



# International Foundation for Gastrointestinal Disorders

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## 2021 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.

This year, IFFGD commemorates 30 years of supporting those living with GI disorders. In 1991, IFFGD was founded by one person struggling with the challenges imposed by a chronic GI disorder. Years later, many others from all walks of life have joined us. IFFGD and the digestive health community have made great strides to raise public awareness of the burdens and unmet needs of illnesses affecting those living with chronic digestive conditions and encourage research into life-altering treatments.

### Patient Perspective: Nancy's Story



Nancy Norton, Founder and  
Past President, IFFGD

In some ways my life has become very unique. Let me begin by assuring you that I consider myself to be a very fortunate individual and, in many ways, as one friend has described it, “I have a big life,” a life that I never envisioned for myself. However, there were days when I felt that I would never leave my home, I felt that my life was over. I could not imagine how I could continue on in life as a person living with bowel incontinence.

Not everyone has been as fortunate as I in the ability to cope and manage incontinence. Bowel or bladder incontinence is a 24-hour, seven day a week challenge. One never escapes it, for many it is even in our dreams.

In 1985 with the delivery of my son, I sustained a 4th degree laceration. I subsequently had two repair surgeries that were unsuccessful in restoring continence. My life changed in one moment of time, from a continent person with a full life, anticipating the birth of my son with an expectation that both mother and child would do well, to a life that no longer holds any spontaneity but rather a life that is focused on control.

Incontinence that results from vaginal delivery is something that was seldom discussed in 1985 and unfortunately, we have not made much progress in including it in discussions with pregnant women today.

## 2021 Legislative Policy Priorities for IFFGD

### Medical Research

- **Please provide the National Institutes of Health (NIH) with \$46.1 billion in funding for fiscal year (FY) 2021, an increase of \$3.2 billion.** 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 GI 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 (S.464/H.R.2163)*.** Step Therapy practices require patients to try and fail one or more treatments before the insurer will cover the treatment originally prescribed. Too often, this leads to delays in proper treatment, worsened health outcomes, and contributes to higher healthcare costs. The Safe Step Act legislation has been reintroduced in both the Senate and the House (*S.464/H.R.2163*) and would require insurers to implement a clear and transparent process for a patient or healthcare provider to request an exception to a step therapy protocol and requires group health plans to grant exceptions if certain protocol is met.

### Education and Awareness

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