Leuven in Belgium.

His research covers different areas related to motility and functional GI disorders. These include better understanding of the complex gut-brain interactions and their role in generating symptoms.

Dr. Van Oudenhove's research is helping to unravel the signals that process sensation and motility, and improve targeted treatments.

**Gary Mawe, Ph.D., The University of Vermont in Burlington, VT –**

**Recipient of the award for Senior Investigator in Basic Science**

Dr. Mawe's research is advancing understanding of how the GI tract functions, with particular emphasis on mechanisms related to the digestive tract (enteric) nervous system, and factors that influence sensory and motor function in the intestines and biliary tract in adults and children.



Dr. Mawe is a Professor in the Department of Anatomy and Neurobiology at the University of Vermont in Burlington, Vermont with additional duties in the Department of Pharmacology and the GI Division of Medicine. He is also an Adjunct Professor of Physiology and Pharmacology at the University of Calgary.

Dr. Mawe has established an internationally renowned translational research program that focuses on how the nervous system regulates motor activity in the intestines and the biliary tract.

His research interests include the understanding of signaling by the neurotransmitter serotonin in the digestive tract; changes in the enteric nervous system in response to and following inflammation; and the mechanism by which smooth muscle function is disrupted in gallstone disease.

He and his colleagues have made discoveries that provide fundamental information about how the digestive organ systems work, and insight about changes that occur in inflammatory and functional/motility disorders.

**Basic Science** is the fundamental approach to understanding how systems work. It takes place in the laboratory and often involves the study of molecules and cells.

**L. Ashley Blackshaw, Ph.D., Queen Mary University in London, England –**

**Recipient of the award for Senior Investigator in Basic Science**

Dr. Blackshaw's research interests focus on understanding sensory motor function within the gut, including the interaction between the digestive tract and the brain; the functions of the immune system and how they relate to conditions like IBS and GERD; and the mechanisms and roles of nutrient sensing (a cell's ability to recognize certain substances).



Dr. Blackshaw is Professor of Enteric Neuroscience at Queen Mary University of London.

He has led a number of fundamental studies, examining subjects such as gastroesophageal reflux disease (GERD) and gastrointestinal sensory mechanisms in tissue.

His work has identified new classes of sensory nerves and demonstrated important therapeutic roles for receptors on these neurons.

He has identified the role of specific genes in motor and sensory function in the GI tract. His work also looks at the ways in which sensory information is processed in the central nervous system.

**Muriel Larauche, Ph.D., The University of California, Los Angeles in Los Angeles, CA –**

**Recipient of the award for Junior Investigator in Basic Science**

Dr. Larauche's research looks at understanding factors involved with and influenced by visceral pain, understanding sex differences in symptom generation, and investigating mechanisms involved with colonic motility alterations and intestinal barrier function in functional GI/ motility disorders.



Dr. Larauche is Assistant Researcher in the Department of Medicine at UCLA in the Division of Digestive Diseases.

Her research is looking at ways to better understand the differences of the visceral pain response of men and women so as to improve treatment options.



## 2013 Research Awards

**Carlo Di Lorenzo, M.D., The Ohio State University  
in Columbus, OH –**

**Recipient of the award for Senior Investigator  
in Pediatrics**

Dr. Di Lorenzo's research looks at pediatric motility and functional gastrointestinal disorders. His work has led to the development of more child-friendly diagnostic testing and effective treatment strategies, including helping patients who have been resistant to prior treatment options.



Dr. Di Lorenzo is Professor of Clinical Pediatrics at The Ohio State University and Chief of the Division of Pediatric Gastroenterology at Nationwide Children's Hospital in Columbus, Ohio.

He also chairs the DHA Children's GI Research Network, the only pediatric consortium aimed at studying functional GI and motility disorders in children.

Dr. Di Lorenzo's research spans every aspect of pediatric motility and functional disorders from the esophagus to the bowel.

He has trained many of the specialists and young investigators working in the field today. His work is helping develop new strategies for helping clinicians as well as children and families manage these chronic digestive conditions.

**Pediatric Science** is the area of medical science concerned with infants, children, and adolescents.

**Niranga Manjuri Devanarayana, M.D., The University of  
Kelaniya in Sri Lanka –**

**Recipient of the award for Junior Investigator  
in Pediatrics**

Dr. Devanarayana's research looks at motility and functional GI conditions in children and adolescents including understanding risk factors for these conditions and quality of life issues. She has worked extensively to understand and highlight the importance of chronic abdominal pain and its relationship to many functional/motility disorders.

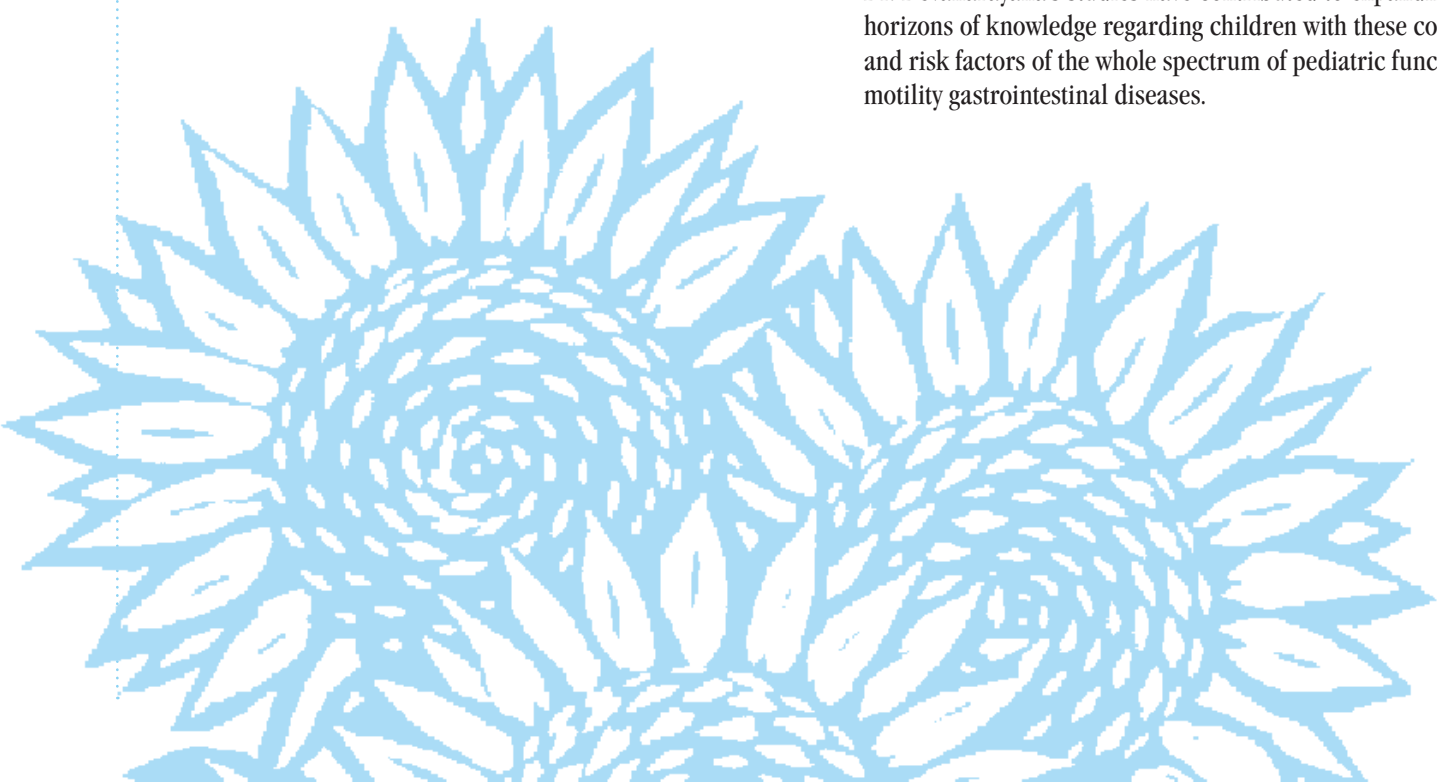


Dr. Devanarayana is Head of the Department of Physiology, Faculty of Medicine at the University of Kelaniya in Sri Lanka.

Her main research area is gastrointestinal function in children with abdominal pain predominant functional/motility gastrointestinal disorders.

Her research also looks at understanding abdominal pain predominant GI conditions, aerophagia, adolescent rumination syndrome, and defecation disorders.

Dr. Devanarayana's studies have contributed to expanding the horizons of knowledge regarding children with these conditions and risk factors of the whole spectrum of pediatric functional/motility gastrointestinal diseases.



**W**hen IFFGD began, in 1991, there was little communication between patients living with functional GI and motility disorders and the companies with the means to develop treatment products and services. Subsequently, IFFGD has worked hard to make the needs of our members known – not only to the clinicians who see patients, but also to the researchers and providers of diagnostic and treatment methods and tools.

In an effort to strengthen our voice, in 1998 we formed the IFFGD Industry Council. The Council provides a forum to help ensure that the voice of our membership is heard.

We invite participation from companies with a demonstrated interest in these disorders. While we are grateful to our Industry Council members for their support, we do not endorse any specific product or company. IFFGD retains unrestricted control over the planning, content, objectives, methods, and execution of all initiatives and projects.

## IFFGD INDUSTRY COUNCIL

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## Treatment News

### Linacotide now Available in Europe

On June 12, 2013 Ironwood Pharmaceuticals and Forest Laboratories announced that linaclotide is available in some countries in Europe (Germany, the UK, and Nordic countries) to treat IBS with constipation (IBS-C). It will become available in more European countries during 2013 with the EU brand name Constella.

Linaclotide, a guanylate cyclase type-C (GC-C) agonist, is a prescription drug used to relieve symptoms of abdominal pain, discomfort, bloating, and bowel symptoms in people who have IBS-C or chronic constipation (CC). It has been shown to be safe and effective in trials. Linaclotide works by increasing the amount of fluid that flows into the bowel, allowing stool to pass more easily, and reducing visceral pain.

Linaclotide (Linzess<sup>®</sup>) has been available in the U.S. to treat IBS-C and CC in adults aged 17 and older since 2012.

Linzess is a capsule taken once daily on an empty stomach, at least 30 minutes before the first meal of the day. Linzess helps relieve constipation by helping bowel movements occur more often. In IBS-C, it may also help ease abdominal pain.

Linzess should not be used in patients 16 years of age or younger. Linzess should not be used in patients with known or suspected mechanical gastrointestinal obstruction. The most common side effect reported during clinical studies was diarrhea.

Ironwood and Forest are co-producing linaclotide in the U.S. Ironwood has out-licensed linaclotide to Almirall, S.A. for development in Europe; and to Astellas Pharma, Inc. for development in Japan, Indonesia, Korea, the Phillipines, Taiwan, and Thailand.

### FDA Advisory Committee on Relistor

On June 11, 2013 Salix announced that the U.S. Food and Drug Administration (FDA) will be holding an advisory committee to review Salix's Supplemental New Drug Application, which seeks to extend the use of Relistor to include patients who are taking opioids to treat chronic pain.

Relistor was approved in the United States in 2008 for short term treatment of opioid-induced constipation, in patients with advanced illness who are receiving palliative care, when response to laxative therapy has not been sufficient. It has also received approval for this indication in other countries.



**What are Phases?** Treatment trials or studies are in phases:

**Phase 1** tests a new drug or treatment in a small group to evaluate its safety, determine a safe dosage range, and identify side effects.

**Phase 2** expands the study to a larger group to see if it is effective and to further evaluate its safety.

**Phase 3** expands the study to an even larger group of people to confirm its effectiveness, monitor side effects, and collect information that will allow the drug or treatment to be used safely.

**Elobixibat Now in Phase III Clinical Trials**

In May 2013, Ferring Pharmaceuticals announced that it has entered Phase 3 trials of elobixibat for the indication of chronic idiopathic constipation (CIC). Two studies are being conducted at close to 200 sites around the world.

Elobixibat is a first-in-class compound under investigation for treatment of CIC, and for IBS with constipation (IBS-C). It works by reducing bile acid absorption in the small intestine. This stimulates bowel movements by increasing fluid secretions and motility in the colon.

In Phase 2b clinical trials, elobixibat (formerly A3309) has been evaluated in patients in the U.S. and Europe for the treatment of CIC. The studies demonstrated clinically meaningful, statistically significant, and dose-dependent improvements. These included increased stool frequency and improved constipation-related symptoms such as straining, stool consistency, and bloating maintained over eight weeks of treatment.

**FDA Approves Lubiprostone to Treat Opioid-Induced Constipation; Drug Already Used to Treat Other Constipation Disorders**

On April 23, 2013 Sucampo Pharmaceuticals, Inc. and Takeda Pharmaceuticals U.S.A. Inc. announced that the U.S. Food and Drug Administration (FDA) has approved its supplemental New Drug Application for lubiprostone (Amitiza) to treat opioid-induced constipation in adult patients with chronic non-cancer pain.

Lubiprostone met the primary endpoint in a phase 3 clinical trial for the treatment of opioid-induced bowel dysfunction in patients with chronic, non-cancer pain, excluding those taking methadone. Opioids are narcotics, such as morphine and codeine, used to treat pain. A number of gastrointestinal (GI) symptoms are potential side effects of using opioid-based medications. The most common symptom is constipation. Other symptoms may include decreased gastric emptying, abdominal cramping, spasm, bloating, and delayed-GI transit.

Lubiprostone was approved by the FDA to treat chronic idiopathic constipation (CIC) in adults in 2006 and to treat IBS with constipation (IBS-C) in adult women in 2008.

Amitiza (lubiprostone) is a prescription drug used to relieve stomach pain, bloating, and straining and produce softer and more frequent bowel movements in men and women who have CIC. It is also used to treat IBS-C in women who are at least 18 years of age.

Amitiza works by increasing the amount of fluid that flows into the bowel and allowing the stool to pass more easily.

**Solesta is Available in the U.S. to Treat Fecal Incontinence**

Solesta has been approved to treat fecal incontinence in the U.S. since 2011 and in Europe since 2006. The drug, a biocompatible tissue bulking agent, was approved by the U.S. Food and Drug Administration (FDA) for the treatment of fecal incontinence in patients 18 years and older who have failed conservative therapy (e.g., diet, fiber therapy, anti-motility medications).

Fecal incontinence is the involuntary loss of bowel control. While the exact mechanism of action has not been identified, it is thought that the Solesta injections may narrow the anal canal and allow for better control of those muscles.

Solesta is an injectable gel delivered into the anal canal in an outpatient procedure taking approximately 10 minutes without the need for surgery or anesthesia.

**Participants Sought for Two Double-blind, Randomised, Placebo-controlled, Phase 3 Trials in Patients with Chronic Idiopathic Constipation to Demonstrate the Efficacy and Safety of Elobixibat 5 mg and 10 mg**

**Purpose of study 1:** 26-week Efficacy and Safety Trial for Patients with Chronic Idiopathic Constipation

**Sponsored by:** Ferring Pharmaceuticals

**Participation:** Eligible male and female patients aged 18 year or older

**Contact:** Clinical Development Support; Email: [DK0-Disclosure@ferring.com](mailto:DK0-Disclosure@ferring.com)

**Purpose of study 2:** 12-week Efficacy and Safety Trial Followed by a 4-week Withdrawal Period for Patients with Chronic Idiopathic Constipation

**Sponsored by:** Ferring Pharmaceuticals

**Participation:** Eligible male and female patients aged 18 year or older

**Contact:** Clinical Development Support; Email: [DK0-Disclosure@ferring.com](mailto:DK0-Disclosure@ferring.com)

It should only be administered by physicians experienced in performing anorectal procedures who have successfully completed a comprehensive training and certification program in the Solesta injection procedure. It should not be used in patients who have active inflammatory bowel disease, immunodeficiency disorders, previous radiation treatment to the pelvic area, significant rectal prolapse, active infections, bleeding, tumors or malformations in the anorectal area, rectal distended veins, an existing implant in the anorectal region, or allergy or hyaluronic acid based products.

The most common side effects associated with Solesta include injection area pain and bleeding. Infection and inflammation of anal tissue are more serious risks, but are less common.

Solesta is a registered trademark of Q-Med AB of Uppsala, Sweden; Oceana Therapeutics acquired exclusive worldwide sales and distribution rights to Solesta in June 2009. In December 2011 Salix Pharmaceuticals, Ltd. acquired all of the outstanding stock of Oceana Therapeutics, Inc.

### **Teduglutide Studied over 52-Week Treatment Period; Approved in the U.S. to Treat Short Bowel Syndrome**

In January 2013, an international multi-center study involving 52 patients looked at the safety, tolerability, and efficacy of teduglutide (Gattex) taken once per day over 52 weeks for the treatment of people with short bowel syndrome (SBS) receiving parenteral nutrition (PN). The study concluded that, for patients with SBS and intestinal failure, the efficacy of teduglutide was maintained over 52 weeks and the safety profile was sufficient to be considered for long-term use.

Gattex is a product of NPS Pharmaceuticals, a specialty pharmaceutical company developing orphan therapeutics for rare gastrointestinal and endocrine disorders. It is a novel peptide involved in

gastrointestinal regeneration and repair (recombinant analog of human glucagon-like peptide 2).

The most common adverse events reported included headache, nausea, and abdominal pain. Of seven patients who withdrew because of adverse events, four were considered treatment related. While the researchers found the safety profile to be acceptable, they advise that physicians closely monitor patients beginning the drug for side effects and possible need to adjust dosage.

Teduglutide (Gattex) was approved by the U.S. Food and Drug Administration (FDA) in 2012 for treatment of adult patients with SBS who are receiving PN support. To help ensure that the benefits of Gattex outweigh the risks for causing other serious conditions, the drug is approved with a Risk Evaluation and Mitigation Strategy, which patients need to discuss with their doctors.

SBS is a rare condition related to poor absorption of nutrients. It typically occurs in people who have a significant portion of their small intestine removed due to disease or injury, and cannot absorb enough water, vitamins, and other nutrients from food. They may then need to use PN and intravenous (IV) fluids, the slow infusion of a solution of nutrients and fluids into a vein.

Gattex works by regeneration of cells in the intestinal lining, slowing down transit through the gut and increasing blood flow, allowing for increased nutrient absorption. In studies, the drug was associated with achieving and maintaining clinically meaningful reductions in PN and IV fluid volume in adult subjects with SBS.

The European Commission granted European market authorization in August 2012 for the medicinal product teduglutide (trade name in Europe: Revestive) as a once-daily treatment for patients with SBS. In March 2013, NPS reacquired the rights to teduglutide outside of the U.S., Canada, Mexico, and Israel from Takeda GmbH.

### **Rifaximin Studied for Treatment of Non-Constipated IBS**

Rifaximin is an antibiotic currently under investigation for the treatment of non-constipation IBS (Non-C IBS) and IBS-related bloating. Rifaximin works by reducing or altering bacteria in the gut. In studies it has been found to improve IBS symptoms of bloating, belly pain, and diarrhea (watery or loose stools) after a 10–14 day course of treatment. It is only slightly absorbed in the gut and is generally tolerated well. Rifaximin has not yet been approved by the U.S. Food and Drug Administration (FDA) for the treatment of IBS.

### **Seeking Participants for Study to Assess Repeat Treatment Efficacy and Safety of Rifaximin 550 mg TID in Subjects with Irritable Bowel Syndrome with Diarrhea (IBS-D)**

**Purpose of study:** This study will evaluate the effectiveness and safety to repeat treatment with rifaximin 550 mg three times a day in patients with IBS with diarrhea who respond to initial treatment of rifaximin 550 mg three times a day.

**Sponsored by:** Salix Pharmaceuticals, Inc.

**Participation:** Eligible male and female patients aged 18 years and older with a diagnosis of irritable bowel syndrome (IBS) with a subtype of diarrhea.

**Contacts:** Rachel Ballard; email: [rachel.ballard@salix.com](mailto:rachel.ballard@salix.com) or Alyson Lineberry; email: [alyson.lineberry@salix.com](mailto:alyson.lineberry@salix.com)



## Are Probiotics Effective for Treating Symptoms of IBS?

Probiotics are live microbiologic organisms, found in foods and supplements, that have natural health benefits. The beneficial properties inherent to each probiotic species are strain specific.

Two randomized, controlled trials have validated the effectiveness of *Bifidobacterium infantis* (*B. infantis*) 35624, a probiotic that has the unique ability to reduce intestinal inflammation, for treating both individual and global IBS symptoms without evidence to suggest an increase in adverse events. The studies reported that the strain appears safe and effective for the treatment of IBS. Increasing data has revealed that changes in inflammation within the gut may play a role in the development of the digestive disorder. A review of the two trials was published in the Volume 104 of *The American Journal of Gastroenterology* in April 2009.

*Bifidobacterium infantis* 35624, trademarked under the name bifantis, is the natural probiotic strain found only in Align, a supplement from The Procter and Gamble Company.

## Gastric Electrical Stimulation for Patients with Severe Gastroparesis

Gastric electrical stimulation (GES) uses a surgically implanted battery operated device on the stomach to try to help control symptoms of nausea and vomiting in gastroparesis when other methods have failed. The Enterra therapy is approved by the U.S. Food and Drug Administration (FDA) as a Humanitarian Device Exemption. The Enterra Therapy System is manufactured by Medtronic, Inc.

A study reported in the April 2013 issue of the *Journal of Gastrointestinal Surgery* looked back at the records of 233 patients who had a GES implanted at a single institution between 2000 and 2011. The investigators found that while most patients reported improvement of gastroparesis symptoms after GES implantation, there is often a need for additional surgical

procedures and occurrence of related complications. Improved understanding leads to practice changes aimed at reducing the rate of complications and additional procedures.

A study reported in the April 2011 issue of the journal *Clinical Gastroenterology and Hepatology* assessed the long-term clinical outcomes of GES therapy. Investigators looked back at records for a period of one to 11 years (4.5 years mean) of 221 patients with severe gastroparesis that were treated with Enterra Therapy System. The reviewers observed significant improvement in symptom scores and reduced medication use in 48% to 53% of patients. Weight increased significantly and in 89% J-tubes could be removed. The therapy was found generally safe and well tolerated, with improvement sustained for up to 10 years. Medtronic partially funded this study.

## IFFGD Research Grants

### Call for Grant Applications Supporting Innovative Research Related to Idiopathic Gastroparesis

#### Description

Grant awards of \$40,000 (pre-tax USD) each in direct costs are available to three (3) investigators for innovative research related to idiopathic gastroparesis.

#### Basis

We are seeking proposals for research in humans that will ultimately lead to improvements in the understanding of idiopathic gastroparesis, its pathophysiology, and the care of patients.

The mission of IFFGD is patient-oriented. Our goal is to fund high-quality research. A preference will be given to clinical research, as well as basic research that is translational in nature.

#### Application Process

Applicants must have completed an M.D., Ph.D., or equivalent degree. The deadline for submitting applications is midnight, Tuesday September 3, 2013. Grant details and application forms are available online at [www.iffgd.org/gp-grants](http://www.iffgd.org/gp-grants).





## Medical and Research News

### Functional Dyspepsia Medication Available in Japan

In early June 2013 Astellas Pharma and Zeria Pharmaceutical announced the launch of Acofide (acotiamide hydrochloride hydrate) for the treatment of functional dyspepsia in Japan. This will be the first approved treatment in a new drug class which has demonstrated effectiveness for functional dyspepsia.

Functional dyspepsia is characterized by chronic or recurrent pain or discomfort centered in the upper abdomen. Though symptom overlap is common among some functional gastrointestinal disorders (FGIDs), it is important not to confuse functional dyspepsia with other common FGIDs like IBS and GERD.

Functional dyspepsia is identified based on symptoms. Additional evaluation by your physician will normally include a physical exam to rule out other possible causes. The actual diagnosis is based on a detailed history to identify symptoms.

### PPI Approved For Use in Children with GERD

In late March 2013, The U.S. Food and Drug Administration (FDA) announced the approval of the proton-pump inhibitor (PPI) Aciphex Sprinkle for treatment of GERD in children ages 1 to 11 years.

Approval of the treatment is based on the results of a multicenter, double-blind, parallel-group clinical trial in children. The study looked at 127 children with GERD confirmed by endoscopy. Overall, 81 percent of children achieved healing during the 12-week treatment period.

The most commonly reported side effects during treatment were cough (14%), vomiting (14%), abdominal pain (12%), diarrhea (11%), fever (10%), headache (9%), upper respiratory tract infection (8%), sore throat (6%), and inflammation of the nasal passages and pharynx (5%).

GERD, or gastroesophageal reflux disease, is very common. It develops when the back-flow (reflux) of stomach contents causes troublesome symptoms and/or complications. Serious health problems can result if it is not treated properly.

### Three FGIMDs Represented in New FDA Patient Perspective Initiative

On April 11, 2013 the U.S. Food and Drug Administration (FDA) announced that three functional gastrointestinal and motility disorders were selected as disease areas to be addressed during the first three years of its Patient-Focused Drug Development. Those conditions are IBS, gastroparesis, and gastroesophageal reflux disease (GERD) with persistent regurgitation symptoms on proton pump inhibitors.

Patient-Focused Drug Development is a five-year initiative, which calls for the FDA to obtain patients' perspectives on specific disease areas, including thoughts on their conditions and available therapies, as well as the impact the conditions have on their daily lives. These perspectives can play a role in developing new drug therapies and provide key knowledge to the FDA as it reviews applications for new drugs in certain disease areas.

The FDA considered comments from patients, caregivers, advocate groups, health care professionals, pharmaceutical companies, and others as they determined the list of disease areas to be addressed during the first three years of Patient-Focused Drug Development.

In October 2012, DHA and IFFGD invited advocates to submit comments to the FDA as they considered which disease areas to be included. We thank all those that participated for their support and activism. The FDA will initiate a second public process to determine the disease areas for consideration for upcoming years of the initiative (a total of 20 areas will be included over the five year period). IFFGD

and DHA will share the opportunity with our advocates when it becomes available.

In addition to public comments, the FDA used the following criteria when selecting the initial 16 disease areas to be considered as part of Patient-Focused Drug Development:

- Disease areas that are chronic, symptomatic, or affect functioning and activities of daily living;
- Disease areas for which aspects of the disease are not formally captured in clinical trials; and
- Disease areas for which there are currently no therapies or very few therapies, or the available therapies do not directly affect how the patient feels or functions.

Patient-Focused Drug Development is part of the Prescription Drug User Fee Act (PDUFA). PDUFA V is the fifth authorization of the act that gives the FDA the ability to collect fees from companies that produce certain human drug and biologic products. These fees then provide the FDA with the resources necessary to maintain and improve the drug review and approval process.

The FDA's full announcement of the disease areas to be addressed in fiscal years 2013–2014, including the full list of disease areas, can be viewed in the Federal Register at <http://www.gpo.gov/fdsys/pkg/FR-2013-04-11/pdf/2013-08441.pdf>



## An Advocate's Journey

By Abigail French, Program Specialist,  
International Foundation for Functional  
Gastrointestinal Disorders

As my plane landed in Washington, DC, I could see the iconic sites out the window. It's almost impossible not to be affected by them. My eyes gazed over the Washington Monument, the Jefferson Memorial, and settled on the Capitol. That stately building was my destination. Over the next couple of days I would be facilitating conversations with legislators about something that is important to me. Functional gastrointestinal and motility disorders (FGIMDs) were on my agenda. I was ready for DHA Advocacy Day.

Things started out on Tuesday night with an informal reception and dinner where I got to meet everyone. People had come from my state and from a few others. Some had been there before and some hadn't, but everyone was really welcoming, friendly, and ready to get things started.



We were privileged to be joined by Stephen James, M.D., the Director of the Division of Digestive Diseases at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) which is part of the National

Institutes of Health (NIH). Dr. James gave us an overview of how the NIDDK conducts and supports research. We learned that one out of 10 grants are able to be funded which left me wondering what could be discovered in grants that are not able to be funded.

As I got to talking to my fellow advocates I realized how diverse and yet how similar our stories were. There were those who talked about their own journeys and others who talked about their daughter's, their sister's, their nephew's, or their husband's. I was struck by a common theme. Each person told a story about illness, about doctor's offices, about disruption to their lives and diets, but each one had a smile on their face. The positive outlook that each advocate had was inspiring and only added to my excitement as I looked ahead to the following day.

After a good night's sleep, we reconvened for a breakfast meeting to prepare for our day on Capitol Hill. We were divided into four teams. Each team would visit the Senators and Representatives of the group members.



*Advocates from Washington DC, Virginia, and New York*

I was paired with advocates from New York, Virginia, and the District of Columbia while those from Pennsylvania, Wisconsin, and North Carolina comprised the other teams.

Before we dispersed onto Capitol Hill, we discussed what we were all going to ask our legislators to do. We had a lot of important issues regarding digestive health on our agenda:

- A request to cosponsor the FGIMD Research Enhancement Act. In the House, the Act has been introduced and therefore has the bill number H.R. 842; however, the Senate still needs a sponsor to introduce the legislation.
- Continued funding for the Gulf War Illness Research Program – our military service members are experiencing symptoms of functional gastrointestinal disorders upon returning from deployment.
- Continued research funding at the National Institutes of Health (NIH). The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is part of NIH and is where most of the federally funded FGIMD research is conducted.
- Support of the National Pediatric Research Network Act which will create a pediatric research consortia and advance research to help understand conditions like FGIMDs in kids. The act has passed in the House and is waiting to be passed in the Senate.



*Advocates from Pennsylvania outside their Senator's office*

And thus began our trip to meet with our legislators. This was my second Advocacy Day and only my third time meeting with Congressional offices. Despite my experience, I couldn't help but feel a little apprehensive. I could sense the same mixture of excitement and nervousness on the faces of my fellow advocates, but in the end the excitement outweighed the nervousness and during our first office visit, my team established a rhythm.



Advocates from North Carolina & Wisconsin with Senator Kay Hagan.

We started by defining what a functional GI or motility disorder is. We then told our personal experiences and how FGIMDs affect our lives or the life of someone we love. After that, we asked them to support items from our legislative agenda. Then we answered any questions that the offices may have had.

Some offices had heard of FGIMDs, while others were learning about these disorders for the first time. One staff member told us not to “mince words,” as he really wanted to hear what it was like to live with a disorder. So we told him – and everyone else we visited that day. Each office listened attentively and took notes on what we were saying and I left each one feeling satisfied with what we had done.

We left the Capitol with a sense of accomplishment, realizing that the first step to making a difference is to talk about these disorders. In all, DHA advocates visited 26 offices spreading the word about FGIMDs and helping legislators understand the problem that so many others in the country are facing.

And I can't help but feel like it worked! Just days after our time on Capitol Hill, H.R. 842 received another cosponsor in Representative Gerald Connolly (VA-11). Seeing such an immediate and direct response to our request shows that our efforts can and do make a difference.

I look forward to the 2014 Advocacy Day and appreciate having the chance to speak out about something that is important.

If you want to be involved with advocacy initiatives read more about it on page 20 or sign up for our news alerts at <https://dha.org/sign-e-news>



Advocates stand together on Capitol Hill for DHA Advocacy Day 2013

## Advocacy Updates – How YOU Can Make a Difference

**An advocate** is a person who takes action about something he/she believes in. An advocate not only speaks out on behalf of himself/herself but also on the behalf of others.

**O**n the previous pages, you read about Abigail's experience in Washington, DC as a digestive health advocate. While Abigail and the other DHA Advocates certainly made a difference at the Capitol, you don't have to travel to Washington, DC to be an advocate.

It is easy to reach out to your Congressperson. Here are three ways to do so:

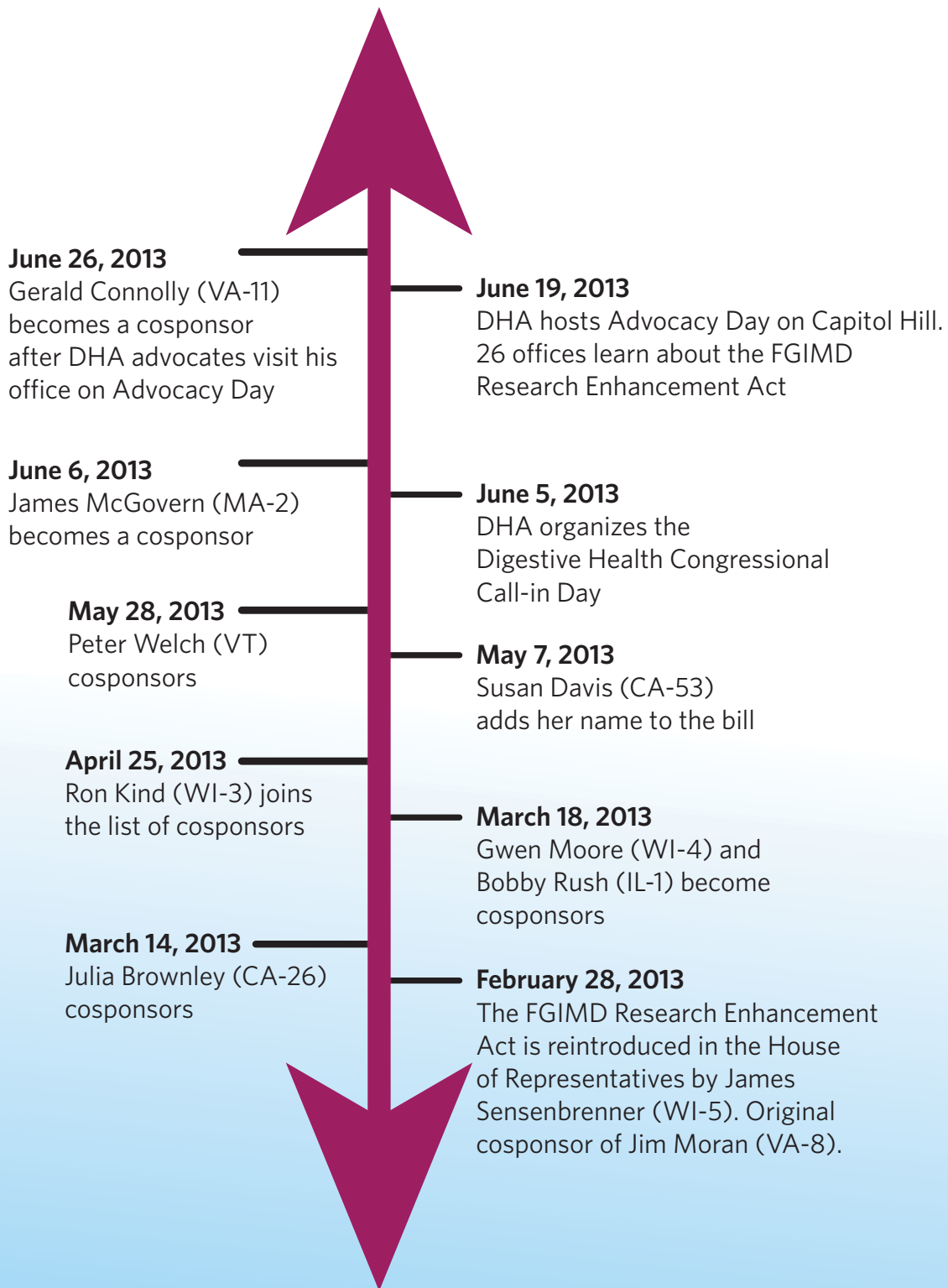
1. You can call your Congressperson by dialing the U.S. Capitol Switchboard at (202) 225-3121. Ask to be connected to your Representative's office.
2. You can email your Representative through our website: [www.iffgd.org/action](http://www.iffgd.org/action)
3. You can fill out the postcard included with this journal and drop it in the mail. We will then make sure it is hand delivered to your House Representative's office.

You don't have to be an expert in order to be an advocate. In fact, your story is most important to your Representative. After all, you are their constituent. Here are a couple of tips:

- Identify yourself as a constituent and thank the staff member for his/her time and attention.
- Briefly explain what FGIMDs are. Use the following "quick facts."
  - o Functional GI and motility disorders (FGIMDs) are conditions that involve improper functioning of the nerves, muscles, and related mechanisms of the digestive tract.
  - o FGIMDs are chronic and some can be fatal.
  - o These conditions are often misdiagnosed or mistreated.
  - o Currently treatment options for FGIMDs are extremely limited and focus on symptom management, no cures are known.
- Share your personal story of how FGIMDs have affected your life, or that of someone you know.
- Explain that The Functional GI & Motility Disorders Research Enhancement Act of 2013 (H.R. 842) will significantly improve our scientific understanding of FGIMDs and stimulate breakthroughs in diagnosis and treatment.
- Ask your Representative to cosponsor H.R. 842.

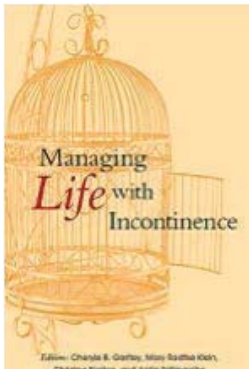


## Timeline of HR 842 - The FGIMD Research Enhancement Act



## Books of Interest

Here is a list of books, authored or edited by knowledgeable healthcare professionals, which provide trustworthy information about a variety of topics relating to gastrointestinal disorders and digestive health.



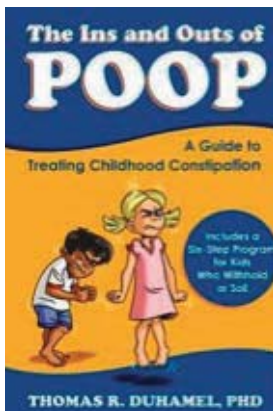
**Title:** *Managing Life with Incontinence*

**Editors:** Cheryle B. Gartley, Mary Radtke Klein, Christine Norton, and Anita Saltmarche

**Publisher:** The Simon Foundation (2012)

Leakage, overactive bladder, fecal incontinence, stress incontinence... whatever you choose to call it, the

fact is that life with incontinence can be challenging. This book provides guidance from leading experts about how to take control of daily life, even when living with incontinence. Chapters include information on treatments, communicating with friends, family, and health professionals, helpful resources, and overcoming stigma. Courageous stories from people who live, and thrive, with incontinence provide encouragement and inspiration. Written specifically for individuals who live day to day with bladder and/or bowel incontinence, the book also provides information useful for physicians and nurses who understand their patients' frustrations and wish to more fully comprehend the quality of life issues facing people with intractable incontinence. Available online at: [www.simonfoundation.org](http://www.simonfoundation.org).



**Title:** *The Ins and Outs of Poop*

**Author:** Thomas R. Duhamel, PhD

**Publisher:** Maret Publishing (2012)

Functional constipation can persist for months or years. Treatment can be stressful for everyone involved, including healthcare providers. It is the most common problem seen in pediatric GI clinics. It can cause young children to soil their underwear (encopresis) without awareness that

they have to use the toilet. It can cause discomfort and pain, and a deep sense of embarrassment in a child. But functional constipation goes away when treated correctly. This book provides a step by step guide to understanding, recognizing, and treating functional constipation, and a plan for parents and providers to work together as a treatment team. Each step is explained in detail along with the tools needed for successful implementation. There are many stories written by parents describing specific aspects of their child's treatment. The illustrated book is written in a light-hearted fashion that emphasizes the good news that with comprehensive care, functional constipation can be dramatically improved. Available online at [Amazon.com](http://Amazon.com).



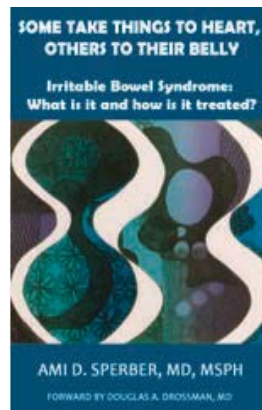
**Title:** *IBS – Free at Last! (2nd Edition)*

**Author:** Patsy Catsos, M.S., R.D.

**Publisher:** Pond Cove Press (2012)

This book describes an easy, step-by-step method for controlling IBS symptoms that may be caused by intolerance to certain carbohydrates (FODMAPS) in your diet. FODMAPS are problematic for those with IBS; they are poorly absorbed in the small intestine and rapidly fermented by bacteria in the gut. The book

includes information to help you understand the link between certain foods and IBS symptoms. It includes menus, tips on shopping and reading labels, and strategies for including your favorite foods in your diet. The second edition offers new recipes and gives answers to the questions frequently asked by readers. Available online at [Amazon.com](http://Amazon.com).



**Title:** *Some Take Things to Heart, Others to Their Belly – Irritable Bowel Syndrome: What is it and how is it treated?*

**Author:** Ami D. Sperber, M.D

**Publisher:** IFFGD (2011)

**Format:** Kindle Edition

If you, a friend, or a family member is suffering from IBS, this book is for you. As a clinician long dedicated to helping people with functional

disorders, Ami Sperber, M.D., provides a fresh and clear guide to help people understand IBS and the diagnostic process. Individuals with IBS will find useful ways to self-manage and gain a greater sense of confidence. The approach is empowering, helping people improve chances for treatment success. The book contains clear and detailed explanations of treatment approaches. These range from diet to complementary and alternative medicine to medications and to combinations of therapies. For quick references or detailed explanations, this book provides it all.

Forward by Douglas A. Drossman, M.D. Available online as an eBook at [Amazon.com](http://Amazon.com). Spiral bound print copy also available by contacting IFFGD.

## Fundraising Update from the Digestive Health Alliance



At DHA.org, individuals whose lives have been impacted by a chronic digestive condition can take action to raise money for research. Committed DHA champions across the country are hosting fundraisers to support increased research and awareness for functional gastrointestinal and motility disorders. Anyone anywhere can help them reach their goals and raise these much needed funds.

**Go online** to [DHA.org/fundraising](http://DHA.org/fundraising) or send donations  
**via mail** to IFFGD 700 W. Virginia Street, #201, Milwaukee, WI 53204

### The Cheryl Aaron Memorial Fund

This organization was founded on the idea of funding research to ultimately find a cure for gastroparesis. Lonnie Aaron created



it in memory of his wife, Cheryl, who lost her battle with the disorder last year. Lonnie is hosting a series of events in his home state of Pennsylvania in the hopes of putting an end to this potentially deadly, yet relatively unknown disease. Lonnie hopes to raise \$20,000 and is halfway to his goal!

### Hirschsprung's Disease Awareness Bracelets for Bryer

Hirschsprung's disease is a blockage of the large intestine due to improper muscle movement in the bowel. It is a congenital condition, which means it is present from birth. It affects about one person in every 5,000 births and many doctors are inexperienced with the disease.



Hirschsprung's usually requires surgery, after

which sufferers can live relatively normal lives. This bracelet is made in honor of Bryer, a young boy with the disease. A goal of \$400 was set and \$130 has been raised so far!

### Completed Fundraiser – Jean Day at the Office

In honor of IBS Awareness Month, one medical office chose IFFGD as their charity of the month. Throughout April, employees could donate \$5 for a chance to wear jeans to the office. In total, more than \$500 was raised through their efforts. Thank you, Digestive Health Specialists of Tacoma, WA!

### The 2nd Annual Awareness Walk for Gastroparesis and Digestive Health

Stephanie started this DHA fundraiser last year in Bellingham, Washington. Now 32 years old, Stephanie has lived with gastroparesis since 2008. She was diagnosed after experiencing extreme digestive distress, inability to eat solid food, and losing



20 pounds in less than two months. Like many other patients, she has gone through a number of medications, procedures, and alternative healthcare options, exhausting enormous amounts of money, not to mention physical and emotional energy. She currently relies on TPN (nutrition through

an IV in her upper arm) for most of her calories after suffering from complications of a feeding tube within her small intestine. It is Stephanie's intention to continue to promote advocacy and raise as much awareness as possible to help the millions worldwide living with gastroparesis, a life altering and at times life-threatening illness. Stephanie is just getting started and has set a goal this year of \$15,000. Last year she raised more than \$3,000!

Opinions expressed by authors are their own and not necessarily those of the International Foundation for Functional Gastrointestinal Disorders (IFFGD). IFFGD does not guarantee or endorse any specific product nor any claim made by an author and disclaims all liability relating thereto.

Occasionally, specific products are cited in articles or acknowledgments. However, no endorsement is intended or implied. Our intention is to focus on overall treatment or management issues or strategies.

The articles in *Digestive Health Matters* are in no way intended to replace the knowledge or diagnosis of your doctor. We advise seeing a physician whenever a health problem arises requiring an expert's care.

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