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Introducing the Digestive Health Alliance

This year marks the 20th Anniversary of the IFFGD. To honor this milestone, we have launched a grassroots initiative known as the Digestive Health Alliance™ (DHA) to further support and empower the Functional Gastrointestinal and Motility Disorders community. Please visit www.dha.org for additional information on DHA’s volunteer-driven programs, events, and activities.

Mission
The Digestive Health Alliance is the grassroots arm of IFFGD. We are a community of individuals affected by Functional Gastrointestinal and Motility Disorders (FGIMDs), digestive conditions about which little is understood and few treatment options exist. Individually, the prevalence of these diseases and disorders varies, and some can be extremely rare, but taken as a whole they impact millions of Americans. Our strength is in our numbers, and it is for this reason that we stand up together and speak out with one voice to advance science, improve patient care, and end the suffering caused by FGIMDs.
Multiple Ways to Get Involved and Join the Effort:

Fundraising
More than 90 percent of every contribution made through DHA goes directly to fund critical research activities focused on improving treatment options and finding cures, such as our Children’s GI Research Network and our Grants & Awards Program.

Upcoming fundraising opportunities include:
- DHA Southeastern Wisconsin Regatta in August, 2011.
- Volunteer led events in communities across the country throughout the year.
Examples of the type of fundraising events organized through the DHA took place in December 2010 when Jessica Ludy ran 26.2 miles in the California International Marathon in honor of a family member with chronic digestive issues; and April 2011 when Renee’ Pickle coordinated the 1st Annual DHA Walk by the Bay in Lynn Haven, FL. The IFFGD digestive health community, along with friends, family members, and community businesses rallied in support of these efforts — providing an inspiration to all of us.

Advocacy
Advocates work as a nationwide grassroots network to advance a legislative agenda that emphasizes bolstering federal support for FGIMDs research and improving patient care. Advocates make a difference by using their stories to educate legislators about FGIMDs and build meaningful relationships with their Members of Congress. Advocacy opportunities include:

- Coordinate congressional outreach through correspondence and local meetings.
- Attend Capitol Hill Advocacy Day and work for change in Washington, D.C.
**Awareness**

Increased awareness is an invaluable part of our overall effort to better educate healthcare providers about these conditions and to expand industry’s investment in innovative treatments. Volunteers take advantage of press and media opportunities in their communities and online by using their courageous stories as powerful tools to get the word out. Awareness opportunities include:

- Tell your Courageous Story online and in print.
- Become an Ambassador and raise the profile of FGIMDs in the media.

**Support**

We help support individuals working through the emotional, lifestyle, and healthcare challenges that come with managing FGIMDs. In this regard, DHA features a number of tools to assist patients in improving their health outcomes and in finding support, such as:

- Personal health management tools, like a Care Locator and a Clinical Trial Locator.
- A vibrant online community where individuals can connect with other people affected by FGIMDs.

**Action Months**

While we work together to advance the field of FGIMDs research, throughout the year we recognize the unique patient experiences that make up the broader digestive health community. Action Months provide the opportunity to fundraise, advocate, and raise awareness around specific conditions, including:

- Rare GI Diseases Action Month, February
- IBS & Lower GI Conditions Action Month, April
- Gastroparesis & Motility Disorders Action Month, July
- GERD & Upper GI Conditions Action Month, November
Advocacy

Capitol Hill Advocacy Day
In April of 2010, thought leaders and patients from across the country convened in Washington, D.C., to educate members of Congress about functional GI and motility disorders and to ask for their support for increased funding for federal research activities and improved patient care. This event featured advocacy training sessions, a review of our legislative priorities, and opportunities to meet other affected individuals.

Our 2011 Capitol Hill Advocacy Day will take place on Tuesday, June 14, and Wednesday, June 15, at the Phoenix Park Hotel in Washington, D.C. All affected individuals are invited to register and participate.

Bill Norton from IFFGD talks to Rep. Stephen Lynch (D-MA-9)
Digestive Disease National Coalition Public Policy Forum

IFFGD participated in the 21st Annual Digestive Disease National Coalition (DDNC) Public Policy Forum in Washington, D.C., in March 2011, by visiting congressional offices to discuss and urge: 1) renewed commitment to fund the National Institutes of Health (NIH); 2) meaningful funding increases for the Food and Drug Administration (FDA); and 3) implementation of the research recommendations of the National Commission on Digestive Diseases.

IFFGD Legislative Agenda

Throughout 2010, advocates conducted outreach to members of Congress to secure cosponsors for House Resolution 1309. This measure was drafted to raise awareness of functional gastrointestinal and motility disorders and to urge the National Institutes of Health (NIH) to expand support for research activities. The resolution was introduced in a bipartisan fashion by Congresswoman Tammy Baldwin (D-WI) and Congressman F. James Sensenbrenner (R-WI), and ultimately attracted eleven cosponsors before the 111th Congress adjourned in December.

As a result of the success of this effort, IFFGD drafted the Functional Gastrointestinal and Motility Disorders Research Enhancement Act, which congressional supporters may introduce in the 112th Congress.

Other IFFGD legislative efforts include:

- Increased funding for the National Institutes of Health (NIH)
- Re-Introduction and Passage of the Pediatric Consortium Establishment Act.
- Including “Functional GI Disorders” within Department of Defense (DOD) Medical Research Activities.
Comments and Testimony

• IFFGD President Nancy Norton, through her position on the Patient-Reported Outcomes Consortium, continues to work with the FDA and industry to improve the development of treatment options for patients with GI disorders.

• IFFGD Development Coordinator Dane Christiansen presented “Impact of Risk Management Programs: Patient Perspective” at the Drug Information Association’s Pharmacovigilance and Risk Management 2011 meeting. In this IFFGD presentation, we urged regulators and industry to carefully consider the patient perspective when communicating risk or weighing risk-benefit of treatments.

• IFFGD continues to urge members of the House and Senate Labor-Health and Human Services and Education Appropriations Subcommittees to increase funding for the FGIMDs research activities.

• IFFGD continues to urge the Department of Veterans Affairs and the Department of Defense to improve health outcomes for deployed military personnel that developed a functional GI disorder as a result of their service.

On behalf of IFFGD, President and Founder Nancy Norton recognized Representative Tammy Baldwin (D-WI-2) for her support for digestive health awareness and research.
Paving the Way for Change

Raising Awareness

In giving voice to patients and their families, IFFGD helps increase understanding and awareness about digestive disorders and their impact, not just on those affected but on the people around them and society at large. IFFGD delivers these messages to audiences through many new and traditional communications vehicles.

This outreach helps to:

- Reassure people affected by a chronic digestive disorder that they are not alone and to empower them to seek help.

- Emphasize to legislators the importance of research for digestive disorders.

- Remind healthcare professionals about patients’ perspectives and needs.

- Invite dialogue and help patients and caregivers find ways to discuss their complex and sometimes embarrassing symptoms.

We increase our efforts every year during IBS Awareness Month in April and GERD Awareness Week in November. In support of these informational campaigns, IFFGD distributes educational messages to the media and provides health reporters, patients, and community groups with Awareness Kits that contain informational publications and fact sheets.
Media Releases

Over the past year, IFFGD helped facilitate a number of stories about digestive disorders. Releases distributed for GERD Awareness Week and IBS Awareness Month provided a basis for media stories that could help increase awareness of these disorders.

November 2010 – GERD Awareness Week

Is It Heartburn or GERD?

April 2011 – IBS Awareness Month

Be Aware of Signs You Should Not Ignore

Special Opportunities

Online Link from RealAge®

During April the RealAge.com web site of Drs. Oz and Roizen posted a banner link to aboutIBS.org.

Los Angeles Times Supplement

IFFGD was invited to participate in a special supplement about Digestive Wellness that appeared in the Los Angeles Times last October. As part of this effort, William Norton contributed an article, “Heartburn or GERD? When to See a Doctor.”
Supporting Research

2011 Research Awards
In April 2011, IFFGD presented research awards to active investigators who are helping increase the medical community’s understanding of functional gastrointestinal and motility disorders while laying the foundation for more and better treatment options for patients. The goal of this program is to encourage clinicians and scientists to initiate digestive health research and to recognize and reward investigators for their efforts. We thank the Selection Committee members who reviewed the applications: Douglas Drossman, MD, Chair; Carlo Di Lorenzo, MD; Reza Shaker, MD; Yvette Taché, PhD; Peter Whorwell, MD; and Jackie Wood, PhD.

Individuals selected for the 2011 awards were recognized at IFFGD’s 9th International Symposium for Functional Gastrointestinal Disorders, held in Milwaukee. We were honored to have Dr. Stephen James, Director of the Division of Digestive Diseases & Nutrition of the National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK), on hand to offer remarks. Dr. James, along with Dr. Drossman, made the presentations.

We thank and congratulate our 2011 Research Award recipients for their outstanding achievements:

**Senior Investigator – Clinical Science**
Ronnie Fass, MD, FACP, FACG, Professor of Medicine, University of Arizona, Southern Arizona VA Health Care System, Tucson, AZ – Dr. Fass currently is involved in several research projects designed to clarify the underlying mechanisms of nonerosive reflux disease, functional heartburn, noncardiac chest pain, gastroparesis, and Barrett’s esophagus as well as to improve diagnostic tools and management methods.

**Senior Investigator – Basic Science**
Million Mulugeta, MVSc, DVM, PhD, Adjunct Professor, Division of Digestive Diseases, School of Medicine, Los Angeles, CA – Dr. Mulugeta is working to create a better understanding of the processes underlying stress-related gastrointestinal disorders in order to develop effective therapies. His research seeks to examine the molecular basis of compounds related to the body’s reaction to stress, and the impact these compounds have on digestive functioning and pain response.
Junior Investigator – Basic Science
Adrian Miranda, MD, Assistant Professor of Pediatrics, The Medical College of Wisconsin, Milwaukee, WI – Dr. Miranda’s research focuses on intestinal pain and functional bowel disorders, including understanding how an adverse, early life experience can cause physical changes in the body that can cause painful conditions affecting the digestive tract later in life. He has investigated new pathways in the development of pain sensitivity and changes in the structure and function of nerves.

Senior Investigator – Pediatrics
Samuel Nurko, MD, MPH, Assistant Professor of Pediatrics, Harvard Medical School, Children’s Hospital Boston, Boston, MA – In his research, Dr. Nurko studies many digestive problems in children ranging from understanding and treating pediatric defecation problems, to examining different aspects of upper-digestive tract conditions that are present in childhood. He has particularly pursued research on esophageal motility disorders and the effect of inflammation on motility.

Senior Investigator – Pediatrics
Sudarshan Jadcherla, MD, DCH, FRCP (Irel.), AGAF, Professor, Department of Pediatrics, Neonatology, Pediatric Gastroenterology & Nutrition Sections, The Ohio State University College of Medicine; Director, The Neonatal and Infant Feeding Disorders Program, The Research Institute at Nationwide Children’s Hospital, Columbus, OH – In his research, Dr. Jadcherla studies the upper digestive tract, specifically the physical and molecular mechanisms of swallowing and airway protection, with a goal of improving safe feeding in children. His clinical research works to pave the way for improved diagnosis and treatments in infant dysphagia, GERD, and chronic lung disease.

Junior Investigator – Pediatrics
Shaman Rajindrajith, MBBS, MD, MRCPCH, Consultant Pediatrician and Senior Lecturer in Pediatrics, University of Kelaniya, Ragama, Sri Lanka – Dr. Rajindrajith’s research is helping provide a better understanding of functional gastrointestinal and motility diseases in children, particularly in the developing world. His current activities include an assessment of gastrointestinal motility in children with abdominal pain related disorders, understanding of aerophagia and cyclic vomiting in Sri Lankan children, and quality of life issues in children.
2011 IFFGD Research Award Recipients and Presenters

Left to Right, 1st Row: Stephen James, MD; William Norton, IFFGD; Nancy Norton, IFFGD; Douglas Drossman, MD; 2nd Row: Million Mulugeta, MD; Shanan Rajindrajith, MD; Sudarsban Jadcherla, MD; Samuel Nurko, MD; Adrian Miranda, MD; Ronnie Fass, MD.
IFFGD Grants
IFFGD continues to support of the Children’s GI Research Network. Many children suffer with painful, disabling, and in some cases life-threatening functional GI and motility disorders. The majority of these conditions progress into adulthood and become increasingly burdensome and difficult to manage. Our Children’s GI Research Network was established to connect pediatric GI research centers across the country so that data could be shared and collaborative research projects could be conducted. The Network is currently executing projects designed to improve diagnosis and treatment of these conditions in children.

Left to Right: Manu Sood, MD, Children’s Hospital Wisconsin; Jeffery Hyams, MD, Connecticut Children’s Medical Center; Carlo Di Lorenzo, MD, Nationwide Children’s Hospital Ohio; Samuel Nurko, MD, Children’s Hospital Boston; Miguel Saps, MD, Children’s Memorial Hospital Chicago. (Not pictured, Paul Hyman, MD, Children’s Hospital New Orleans)
Providing Information & Support

Call Center
Each year, thousands of people call IFFGD’s toll-free phone number or send letters or emails asking for help. IFFGD’s caring, knowledgeable staff responds to all these inquiries, helping callers find reliable, medically sound information and sort out treatment options that can seem overwhelming and confusing.

Internet
Many of the individuals who contact us each year first learn about IFFGD online. We maintain a family of websites, providing a credible Internet resource. These sites include:

- IFFGD.org
- aboutConstipation.org
- aboutIBS.org
- aboutIncontinence.org
- aboutGERD.org
- aboutgiMotility.org
- aboutKidsGl.org
- giResearch.org
- DHA.org

IFFGD also maintains a vibrant presence on Facebook, the popular online social community. More than 2,000 “friends” receive our regular updates and postings. This interactive forum also provides a way for people to post questions and engage in conversations about a wide ranging number of topics regarding their digestive health.
The IFFGD quarterly publication, *Digestive Health Matters*, provides readers throughout the world with accurate, up-to-date information about digestive health. It also offers perspectives for general audiences on scientific advances. Professionals are updated on current topics that are relevant to their practices, research interests, and patient concerns. Distribution is in print and online.

Information provided is aimed at educating, increasing awareness, enhancing the doctor-patient relationship, improving outcomes, and mobilizing the community to take action around issues of interest. This includes . . .

- Original articles to reliably inform about general health topics
- Research news about new findings
- Treatment news about progress in new and developing products from our Industry Council members
- Community news and stories about personal experiences and actions of patients or family members
- Foundation news about our activities
- Legislative, regulatory, and action alerts

**Publications Library**

With more than 240 fact sheets and brochures, persons interested in a functional GI or motility disorder can find a wealth of helpful information. Much of the information in our library is written by thought leaders specifically for IFFGD readers and is not available through other sources.
Reaching out to Clinicians and Scientists

International Symposium on Functional Gastrointestinal Disorders

The 9th International Symposium on Functional Gastrointestinal Disorders was held from April 8 to 10, 2011, in Milwaukee, Wisconsin. IFFGD jointly sponsored this biennial symposium with the University of Wisconsin School of Medicine and Public Health, Office of Continuing Professional Development in Medicine and Public Health.

This unique program attracted a multidisciplinary audience of scientists, researchers, clinicians and industry leaders from all over the world.

Leading experts presented information and led discussions. Interactive sessions and networking opportunities produced stimulating discussions, lively exchanges of ideas, and collaborative opportunities.

The knowledge gained benefited investigators, clinicians and, ultimately, patients with functional gastrointestinal and motility disorders.
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.

In 2010, IFFGD participated in eight major meetings:

- American College of Gastroenterology
- American Society of Colon and Rectal Surgeons
- Digestive Disease Week
- National Conference for Nurse Practitioners
- Neurogastroenterology and Motility 2010 Joint International Meeting
- Pri-Med Midwest
- Pri-Med South
- World Continence Meeting

IFFGD exhibited at a public health fair held at the James R. Thompson Center in Chicago, Illinois, held in conjunction with World Continence Week.
A Strong Voice in the Health Community

IFFGD is represented in many leadership positions in the health care community including:

Nancy J. Norton

- Commissioner, National Commission on Digestive Diseases, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)
- Member, Patient Reported Outcomes (PRO) Consortium, IBS Working Group, Critical Path Institute
- Rome Foundation, Severity Committee Member
- Pelvic Floor Disorders Network, NICHD, Advisory Board
- University of North Carolina Center for Functional GI and Motility Disorders, Advisory Board
- Advisory Board Member, Simon Foundation for Continence
- American Neurogastroenterology and Motility Society, Ad Hoc Council Member
- Digestive Disease National Coalition, Treasurer, Former Chairperson

Dane Christiansen

- National Digestive Disease Information Clearinghouse, Board Member
IFFGD in the Media

IFFGD is regularly contacted by reporters seeking reliable information about GI topics or fact-checking for articles. IFFGD also often arranges interviews for reporters with members of our Medical Advisory Board and/or patients.

In addition to directly providing information or connecting them with various patient or professional resources we are regularly directly quoted or referenced in various media.

Over the past year these have included a range of diverse outlets online or in print such as . . .

- Los Angeles Times
- New York Times
- CNN
- WebMD
- RealAge
- LiveStrong
- Health Day News
- Exceptional Parent Magazine
- Modern Medicine
- Medical News Today
- EndoNurse
- Gastroenterology & Endoscopy News

among many others.
IFFGD is a nonprofit organization designated under the U.S. IRS code 501(c)(3). Started in 1991 by one person struggling with the challenges of a chronic GI disorder, our mission is to inform, assist, and support people affected by gastrointestinal disorders.