WHO WE ARE

IFFGD is a registered nonprofit education and research organization. Our mission is to inform, assist, and support people affected by gastrointestinal (GI) disorders.

We work with patients, families, physicians, nurses, practitioners, investigators, regulators, employers, and others to:

- Broaden understanding about GI disorders,
- Support and encourage research, and
- Improve digestive health in adults and children.
Our Commitment

IFFGD was founded in 1991 by a single person struggling with the challenges posed by a chronic gastrointestinal (GI) disorder. At that time, few people were talking about these conditions privately, much less in a public setting. Patients often bore the burden of their symptoms in silence, reluctant to discuss them even with their doctor or other healthcare providers. In response to the lack of awareness and understanding among patients and the public, IFFGD made it their mission to work with the medical community, scientists, employers, policymakers and regulators in the government, and others to fill the knowledge gap and improve the lives of the millions of people around the world affected by these disorders.

Much has changed in the more than two decades since then, but our commitment to this mission remains the same. We work to raise global awareness of the prevalence and burden of these conditions, reducing the stigma often associated with symptoms and encouraging patients and others to engage in open and honest conversations. We collaborate with key thought leaders in the field to provide accessible education to patients, their family members and friends, and the public. And, we encourage and support research aimed at advancing the understanding and treatment of these disorders and improving patient care.

These efforts are made possible through the collaborative energies and contributions of many. We are pleased to thank you for your work on behalf of this patient community as we look back at some of our activities and accomplishments in 2017.
LETTER FROM THE PRESIDENT | 2018

Ceciel Rooker

As we approach DDW 2018, my first year as Executive Director of IFFGD is coming to a close. I continue to be grateful and amazed by the trust and support so many have placed in me to lead this incredible organization which has been important for patients and their families for many years. The legacy built by Nancy and Bill Norton is based on integrity, passion and a strong commitment to serving patients. I am committed to continuing the mission and am thankful to all those who, working together, will join me in this journey.

So far it has been an exciting year filled with learning, networking and growth for both IFFGD and myself. During this time, I have worked to learn more about the needs and lives of patients with gastrointestinal illness by spending many hours speaking with patients, physicians, researchers and industry professionals. Many people have shared their stories which has helped to broaden my knowledge of these disorders and their impact on patients. When I started this journey, I felt that I was well informed but as I look back now I am amazed at what I have learned from these individuals in this short time. It inspires me to work toward more knowledge and ways to move forward with our mission.

Through these conversations, I have received feedback on current programs and creative ideas for the future. The IFFGD team comprises Jamie DuMont, Director of Operations; Tegan Gaetano, Public Relations and Advocacy Director and Emily Taylor, Administrator. Together with our faithful volunteers Dianne Bach, Michael Stolar and Erin Slater, we have spent hours organizing thoughts, ideas and possibilities to frame IFFGD’s future. We have begun to lay the groundwork for new programs and for reinforcing existing ones. I am excited about the opportunities that lay before us and am looking forward to what the future brings.

Thank you for your support of patients through the years; we look forward to continued collaborations and future partnerships.

EDUCATION & SUPPORT

Online Support - Websites

As information becomes increasingly available online, more people are turning to the Internet for answers to their health questions. IFFGD’s family of websites continue to be our most important means of reaching patients, healthcare providers, and the general public, providing accessible, evidence-based information and raising awareness for the conditions we address.

Our sites are:
iffgd.org | aboutConstipation.org | aboutIBS.org
aboutGERD.org | aboutGastroparesis.org | aboutKidsGI.org
aboutgiMotility.org | aboutIncontinence.org
Online Support - Digestive Health Monthly eNewsletter
While our websites have the potential to reach the greatest number of people and are the focus of our educational outreach, we are currently engaged in expanding and improving the ways that we reach people. Our complimentary eNewsletter, Digestive Health Monthly, is distributed to more than 8,000 people monthly and continues to attract new subscribers. The eNewsletter contains the latest news about treatments, research breakthroughs, and the ongoing efforts of IFFGD and the broader digestive health community to educate and raise awareness. We invite you to sign up to receive this monthly communication at www.iffgd.org/stay-connected/join-e-newsletter.

Social Media
Social media is changing the way patients interact and engage in meaningful conversations about their healthcare. As a part of our ongoing campaign to be in front of worldwide social media audiences, we have actively communicated educational content to inform patients and the public about key health issues. We also use social media to promote awareness dates and campaigns aimed at mobilizing action for IFFGD’s annual National Advocacy Day. Through our presence on social media we continue our mission of providing education, assistance, and support to people affected by chronic GI conditions. Join the conversation at:
• Facebook.com/IFFGD
• Twitter.com/IFFGD
• LinkedIn.com/company/IFFGD

Reporter’s Guide to IBS and Working with the Media
To encourage coverage of these disorders and ensure accurate reporting, IFFGD serves as a resource for medical writers and other media influencers. We work closely with the media to provide accurate, up-to-date information, as well as, connect them with researchers, patients, and others for their stories. Over the last year, IFFGD was featured in stories on major online news and media outlets including The Huffington Post, Reader’s Digest, Healio, WebMD, Shape Magazine, Woman’s Day, Refinery29, Parade Magazine, Medical News Today, and Medpage Today. In 2017, IFFGD published, Reporter’s Guide to Irritable Bowel Syndrome, Second Edition, designed to provide reporters and other members of the media with information about IBS prevalence, financial and personal costs, symptoms, and treatments. While IBS is increasingly being reported on by the media, there is still a need to further educate those who suffer with the disorder as well as the public. The Guide was distributed to writers and reporters with an interest in health, lifestyle, and medical news and is available for free download on our website. Download all three of our Guides at www.iffgd.org/iffgd-media/reporters-guides.

Print Education
IFFGD produces and distributes a wide range of print publications aimed at helping people better understand their condition and more effectively work together with their healthcare providers to achieve their health goals. The IFFGD Publications Library contains more than 250 fact sheets and brochures. These are distributed in print and online directly to the public, to clinics, and at medical meetings, health fairs, and other public events. Browse the library at www.iffgd.org/resources/publications-library-home.

New titles include:
• Understanding and Managing Pain in Irritable Bowel Syndrome (IBS)
• Common Questions About Pain in Irritable Bowel Syndrome (IBS)
• Cognitive Behavioral Therapy for IBS and Other Functional Gastrointestinal Disorders
A commitment to supporting the advancement of the science through research is central to our mission at IFFGD. In addition to advocating for a greater federal investment for research into the basic understanding and clinical care of these disorders, we are committed to finding new ways to promote and fund investigation in this field.

Research

Gastroparesis in the Community Survey
Developed by IFFGD in collaboration with clinical researchers at Temple University School of Medicine, a confidential online research survey of 1,423 respondents entitled “The Burdens, Concerns, and Quality of Life of Adults with Gastroparesis” was published in the peer-reviewed medical journal Digestive Diseases and Sciences in January 2017.

In September, IFFGD President, Ceciel T. Rooker, presented the U.S. Food and Drug Administration (FDA) with results of this survey, following up on remarks from IFFGD at the FDA Patient-Focused Drug Development meeting on functional gastrointestinal disorders in 2015.

2018 IFFGD Research Recognition Awards
In September, IFFGD announced acceptance of applications and nominations for the 2018 IFFGD Research Recognition Awards.

These Awards recognize and support young investigators with a record of research interest and accomplishment in neurogastroenterology, and especially, in the basic mechanisms and clinical aspects of functional gastrointestinal and motility disorders. The Awards are intended to encourage the participation of clinicians and scientists in multidisciplinary efforts aimed at advancing the understanding and treatment of these disorders in adults and children. To date, IFFGD has presented awards to 38 investigators from around the world engaged in research into these conditions.
Awareness and advocacy are often considered as two sides of the same coin. The more we raise awareness and talk openly about the needs of the millions of Americans affected by chronic GI disorders, the greater our ability to make meaningful connections and inspire others to join the broader conversation in public and on Capitol Hill. IFFGD has been a voice on the Hill for years, educating key decision makers to bring greater attention to this patient community and help influence support for activities at NIH, FDA, and other health and human service agencies.

“An advocate acts as a voice for oneself and for others in the community and seeks to empower others to speak up and promote their best interests.”
- Melissa, IFFGD Advocate

H.R. 1187: The Functional GI and Motility Disorders Research Enhancement Act
IFFGD continues to work to strengthen federal research of chronic GI disorders through advocacy for The Functional Gastrointestinal and Motility Disorders Research Enhancement Act, reintroduced in the House of Representatives in March 2017 as H.R. 1187. In addition to raising critical awareness of the needs of patients affected...
by functional GI and motility disorders, passage of this bill will:
• Grant the 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 (DoD) and the Veterans Administration (VA) when appropriate, and
• Call on the FDA to improve the review, approval, and oversight of treatments for these conditions.

We have worked closely with the office of Congressman F. James Sensenbrenner, Jr. (WI-5) on the reintroduction of this bill. In addition to the Congressman, the bill has been cosponsored by 9 other House Members.
- Mark Pocan (WI-2)
- David Loebsack (IA-2)
- Thomas Suozzi (NY-3)
- Gwen Moore (WI-4)
- Donald Payne, Jr. (NJ-10)
- Eliot Engel (NY-16)
- Alcee Hastings (FL-20)
- Ron Kind (WI-3)
- Andre Carson (IN-7)

Advocacy Day
On September 12, 2017, IFFGD sponsored its 8th annual National Advocacy Day. On this day digestive health advocates from across the U.S. were invited to contact their House Members of Congress to cosponsor The Functional Gastrointestinal and Motility Disorders Research Enhancement Act of 2017 (H.R. 1187). In the months following this event, we have collaborated with constituents in key districts to continue to gain support for this piece of legislation.

DDNC Public Policy Forum
In March 2017, we again took part in the annual Digestive Disease National Coalition (DDNC) Public Policy Forum in Washington, DC. Working with patients and their families, healthcare providers, and other organizations in the field of digestive health, we joined together to educate our Members of Congress about issues important to the greater digestive health community.

Dear Colleague Letter
In April 2017, Congressman Bobby Rush (IL-1) circulated a Dear Colleague letter encouraging his fellow Representatives to sign on to a letter to the House Labor, Health and Human Services, and Education Appropriations Subcommittee members encouraging the committee to support implementation of the research recommendations of the 2009 National Commission on Digestive Diseases Report, entitled “Opportunities and Challenges in Digestive Diseases.” In addition to the Congressman, the letter received support from 5 other Members of Congress.
- Niki Tsongas (MA-3)
- Yvette Clarke (NY-9)
- Linda Sanchez (CA-38)
- Danny Davis (IL-7)
- Jackie Speier (CA-14)

Health Observances
The U.S. Department of Health and Human Services (HHS) maintains a National Health Observance (NHO) calendar to organize the promotion of health issues important to the American people around specific days, weeks, or months. Each year during these times, IFFGD coordinates awareness campaigns aimed at broadening national awareness and understanding of these health issues, encouraging coverage in the media, and making connections with affected individuals who may benefit from our support.
IBS Awareness Month – April 2017 marked the 20th annual IBS Awareness Month. IBS Awareness month was first designated by IFFGD in 1997 to encourage individuals who may be experiencing symptoms to speak to a doctor or other healthcare provider and obtain an accurate diagnosis. IFFGD’s focus during this awareness campaign was messaging relaying the importance of a strong doctor-patient relationship in managing this chronic and complex illness.

Gastroparesis Awareness Month – This awareness month was first designated on the NHO calendar by IFFGD in 2016. In 2017, we recognized Gastroparesis Awareness Month with a release reporting the findings of “The Burdens, Concerns, and Quality of Life of Adults with Gastroparesis,” a research survey published by IFFGD and researchers from Temple University School of Medicine. This research showed a profound reduction in the general health and social functioning of adults with the condition and demonstrated the need for greater awareness and treatment improvements targeting not only symptoms, but also quality of life issues.

GERD Awareness Week –During the week of Thanksgiving 2017, we observed GERD Awareness Week, first designated by IFFGD in 1999. To raise awareness for this common and bothersome disorder, we offered ways to distinguish between holiday heartburn and GERD, as well as, a few tips to help alleviate symptoms during the holiday season.
We are grateful to the individuals and companies who make our work possible and help us fulfill our mission to inform, assist, and support people affected by chronic GI disorders.

We are pleased to individually recognize the members of the IFFGD Industry Council for their support over the past year.

**IFFGD is grateful to its Industry Council members:**

**Patron Level Members**
Salix Pharmaceuticals
Shire Pharmaceuticals

**Associate Level Members**
Allergan, plc
Aries Pharmaceuticals, Inc. works.
Commonwealth Diagnostics International, Inc.
Ironwood Pharmaceuticals
Nestlé Health Science
QOL Medical, LLC
Shionogi Inc.
Synergy Pharmaceuticals
Vanda Pharmaceuticals

IFFGD is supported solely by companies in the GI field and gifts from patients. We have re-established the IFFGD Industry Council which meets twice year, during Digestive Disease Week in the Spring the ACG meeting in the Fall.

**SUMMARY**

Over the past year, IFFGD continued to promote education, awareness, advocacy, and research programs and initiatives consistent with our mission to improve the lives of people affected by chronic GI disorders. We are grateful to the many individuals - patients and family members, healthcare providers, researchers, Industry leaders, policymakers and regulators, and all others - who have supported IFFGD and our mission since its founding in 1991. We celebrate these achievements and successes with you as we look forward to what next year will bring. Thank you.