



International Foundation for
Functional Gastrointestinal Disorders

IFFGD

Information. Assistance. Support.

DigestiveHealth Matters

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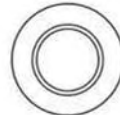
GERD Awareness Week

November 24-30, 2013

15 Tips to Manage Your Symptoms this Holiday



1) Schedule an earlier meal.



9) Use smaller plates.



2) Serve light appetizers.



10) Substitute water for soda.



3) Stay active.



11) Watch the desserts.



4) Don't smoke.



12) Skip the after-dinner mint.



5) Nix the juice.



13) Slow down.



6) Season lightly.



14) Stay awake!



7) Limit your drinks.



15) Talk to your doctor.



8) Pass on deep frying your turkey.

To learn more, visit aboutGERD.org



Recognizing GERD Awareness Week – 15 Tips to Keep Reflux at Bay during the Holidays

GERD Awareness Week was first designated by IFFGD in 1999 to help people with symptoms understand the condition and find help. The special event takes place each year during the week of Thanksgiving, a time when heartburn, the most common symptom of GERD, can easily arise and put a damper on festivities like family meals and football parties.

In recognition of the 15th annual GERD Awareness Week, here are 15 suggestions for curbing your gastroesophageal reflux disease (GERD) symptoms this holiday season.

1. **Schedule an earlier meal.** It's best not to eat late at night if you suffer from GERD.
2. **Serve light appetizers.** Fatty foods like chips, dips, and cheeses are slow to empty from the stomach and more likely to aggravate symptoms.
3. **Stay active.** Stick with your exercise routine during the holidays, as weight loss can help alleviate GERD symptoms.
4. **Don't smoke.** Nicotine weakens the muscles within your food pipe that prevent back flow (reflux) of stomach contents.
5. **Nix the juice.** Citrus fruits and juices, like grapefruit, orange, and tomato, are acidic and can worsen GERD symptoms.
6. **Season lightly.** Spicy foods, as well as things like onions and garlic, often bother people with GERD and make heartburn worse.
7. **Limit your drinks.** Whether wine at dinner or beer during the game, alcohol can worsen reflux.
8. **Pass on deep frying your turkey.** Fried foods are known to exacerbate GERD symptoms.
9. **Use smaller plates.** Eating large meals can trigger symptoms, so try smaller meals spread throughout the day.
10. **Substitute water for soda.** Caffeinated and carbonated beverages are both notorious heartburn aggravators.
11. **Watch the desserts.** Chocolate might be a favorite, but it often bothers people with GERD.
12. **Skip the after-dinner mint.** Peppermint is another heartburn irritant.
13. **Slow down.** Physical exertion after a meal can lead to reflux.
14. **Stay awake!** While the turkey might make you sleepy, fight the urge take a nap. Lying down within 3 hours after eating can cause GERD symptoms to flare up.
15. **Talk to your doctor.** An accurate diagnosis is the first step to receiving the most effective treatment.

GERD is a chronic disease that can occur when stomach contents repeatedly flow backwards into the esophagus (food pipe). Though generally treatable, serious complications can result if GERD is not treated properly.

“Heartburn that happens more than once a week, worsens, or continues over time may signal a more serious condition like GERD,” said J. Patrick Waring, M.D., a gastroenterologist at Digestive Healthcare of Georgia in Atlanta. “Talking about it with a doctor will help sort this out and determine how best to manage symptoms.”

See your doctor if you have symptoms of GERD, like frequent or longstanding heartburn, difficulty swallowing, or a sour taste in the mouth among others. For more information about the condition, visit our dedicated website, www.aboutgerd.org.



More from the 10th International Symposium on Functional Gastrointestinal Disorders

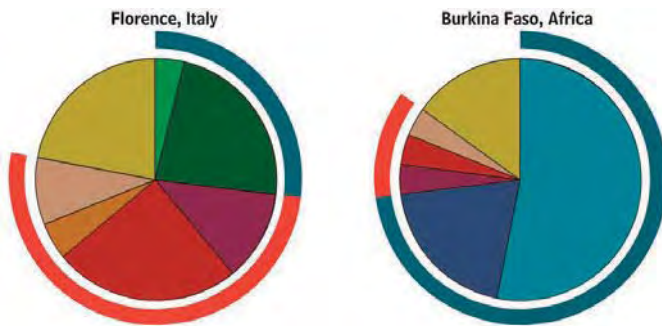
Nearly 400 physicians, researchers, and other health care professionals traveled to Milwaukee for our 10th International Symposium on Functional Gastrointestinal (GI) Disorders in April. Leaders in the GI field presented cutting edge knowledge on functional GI and motility disorders and treatments to other professionals who treat patients with these conditions across the world. In the last issue of *Digestive Health Matters* we highlighted three topics that were discussed at the meeting – **What we Know: An integrated understanding of the functional disorders; Global Epidemiology: How widespread are they;** and **New Concepts in Pathophysiology of Functional GI Disorders: Causes and mechanisms.** Here, we share three more interesting areas that were covered during the three day conference.

Children and Functional GI and Motility Disorders

“Children are not small adults and adults are not big children.” Christophe Faure, M.D., Centre Hospitalier Universitaire Sainte-Justine, Montreal, Canada

According to research published in 2009, almost four billion dollars were spent annually in the U.S. just on treatment of childhood constipation. Based on Rome III criteria, 87 percent of these kids had functional constipation.

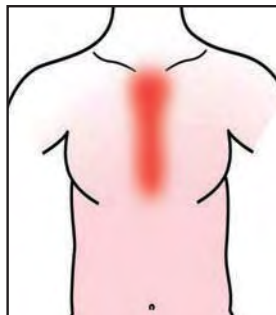
Early painful experiences, trauma, and social learning can influence symptom presentation of functional gastrointestinal and motility disorders (FGIMDs) in children. Miranda van Tilburg, Ph.D., University of North Carolina, Chapel Hill, NC, reviewed painful experiences during infancy which can impact normal nerve growth and increased risk for developing FGIMDs. During these early years, the part of the central nervous system that controls pain is maturing. However, inflammation and painful experiences, such as injuries to the GI tract, events associated with abdominal pain, and learned social behaviors, can cause changes to the pain control system.



Diet can affect your microbiota. These charts represent the differences in the microbiota of children in Italy (left) versus in Africa (right), who have very different types of diets.

The good news is that researchers are getting a handle on what is going wrong in the gut and on a cellular level. These insights may offer the basis for treatment strategies. New research studies have found differences in microorganisms in the gut (microbiota) of children with irritable bowel syndrome (IBS). The intestinal flora makeup of kids with diarrhea prominent IBS (IBS-D) and abdominal pain was different than that of kids without functional gastrointestinal conditions.

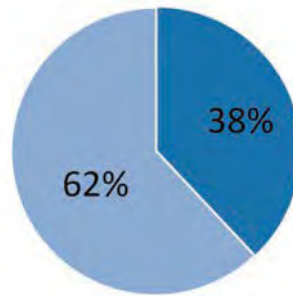
Difficult to Treat Heartburn



Gastroesophageal reflux disease (GERD) is a condition which develops when the back-flow (reflux) of acidic or non-acidic stomach contents causes troublesome symptoms and/or complications. The most frequent symptom of GERD is heartburn. Proton pump inhibitors (PPIs) are drugs that work by limiting acid secretion in the stomach. They are often prescribed to treat symptoms of GERD.

A pictogram used to help diagnose patients with heartburn or GERD. Patients are asked, “How often did you feel a burning pain in the red area shown in the picture – that is, behind the breastbone?”

But why do some people still experience persistent heartburn while taking a PPI? When there is no response to a PPI taken once daily, it may be due to non-erosive reflux disease (not caused by acidic reflux) or functional heartburn. When there's no response to a PPI taken twice daily, it is probably functional heartburn.



Of those who take a PPI once per day, about 38% still experience symptoms. Of those, about 62% experience their symptoms mostly at night.

“There are various underlying mechanisms that can lead to proton-pump inhibitor failure and some may even overlap in the same patient. The functional heartburn group provides most of the PPI failure (twice daily patients),” notes Ronnie Fass, M.D., MetroHealth Medical Center, Cleveland, OH.

Unfortunately, upper endoscopy (a test to see inside the upper GI tract) has a limited role in evaluating persons who failed PPI once or twice daily. A pH test that measures acidic or non-acidic reflux in the esophagus provides the best information in evaluating individuals with chronically unmanageable heartburn on treatment.

Lifestyle and dietary modifications are the first line of treatment. Other medications may help reduce esophageal pain, including low-dose antidepressants. Acupuncture and cognitive behavioral therapy may also be helpful in controlling the symptoms of heartburn that has not responded to other treatments.

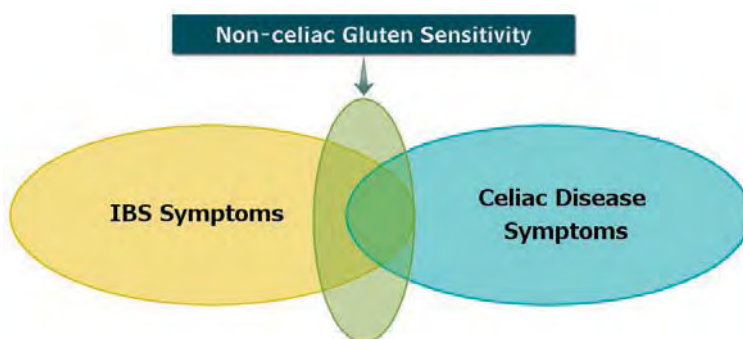


Food Allergies and Sensitivities

“How gluten sensitivity contributes to FGIDs remains unclear but multiple mechanisms are implicated.” Shelia E. Crowe, M.D., University of California, San Diego, San Diego, CA

For many IBS patients, food choices provoke symptoms. Research supports an association between symptoms and specific dietary components such as tryptophan and gluten. Too much or too little tryptophan can influence both levels of anxiety and GI symptoms. The link between gluten sensitivity and GI symptoms in classic celiac is very clear. IBS patients may not have celiac disease, but gluten may still induce their IBS symptoms.

Celiac disease can coexist with or even mimic IBS and other FGIMDs for some people. For others, the mechanism of gluten sensitivity in IBS remains unclear. Though we do not have direct evidence, research suggests a link between gluten and IBS symptoms. Scientists found that immunity markers present in gluten sensitivity may not be altered in celiac disease. Australian researchers discovered that a group of white blood cells (macrophages) behaved abnormally after gluten ingestion. They also found that a protein found in gluten called gliadin increased the number of these cells. Putting it all together, they believe that partially digested fragments of gluten trigger this immune response which in turn provokes dysfunction in the gut.



There is significant overlap between symptoms of IBS and of Celiac Disease. Non-celiac gluten sensitivity may be a separate disorder that falls between these two.

Looking Back at 2012 and 2013



Commitment to the Future

For more than two decades, IFFGD has worked to inform, assist, and support people affected by functional gastrointestinal (GI) and motility disorders. We are grateful to receive support for this mission from the broad functional GI and motility disorders community, including patients, physicians, donors, advocates, policy makers, and others. It is a diverse community and one that shares a common goal – to see patient care improved.

IFFGD addresses the needs of the digestive health community. We have always believed, as the Institute of Medicine Research Roundtable once said:

- that quality of care depends on the quality of information underlying health care decisions,
- that all stakeholders draw upon, as well as invest in, this information enterprise, and
- that patients must be engaged as essential stakeholders.

At IFFGD, we are committed to these principles as we work to provide education, raise awareness, and support research. Each of these plays a vital role in the ongoing process toward the goals to increase understanding and improve health outcomes. These goals are attainable when we all work together.



Our grassroots organization, the Digestive Health Alliance (DHA), was created for this purpose. DHA is a community of individuals whose lives are affected by functional GI and motility disorders. Through coordinated awareness, advocacy, and fundraising activities, we work together to inspire change.

IFFGD and DHA speak on behalf of the millions of individuals and families worldwide who are living with the effects of these complex digestive conditions. Here is a look at our activities for the last 18 months:



Awareness and Advocacy

Awareness and advocacy often go together. They involve outreach to the public at large, employers, educators, and policy makers to increase understanding about functional GI and motility disorders.

Advocacy in Action

Advocacy is an important part of raising awareness. It means taking action to educate policy makers who control funding or in other ways significantly influence the activities of the National Institutes of Health (NIH), U.S. Food and Drug Administration (FDA), and other health and human services agencies. Policy makers will respond to constituent concerns – but only if those concerns are brought to their attention and explained.

The FGIMD Research Enhancement Act

Throughout 2012 and 2013 the digestive health community asked members of Congress to sign on to *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act*. We were successful in having this landmark bill introduced in the U.S. House of Representatives in the 112th Congress, which ended on January 3, 2013. In the new 113th Congress, the bill was reintroduced in the House as H.R. 842. As members heard from their constituents, they learned about these conditions and the needs of those affected. If you have not already done so, we encourage you to go to our web page at www.IFFGD.org/hr842action to send a message to your congressperson in support of this legislation.

In addition to raising critical awareness of functional GI and motility disorders and the needs of stakeholders, passage of this bill in the House and Senate will:

- Grant NIH new authority to initiate innovative research projects
- Establish a Centers of Excellence Program in this area
- Coordinate research activities with the Department of Defense and the Veterans Administration when appropriate
- Call on the FDA to improve review, approval, and oversight of treatments for functional GI and motility disorders

Advocates on Capitol Hill

Together we continue to speak out for increased government funding to advance the science of functional GI and motility disorders. In June we hosted members of DHA for Advocacy Day in Washington, DC. Digestive health advocates from six states went to Capitol Hill to explain to their congressional offices the importance of research and improved the treatments.



Patients and family members shared firsthand accounts with congressional offices, demonstrating how essential support is for *The Functional GI and Motility Disorders Research Enhancement Act* (H.R. 842). This is a ground-breaking piece of legislation that will expand research at NIH and call on the FDA to improve the review, approval, and oversight of treatments for functional GI and motility disorders.



After sharing their personal experiences with the congressional offices, the DHA advocates left the Capitol feeling empowered and hopeful they had made a difference. It soon became evident that they had. Since our trip to DC, five Representatives have signed on to support this landmark bill and we are hopeful that H.R. 842 will be introduced in the Senate.



Support for Veterans

During IBS Awareness Month we focused on veterans, many of whom are finding themselves faced with functional gastrointestinal disorders after returning from service in Gulf War regions. Our press release, *Turning Attention to Returning Vets During IBS Awareness Month*, focused on the fact that veterans and active military personnel disproportionately represent those suffering from IBS, dyspepsia, and other functional GI disorders, due to their exposure to increased risk factors.



In 2012 IFFGD again testified before the Senate Defense Appropriations Subcommittee asking that functional GI disorders be included on the list of conditions eligible for study through the Department of Defense's Gulf War Illness Research Program. For some Senators, it was the first they heard of the association between functional GI disorders and Gulf War veterans, and the first they were made aware of the IOM report, *Gulf War and Health Volume 8: Update of Health Effects of Serving in the Gulf War*. In fiscal year 2012 funds were dedicated specifically for Gulf War Illness in the Department of Defense research program. The funding for the Gulf War Illness Research Program was renewed in fiscal year 2013 and functional GI disorders were once again included.

Patient-Focused Drug Development Initiative (PDUFA-V)

In October 2012 we provided our written statement to the FDA in support of including irritable bowel syndrome (IBS) for specific consideration through the Patient-Focused Drug Development initiative as part of the Prescription Drug User Fee Act V (PDUFA-V) authorization. In April 2013, the FDA announced that three functional GI and motility disorders – IBS, gastroparesis, and GERD with persistent regurgitation symptoms on proton pump inhibitors – were selected as disease areas to be addressed.

Our IBS survey publications have provided a framework for seeking to better understand severity, need, and risk-benefit behavior, incorporating the patient perspective, as referenced by the FDA as they publicly launched this initiative.

U.S. National Health Observances Calendar

Over fifteen years ago, IFFGD designated **IBS Awareness Month** in April and **GERD Awareness Week** as the week of Thanksgiving in November. These two special events are listed on the U.S. Health Observances Calendar. Many other groups and individuals use these times to sponsor health events and stimulate awareness of these health issues.



DDNC Public Policy Forum



On March 3–4, 2013 we took part in the 23rd Annual Digestive Disease National Coalition (DDNC) Public Policy Forum in Washington, DC. We joined with patients, health care providers, industry representatives, lawmakers, and their legislative staff for two days of legislative updates and advocacy activities. This event provided us with another opportunity to meet with Members of Congress from across the nation, and urge their support on issues of concern to the digestive disease community, including scientific research, patient care, and prevention.

IFFGD Legislative Agenda for 2013

We invite your participation in supporting our legislative agenda, which will continue into the upcoming year:

- Support for *The Functional GI and Motility Disorders Research Enhancement Act* (H.R. 842)
- Support for funding NIH at a level of at least \$32 billion annually
- Support for funding the Gulf War Illness Research Program
- Support for the *National Pediatric Research Network Act* (H.R. 225/S. 424), which calls on NIH to establish 20 pediatric research consortia

Professional Meetings and Alliances

Throughout the year IFFGD participates in major medical meetings to make reliable information about functional GI and motility disorders available to health professionals, as well as to discuss issues surrounding the diagnosis and treatment of these chronic conditions. In 2012 and 2013, we attended and exhibited at meetings including:



- American College of Gastroenterology
- American Neurogastroenterology and Motility Society
- Digestive Disease Week (DDW)
- Rome Foundation Annual Meeting at DDW
- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition
- The University of North Carolina (UNC) School of Medicine: Expert Update on Treatments for Functional GI Disorders – A Symposium for Patients

Fundraising

Through DHA, members of the digestive health community are coming together and stepping up to fundraise for research and donating proceeds to IFFGD. Here are a few fundraising highlights from 2013, some of which directly funded our 2013 Gastroparesis Research Grants and made these special gifts possible.



Lonnie

Lonnie has an ambitious goal of raising \$20,000 for gastroparesis research and he's more than half way there! Throughout the year, Lonnie hosts events in his community – golf outings, bowl-a-thons, restaurant events, you name it – all in order to raise awareness for gastroparesis and bring in money for research for increased and improved treatments for the condition. Lonnie's wife Cheryl Aaron passed away in 2012 as a result of gastroparesis and he started the Cheryl Aaron Memorial Fund in her honor. Lonnie is dedicated to making a difference for this community. He joined us for Advocacy Day on Capitol Hill and works tirelessly hosting fundraising events and serving as an awareness ambassador all year long. You can support Lonnie in reaching his goal by visiting www.dba.org/dw/fundraisers/1027.



Stephanie

For the second year in a row Stephanie, a DHA champion who is inspiring others with her positive attitude and her pursuit to raise funds for gastroparesis research, hosted the Annual Awareness Walk for Gastroparesis and Digestive Health. On September 7, 2013, Stephanie, together with her family and friends, took to the trails in Bellingham, WA, wearing their green awareness t-shirts and spreading the word about why research for gastroparesis is so important. Stephanie hopes to expand the Awareness Walk and inspire others to host walks across the country in the future. Read more about Stephanie at www.dba.org/raise-awareness/stories/627/dba-champion-stephanie.



Geri

Geri came to DHA this year and hit the ground running, literally. This fall Geri ran a half marathon to raise money and awareness for the need for gastroparesis research. By sharing the link to her online fundraiser with friends, family, co-workers, and other members of the digestive health community, Geri surpassed her fundraising goal of \$1,310, inspiring gifts totaling more than \$1,430! See Geri's fundraising page and successes at www.dba.org/dw/fundraisers/1044.



Support of Research

DHA Children's GI Research Network

During the past year, thanks to financial contributions from donors, we have been able to continue to support the DHA Children's GI Research Network. By pooling resources and data, the network is working to improve diagnosis and treatment of functional GI and motility disorders in children. It is the only pediatric consortium addressing these conditions. If the *National Pediatric Research Network Act* (H.R. 225/S. 424) is passed, this network will be well positioned to apply for NIH support. The 7 centers currently involved are:

- Nationwide Children's Hospital, Columbus, OH
- Children's Hospital, Louisiana State University, New Orleans, LA
- Connecticut Children's Hospital, Hartford, CT
- Children's Hospital of Wisconsin, Milwaukee, WI
- Children's Memorial Hospital, Chicago, IL
- Children's Hospital Boston, Boston, MA
- Emma Children's Hospital, Amsterdam, The Netherlands

2013 IFFGD Research Awards

Continuing our commitment to research, in April we presented IFFGD Research Awards to eight active investigators whose work is advancing the understanding of functional GI and motility disorders in adults and children. The following eight researchers were recognized at our symposium:

- Enrico Corazziari, M.D., Università La Sapienza, Rome, Italy, Senior Clinical Investigator
- Jan Tack, M.D., Ph.D., University Hospitals Leuven, Leuven, Belgium, Senior Clinical Investigator
- Gary Mawe, Ph.D., University of Vermont, Burlington, VT, Senior Basic Investigator
- L. Ashley Blackshaw, Ph.D., Queen Mary University, London, England, Senior Basic Investigator
- Carlo Di Lorenzo, M.D., The Ohio State University, Columbus, OH, Senior Pediatric Investigator
- Niranga Manjuri Devanarayana, M.D., University of Kelaniya, Sri Lanka, Junior Pediatric Investigator
- Lukas Van Oudenhove, Ph.D., University of Leuven, Leuven, Belgium, Junior Clinical Investigator
- Muriel Larauche, Ph.D., University of California, Los Angeles, Los Angeles, CA, Junior Basic Investigator



Award Recipients (Left to Right): Muriel Larauche, Ph.D.; Lukas Van Oudenhove, Ph.D.; Jan Tack, M.D., Ph.D.; Niranga Manjuri Devanarayana, M.D.; Enrico Corazziari, M.D.; L. Ashley Blackshaw, Ph.D.; Gary Mawe, Ph.D.; Carlo Di Lorenzo, M.D..

2013 IFFGD Research Grants

Investigators from across the globe answered our call for applications for three research grants to advance the understanding of idiopathic gastroparesis. These grants were made possible by donations made specifically in the interest of advancing research of this poorly understood disorder, including donations from several DHA fundraisers. The applications have been sent to a selection committee made up of leaders in the field for review.

In this era of federal budget constraints, support for seed grants is becoming increasingly difficult. We are committed to helping fill the gap, and also promoting interest and opportunity in the field of functional GI and motility disorders. We look forward to presenting these grants in early 2014.

Idiopathic Gastroparesis Research Grant Selection Committee Members:

Kenneth L. Koch, M.D.

Henry P. Parkman, M.D.

P. Jay Pasricha, M.D.

J. Patrick Waring, M.D.

William E. Whitehead, Ph.D.,
Committee Chair

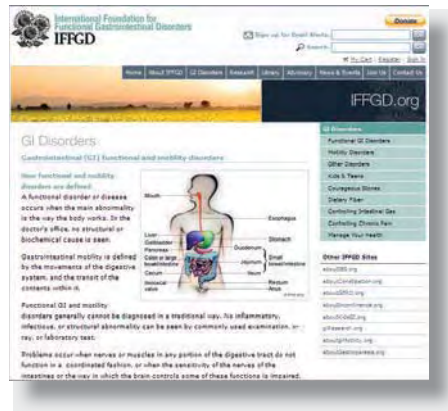
Education

Online Support

IFFGD provides educational resources and ongoing support to people looking for help with functional GI and motility disorders. People contact our office – by mail, phone, email, and online – seeking reliable information and answers to questions that help them better understand their conditions, find care, and manage symptoms most effectively over a long term.

We maintain 10 different websites that provide resources to those looking for credible information and community support for different aspects of digestive health:

- IFFGD.org
- aboutConstipation.org
- aboutGastroparesis.org
- aboutGERD.org
- aboutGIMotility.org
- aboutIBS.org
- aboutIncontinence.org
- aboutKidsGI.org
- giResearch.org
- DHA.org – *this site was redesigned and reprogrammed this year to create a more interactive and community-friendly environment for those looking to get involved*



Our social media presence is active and growing. Join the discussion at:

- Facebook.com/IFFGD
- Facebook.com/DigestiveHealthAlliance
- Twitter.com/IFFGD
- Twitter.com/WeAreDHA



Earlier this year we launched an e-newsletter, *Digestive Health Monthly*, sharing information about functional GI and motility disorders, opportunities to get involved, as well as updates on the progress our collective efforts are making toward improving treatments and creating hope for those living with these conditions. Even if you're a member of IFFGD, you're not automatically subscribed to the e-newsletter. To make sure you're getting all of our latest news, go to *IFFGD.org* and sign up for email alerts in the top right corner of the webpage.

Print Publications

We produce publications aimed at educating, increasing awareness, enhancing the doctor-patient relationship, improving outcomes, and mobilizing the patient community to take action around areas of interest. Our Publications Library contains more than 250 fact sheets and brochures about various aspects of chronic digestive disorders. *Digestive Health Matters*, our official publication, provides practical information and news about digestive health and community events.

Topics are chosen to:

- inform about general health issues
- explain news about research and new treatments
- empower patients and families to participate in their own health and well-being

During the past year we have produced several new publications on topics including bloating and distension, sleep and GERD, sphincter of Oddi dysfunction, and scleroderma. These materials are created to meet the needs expressed by our diverse audience and engage various stakeholders, in keeping with our ultimate goal of improving care.



Treatment Related Risk, Benefit, and Access in Functional GI and Motility Disorders

Over the years we have provided information about the experiences and needs of patients with functional GI and motility disorders, along with the various stakeholders who serve them. For example, results of our earlier surveys *IBS in the Real World* and *IBS Patients: Their Illness Experience and Unmet Needs* have contributed to making these conditions a growing part of public dialogue and consciousness.

In 2012 we published *Treatment Related Risk, Benefit, and Access in Functional GI and Motility Disorders*, which further explores our survey data. Looking at the experience of the IBS community with the drug alosetron as an example, this publication reflects upon how treatment delivery can break down, as well as actions that can help ensure that safer, effective treatments are made available to patients in need.

Short Bowel Syndrome (SBS)

Treating and managing short bowel syndrome is challenging for all parties concerned. This publication was new in 2013 and is intended to help people with the condition, as well as their family members and caregivers, understand why symptoms occur and provide an overview of management strategies.

Gastroparesis

Gastroparesis is poorly understood. More awareness is needed about recognizing the condition. Our gastroparesis brochure, new this year, addresses frequently asked questions and provides an overview to help patients and family members understand gastroparesis and how it may be treated and managed.

Irritable Bowel Syndrome (IBS)

This year we updated and revised our irritable bowel syndrome (IBS) brochure and also created a companion document to address commonly asked questions about the disorder. Both publications can be used to help understand the basics of the condition, as well as treatment options to best manage symptoms.

Professional Symposium

The 10th International Symposium on Functional Gastrointestinal Disorders took place in April 2013 in Milwaukee. The biennial event represents 20 years of support for multi-disciplinary professional education in the field of functional GI and motility disorders. The meeting is jointly sponsored by the University of Wisconsin School of Medicine and Public Health, Office of Continuing Professional Development in Medicine and Public Health; and by IFFGD.

This year nearly 400 physicians, psychologists, researchers, fellows, physicians assistants, and other health care professionals came together to review advances in the field, network with peers, and discuss best practices for caring for patients living with these chronic conditions.



Audio recordings from selected general sessions at the symposium on the following topics are available for download on our website at www.iffgd.org/site/news-events/events/professional-symposia/2013-symposium/audio.

- **Clinical Approach** moderated by Douglas A. Drossman, M.D.
 - o Global Epidemiology – Eamonn Quigley, M.D.
 - o What's New in Pathophysiology of FGIDs – Giovanni Barbara, M.D.
 - o Integrated Approach to FGIDs – Douglas A. Drossman, M.D.
- **Hot Topics** moderated by William D. Chey, M.D.
 - o What is the Link Between the Gut Microbiome and FGIDs – Willem M. de Vos, Ph.D.
 - o Food and GI Symptoms: Effects on Permeability, Immunology, Motility, and Sensation – Elena Verdú, M.D., Ph.D.
 - o Manipulating the Gut Microbiome as a Treatment Strategy for Functional GI Disorders – Magnus Simrén, M.D., Ph.D.
- **Neurogenesis, Neuroplasticity, and FGIDs** moderated by Gary Mawe, Ph.D. and Keith A. Sharkey, Ph.D.
 - o Emerging Topics in Neurogastroenterology and Motility – Keith A. Sharkey, Ph.D.
 - o Neurogenesis in the Adult Enteric Nervous System – Michael D. Gershon, M.D.
 - o Visceral Hypersensitivity – Stephen J. Vanner, M.D.
 - o Pain, Emotion, and Interoception – Irene Tracey, Ph.D.
- **State-of-the-Art on What's New in Pediatric FGIDs** moderated by Paul Hyman, M.D.
 - o What's New in Pathophysiology of Pain Predominant FGIDs – Christopher Faure, M.D.
 - o What's New in Pathophysiology of Defecation Disorders – Samuel Nurko, M.D.
 - o What's New in Diagnosis of Upper GI Tract FGIDs – Manu Sood, M.D.
 - o What's New in Diagnosis of Defecation Disorders – Carlo Di Lorenzo, M.D.
- **Clinical Application** moderated by Lin Chang, M.D.
 - o Maximizing the Physician/Patient Relationship – Alben Halpert, M.D.
 - o Central Pharmacological Treatments for FGIDs – Douglas A. Drossman, M.D.
 - o New and Emerging Treatments of the Gut – William D. Chey, M.D.
 - o Behavioral Treatments for FGIDs – Laurie Keefer, Ph.D.



Summary

As we celebrate all that was accomplished for the digestive health community this past year, we also look to the future. Education, awareness, advocacy, fundraising, and research continue to be areas where IFFGD and DHA are focusing our efforts.

IFFGD will continue to work with the FDA on increasing patient access to treatments for functional GI and motility disorders. Our gastroparesis research grants will be awarded in 2014 and with support from people like you, we plan to continue to fund research grants and awards. We will continue to represent the patient population at professional meetings. Currently we are working on a mobile app where individuals will be able to access to our information on IBS with constipation and chronic constipation from their smartphones and tablets. We are anxious to see what kinds of activities and fundraisers members of DHA have planned for the year and can't wait to bring more voices to Capitol Hill for our next Advocacy Day in Washington, DC There are many good things to come and we look forward to sharing them with all of you.

Whether through raising awareness, advocating on behalf of patients, or supporting research to advance science, we are committed to the work that we do together. Thank you for your ongoing support of our mission and for helping us work to improve care for all those whose lives are impacted by functional GI and motility disorders.



When 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

Elobixibat for Treatment of Chronic Constipation Now in Phase 3 Clinical Trials

Phase 3 trials of elobixibat for the indication of chronic idiopathic constipation (CIC) have begun. Ferring Pharmaceuticals reports that two studies are being conducted at close to 200 sites around the world. In Phase 2b clinical trials in the U.S. and Europe, elobixibat (formerly A3309) demonstrated clinically meaningful, statistically significant, and dose-dependent improvements, including increased stool frequency and improved constipation-related symptoms such as straining, stool consistency, and bloating maintained over eight weeks of treatment.

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.

Participants Sought for Two Double-blind, Randomized, 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: DKO-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: DKO-Disclosure@ferring.com

Linacotide (Constella) Available in Europe for Treatment of IBS-C

Linacotide is the first medicine approved by the European Commission for the symptomatic treatment of moderate to severe irritable bowel syndrome with constipation (IBS-C) in adult patients. It will become available in an increasing number of European countries during 2013 with the EU brand name Constella.

Linacotide, 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. It works by increasing the amount of fluid that flows into the bowel, allowing stool to pass more easily, and reducing visceral pain.

Linacotide (Linzess) has been available in the U.S. to treat IBS-C and CC in adults aged 18 and older since 2012. Linzess should *not* be used in patients 17 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.

Linacotide is being co-produced in the U.S. by Ironwood and Forest. Ironwood has out-licensed linacotide to Almirall, S.A. for development in Europe; and to Astellas Pharma, Inc. for development in Japan, Indonesia, Korea, the Philippines, Taiwan, and Thailand.



Rifaximin Studied for Treatment of Non-Constipation IBS

Rifaximin is an antibiotic currently under investigation for the treatment of non-constipation Irritable Bowel Syndrome (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 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 the 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.

Contact: Rachel Ballard, rachel.ballard@salix.com; or Alyson Lineberry, alyson.lineberry@salix.com; Be sure to refer to this study by its ClinicalTrials.gov identifier: NCT01543178

Clinical Trial of Lubiprostone Liquid Formulation for Treatment of Chronic Constipation

The makers of lubiprostone (Amitiza) have announced a randomized, placebo-controlled, double-blinded, multi-center study of a liquid form of lubiprostone in adult subjects with chronic idiopathic constipation (CIC). The trial is expected to enroll 152 patients with CIC at approximately 11 sites in the U.S. A liquid formulation could possibly offer an alternative dosing option for a wider range of patients.

Lubiprostone is Approved by the FDA to Treat Opioid-Induced Constipation

Sucampo Pharmaceuticals, Inc. and Takeda Pharmaceuticals U.S.A. Inc. announced earlier this year that the U.S. Food and Drug Administration (FDA) approved the supplemental New Drug Application for lubiprostone (Amitiza) to treat opioid-induced constipation in adult patients with chronic non-cancer pain. The drug was approved to treat chronic idiopathic constipation (CIC) in adults in 2006 and to treat IBS with constipation (IBS-C) in adult women in 2008.

Amitiza is a prescription drug used to relieve abdominal 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.

The drug 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.

New Findings Reported that Support Long-Term Use of Gattex for Treatment of Short Bowel Syndrome

New data from a two-year study by NPS Pharmaceuticals supports the long-term use of Gattex for injection in adult patients with short bowel syndrome (SBS). The findings were published as an abstract and presented at the American College of Gastroenterology (ACG) Annual Scientific Meeting and Postgraduate Course in San Diego, CA in October 2013. Patients in the study using Gattex beyond one year continued to be able to reduce their support on parenteral nutrition.

The open-label extension study included 88 adult patients with SBS. Investigators reported that the long-term use of Gattex in patients with SBS resulted in additional, clinically meaningful reductions in the volume and days per week of parenteral support requirements in this extension study. Thirteen patients in the study achieved complete independence from parenteral support with long-term Gattex therapy. No new unexpected safety concerns were observed with long-term Gattex treatment and the product's safety profile remains consistent with the product's label.

Gattex is a product of NPS Pharmaceuticals, a specialty pharmaceutical company developing orphan therapeutics for rare gastrointestinal and endocrine disorders. The drug 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 parenteral nutrition (PN) and intravenous (IV) fluid volume in adult subjects with SBS.

Gattex was approved by the U.S. Food and Drug Administration (FDA) in 2012 for treatment of adult patients with SBS who are dependent on parenteral 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. 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.

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. They cannot absorb enough water, vitamins, and other nutrients from food and may then need to use parenteral nutrition and intravenous fluids.



Solesta Available in the U.S. to Treat Bowel Incontinence

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

Medical and Research News

Review of Evidence for the Use of Probiotics in Managing Lower GI Symptoms

An article published in August by several leading European gastroenterologists in the journal *Alimentary Pharmacology and Therapeutics* has produced a consensus report which may be helpful to doctors and their patients in deciding whether to try specific probiotics for specific lower GI symptoms.

The authors performed a systematic review of randomized, placebo-controlled clinical trials on probiotics in adults. They sought to determine the level of available evidence to support the use of specific probiotics, as a reference to physicians who could then make evidence-based recommendations to their adult patients.

They found high levels of support for a role for specific probiotics in the management of overall symptoms and abdominal pain in patients with irritable bowel syndrome (IBS), and for preventing or reducing antibiotic associated diarrhea. They found moderate evidence to support a role for specific probiotics in managing overall symptoms in patients with diarrhea prominent IBS (IBS-D); improving bowel movements and bloating/distension in patients with IBS; and improving some aspects of health-related quality of life. The authors note that these findings are specific to individual strains or formulations of probiotics and cannot be extrapolated to other products. Further studies are needed to establish similarly high levels of evidence for the role of probiotics in treating other symptoms or other functional GI disorders.

FDA Advisory Committee Will Consider Extended Use of Relistor, a Drug for Opioid-Induced Constipation

The U.S. Food and Drug Administration (FDA) will be holding an advisory committee meeting in March 2014 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 U.S. 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.

Chronic Constipation and Bowel Incontinence More Likely in Kids with ADHD

A large scale retrospective study has shown that children with attention-deficit/hyperactivity disorder (ADHD) are significantly more likely to suffer from chronic constipation and bowel incontinence than kids without ADHD.

The study, published in the journal *Pediatrics*, looked at the medical records of more than 700,000 children. Researchers found that constipation nearly tripled and fecal incontinence increased six-fold among kids with ADHD. Children with ADHD also tended to see their doctor for their bowel problems more often, possibly suggesting that their constipation and bowel incontinence was more severe.

The study was limited to the children of active-duty military personnel. Further prospective research in the general population is needed, but parents of children with ADHD may wish to discuss these findings with their child's doctor if they have concerns about their child's digestive health.





Clinical Corner

If you or a family member is struggling with chronic or recurring GI symptoms, you probably know how challenging it can be to find reliable treatment information. Clinical Corner provides answers from digestive health professionals to commonly asked questions and commentary on current issues in the GI field.

Misunderstood Functional GI Disorders: Gymnast’s Case Shows Why We Must Accept FGIDs as a Chronic Disorder



By: Douglas A. Drossman, M.D.

The *New York Times Magazine* recently posted a case report of a 15-year old world class gymnast who mysteriously developed abdominal cramps, diarrhea, constipation, and an inexplicable swelling (distension) of her abdomen. Numerous diagnostic tests, including MRIs and ultrasounds, and trips to a half dozen hospitals, including the Mayo Clinic, left gastroenterologists, neurologists, urologists, psychiatrists, surgeons, physical therapists, an endocrinologist, and a cardiologist scratching their heads in wonder. No one understood why the girl looked pregnant or why she couldn’t go to the bathroom without laxatives.

When the tests kept coming back negative the doctors began to suspect that, “there was nothing really wrong: it was in her head.” The girl was placed on numerous treatments without benefit including hypnosis, acupuncture, Chinese herbals, and prescription medications.

In the end, one pediatric gastroenterologist came to the conclusion that she must have a functional gastrointestinal disorder (FGID). More specifically she had irritable bowel syndrome (IBS) that was associated with a not uncommon condition (to those with a specialty in FGIDs) known as abdominal-phrenic dyssynergia. With this condition abdominal muscles relax when they should contract and the diaphragm contracts when it should relax, leading to distension. This is not an increase of gas or fluid in the abdomen; it’s a pushing out of the abdominal wall that can come and go during the day depending on meals, the degree of pain, stress levels, and other factors involving body functions. In addition, her constipation was due to incomplete relaxation of the pelvic floor muscles called pelvic floor dyssynergia, which responded to biofeedback treatment.

I am fascinated by this article, not because we are dealing with “mystery diagnoses” (we see a large number of patients with similar abdominal distension and dozens of patients with pelvic floor dyssynergia in our practice each year). What interests me is the high level of public interest that leads this case to be featured in the *New York Times*. What is it that renders so much attention? And what are the problems with this kind of attention? There are several factors we should consider:

Biopsychosocial model

An approach which proposes that illness and disease result from simultaneously interacting systems at the cellular, tissue, organismal, interpersonal, and environmental level. It incorporates the biologic aspects of the disorder with the unique psychosocial features of the individual, and helps explain the variability in symptom expression among individuals having the same biologic condition.

- **The diagnosis of a functional GI disorder was made after many expensive and unneeded tests were performed, and by exclusion.** IBS and other functional GI disorders are positive diagnoses. To recognize and accept these conditions as real will lead to fewer unneeded studies to “exclude organic disease.” The Rome Foundation has established positive diagnostic criteria that are well accepted in the field.
- **When diagnostic studies were negative, it was presumed that the patient had a psychiatric problem.** This relates to a misunderstanding of the nature of disease and illness called dualism: “*If the studies are negative then the symptoms must be in her head.*” It is more appropriate to understand this from the Biopsychosocial model of illness and disease. (Learn more online by viewing this video of Dr. Drossman discussing doctor-patient communication – www.youtube.com/watch?v=IDAG0rIR-bo.)

Pelvic Floor Dyssynergia

An example of anorectal dysfunction that can contribute to constipation is a condition called Pelvic Floor Dyssynergia (also referred to as anismus). It is marked by the failure of pelvic floor muscles to relax, or a paradoxical contraction of the pelvic floor muscles, with defecation.

The pelvic floor is composed of a group of muscles that span the underlying surface of the bony pelvis, which function to allow voluntary urination and defecation. “Paradoxical contraction” refers to an abnormal increase of pelvic floor muscle activity with defecation, rather than the normal decrease in muscle activity that is necessary in order to have a normal bowel movement. This condition can contribute to some forms of constipation, complaints of incomplete evacuation, and straining with stool.

Because pelvic floor muscles are controlled voluntarily, their function can be improved through various learning procedures – such as biofeedback.

What is biofeedback?

Biofeedback is a neuromuscular reeducation tool therapists can use to tell if certain processes in our bodies are working correctly. It is a painless process that uses a computer and a video monitor to display bodily functions of which we are usually unaware. Special sensors measure these functions, which are displayed as sounds we can hear, or as linegraphs we can see on a computer screen. In this way, we receive information (feedback) on how our bodies work.

The therapist helps us to use this displayed information to modify or change abnormal responses to more normal patterns. That may mean increasing a response, decreasing a response, or learning to coordinate two responses more effectively.

- **Once the diagnosis was made the patient had a miraculous cure to the treatment.** I think we can all identify with this young athlete whose life was put on hold as she had to suffer with this disabling condition. But the article leads us to believe that her biofeedback treatment led to dramatic cure. I believe there is some poetic license taken here to lead us to this satisfying ending. Yes, the pelvic floor dyssynergia does respond to anorectal biofeedback, but the abdominal distension is a more complex physiological entity and should not respond to that. Patients with functional GI disorders must often deal with a lifelong history of symptom relapses and remissions or must try to control constant symptoms every day. This is the reality. While we can hope for cure which occurs with some patients, the majority need to accept FGIDs as a chronic disorder. But much like migraine headaches and arthritis, there are treatments that can reduce symptoms intensity and improve quality of life.

I'm sure this type of article may lead many patients to physicians who will do more and more studies to rule out “organic” disease in the hopes of achieving a cure. As physicians and patients are so afflicted, we need to understand that diagnosis and treatments are at hand once we give up a few misconceptions.

For a link to the *New York Times* article and to read Dr. Drossman's full post, as well as the articles referenced in Dr. Drossman's article, visit: <http://drossmancenter.com/misunderstood-functional-gi-disorders/>.

Dr. Drossman currently sees patients at his practice, Drossman Gastroenterology, in Chapel Hill, North Carolina. You can learn more about his practice at www.drossmangastroenterology.com.



Advocate for Veterans and FGID Research

You can help make FGID research happen.

Right now Congress has the chance to fund research into functional gastrointestinal disorders (FGIDs) through the Department of Defense's Gulf War Illness Research Program. There is a connection between the development of functional GI disorders and deployment in the Gulf War region.

FGIDs have been included as a condition eligible for study in the Gulf War Illness Research Program since fiscal year (FY) 2012, and we want to see this continue in FY 2014. The program is funded by the House and Senate in the annual appropriations process, as part of the Congressionally Directed Medical Research Program.

The Gulf War Illness Research Program:

- Provides expanded research at the Department of Defense
- Highlights the impact of Gulf War Illness on service members
- Works to improve the health and lives of affected service members and their families

Research into FGIDs and veterans will benefit not only the many veterans affected by these conditions, but the millions of Americans who suffer with these disorders every day.

As stated in a recent Senate report, medical research being conducted by the Department of Defense yields medical breakthroughs for service members and often translates to the civilian population, as well.

The Department of Defense's Gulf War Illness Research Program is one of the few areas of federally funded research on FGIDs. Research on functional GI disorders has been historically under-funded, and these chronic conditions can benefit greatly from increased research opportunities.

The majority of FGIDs are painful, debilitating, and chronic. Long after a soldier's tour is over, the FGID and its symptoms can remain.



When veterans speak for themselves, they tell us:

"I was diagnosed with IBS while on active duty ...

I was able to cope for about 25 years before the IBS started to get progressively worse. Today it is my nightmare."

"None of my GI problems existed prior to my deployment and they simply do not seem to go away afterwards."

"Since returning from Iraq, I have had issues with my gastrointestinal tract ... While speaking with several of my former soldiers I came to realize that they are experiencing the same signs and symptoms."

What can you do? You can tell Congress how important research is to you.

You can help make research happen. Contact your legislators today and ask them to support the inclusion of Gulf War Illness research in the Department of Defense's Congressionally Directed Medical Research Program for FY 2014.

Call the Capitol Hill switchboard at (202) 224-3121 and ask to be connected to your Senator or Representative's office. Once you're connected, here's a guide of what to do (or if you'd rather send an email, you'll find a link at the end of this article):

1. Identify yourself as a constituent and ask to speak with the staff member responsible for health issues.
You can leave a voicemail if they are unavailable.
2. Thank the staff member for taking your call.
3. Ask your Member of Congress to support *funding for the Gulf War Illness Research Program in the Department of Defense's Congressionally Directed Medical Research Program* in fiscal year 2014.
4. Briefly explain how this research will benefit veterans and the entire digestive health community.
 - o Included among the conditions eligible for study under the Gulf War Illness Research Program are functional gastrointestinal disorders, such as irritable bowel syndrome and functional dyspepsia.*
 - o The majority of functional GI disorders are painful, debilitating, and chronic.*
 - o Current treatment options for these conditions are extremely limited and focus on symptom management, no cures are known.*
 - o Long after a soldier's tour is over, the functional gastrointestinal disorder and its symptoms can remain.*
 - o Research into FGIDs and veterans through the Department of Defense's Gulf War Illness Research Program will benefit not only the many veterans affected by these conditions, but the millions of Americans who suffer with these disorders every day.*
5. Tell them briefly why this is important to you.
 - o If you are a veteran affected by a functional GI disorder, consider sharing your experience and asking for continued research to improve understand and treatment options.*
 - o If you are a patient with a functional GI disorder, briefly explain your struggle with your condition and your need for better care or treatments.*
 - o If you are a friend or family member of someone affected, you might briefly share their story and how it has impacted your community.*
 - o If you are a healthcare professional, you could address the needs of your patients and the possibilities you see for continued research.*
 - o If you are none of the above, but think that investments in the health of every American is important, you can say so.*
6. Give the aide your contact information and ask to be informed about the actions your Member of Congress takes in response to your request.
7. Thank the person you spoke with for their time and consideration.
8. Let us know how it went! Call us at (414) 964-1799, so that our representatives in Washington, DC can follow up on your outreach on Capitol Hill.

To send an email

Prefer to send an email? Add your story to a pre-drafted email to your Members of Congress about the Gulf War Illness Research Program at www.iffgd.org/gulfwar2014action.



Government Shutdown During 2013 Impacted Medical Research

On October 1, 2013, the federal government ceased many functions, beginning what is known as a “government shutdown,” which lasted for 16 days. Many functions throughout the government stopped due to a gap in appropriations, including at the National Institutes of Health (NIH). NIH is the medical research agency of the United States. The scientific discoveries made possible by NIH contribute to the health of all Americans and to people around the globe.



How the NIH was Affected

During the government shutdown, the 27 Institutes and Centers that make up NIH ceased most operations, along with the rest of the federal government. Once the shutdown ended, it took several weeks for NIH to reestablish normal operations.

Enrollment in clinical trials sponsored by NIH was halted during the shutdown. Research conducted directly by NIH also froze during this time, and not all researchers will be able to seamlessly pick up where they left off before the shutdown.

Research already funded but not directly conducted by NIH was allowed to continue during the shutdown. However, new research applications were not processed during this time and support was not available to researchers with previously awarded grants.

Under post-shutdown funding, NIH continues with a budget that is 7.8% below fiscal year 2012 levels (a cut of roughly \$2.5 billion annually). We, along with others in the public health community, have advocated for an increase in NIH funding to at least \$32 billion annually in order to maintain current research projects and implement critical new research initiatives.

Any funding cuts, or even level funding, for NIH amounts to a delay in the overall effort to improve treatment options and find cures for those affected by digestive health conditions.

What You Can Do

You can take action to help maintain funding at NIH. Tell your Representative and Senators that medical research through the NIH benefits all Americans. Ask them to vote for funding increases to NIH to at least \$32 billion annually. You can call or email. Find contact information for your Members of Congress at www.capwiz.com/iffgd.

Community News

DIGESTIVE HEALTH ALLIANCE

Malinda's Personal Story from DHA.org

I started running when I was 22. Over the last 18 years, I have run dozens of races and completed 8 marathons while living with chronic illness. I have gastroparesis (delayed stomach emptying) which causes severe stomach pain, nausea and vomiting. There is no cure for this condition and only a few treatments available which offer temporary relief.

After many years of failed treatments, hospitalizations and feeding tubes, I had a gastric neurostimulator (stomach pacemaker) implanted on March 3, 2011. While the pacemaker has provided some relief, my symptoms continue to be debilitating. I continue to run whenever possible even when I'm experiencing stomach pain and nausea. However, there are many days that I cannot run because of vomiting and fatigue.



I did not run for weeks when I met Joan Benoit Samuelson at the Credit Union Cherry Blossom 10 Miler Expo. During her talk, she kept repeating “run your own race” – inspiring words that I needed to hear at the time. It can be an emotional struggle when I want to run but my body won't let me. It is especially difficult when I see my identical twin sister running consistently and surpassing her race goals.

I have learned that I cannot compare myself to my twin or any other runner. I cannot even compare myself to the runner I was before I got sick. My body has changed and my running has changed. I have become the “go with the flow” slow runner and that is the runner I am meant to be today. I am truly grateful for every step that I am able to run. I appreciate every moment when I run – that is why I run without expectations, without time goals, without music, without a Garmin, but always with gratitude. My twin and I dubbed ourselves “Twins Run in Our Family” since we are identical twins and opposite runners.

On her photo, Joan Benoit Samuelson wrote “Wishing you a great run through life” and I am determined to do just that!

You can follow Malinda's journey through her story on our website www.dha.org/raise-awareness/stories/45/malinda.



Stay in the know by signing up for our monthly email newsletter, where you will find more stories like Malinda's, as well as other information on digestive health and updates from the DHA community.

Sign up at www.dha.org/sign-e-news.

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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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Editorial Staff:

Editor: William Norton
Assistant: Jill Godsey
Assistant: Susan Schneck
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Associate Editors:

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Douglas Drossman, M.D.
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This issue of *Digestive Health Matters* is sponsored, in part, by Forest Laboratories, Inc., Ironwood Pharmaceuticals, Inc., and the members of IFFGD. We are grateful for their continued support of IFFGD.

 **Forest Laboratories, Inc.**


Ironwood

Our Unique Mission: The International Foundation for Functional Gastrointestinal Disorders (IFFGD) is a nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal disorders. IFFGD has been working since 1991 with patients, families, physicians, practitioners, investigators, employers, regulators, and others to broaden understanding about gastrointestinal disorders and support research.



**International Foundation for
Functional Gastrointestinal Disorders
IFFGD**

700 W. Virginia St., #201
Milwaukee, WI 53204
Toll-free (U.S.): 888-964-2001
Business: 414-964-1799
Fax: 414-964-7176
E-mail: iffgd@iffgd.org
www.iffgd.org
www.aboutconstipation.org
www.aboutibs.org
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