



# International Foundation for Gastrointestinal Disorders

IFFGD, 3015 Dunes West Blvd, STE 512, Mount Pleasant, SC 29466

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## 2020 Legislative Agenda

### About the Foundation

The International Foundation for Gastrointestinal Disorders (IFFGD) is a registered nonprofit education and research organization dedicated to informing, assisting, and supporting people affected by gastrointestinal (GI) disorders. IFFGD works 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.

### About Functional GI Disorders

Functional GI and motility disorders are the most common GI disorders in the general population. These disorders are classified by symptoms related to any combination of the following: motility disturbance, visceral hypersensitivity, altered mucosal and immune function, altered gut microbiota, and altered central nervous system (CNS) processing. Some examples of functional GI disorders are: dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome.



### Patient Perspective: Alyssa's Story

I was **four years old** when I started experiencing problems with my stomach. I would be in the bathroom for 45 minutes at times. My mother took me to the gastroenterologist and many other doctors, who then referred me to a dietitian and nutritionist. I have experienced every test you could think of, including two endoscopies.

I was diagnosed with irritable bowel syndrome (IBS) in 4th grade, years after my symptoms began. Though I suffer with this disorder, I have never let it stop me from anything I have wanted to accomplish.

As I am now junior in high school, my life is busy and stressful. Diet and stress-management are key in helping manage my symptoms. I also try things like meditation, avoiding foods that hurt me, and continuing to do the things I love with my friends and family. I currently do web shows with Nickelodeon and other companies, model for many different brands, have been in New York and Philly fashion week, theater performances and more!!

I am currently Miss East Coast USA National Ultimate Grand Supreme, and I use my title to spread awareness and help others affected by GI illness. Many foods I eat cause pain, every time I use the bathroom could be a tough time, but this has never stopped me from doing anything. I am hoping to use my experienced to shed some light on this horrible disease, inform others, and be helpful to all.

***Informing, assisting, and supporting people affected by gastrointestinal disorders.***

## 2020 Policy Priorities

### Medical Research

- **Please work to advance *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act (HR 3396)*.** This legislation focuses on bolstering research and increasing awareness of functional GI disorders and seeks increased coordination on research across the federal government. Please contact the following offices to cosponsor this effort:
  - Rep. Jim Sensenbrenner (R-WI-05): [Ben.Steinhafel@mail.house.gov](mailto:Ben.Steinhafel@mail.house.gov) or 5-5101
  - Rep. Gwen Moore (D-WI-04): [Caroline.Frauman@mail.house.gov](mailto:Caroline.Frauman@mail.house.gov) or 5-4572
- **Please provide the National Institutes of Health (NIH) with \$47 billion in funding for fiscal year (FY) 2021, as proposed by the House LHHS bill.** Strengthening the nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people. NIH sponsors groundbreaking initiatives like the Stimulating Peripheral Activity to Relieve Conditions (SPARC) Initiative that is having a powerful impact on new treatments for gastrointestinal disorders. Please also ensure proportional funding increases for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which supports basic, clinical, and translational research on aspects of gut physiology regulating motility and clinical trials through the Motility and Functional GI Disorders Program.
- **Please support Gulf War Illness research at the Department of Defense (DoD) and the Department of Veterans Affairs (VA).** Gulf War Medically Unexplained Illnesses are characterized by multiple diverse symptoms, including gastrointestinal problems that could not be explained by established medical diagnoses or standard lab tests. Approximately 25-32% of Gulf War veterans continue to experience symptoms associated with their deployment. The DoD Gulf War Illness Research Program (GWIRP) and the VA Gulf War Research Program allow talented researchers to work at finding the reasons behind this high prevalence and seek ways to reduce these challenges during future conflicts.

### Patient Access to Treatments

- **Please work to limit patient out-of-pocket costs and curb current and future payer tactics to shift costs onto patients.** Many patients face financial barriers to obtaining quality care and innovative treatments. IFFGD supports policy and regulations that facilitate patient access to care by strengthening the patient-provider decision-making relationship, limiting patient out-of-pocket spending, and curbing cost-shifting practices by third-party payers, including step therapy, non-medical switching, and co-pay accumulator adjustment programs.
- **Please work to advance the Safe Step Act (HR 2279/S.2546).** This bill would establish guidelines for appealing step therapy protocols under ERISA health plans.

### Education and Awareness

- **Please support \$3,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC), as proposed by the House LHHS bill.** Patients with FGIMDs frequently suffer for years before receiving an accurate diagnosis, exposing them to unnecessary and costly tests and procedures including surgeries, as well as needless suffering and expense. Functional GI and motility disorders are among the most common digestive disorders in the general population. They affect an estimated 1 in 4 people in the U.S. and account for 40% of GI problems seen by medical providers. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes.



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## **ISSUE BRIEF: *The Functional GI and Motility Disorders Research Enhancement Act (HR 3396)***

### **Background**

Functional gastrointestinal (GI) and motility disorders are the most common digestive disorders in the general population, affecting an estimated 1 in 4 people in the U.S. These conditions can affect any part of the digestive tract, from the esophagus to the stomach to the small and large intestines, and include dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome, among others. Symptoms range from discomforting to life-threatening and affect individuals of all ages – men, women, and children. But despite the prevalence and severity of these conditions, little is understood scientifically, and treatment options are extremely limited – no cures are known.

Patients and families living with functional GI and motility disorders often suffer for years before receiving an accurate diagnosis and are faced with a lack of safe and effective treatment options. Current treatments generally focus on the management of complex symptoms long-term. Inadequate education for physicians as well as the public often leads to unnecessary diagnostic procedures, errors in treatment, and social stigma for afflicted individuals.

Greater understanding of these conditions, through innovative research into their basic mechanisms and clinical care, and improved provider education and public awareness are necessary to improve outcomes for the millions of patients and families affected and bolster the health of the American people.

### **Congress Can Help**

*The Functional Gastrointestinal and Motility Disorders Research Enhancement Act* seeks to advance our scientific understanding of functional GI and motility disorders and improve treatment options by:

- Implementing the research recommendations of the National Commission on Digestive Diseases to expand the NIH functional GI and motility disorders research portfolio
- Providing support for the establishment of centers of excellence on FGIMDs,
- Supporting innovative approaches to educating health care providers and patients on strategies that improve patient-provider relationships and care,
- Expanding emerging research initiatives into pediatric functional GI and motility disorders through improved coordination among relevant NIH Institutes and Centers
- Allowing for periodic joint-agency scientific meetings between federal agencies and stakeholders with an interest in functional gastrointestinal disorders research, including NIH, DOD, and the VA,
- Stimulating treatment development by calling on the US Food and Drug Administration (FDA) to expand and advance efforts to craft guidance for industry that establishes a formal process for the review, approval, and monitoring of new drugs for the treatment of functional GI and motility disorders.

***Informing, assisting, and supporting people affected by gastrointestinal disorders.***