IFFGD
International Foundation for Functional Gastrointestinal Disorders

Working for Patients & Their Families With Physicians, Nurses and Other Health Professionals We’re Putting it All Together
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Paving the Way for Change

Since 1991, IFFGD (the International Foundation for Functional Gastrointestinal Disorders) has been increasing understanding and raising awareness about FGIMDs (functional gastrointestinal and motility disorders). Individually, the prevalence of these diseases and disorders varies; taken as a whole, they impact millions of people worldwide.

In bringing together patients, their families, clinicians, researchers, and health professionals, IFFGD helps form a more unified digestive health community. Together, we share common goals to help advance science and improve patient care. Our aim is to end suffering caused by FGIMDs and improve quality of life for all those affected.

Specifically, we work to:

- Empower patients and families by helping people better understand their condition and the resources available to them;
- Provide patients and their families with ways they can direct their energies to make positive changes, including advocacy and fundraising for research;
- Create a vivid picture of the patient experience to help legislators, scientists, and funding organizations understand and embrace the critical need for research;
- Support research in an effort to lay the foundation for more and better treatment options;
- Convey patients’ perspectives to the health care community and the public at large.

Ways that we accomplished these goals in the past year are outlined on the following pages.
The Digestive Health Alliance (DHA) is the grassroots arm of IFFGD. Through the DHA website (DHA.org), Facebook, and Twitter pages people can come together to take action through coordinated fundraising, advocacy, and awareness efforts. Everyone who takes part is helping to advance science and support meaningful change that will improve the quality of life for people affected by FGIMDs.

The “I Support Digestive Health Alliance” banner pictured here was created by children at a DHA fundraiser held last summer.

Personal Fundraising

DHA supporters personally collect donations and host fundraising events in their communities to raise money for critical research activities. Children and adults take part. Some of the DHA fundraisers that took place last year include:

- DHA Walk by the Bay, Lynn Haven, FL;
- Farmington Canal Trail 5K Walk-A-Thon, Farmington, CT;
- Give a Quarter, Save a Quarter, Columbia, MD;
- Employees fundraiser, HP Enterprise Services, Raleigh, NC;
- Pumpkin Pie Bike Ride, Ottawa, IL, 100-mile bike ride;
- Dam to Dam Loop, Delft, Netherlands, 10-mile run for DHA.

“Everyone who takes part is helping to advance science and support meaningful change...”
**Personal Advocacy**

Through the DHA, individuals can organize their own advocacy campaigns. Here is one example.

**Grant’s Story**

Grant is a delightful 5-year-old with GI issues. From birth he suffered with pain and distension. Treatments were ineffective.

Grant was sick and his parents were exhausted when, after years of searching, they finally found a GI specialist who helped. Grant was diagnosed with Chronic Intestinal Pseudo Obstruction. His symptoms are managed with a combination of medicine and diet. About half of Grant’s food is taken in through a feeding tube. With no cure, and wanting to improve Grant’s quality of life, his family hopes and prays that answers will be found through research. And they are taking action.

**Friends and Family Making a Difference**

At year end, Grant’s family asked everyone on their holiday card list to help support HR 2239, a bill currently before the U.S. House of Representatives that is focused on research for functional GI and motility disorders like the one Grant suffers with. A description of the journey endured while trying to find effective treatments was sent to friends and family members. They could then reply with a note card that was included, addressed to the Digestive Health Alliance, providing their name and address along with a message of support for HR 2239. We then identified the Congressional representative for everyone who responded and delivered the cards to those representatives’ offices. In this way, the family was able to reach representatives beyond their own Congressional district to share Grant’s compelling story and raise critical awareness.
Seeking Answers through Research

“Medical research is the search for cures to illness and disease. (It’s) like a detective story, always searching for new leads to follow. It is very important to sustain medical research.”

– Elias Zerhouni, MD, Former Director of the National Institutes of Health

People involved with research spend years – careers – searching for answers that will lead to improved health. Your generous support makes it possible for IFFGD to help effectively sustain that research for the FGIMD community.

Searching for the Cure for Children: The DHA Children’s GI Research Network

In 2008, the DHA Children’s GI Research Network was formed with funding from IFFGD. (Initially the network was called PAIN FREE.) The network brings together six of the foremost pediatric FGIMD clinical researchers from across the country to share data and collaborate on studies. Their single purpose is to improve the quality of life for children with these complex conditions.

As a result of this ongoing cooperative effort, the network is now executing projects designed to improve diagnosis and treatment of childhood FGIMDs.

Network Researchers

Carlo Di Lorenzo, MD, Columbus, OH
Jeffrey Hyams, MD, Hartford, CT
Paul Hyman, MD, New Orleans, LA
Samuel Nurko, MD, MPH, Boston, MA
Manu Sood, MD, Milwaukee, WI
Miguel Saps, MD, Chicago, IL
IFFGD Research Awards

In April 2011, IFFGD presented research awards to six active investigators who are dedicated to furthering our understanding of functional gastrointestinal and motility disorders. Here are the recipients and, briefly, their areas of research:

**Ronnie Fass, MD, FACP, FACG, Clinical Science** – Improving diagnosis and treatment of conditions such as reflux disease, functional heartburn, noncardiac chest pain, gastroparesis, and Barrett’s esophagus.

**Sudarshan Jadcherla, MD, FRCP, DCH, Pediatrics** – Improving diagnosis and treatments in infant dysphagia, GERD, and chronic lung disease.

**Adrian Miranda, MD, Basic Science** – Understanding pathways in the development of pain sensitivity and changes in the structure and function of nerves.

**Million Mulugeta, MVSc, DVM, PhD, Basic Science** – Examining the molecular basis of the body’s reaction to stress, digestive functioning, and pain response.

**Samuel Nurko, MD, MPH, Pediatrics** – Understanding upper digestive tract conditions present in childhood, esophageal motility disorders, and the effect of inflammation on motility.

**Shaman Rajindrajith, MBBS, MD, MRCPCH, Pediatrics** – Understanding of functional gastrointestinal and motility diseases in children, particularly in the developing world.
Advocacy

*Advocates are people who speak out about something they believe in on behalf of themselves and/or others.*

**HR 2239: The First Federal Research Bill for FGIMDs**

In an effort to strengthen federal research of FGIMDs and improve the development of innovative treatment options for these conditions, IFFGD and grassroots advocates have been working with legislators to introduce the first ever federal research bill focused on FGIMDs. As a result of this sustained congressional outreach, the Functional Gastrointestinal and Motility Disorders Research Enhancement Act of 2011 has been introduced in the U.S. House of Representatives with bill number HR 2239.

In addition to raising critical awareness of functional GI and motility disorders and the needs of patients, passage of this landmark legislation will:

- Grant the National Institutes of Health (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 Food and Drug Administration (FDA) to improve the review, approval, and oversight of treatments for FGIMDs.
Capitol Hill Advocacy Day

In June of 2011, DHA advocates from across the country gathered in Washington, DC, for a two-day advocacy event. The first day featured advocacy training sessions, a review of our legislative agenda, updates on federal research, and a networking dinner. On the second day, advocates traveled to Capitol Hill in teams for a series of meetings with Congressional staff and members of Congress to urge support for a legislative agenda to strengthen research about FGIMDs and improve patient care.

The 2012 DHA Advocacy Day event is scheduled to take place on June 19–20, 2012 in Washington, DC.
Fiscal Year 2012 Appropriations

We thank all of the people who step forth as advocates on behalf of those affected by functional GI and motility disorders. We appreciate the response of U.S. Congressional Members to the calls by IFFGD/DHA and advocates to provide funding in areas important to the digestive health community.

Here are several provisions included in the Fiscal Year 2012 Appropriations bill that was passed by Congress and signed into law by the President at the close of 2011.

Highlights include:

- **Support for Veterans with Gulf War Illness**
  The Fiscal Year 2012 budget dedicates funding specifically for Gulf War Illness research through the Department of Defense. 2012 Funding: $10 million, no comparable funding in Fiscal Year 2011.

- **National Institutes of Health (NIH)**
  The NIH is the nation’s medical research agency and the largest source of funding for medical research in the world. 2012 Funding: $30.7 billion, an increase of $300 million over Fiscal Year 2011.

- **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**
  The NIDDK is the principal NIH institute that conducts and supports research for FGIMDs. 2012 Funding: $1.84 billion, an increase of $8.22 million over Fiscal Year 2011.

- **The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**
  This NIH institute supports research regarding FGIMDs in children. 2012 Funding: $1.32 billion, an increase of $6.05 million over Fiscal Year 2011.

- **The National Institute of Environmental Health Sciences (NIEHS)**
  This NIH institute supports research on environmental factors that may impact the onset of FGIMD symptoms. 2012 Funding: $686.87 million, an increase of $3.15 million over Fiscal Year 2011.

cont.
Highlights cont.

- **The National Institute on Aging (NIA)**
  The NIA supports research relating to FGIMDs in elderly people. 2012 Funding: $1.10 billion, an increase of $5.05 million over Fiscal Year 2011.

- **The National Center for Advancing Translational Sciences (NCATS)**
  This newly created NIH center will develop new models for public-private ventures that will more rapidly turn basic research into treatments for patients. 2012 Funding: $576.46 million, no comparable funding in Fiscal Year 2011.

**Digestive Disease National Coalition Public Policy Forum**

IFFGD participated in the 22nd Annual Digestive Disease National Coalition (DDNC) Public Policy Forum in Washington, DC on March 4–5, 2012. This event provided IFFGD with the opportunity to meet with legislators and urge their support for scientific research, patient care, and prevention.

**Digestive Health Alliance on the Hill**

Digestive Health Alliance Advocate and U.S. Army (ret.) Veteran Brian Bird (left) and IFFGD’s William Norton (right) met with U.S. Congressman Paul Ryan (R-5-WI) in Washington, DC to discuss the need for research funding for functional GI disorders among veterans and ask for support of the Functional GI and Motility Disorders Research Enhancement Act.
Giving Voice to Veterans’ Needs

Otherwise healthy veterans are incurring chronic health conditions at higher rates than the general population after returning home from service in the Gulf War regions of Afghanistan and Iraq. Debilitating functional gastrointestinal disorders, such as cyclic vomiting syndrome (CVS) and irritable bowel syndrome (IBS) are among the health conditions cited.

The DHA and Friends of VA Medical Care and Health co-sponsored a briefing in Washington, DC, on October 27, 2011, attended by U.S. House and Senate legislative staff members, officials from the Veterans Administration, and representatives from a number of veterans’ advocacy organizations.

Attendees were briefed on how service in the Gulf War regions impacts the health of our returning soldiers, the current state of care and research, and what can be done to help improve the lives of these service men and women.

Advocates Brian Bird, U.S. Army (ret.), and Brennan Spiegel, MD, spoke about functional gastrointestinal disorders.

Advocates: Brennan Spiegel, MD; William Norton, IFFGD; Brian Bird
Providing Information & Support

Call Center
Thousands of people contact IFFGD each year, by email, regular mail and phone, asking for information and help. IFFGD’s knowledgeable and compassionate staff answers all these requests, providing medically sound information to help them better understand these conditions and sort out their treatment options.

Internet
Many of the individuals who contact us each year first learn about IFFGD online. We maintain a complete family of websites, providing credible information about many different aspects of digestive health.

IFFGD.org
aboutConstipation.org
aboutIBS.org
aboutIncontinence.org
aboutGERD.org
aboutgiMotility.org
aboutKidsGI.org
DHA.org
giResearch.org

IFFGD and DHA also maintain a vibrant social media presence on Facebook and Twitter.
Digestive Health Matters

Our publication, *Digestive Health Matters*, provides readers from around the world with practical information about digestive health. The publication provides important perspectives, scientific advances, advocacy news, and updates for general audiences, researchers and professional health care providers. Distribution is in print and online.

**Issues contain articles that cover the following areas:**

- Original articles on general digestive health topics;
- Research news about new findings;
- Treatment updates about new and developing products from our Industry Council members;
- Foundation news with information about IFFGD activities;
- Legislative updates;
- Community news and stories about personal experiences and actions from people living with digestive disorders.
Publications Library

IFFGD maintains an extensive library with more than 250 fact sheets and brochures about various aspects of chronic digestive disorders. The majority of these fact sheets and publications were written by thought leaders specifically for IFFGD readers. They are not available through other sources.

Some of our newest publications are:

- Functional Abdominal Pain in Children and Adolescents (844)
- Infant Regurgitation (845)
- Traveling with Gastroparesis (552)
- Easy Read: Talking to Your Doctor About Incontinence (321)
- Como Hablar con tu Medico Acerca de la Incontinencia (321S)
- Easy Read: Medical Treatment and Management of Incontinence (320)
- Manejo y Tratamiento Medico de la Incontinencia (320S)
- Managing Incontinence: A survey of Those Who Live With It (319)
- Serotonin: What Is It Doing in My Gastrointestinal Tract? (243)
- Could Probiotics Help Alleviate Your Functional GI Symptoms? (246)
- Changes You Should Not Ignore If You Have IBS (247)
- Avoiding Drug Adverse Effects (248)
- Report from the 9th Intl Symposium on Functional GI Disorders (250)
- Dietary Triggers for IBS Symptoms: The Low FODMAP Diet Approach (251)
- Understanding Functional GI Disorders (252)
- Returning Heroes: Chronic Disease and Overseas Deployment (253)
- Buying Health Products and Services Online (256)
- What an Awesome Machine: the Digestive System (258)
eBook Publication

We published our first eBook last year. *Some Take Things to Heart, Others to Their Belly – Irritable Bowel Syndrome: What is it and how is it treated?* is written by Ami D. Sperber, MD. The book provides a fresh and clear guide to help people understand the many aspects of dealing with IBS, including ways to self-manage, gain a greater sense of confidence, and improve chances for treatment success.

“...A fresh and clear guide to help people understand the many aspects of dealing with IBS, including ways to self-manage, gain a greater sense of confidence, and improve chances for treatment success.”
Awareness Campaigns

IFFGD distributes information each year during IBS Awareness Month in April and GERD Awareness Week in November. Press releases are distributed to media throughout the U.S. These releases include an invitation for free informational brochures and fact sheets. Free health kits also are sent to professionals who distribute them to their constituents. This year we also distributed public service announcements about IBS.

April 2012 – IBS Awareness Month

Public Service Announcements

We distributed public service announcements (PSAs) for TV and radio to raise awareness about IBS. The PSAs also encourage people with symptoms to talk to their health care providers and take an active approach to managing their condition. The announcements feature the personal experience of an IBS patient and comments from a physician. IFFGD was able to produce the PSAs in partnership with Takeda Pharmaceuticals and Sucampo Pharmaceuticals.

IBS affecting Gulf War Region Veterans

Our messages this year also included press releases about the high numbers of veterans returning from the Gulf War regions of Iraq and Afghanistan who are experiencing symptoms of IBS and other functional gastrointestinal disorders.

November 2011 – GERD Awareness Week

Is Your Child’s Reflux/Spitting Up a Point of Concern?

For most infants, spitting up is perfectly normal. But children who reflux a lot may need to see a doctor.
A Strong Voice in the Health Community

International Symposium on Functional Gastrointestinal Disorders

The 10th International Symposium on Functional Gastrointestinal Disorders will be held from April 12–14, 2013 in Milwaukee, WI, USA.

This biennial symposium, jointly sponsored by IFFGD with the University of Wisconsin School of Medicine and Public Health, Office of Continuing Professional Development in Medicine and Public Health, has been described as an “educational jewel” for its collaborative nature and the depth and breadth of information presented.

The next symposium will follow in this successful tradition, with a full slate of general sessions, mini symposia on a wide range of topics regarding functional GI and motility disorders. Throughout the symposium, professionals from a variety of different disciplines will have opportunities to improve their clinical skills and learn about new and upcoming scientific advancements.

2011 Symposium participants in general session.
Other Professional Meetings

IFFGD exhibits at major medical meetings where we are able to talk and interact with clinicians and investigators about issues surrounding the diagnosis and treatment of functional GI and motility disorders. IFFGD participated in six major meetings in 2011:

- 9th International Symposium on Functional Gastrointestinal Disorders
- Treatment of Bowel, Bladder and Pelvic Floor Disorders
- American College of Gastroenterology
- American Neurogastroenterology and Motility Society Meeting/Functional Brain Gut Research Group
- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition
- Digestive Disease Week

Helping Shape Future Directions

Nancy Norton, founder and president of IFFGD, has held numerous leadership positions in the health care community, including:

- Commissioner, National Commission on Digestive Diseases, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH);
- Council Member, NIDDK;
- Member, Patient Reported Outcomes (PRO) Consortium, IBS Working Group, Critical Path Institute;
- Member, Advisory Committee to the Director of the Office of Research on Women's Health (CRWH);
- Severity Committee Member, Rome Foundation;
- Advisory Board Member, Pelvic Floor Disorders Network, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD);
- Advisory Board Member, Simon Foundation for Continence;
- Treasurer, Former Chairperson, Digestive Disease National Coalition.
IFFGD in the Media

Reporters and writers often contact IFFGD for information needed for articles about chronic digestive disorders. We sometimes link reporters with IFFGD Advisory Board members who agree to be interviewed. In addition, IFFGD often is quoted directly or referenced in news articles.

Some of the stories that have quoted IFFGD in the past year are listed here.

<table>
<thead>
<tr>
<th>Date</th>
<th>Article/Program Title</th>
<th>Source</th>
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<tr>
<td>03-29-2011</td>
<td>“During April, IBS Awareness Month, Be Aware of Signs You Should Not Ignore”</td>
<td>Boston Business Journal</td>
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<td>03-29-2011</td>
<td>“During April, IBS Awareness Month, Be Aware of Signs You Should Not Ignore”</td>
<td>KFLX-Fox TV (West Palm Beach, FL)</td>
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<td>03-29-2011</td>
<td>“IBS Awareness Month: Signs You Should Not Ignore”</td>
<td>KFMB-Radio &amp; TV (San Diego, CA)</td>
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<td>04-01-2011</td>
<td>“International IBS Awareness Month”</td>
<td>Precise Forward Planning Service</td>
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<td>April 2011</td>
<td>“April is IBS Awareness Month”</td>
<td>realage.com</td>
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<td>April 2011</td>
<td>“Are You Familiar With IBS?”</td>
<td>Healthy Woman Today</td>
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<td>04-12-2011</td>
<td>“Dr. Sudarshan Jadcherla Receives Pediatric Science Award”</td>
<td>nationwidechildrens.org/</td>
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<td>04-13-2011</td>
<td>“IFFGD Presents Award to Milwaukee Pediatric GI Researcher”</td>
<td>wisbusiness.com</td>
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<td>05-04-2011</td>
<td>&quot;IBS Advocacy Opportunity&quot;</td>
<td>about.com</td>
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<td>07-12-2011</td>
<td>&quot;IBS Advocacy: New Bill Needs Your Help&quot;</td>
<td>about.com</td>
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<td>08-01-2011</td>
<td>“Day of Fun on Lake Michigan to Benefit Kids GI Research”</td>
<td>Caledonia (WI) Patch</td>
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<td>08-01-2011</td>
<td>“Day of Fun on Lake Michigan to Benefit Kids GI Research”</td>
<td>milwaukeemoms.com</td>
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<td>08-01-2011</td>
<td>“DHA Southeastern Wisconsin Regatta”</td>
<td>onmilwaukee.com</td>
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<td>08-21-2011</td>
<td>“Regatta Raises Awareness, Funds”</td>
<td>Kenosha News</td>
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<td>08-22-2011</td>
<td>“How to Find an IBS Doctor”</td>
<td>about.com</td>
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<td>Fall 2011</td>
<td>“10 Foods That Help Relieve Constipation”</td>
<td>everydayhealth.com</td>
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<td>10-11-2011</td>
<td>“Taming Irritable Bowel Syndrome”</td>
<td>Healthymagination blog</td>
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<td>11-02-2011</td>
<td>“Best IBS Resources”</td>
<td>about.com</td>
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<td>“Veterans Day and IBS”</td>
<td>about.com</td>
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<td>12-05-2011</td>
<td>“Is Your Child’s Reflux/Spitting Up A Point of Concern?”</td>
<td>Troy Somerset Gazette (Troy, MI)</td>
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<td>12-08-2011</td>
<td>“Is Your Child’s Reflux/Spitting Up A Point of Concern?”</td>
<td>Atkinson County Citizen (Pearson, GA)</td>
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<td>Hesperia (CA) Resorter</td>
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<td>“Is Your Child’s Spitting Up A Point of Concern?”</td>
<td>KXO-Radio (El Centro, CA)</td>
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<td>12-26-2011</td>
<td>“Is Your Child’s Spitting Up A Point of Concern?”</td>
<td>Odessa (TX) American</td>
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<td>January/February 2012</td>
<td>“GIs and G.I.s”</td>
<td>Disabled American Veterans Magazine</td>
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<td>1-04-2012</td>
<td>“Is Your Child’s Reflux/Spitting Up A Point of Concern?”</td>
<td>Sutherland (VA) Monitor</td>
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<td>1-09-2012</td>
<td>“Is Your Child’s Reflux/Spitting Up A Point of Concern?”</td>
<td>Hughesville (PA) East Lycoming Shopper &amp; News</td>
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<td>1-11-2012</td>
<td>“Is Your Child’s Reflux/Spitting Up A Point of Concern?”</td>
<td>Franklinville (NJ) Sentinel</td>
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<td>02-28-2012</td>
<td>“IBS in Veterans”</td>
<td>about.com</td>
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