IFFGD
International Foundation for Functional Gastrointestinal Disorders

Education and Research
Working for Patients
With Physicians and Allied Health Professionals
We’re Putting it All Together
Providing Support

Call Center

IFFGD’s toll-free phone number and email account put people in touch with a caring, knowledgeable representative that can assist them in seeking help for symptoms and sorting out treatment options that can seem overwhelming and confusing.

Publications Library

With over 100 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 to laypeople through any other source.

Some of our new article topics include:
- What is Pelvic Pain?
- Chronic Constipation
- GERD from Diagnosis to Treatment
- Pregnancy and IBS
- Complementary and Alternative Treatments
- Does IBS Cause other Disease?
- Gastroparesis
- IBS or Something Else?
- Alarm Symptoms – Cause for Alarm?
- IBS in Children
- Managing Bowel Incontinence: Dietary Measures
- Problems after Surgery for Hirschsprung’s Disease
- Achalasia
- Long-term Safety of PPIs
- Gastroparesis: Dietary and Nutritional Recommendations
- Treatment-Resistant Constipation in Children
Paving the Way for Change

Raising Awareness

IFFGD continually works to raise awareness and understanding about digestive disorders and the burden they create for individuals, families, and society. With the help of the media, our messages reach a wide audience. The benefit from this is immeasurable.

- People affected by a digestive disorder learn they are not alone and find the courage to seek help
- Legislators understand the importance of supporting research for digestive disorders
- Healthcare professionals are reminded of the patient perspective in these chronic conditions and why it is important to help them find relief
- 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. The kits are available upon request to anyone who contacts IFFGD.
Press Releases

Throughout the previous year, newspapers across the country printed IFFGD releases.

April, 2005
Bringing One Of America's Most Common Health Issues To Light
Understanding IBS Reduces Stigma Associated With Condition, Helps Sufferers Get Treatment

November, 2005
GERD Costs America Nearly $2 Billion Each Week in Lost Productivity
GI Disorder Affects 5 to 7 Percent of People Worldwide

February, 2006
Is It Irritable Bowel Syndrome Or Something Else?

March, 2006
Nancy Norton one of Five New Members Named to NIH Advisory Committee on Research on Women's Health

April, 2006
Nancy Norton Named to National Commission on Digestive Diseases
Educating Healthcare Professionals

**International Symposium on Functional Gastrointestinal Disorders**

The 6th International Symposium on Functional Gastrointestinal Disorders was hosted by IFFGD on April 7-10, 2005.

This biennial meeting has been described as "an educational jewel," attracting hundreds of scientists and health care professionals from around the world as well as representatives of the National Institutes of Health and the Food and Drug Administration.

The unique meeting provides a full schedule of plenary sessions and workshops devoted solely to functional GI and motility disorders. In 2005, over 80 noted international experts in the field of functional gastrointestinal disorders presented new and developing knowledge for the benefit of investigators, health care providers, and ultimately patients.

The symposium is jointly sponsored by the Office of Continuing Medical Education, University of Wisconsin Medical School and the International Foundation for Functional Gastrointestinal Disorders in cooperation with the Functional Brain-Gut Research Group.

**Save the date!**
7th International Symposium on Functional Gastrointestinal Disorders
April 12-15, 2007
The Pfister Hotel, Milwaukee Wisconsin
Reaching out to Clinicians

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.

During 2005, IFFGD exhibited in five major meetings:
- 6th International Symposium on Functional Gastrointestinal Disorders
- ASCRS (American Society of Colon and Rectal Surgeons)
- DDW (Digestive Disease Week)
- ACG (American College of Gastroenterology)
- AAFP (American Academy of Family Physicians)

Film and television personality Cybill Shepherd visits the IFFGD booth during DDW, 2005
Educating Patients

Digestive Health Matters

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

*Digestive Health Matters* goes out to 120 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:

- Gastroparesis
- Chronic constipation
- Achalasia
- Alarm symptoms
- Hirschsprung’s disease
- Constipation in children
- Is it IBS or something else?
- Biofeedback and incontinence
INTERNET

IFFGD hosts a family of eight websites, providing a credible internet resource. With an excess of questionable and biased information available online, our presence as a trusted provider of healthcare information is more important than ever.

Coming Soon: A New look for IFFGD Websites
Supporting Research

Research Awards

In 2005, IFFGD once again presented research awards to active investigators who have a record of research interest in basic mechanisms or clinical aspects of functional gastrointestinal and motility disorders.

The awards are intended to help young investigators get started in their research and to acknowledge more senior investigators for their contributions to the overall knowledge of gastrointestinal disorders.

The individuals selected for awards were recognized at IFFGD's 6th International Symposium for Functional Gastrointestinal Disorders held in Milwaukee, WI on April 7-10, 2005. Allen M. Spiegel, MD, former Director, NIH National Institute of Diabetes and Digestive and Kidney Diseases participated in the ceremony and presentation of the awards.

We congratulate the 2005 IFFGD Research Award recipients for their outstanding achievements:

**Senior Investigator - Clinical Science**
Fernando Azpiroz, MD, PhD
Hospital General Vall d'Hebron, Barcelona, Spain

**Senior Investigator - Basic Science**
Yvette Tache, PhD
West LA-VA Medical Center, UCLA,
Los Angeles, CA
Junior Investigator - Clinical Science
Shaheen Hamdy, MRCP, PhD
Hope Hospital, Salford, United Kingdom

Junior Investigator - Basic Science
Michael Pezzone, MD, PhD
University of Pittsburgh, Pittsburgh, PA

Pediatric Investigator - Clinical Science
Rachel Rosen, MD, MPH
Children’s Hospital Boston, Boston, MA

Pediatric Investigator - Basic Science
Bridgett Southwell, PhD
Murdoch Childrens Research Institute, Royal
Children’s Hospital, Melbourne, Australia

2005 IFFGD Research Award Recipients

Pictured: Southwell, Pezzone, Tache, Drossman, Norton, Spiegel, Rosen, Azpiroz, and Hamdy
IFFGD Hill Day

On May 3, 2006, IFFGD brought together thought leaders in the field of functional GI and motility disorders to encourage increased funding of biomedical research at the National Institutes of Health (NIH).

Six teams made a total of thirty-three Congressional visits to educate Senators and Representatives about the impact functional GI and motility disorders have on their constituents and stress the need for NIDDK to sponsor additional research in this area. NIDDK currently uses 1% of its budget to investigate these disorders.

Congressman Eliot Engel (D-NY) was honored for his support of this issue with an IFFGD Congressional Leadership Award during a dinner hosted in his honor.
IFFGD Hill Day participants
Front to back, left to right: Lin Chang, MD; Marcelo Barreiro, MD; Lucinda Harris, MD; Carmen Butschlick, IFFGD; Nicholas Talley, MD; Nancy Norton, IFFGD; Sara Arnold, IFFGD; Henry Parkman, MD; Douglas Drossman, MD; Braden Kuo, MD; Carlo DiLorenzo, MD; Audra Baade, IFFGD; Albena Halpert, MD; G. Richard Locke III, MD; William Chey, MD; Susan Lucak, MD; Cara O’Brien, IFFGD; Emeran Mayer, MD; Jackie Wood, PhD; William Norton, IFFGD; Nancy Hartman, IFFGD; Margaret Heitkemper, PhD
Congressional Testimony

IFFGD has worked for years to encourage U.S. Congressional funding of functional GI and motility disorders through the National Institutes of Health (NIH). In 2005, IFFGD once again provided testimony to Congress, advocating for increased funding for functional GI disorders research at the National Institutes of Health (NIH).

IFFGD Congressional Testimony Regarding Fiscal Year 2006 Funding for Functional Gastrointestinal and Motility Disease Research

Summary of Fiscal Year 2006 Recommendations:

- Provide a 6% increase for FY 2006 to the National Institutes of Health (NIH) budget. Within NIH, provide proportional increases of 6% to the various institutes and centers, specifically, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

- Continue to accelerate funding for extramural clinical and basic functional gastrointestinal research at NIDDK.

- Continue to urge NIDDK to develop a strategic plan on Irritable Bowel Syndrome with the purpose of setting research goals on IBS and functional bowel diseases and disorders.

- Urge the National Institute of Child Health and Human Development (NICHD) and NIDDK to continue to support research into fecal and urinary incontinence, including the development of a standardization of scales to measure incontinence severity and quality of life and to
develop strategies for primary prevention of fecal incontinence associated with childbirth.

- Provide funding to NIDDK and the National Cancer Institute (NCI) for more research on the causes of esophageal cancer.

Report language submitted on behalf of IFFGD to the Senate Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill, 2006

**Incontinence.** – Many otherwise healthy, active individuals suffer from incontinence. Fecal incontinence, also called bowel incontinence, affects people of all ages and is associated with a wide variety of causes. The Committee is pleased that NIDDK is contributing to the development of standardized approaches to measure incontinence and urges NIDDK to continue collaborating with NICHD on the incontinence state-of-the-science conference and on appropriate follow-up to this conference.

**Irritable Bowel Syndrome.** – The Committee is pleased that NIDDK is formulating an action plan for digestive diseases and that irritable bowel syndrome [IBS] will be a focus area of this overall plan. However, given the increasing frequency of IBS and the Committee’s long-standing interest in this condition, the Committee strongly urges the NIDDK to complete this digestive disease plan as quickly as possible.
A Strong Voice in the GI Community

**IFFGD President Appointed to NIH Advisory Committee**

Nancy Norton, Founder and President of the International Foundation for Functional Gastrointestinal Disorders was one of five new members appointed to the Advisory Committee on Research on Women’s Health (ACRWH) of the National Institutes of Health (NIH).

The ACRWH was established to ensure that research conducted and supported by NIH adequately addresses issues regarding women’s health. The committee is composed of up to 18 members who are appointed by the NIH director.

**IFFGD President Appointed to the National Commission on Digestive Diseases**

Nancy Norton is one of sixteen members appointed to the National Commission on Digestive Diseases.

The Commission will develop a Long-Range Research Plan for Digestive Diseases. As part of the Research Plan, the Commission will assess the state-of-the-science in digestive diseases and the related NIH research portfolio, with a view toward identifying areas of research challenge and opportunity. The Commission's Research Plan will then guide the NIH—along with the investigative and lay communities—in pursuing important research avenues to combating digestive diseases.
Digestive Disease National Coalition

In March of 2006, IFFGD participated in the Digestive Disease National Coalition’s Public Policy Forum. Coalition members met with Congressional staff to raise their awareness about the impact of digestive disease in the community and stress the importance of research to find new and more effective treatments.

IFFGD representatives met with the offices of Senators Herb Kohl and Russ Feingold, as well as Representatives Gwen Moore and F. James Sensenbrenner. We advocated for increasing funding for the National Institutes of Health by 5 percent. Specifically we asked for an increase within the National Institute of Diabetes, Digestive and Kidney Diseases, where the majority of funding for digestive diseases takes place.
Liaisons with Professional Groups

American Motility Society (AMS)

We are pleased to have introduced a new column in *Digestive Health Matters* contributed by members of the American Motility Society (AMS). The articles contain practical information for patients affected by gastrointestinal motility disorders, and are accompanied by information from AMS about activities and challenges in the field.

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. More recently, we are pleased to have introduced a new patient education column in *Digestive Health Matters* contributed by members of FBG. The column will look at research advances and include management tips from clinicians along with other helpful topics.
**IFFGD in the News**

**JAMA**

In March of 2006, IFFGD was cited and quoted in the *JAMA* Medical News and Perspectives section: “Silence Masks Prevalence of Fecal Incontinence.” Despite its prevalence, fecal incontinence continues to be hidden in our society. People affected by it conceal it from friends and are reluctant to speak about it even to their doctors. We applaud *JAMA* for addressing this issue and raising the level of dialogue around fecal incontinence.

**On the Local Radar**

As an international foundation, IFFGD is gaining recognition among patients and healthcare professionals globally. Until recently, however, we remained virtually unknown to the community that has been our home for 15 years.

In April, *The Milwaukee Journal Sentinel* featured IFFGD in an article called, “Foundation broke the ice for millions with digestive disorders.” In addition, an interview with Nancy Norton was broadcast on Milwaukee’s *National Public Radio*.

We have received a good deal of positive feedback from people in the community, with many surprised they had not learned about IFFGD earlier.