



**IFFGD**

**Working Toward Change**

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**IFFGD**  
International Foundation for  
Functional Gastrointestinal Disorders

**Education and Research  
Working for Patients  
With Physicians, Nurses and  
Other Health Professionals  
We're Putting it All Together**



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# Paving the Way for Change

## Raising Awareness

IFFGD works to raise awareness and understanding about digestive disorders and the burden they create for individuals, families, and society. We deliver these messages to a wide audience through a variety of types of media. The benefits from this outreach are immeasurable.

- People affected by a digestive disorder learn they are not alone and are empowered to seek help
- Legislators understand the importance of supporting research for digestive disorders
- Healthcare professionals are reminded of the patients' perspectives and needs in these chronic conditions
- Symptoms that may seem unmentionable become easier to talk about

We intensify our awareness efforts during IBS Awareness Month in April and GERD Awareness Week in November. In support of these events, IFFGD releases educational messages to the media and provides specialized Awareness Kits with informational brochures and fact sheets.

## Media Releases

April 2008

### Is it IBS?

Millions of people living with the symptoms of irritable bowel syndrome (IBS) do not know they have the disorder . . .

November 2007

### When Is Simple Heartburn Not So Simple?

Most of us have felt it-burning pain that starts behind the lower breastbone and may even radiate up toward . . .

## Reaching Employers

Employees who have IBS want to remain productive members of the work force. As a way to help employers understand how they can help achieve this goal, IFFGD participated in the 2008 edition of *Health Care Buyer*, an annual resource that reaches CFOs, wellness managers, benefits directors and human resource professionals at 20,000 companies throughout the U.S. employing 550 or more employees. IFFGD provided a guest column entitled, "The High Cost of IBS: Understanding & Addressing Issues Can Improve Productivity & Performance" and an advertorial introducing IFFGD as a resource.

*I manage:*

- the marketing department
- the office mentoring program
- my symptoms of IBS

*IBS. A little knowledge can make a big difference.*

Symptoms of Irritable Bowel Syndrome (IBS) can be managed. Let the International Foundation for Functional Gastrointestinal Disorders (IFFGD) be a resource for you. We can help your employees be the productive workers they want to be.

For more information, call (888) 964-2001 or visit [www.aboutIBS.org](http://www.aboutIBS.org) or [www.iffgd.org](http://www.iffgd.org).

## Conducting Research

### IBS Unmet Needs Survey

More than 2,000 people have participated to date in a comprehensive online study conducted by IFFGD in collaboration with the UNC Center for Functional GI and Motility Disorders. The goal of the study is to help determine the illness experience and unmet needs of people who have been diagnosed with irritable bowel syndrome. A report on the 2007 findings will be released in 2008.

### Focus Groups

In October 2007, IFFGD, working with the Rome Foundation, conducted three focus groups to help better understand the personal impact of irritable bowel syndrome (IBS). Sixteen people who have been diagnosed with IBS participated. The focus groups were moderated by IFFGD Advisory Board Members Douglas Drossman, MD and Lin Chang, MD, who are well known for their work in treating and studying IBS. Participants described with candor their symptoms, which ranged from moderate to severe. Their comments will help ensure that the patient perspective is accurately represented in clinical research.

## Supporting Research

### 2008 Research Grants

In January 2008, IFFGD issued a call for applications for two research grants – one supported by a generous donation from the Schooner Foundation and one by IFFGD – each in the amount of \$50,000. The grants will be awarded in September 2008.

These grants are available to investigators for research related to functional gastrointestinal and motility disorders, and neurogastroenterology. IFFGD is seeking proposals for research that will ultimately lead to improvements in the understanding of these disorders, their pathophysiology, and the care of patients. A preference is given to clinical research, as well as basic research that is translational in nature.

### 2007 Research Awards

In April 2007, IFFGD presented research awards to six active investigators working to understand the functional gastrointestinal and motility disorders in adults and children. The recipients were:

- **Bruce D. Naliboff, PhD**, Senior Investigator, Clinical Science
- **Magnus Simrén, MD, PhD**, Junior Investigator, Clinical Science
- **Brennan M. R. Spiegel, MD, MSHS**, Junior Investigator, Clinical Science
- **Sylvie Bradesi, PhD**, Junior Investigator, Basic Science
- **Paul E. Hyman, MD**, Senior Investigator, Pediatrics
- **Miranda A. L. van Tilburg, PhD**, Junior Investigator, Pediatrics

## 2009 Research Awards

In 2009, IFFGD will again present research awards to active investigators who have a record of research interest in basic mechanisms or clinical aspects of functional gastrointestinal and motility disorders, and neurogastroenterology. These awards are intended to encourage young investigators to enter into this area of digestive health research and to acknowledge more senior investigators for their contributions to the overall knowledge of gastrointestinal disorders.

Individuals selected for the 2009 awards will be recognized at IFFGD's 8th International Symposium for Functional Gastrointestinal Disorders, which will be held in Milwaukee, Wisconsin, next April.



## Advocacy

### IFFGD Hill Day

On April 1–2, 2008, IFFGD brought together thought leaders in the field of functional gastrointestinal and motility disorders in Washington, DC, for the IFFGD's Capitol Hill Day. Participants had the opportunity to be briefed on current legislative issues. They also engaged in a day of visits with their members of Congress to inform them of issues affecting the functional gastrointestinal disorders community and urge their support of IFFGD's legislative priorities. We were also pleased to honor Wisconsin Senator Herb Kohl for his support of these issues with an IFFGD Congressional Leadership Award.



Senator Herb Kohl (D-WI) was honored for his support of digestive disease research with an IFFGD Congressional Leadership Award presented by Nancy Norton.

## IFFGD Hill Day Participants



Front to back, left to right: Nicholas Talley, MD; Susan Lucak, MD; Carmen Butschlick; Douglas Drossman, MD; Carlar Blackman; Kimberly Meyer; William Chey, MD; Cathy Coulter; Lucinda Harris, MD; Cara O'Brien; J. Patrick Waring, MD; William Whitehead, PhD; Henry Parkman, MD; Nancy Norton; Ann Ouyang, MD; Nancy Hartman; Dane Christianson; Dale Dirks; Carlo Di Lorenzo, MD; Brennan Spiegel, MD; William Norton; Shaoyong Yu, MD; Braden Kuo, MD; Jack Wood, PhD; Margaret Heitkemper, PhD

## IBS Research and Treatment Act

Recent discoveries have led to potential advancements in the field of irritable bowel syndrome (IBS) research. To capitalize on these promising areas of endeavor, IFFGD has been working with the office of Congressman Eliot Engel (D-NY-17th) to draft legislation which would create an NIDDK-coordinated research and treatment network for IBS.

## Digestive Disease National Coalition Public Policy Forum and Institutional Member Forum

On March 9th and 10th, 2008, advocates representing the digestive disease community attended the 18th Annual Digestive Disease National Coalition (DDNC) Public Policy Forum and Institutional Member Forum in Washington, DC. The DDNC is the foremost voice of digestive disease patient organizations, physician societies, and industry partners on Capitol Hill. IFFGD's broader legislative priorities were well represented on Capitol Hill as Forum attendees met with members of Congress.

## FDA Guidance Document on IBS Treatments

Patient access to functional gastrointestinal disorders treatments has been greatly reduced due to regulatory ambiguities at the FDA. Furthermore, the vague regulatory requirements have coupled with the current lack of resources at FDA to create a situation where few functional gastrointestinal disorders treatments are being developed. To address these circumstances, IFFGD has been working with medical researchers, Congress, and the FDA to have a guidance document released which would outline the approval pathway for functional gastrointestinal treatments and the implications of adverse events that occur during post-market surveillance.

# Providing Information & Support

## Call Center

Through IFFGD's toll-free phone number and email correspondence, caring, knowledgeable IFFGD staff members assist thousands of people each year who are looking for help for symptoms. IFFGD staff members patiently listen to callers and help them find reliable information and sort out treatment options that can seem overwhelming and confusing.

## Internet

IFFGD maintains a family of eight websites, providing a credible internet resource. These websites are continually updated with new content. Some of the features added most recently include:

- A Video Corner page featuring top clinicians and researchers discussing key topics in easy-to-understand tone.
- A Clinical Corner page where digestive health professionals on our medical Advisory Board provide comprehensive answers to puzzling questions about digestive health.
- The addition of health information in Spanish.
- A Courageous Stories page where individuals with functional GI disorders, motility disorders, or pelvic floor disorders share their personal experiences of daily living with these chronic conditions. The content is previewed before posting and editorial comment is often provided. This is an insightful section of our websites with often therapeutic benefit.

## Digestive Health Matters

The IFFGD quarterly publication, *Digestive Health Matters* provides practical information about digestive health. It also interprets recent discoveries in basic science, offering new perspectives for general audiences. Professionals are updated on current topics that are relevant to their practices, research interests, and patient concerns.



*Digestive Health Matters* has provided readers in 127 countries with accurate, up-to-date healthcare information. Each issue is filled with original content authored specifically for our readers based on their feedback. Recent topics include:

- Chronic Pain Management Tips
- Helping Children and Adolescents Cope with Abdominal Pain
- Sex Differences in Abdominal Pain
- Dietary Aspects of Irritable Bowel Syndrome
- Procedure Costs and Surgical Rates in IBS Patients
- Changes in Bowel Control at Childbirth
- What Patients Know and Would Like to Know about IBS
- Bowel Incontinence and Aging
- Distal Esophageal Spasm (formerly Diffuse Esophageal Spasm)

## Publications Library

With more than 200 fact sheets and brochures, persons affected by 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.

### New Publications

- Stress and Irritable Bowel Syndrome: Unraveling the Code
- What Patients Know About Irritable Bowel Syndrome (IBS) and What They Would Like to Know
- Relationships and Irritable Bowel Syndrome
- Understanding Intestinal Gas
- Nocebo Effects: They can Impair Health Care
- Medical Procedure Costs and Surgical Rates in Patients with Irritable Bowel Syndrome
- Why Does Milk Bother Me?
- How to Prepare for Tests
- Dietary Aspects of Irritable Bowel Syndrome
- The Medical History: How to Help Your Doctor Help You
- Chronic Pelvic Pain and the Overlap of Chronic Pelvic Pain Disorders
- Neurogenic Dysphagia: Disorders and Conditions that Disrupt Swallowing
- Home Based Guided Imagery to Treat Pediatric Functional Abdominal Pain

## Reaching out to Clinicians and Scientists

### Professional Meetings

IFFGD exhibits at major medical meetings to talk with clinicians about issues surrounding the diagnosis and treatment of functional GI and motility disorders. IFFGD exhibited in five major meetings in 2007.



### International Symposium

The 8th International Symposium on Functional Gastrointestinal Disorders will be hosted by IFFGD on April 17-19, 2009 at the Pfister Hotel, in Milwaukee, Wisconsin.

## Partnerships with Professional Groups

### American Neurogastroenterology and Motility Society (ANMS)

We are pleased to provide a column in *Digestive Health Matters* contributed by members of the American Neurogastroenterology and Motility Society (ANMS).

### Functional Brain-Gut Research Group (FBG)

Functional Brain-Gut Research Group (FBG) – IFFGD has long maintained an association with the Functional Brain-Gut Research Group. FBG has been supportive of our physician education efforts, notably the biennial International Symposium on Functional GI Disorders.

### Rome Foundation

Nancy Norton is a Committee Member on the Rome III: The Functional Gastrointestinal Disorders working team on Gender, Age, Society, Culture, and the Patient's Perspective.

## A Strong Voice in the Health Community

### IFFGD President Presented Patient Perspective to NIH State of the Science Conference

Nancy Norton, founder and president of the International Foundation for Functional Gastrointestinal Disorders (IFFGD), presented the “Impact of Fecal and Urinary Incontinence on Health Consumers - Barriers on Diagnosis and Treatment - A Patient Perspective” at a State-of-the-Science Conference held in December 2007. The conference was sponsored by the Office of Medical Applications of Research (OMAR) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the NIH.



Following the series of scientific presentations and open public discussions, an impartial, independent panel issued a Conference Report on the Prevention of Fecal and Urinary Incontinence in Adults.

IFFGD was instrumental in bringing this conference about. We are working now to see that the report's conclusions are well known and that Congress supports the report's recommendations.

### Membership on National Commission on Digestive Diseases

The NIDDK division of the National Institutes of Health (NIH) established the National Commission on Digestive Diseases to draft a Long-Range Research Plan for Digestive Disease Research. The Commission's Research Plan will provide guidance to the NIH, the investigative community, and the voluntary health community in pursuing promising avenues to address digestive diseases. IFFGD's president and founder, Nancy Norton, was one of 16 Commissioners appointed by the director of the NIH to serve on the Commission. She has been working to further functional gastrointestinal disorders research as the Vice Chair of the Commission's Functional Gastrointestinal Disorders and Motility Disorders Working Group. Additionally, she serves as Vice Chair of the Diseases of the Colon and Rectum Work Group.

In 2008, the commission will release a Long-Range Research Plan for Digestive Diseases that addresses 12 major themes for digestive diseases. IFFGD will engage members of Congress to promote the report and encourage swift implementation of its recommendations.

### Membership on Advisory Committee on Research on Women's Health

As a Member of the Advisory Committee to the Director of the Office of Research on Women's Health, Nancy Norton is one of up to 18 members appointed by the director of the National Institutes of Health. This committee provides input about appropriate research activities to be undertaken by the national research institutes with respect to women's health research. It also makes recommendations regarding the inclusion of women in clinical trials.

## IFFGD in the Media

February 20, 2008	“Thomson Today”	www.PR-USA.net
February 15, 2008	“Harnessing the Mind to Manage Irritable Bowel Syndrome”	Health Day News
February 14, 2008	“NIH Report on Digestive Disease Research”	About.com
February 4, 2008	“Administration Request for FDA Fails to Meet U.S./Global Needs”	www.centredaily.com
November 24, 2007	“GERD: A Growing Concern”	Health Scout News
October 4, 2007	“Heartburn Can Indicate Serious Disorder”	The Sacramento Observer
September 19, 2007	“AST-120, A Platform Drug with Potential in 5 Indications”	PharmaLive.com
September 15, 2007	“Enemas are Ineffective in Pediatric Constipation”	Family Practice News
August 14, 2007	“Acid Reflux Test Easier to Swallow”	Newark (GA) Ledger-Enquirer
August 1, 2007	“Functional Abdominal Pain Linked to Depression”	Pediatric News
July 13, 2007	“Advocate South Suburban Hospital Suggests Ways to Avoid Heartburn At Summertime Gatherings”	Medical News Today
June 25, 2007	“Incontinence”	www2.oprah.com

June 1, 2007	“Coping Profiles May Help Treat Abdominal Pain”	Family Practice News
May 23, 2007	“Survey Identified Everyday Impact of Digestive Disease on Moms and Kids”	PR Newswire
May 17, 2007	“Deadly Infection an Evolving Threat”	Bangor Daily News
May 1, 2007	“Diverticulitis”	Care Notes (en espanol)
May 1, 2007	“IBS Vs. IBD and Other Tummy Aches”	Medical Laboratory Observer
April 29, 2007	“Esquire Is Looking for a Few Good Men” (Celebrity Handbag Auction)	Chicago Tribune
April 26, 2007	“Buy Celeb Handbags for a Good Cause”	ETonline
April 24, 2007	“Bag It” (Celebrity Handbag Auction)	Milwaukee Journal Sentinel
April 22, 2007	Morning News (Celebrity Handbag Auction)	WTMJ-TV (NBC, Milwaukee)
April, 2007	“IBS Awareness”	Homewatch Care Givers

Oprah & Friends. On June 25, 2007 Nancy Norton of IFFGD was featured on Oprah & Friends Radio. Dr. Mehmet Oz talked with Nancy about causes of incontinence and what people can do to find treatment.

## IFFGD

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