



March 21 - 26

Be Active. Be Heard. Make a Difference

# 2021 Virtual Advocacy Event



## HOW TO PREPARE YOUR STORY

Your personal story is the highlight of your legislative calls and emails. Take time to write down your story and familiarize yourself with the key points you want to make clear as you are advocating. Use the guide and prompts below as you write and prepare to share your story.

Begin by asking yourself: “How has a gastrointestinal disorder affected my life?”

- Write down your story. Try keeping it to 3-4 minutes.
- Review your story with a family member or friend.
  - Is your message clear?
  - Have you expressed your story concisely?
- Practice saying your story out loud, especially if you are calling into your legislative office.
- Follow the script provided in this preparation packet.

Are you unsure of how to begin writing your story? The following are a few discussion points to help you get started:

- What is your condition?
- How does it affect your daily life?
- When were you diagnosed?
- How long did it take to receive a diagnosis?
- How do you manage your condition?
- Has it changed over time?
- What compelled you to advocate?

You may want to include all of these discussion points or just a few. Add any information that you find necessary as you are creating your unique personal story to share.



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## SAMPLE CALL/EMAIL SCRIPT

Good Morning/Afternoon,

My name is \_\_\_\_\_ and I live in \_\_\_\_\_.

I am an advocate with the International Foundation for Gastrointestinal Disorders (IFFGD). IFFGD advocates for all persons affected by functional gastrointestinal (GI) and motility disorders and supports a legislative and policy agenda that meets the needs of the GI patient and caregiver community. IFFGD is a registered nonprofit education and research organization who seeks to inform, assist, and support people affected by GI disorders.

Functional GI and motility disorders (FGIMD’s) are the most common digestive disorders, affecting an estimated 1 in 4 people in the U.S. These conditions can affect any part of the digestive tract (i.e. esophagus, stomach, intestines), and include dyspepsia, gastroparesis, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), bowel incontinence, and cyclic vomiting syndrome, among many others. Symptoms range from mild to life-threatening and affect individuals of all ages.

Those living with GI conditions often suffer for years before receiving an accurate diagnosis, are faced with a lack of safe and effective treatment options, and social stigma. Despite the prevalence and severity of these conditions, little is understood scientifically, and treatment options are extremely limited with no known cures. Greater understanding through innovative research, improved provider education, and public awareness are necessary to improve outcomes for the millions of affected and bolster the health of the American people.

**{Share your functional GI and motility disorder experience. Be concise but let them know how this has affected your life.}**

I am **calling/writing** today to ask for \_\_\_\_\_ **(Name of Senator or Representative)’s** help.

Please work to advance the *Safe Step Act* (S.464/H.R.2163). Step therapy occurs when a patient is required to try and fail on insurer-preferred medications before they will agree to cover the treatment chosen by the patient and their healthcare provider.



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Step therapy often delays treatment, and for many people leads increased expenses and worsened health outcomes. This legislation seeks to:

- Require health plans to implement a clear appeal process
- Establish a time frame by which insurance companies must respond to appeals
- Establish exceptions to allow a patient to be exempt from step therapy when medically appropriate

We ask for support in funding at the National Institutes of Health (NIH) at \$46.1 billion, with proportional funding increases for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), research and clinical trials through the Motility and Functional GI Disorders Program. The NIH sponsors groundbreaking initiatives that have a powerful impact on new treatments for GI disorders.

Please support the Department of Defense (DOD) Gulf War Illness Research Program and the Department of Veterans Affairs (VA) Gulf War Research Program allowing researchers to work at finding the reasons behind this high prevalence and seek ways to reduce these challenges. Our military and veterans are disproportionately affected by GI disorders, with 25-32% of Gulf War veterans still experiencing symptoms.

Health coverage and access are critically important to GI patients and the entire community. We ask that Congress maintains and support crucial patient protections that promote access and prevent financial hardships. Specifically, please work to:

- limit patient out-of-pocket costs and curb current and future payer tactics to shift costs onto patients,
- support coverage of necessary medical foods.

If you have any questions or need any additional information, please contact IFFGD's Washington Representative Philip Goglas II, at [Goglas@hmcw.org](mailto:Goglas@hmcw.org) or (202) 544-7499.

Thank you again for your time and consideration of these requests. Please consider me a resource for you and your office about any health related and patient issues.

Sincerely,

**{Your Name}**  
**{Your Address}**