



International Foundation for Gastrointestinal Disorders

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

Tel: 414-964-1799 • Website: iffgd.org • Email: iffgd@iffgd.org

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 or 5-5101
 - Rep. Gwen Moore (D-WI-04): 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.

ISSUE BRIEF: Recommendations of the National Commission on Digestive Diseases for Functional GI & Motility Disorders

Background

The National Commission on Digestive Diseases was chartered in 2005 in response to congressional report language accompanying the FY 2005 Labor-Health and Human Services appropriations bills in the House and Senate. The Commission was tasked with reviewing the state of the science in digestive diseases research and developing a 10-year plan for digestive diseases research that is consistent with the NIH mission and aimed at improving the health of the Nation through research.

The Commission's recommendations are organized into 12 scientific topic areas (including FGIMDs) that categorize digestive diseases by common etiology, mechanism, affected organ system, or other considerations.

For each topic area, the Commission provided: an overview of common diseases or conditions; a review of significant research advances; a description of high-impact, forward-looking, science-based research goals; and a discussion of major barriers to research progress and steps to overcome those challenges.

Recommendations for Functional Gastrointestinal Disorders and Motility Disorders

Functional GI disorders and motility disorders, such as irritable bowel syndrome, functional dyspepsia, and gastroesophageal reflux disease, take a significant toll on the health and well-being of many Americans.

The Commission offers several research goals designed to: improve our understanding of normal motility and secretory activities of the GI tract, discover the physiologic changes that lead to disease, and develop more effective therapies to prevent, treat, or reverse these disorders.

- 1) Research efforts are needed on the numerous systems and processes that may be impaired in functional GI and motility disorders, including: brain-gut interactions, the enteric nervous system, interstitial cells of Cajal and smooth muscle cells, pain and sensory mechanisms, the gut mucosa and musculature, the intestinal microflora, and immune and inflammatory responses.
- 2) It is important to define how factors such as genetic differences, age, sex, and gender influence a person's susceptibility to these disorders.
- 3) Many individuals with diabetes develop GI motility disorders, such as gastroparesis and constipation. As the rate of diabetes continues to rise in the U.S., research on how diabetes affects the GI tract is increasingly important.
- 4) Ultimately, research to discover the basic mechanisms of disease must be translated into new technologies, pharmacological therapies, and behavioral strategies to effectively treat all patients afflicted with functional GI and motility disorders.

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

Cosponsor H.R. 3396, the Functional Gastrointestinal and Motility Disorders Research Enhancement Act

Dear Colleague:

Please join us in supporting H.R. 3396, *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act*.

Functional gastrointestinal and motility disorders (FGIMDs) are among the most common health disorders in the general population. These conditions can affect any part of the digestive tract, including the esophagus, stomach, and the small and large intestines. FGIMDs are typically 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.

Symptoms of these disorders can be disabling and in some instances life-threatening, and few effective therapies exist. Treatment generally focuses on management of complex symptoms over a long term. Some examples of functional gastrointestinal disorders are: dyspepsia, gastroparesis, irritable bowel syndrome, gastroesophageal reflux disease, bowel incontinence, and cyclic vomiting syndrome. Patients with FGIMDs can suffer for years before receiving a diagnosis and only have access to few effective treatments due to a lack of proper education for physicians.

Representatives Jim Sensenbrenner and Gwen Moore have reintroduced *The Functional Gastrointestinal and Motility Disorders Research Enhancement Act* to expand, advance, and better coordinate NIH research activities for FGIMDs and support innovative approaches to educating patients and health care providers about strategies that improve care.

To cosponsor, or if you have any questions, please contact:

- Ben Steinhafel (Rep. Jim Sensenbrenner) at ben.steinhafel@mail.house.gov or 5-5101
- Caroline Frauman (Rep. Gwen Moore) at caroline.frauman@mail.house.gov or 5-4572

Sincerely,

F. James Sensenbrenner, Jr.
U.S. House of Representatives

Gwen Moore
U.S. House of Representatives



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ISSUE BRIEF: Functional GI and Motility Disorders (FGIMDs)

About Functional GI and Motility Disorders

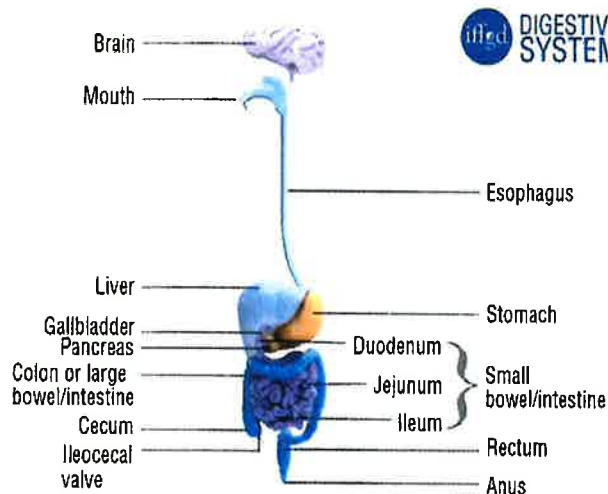
Functional gastrointestinal (GI) and motility disorders are the most common GI disorders in the general population. These conditions can affect any part of the digestive tract, from the esophagus to the stomach to the small and large intestines. In the absence of structural abnormalities that can be observed with routine diagnostic tests, 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.

Symptoms of these disorders can be disabling or even life-threatening and few effective therapies exist. Treatment generally focuses on management of complex symptoms over a long term.

Some examples of functional GI disorders are: dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome.

Upper to mid GI tract

- Gastroesophageal reflux disease (GERD)
- Functional chest pain
- Gastroparesis (delayed gastric emptying)
- Dysphagia
- Achalasia
- Functional dyspepsia
- Sphincter of Oddi dysfunction
- Cyclic vomiting syndrome (CVS)



Mid to lower GI tract

- Irritable bowel syndrome (IBS)
- Bowel incontinence
- Functional abdominal pain
- Chronic intestinal pseudo-obstruction
- Small intestinal bacterial overgrowth (SIBO)
- Hirschsprung's disease
- Short bowel syndrome (SBS)

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Centers for Disease Control and Prevention Functional GI and Motility Disorders

Background

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Symptoms of these disorders can be disabling or even life-threatening and few effective therapies exist. Treatment generally focuses on management of complex symptoms over a long term. Some examples of functional GI disorders are: dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome.

Please provide \$5,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).

Justification

- Functional GI and motility disorders are the most common GI 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.
- The social and economic costs of gastrointestinal disorders are enormous. For those with severe symptoms the disorders can be debilitating, leaving them unable to fully participate in life and work.
- Much remains unknown about these disorders. Poor provider education on functional GI and motility disorders routinely leads to misdiagnosis and under-treatment for patients. Confusion and misunderstanding among patients and providers often result in poor patient outcomes.
- The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) supports programs that work to increase public awareness and improve professional education. A CDC program focused on surveillance, provider education, and public awareness would increase diagnoses and improve patient outcomes.



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ISSUE BRIEF: Digestive Health Issues Impacting Military Personnel

Functional GI Disorders and the Military Service Connection

Many veterans returning from service in Gulf War regions find themselves faced with gastrointestinal (GI) illness. Veterans and active military personnel disproportionately represent those suffering from a functional GI disorder due to their exposure to increased risk factors, including severe stress and infections of the digestive tract. The service connection of these conditions has been extensively studied, and a **2016 Institute of Medicine report, entitled *Gulf War and Health: Update of Health Effects of Serving in the Gulf War*, identified functional GI disorders along with three other multi-symptom illnesses present in veterans as directly related to their service during the Gulf War.**

Most of these conditions are debilitating, characterized by chronic and often unpredictable symptom episodes. Long after a soldier's tour is over, and the stress or infection subsides, the digestive disorder and its symptoms can remain. It is for this reason that the **Department of Veterans Affairs (VA) recognizes that there is a "presumptive service connection" for veterans suffering with functional GI disorders following their service during the Gulf War.**

Members of Congress Can Help

The Department of Defense (DOD) conducts important research into medical conditions that impact veterans and active-duty military personnel through its Congressionally Directed Medical Research Program (CDMRP). The House and Senate Defense Appropriations bills fund the DOD CDMRP's Gulf War Illness Research Program (GWIRP), which provides an important source of funding for GI research. Research into these conditions in veterans through the GWIRP will benefit not only the many veterans affected by these conditions, but the millions of Americans who suffer with these disorders every day.

The House Defense Appropriations bill for FY 2020 has proposed \$22 million for the Gulf War Illness Research Program (GWIRP). **Legislators must work to ensure that at least \$22 million is provided for the GWIRP as they work to finalize appropriations for FY 2020.**

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ISSUE BRIEF: IFFGD Research Awards and Grants Programs

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About IFFGD's Research Awards and Grants

Since 2003, IFFGD has supported and encouraged the participation of clinicians and scientists in multidisciplinary efforts aimed at providing a better understanding of chronic GI disorders through our Research Awards and Grants. With these funding opportunities, we recognize the contributions of researchers to broadening the basic understanding and clinical care of these conditions on behalf of patients and their families. Through research, patients have hope for new treatments, and perhaps one day, cures.

2019 Research Award Recipients

In recognition of the importance of research in shaping the future of the treatment and care of chronic GI disorders, IFFGD was pleased to honor three young investigators in May as recipients of the 2019 IFFGD Research Recognition Awards. The three honorees were recognized during Digestive Disease Week (DDW) in San Diego, CA. The awards were presented by Ceciel T. Rooker, President and Executive Director of IFFGD, and William Whitehead, PhD, Chair of the IFFGD Research Awards Peer-Review Selection Committee.

The work of these young investigators contributes to our growing understanding of these complex conditions and how to improve their treatment.



Award Recipients and Presenters (Left to Right): Arpana Gupta, PhD, G. Oppenheimer Center for Neurobiology of Stress and Resilience; David Levinthal, PhD, University of Pittsburgh Medical Center; Ceciel T. Rooker, IFFGD; William Whitehead, PhD, UNC Center for Functional GI and Motility Disorders; Marc Benninga, MD, PhD, for Ilan Koppen, MD, PhD, University of Amsterdam Academic Medical Center.

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