

Be Active. Be Heard. Make a Difference.

Thank you for taking the time to join us as we to advocate for the gastrointestinal illness community. Together, we can make the voice of the digestive health community heard and encourage Congress to prioritize actions that will lead to greater awareness and the development of new treatment options and cures.

In this packet, you will find information to help you prepare for the IFFGD Advocacy Call-in Day on Monday, July 27, 2020. We hope you will find this informative and helpful in your preparation. If you have any comments or questions, please contact us at advocacy@iffgd.org.



The icon to the left is located throughout this packet on pages that have a corresponding advocate training video. For a visual learning experience, click on this icon to be directed to IFFGD’s Advocate Training webpage.

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IFFGD's 2020 LEGISLATIVE PRIORITIES

Medical Research

- We seek 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.
 - To learn more, visit: <https://www.congress.gov/bill/116th-congress/house-bill/3396> and see page 4 below
- We encourage Congress to provide the National Institutes of Health (NIH) with \$47 billion in funding for fiscal year (FY) 2021, as proposed in the House LHHS bill. Strengthening the nation's biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and wellbeing 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. We are also asking that they 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.
- We encourage support for 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

- We encourage congress 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 and nonmedical switching. Specifically,

- We encourage congress to advance the Safe Step Act (HR 2279/S.2546). This bill would establish guidelines for appealing step therapy protocols under ERISA health plans.
- We encourage congress to advance the Medical Nutrition Equity Act (HR 2501/S.2546). This bill expands coverage under Medicare, Medicaid, other specified federal health-care programs, and private health insurance to include foods, vitamins, and individual amino acids that are medically necessary for the management of certain digestive and metabolic disorders and conditions.

Education and Awareness

- We encourage Congress to support \$3,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) as proposed in 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.

**H.R. 3396:*****The Functional Gastrointestinal and Motility Disorders Research Enhancement Act of 2019***

Introduced in House (06/20/2019)

H.R. 3396 seeks to advance our scientific understanding of functional GI and motility disorders and improve treatment options. This bill allows the National Institutes of Health to expand, intensify, and coordinate its activities with respect to functional gastrointestinal and motility disorders (FGIMDs), including by

- expanding basic and clinical research into FGIMDs by implementing the research recommendations of the National Commission on Digestive Diseases,
- providing support for the establishment of centers of excellence on FGIMDs,
- supporting innovative approaches to educating health care providers and patients regarding strategies that improve patient-provider relationships and care,
- directing the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to provide the necessary funding for the continued expansion and advancement of the FGIMDs research portfolio, and
- directing NIDDK and the Eunice Kennedy Shriver National Institute of Child Health and Human Development to expand research into FGIMDs that impact children.

H.R. 3396 also allows for,

- The Department of Health and Human Services to engage in public awareness and education activities to increase understanding and recognition of FGIMDs, and
- Periodic joint-agency scientific meetings between federal agencies and stakeholders with an interest in FGIMD 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.

H.R. 3396 COSPONSORS

We are grateful for the support of Representative James F. Sensenbrenner Jr. [R-WI-5] and Representative Gwen Moore [D-WI-4] for re-introducing the *Functional Gastrointestinal and Motility Disorders Research Enhancement Act* to the House of Representatives on June 20th, 2019. The following list includes all cosponsors of this bill. If your Representative is on this list, instead of asking for their support, consider thanking them for their dedication to those affected by gastrointestinal and motility disorders.

ARIZONA

Rep. O'Halleran, Tom [D-AZ-1]
Rep. Gosar, Paul A. [R-AZ-4]

CALIFORNIA

Rep. Brownley, Julia [D-CA-26]
Rep. Porter, Katie [D-CA-45]

COLORADO

Rep. Neguse, Joe [D-CO-2]
Rep. Perlmutter, Ed [D-CO-7]

DELAWARE

Rep. Blunt Rochester, Lisa [D-DE-At Large]

ILLINOIS

Rep. Rush, Bobby L. [D-IL-1]

IOWA

Rep. Loebsack, David [D-IA-2]

KENTUCKY

Rep. Massie, Thomas [R-KY-4]

NEVADA

Rep. Lee, Susie [D-NV-3]

NEW JERSEY

Rep. Van Drew, Jefferson [R-NJ-2]

NEW YORK

Rep. Suozzi, Thomas R. [D-NY-3]
Rep. Rose, Max [D-NY-11]

NORTH CAROLINA

Rep. Price, David E. [D-NC-4]

PENNSYLVANIA

Rep. Fitzpatrick, Brian K. [R-PA-1]

TEXAS

Rep. Vela, Filemon [D-TX-34]

WASHINGTON D.C.

Rep. Norton, Eleanor Holmes [D-DC-At Large]

WISCONSIN

Rep. Pocan, Mark [D-WI-2]
Rep. Kind, Ron [D-WI-3]
Rep. Moore, Gwen [D-WI-4]
Rep. Sensenbrenner, F. James, Jr. [R-WI-5]



TALKING POINTS AND FACTS FUNCTIONAL GI AND MOTILITY DISORDERS:

- Functional gastrointestinal and motility disorders (FGIMD) affect 1 in 4 people in the U.S. – men, women, and children.
- The conditions are a serious issue for many military veterans – part of Gulf War Illness.
- The conditions involve improper functioning of the nerves, muscles, and related mechanisms of the digestive tract.
- Many are chronic and some can be fatal. There is a wide range of disease severity, and symptoms range from discomforting to life-threatening.
- These conditions are often misdiagnosed or mistreated. Patients often suffer for years before receiving an accurate diagnosis.
- Currently, treatment options are extremely limited, not always effective, and focus on symptom management – no cures are known.
- Lack of public education and awareness has resulted in social stigma for afflicted individuals.
- Greater understanding of these conditions, improved provider education and public awareness will improve outcomes for the millions of patients and families affected and bolster the health of the American people.



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.



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 FGIMD's 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 *Functional GI and Motility Disorders Research Enhancement Act* (HR 3396). This bipartisan, budget neutral bill focuses on increasing research and awareness of functional GI disorders by:

- bolstering the NIH's 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 to improve patient-provider relationships and care, and
- encouraging increased collaboration among federal agencies.

Please cosponsor this important legislation by contacting the offices below:

- 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

We ask for support in funding the National Institutes of Health (NIH) at \$47 billion as proposed in the House LHHS bill 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,
- allow young adults to stay on family coverage until they are 26,
- advance the Safe Step Act (HR 2279/S.2546), establishing guidelines for appealing step therapy protocols,
- support coverage of necessary medical foods through the Medical Nutrition Equity Act (HR2501/S3657) and Medical Nutrition Therapy Act (HR 6971).

If you have any questions or need any additional information, please contact IFFGD's Washington Representative Philip Goglas II, at 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}



HOW TO LOCATE YOUR LEGISLATOR

You can locate your legislator using the instructions below. If you have any difficulty locating your Representative or Senator, or would like us to locate them for you, please email advocacy@iffgd.org with your name and address where you are registered to vote.

To make the most of your call or email, you may want to review your legislator's website. If you better understand their platforms and views, it may help you best portray your story and legislative asks as a constituent.

To find and contact your ***U.S. Representative:***

1. Visit the House of Representatives website <https://www.house.gov/>
2. Conduct a search using the **Find Your Representative** zip code search box in the upper right corner (enter your zip code and click LOOK UP).



Visitors | Educators and Students | Media | Doing Business with the House | Employment

SEARCH

UNITED STATES HOUSE of REPRESENTATIVES

116th Congress, 2nd Session · The House is not in session.

REPRESENTATIVES | LEADERSHIP | COMMITTEES | LEGISLATIVE ACTIVITY | THE HOUSE EXPLAINED

CONGRESSIONAL APP CHALLENGE CODE FOR CONGRESS

Legislative Activity

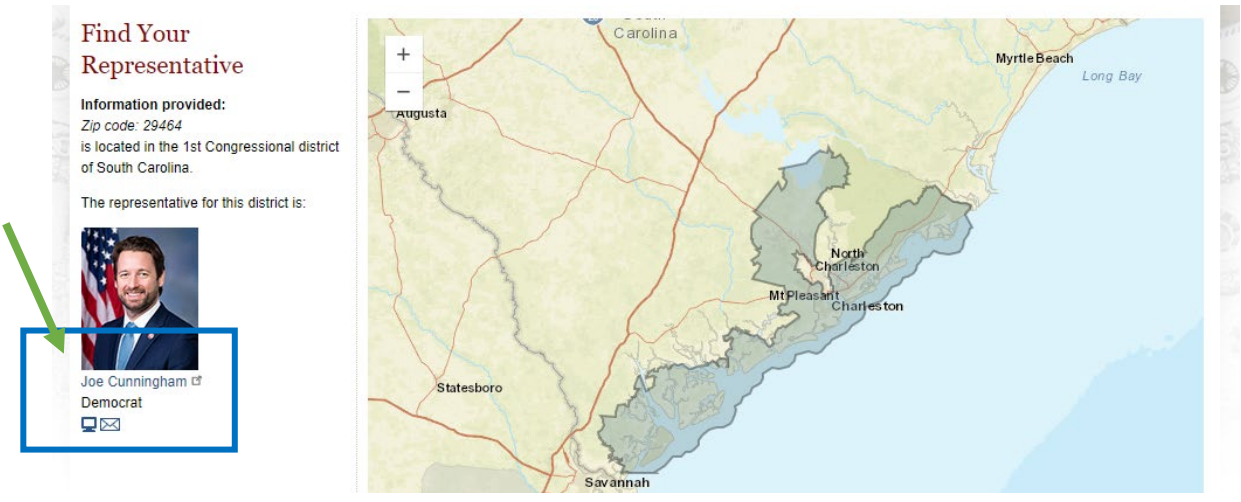
Committee Schedules | Floor Proceedings | Recent Votes | Bills & Reports

Tuesday, July 7, 2020

Watch Most Recent House Floor Activity

Time (ET)	Session
9:00 am	FY 2021 Homeland Security Subcommittee Markup

3. On the results page is a photo of your Representative(s), links to the Representative's personal website and online contact form, and a map of the congressional district.



To get information on exactly how to use this information, please see the following options:

Use your mouse to click your representatives name to be sent to your representatives' official website

Find Your Representative

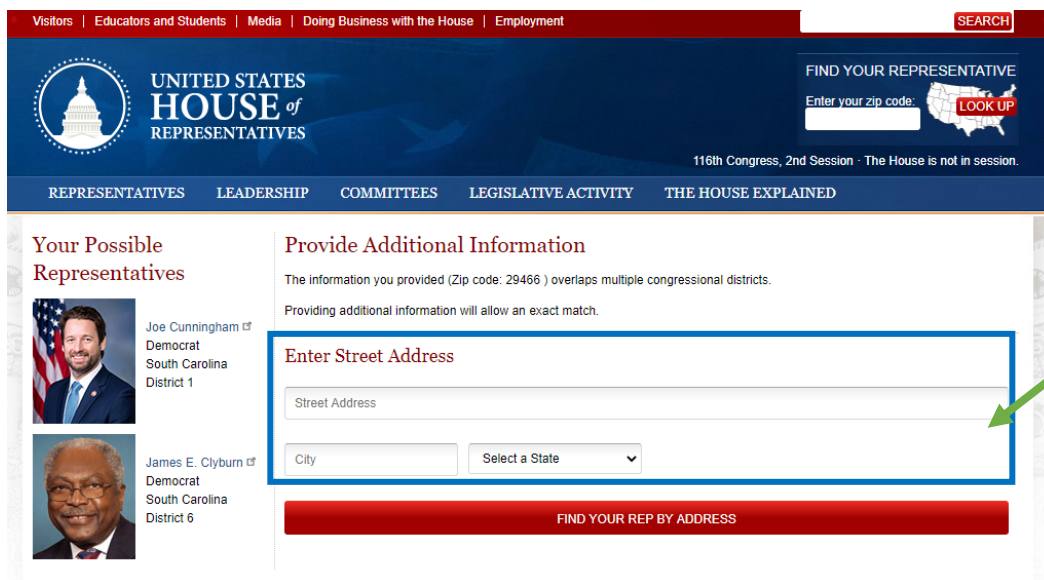
Information provided:
Zip code: 29464
 is located in the 1st Congressional district of South Carolina.

The representative for this district is:

Use your mouse to click on the envelope icon to fill out a web-based form to contact your representative

Joe Cunningham Democrat

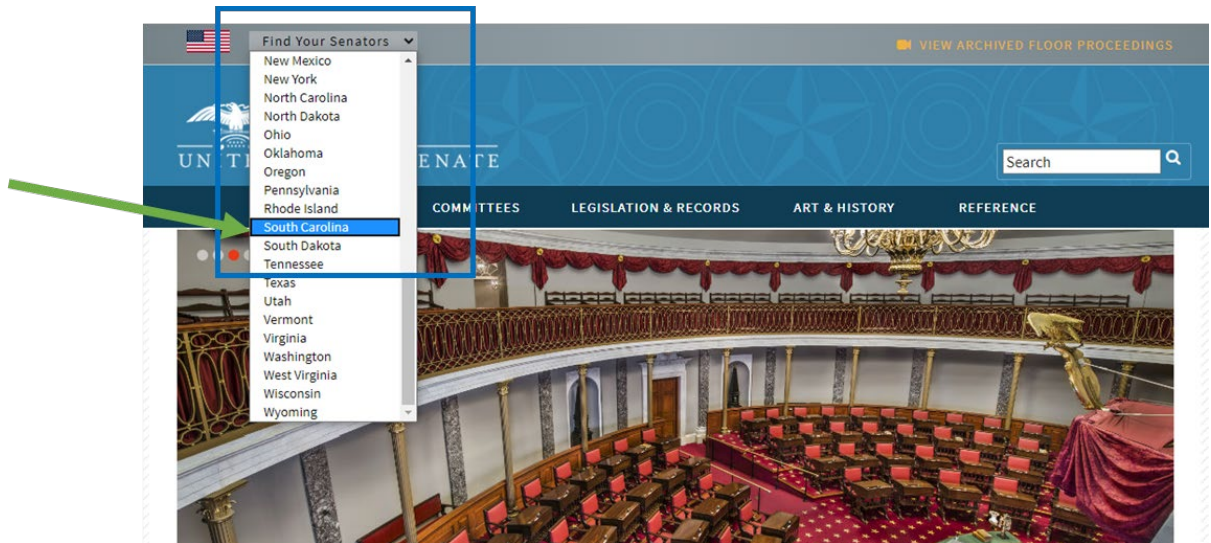
4. In the event your zip code overlaps with multiple congressional districts, the results page will include boxes to input your mailing address to find the correct Representative.



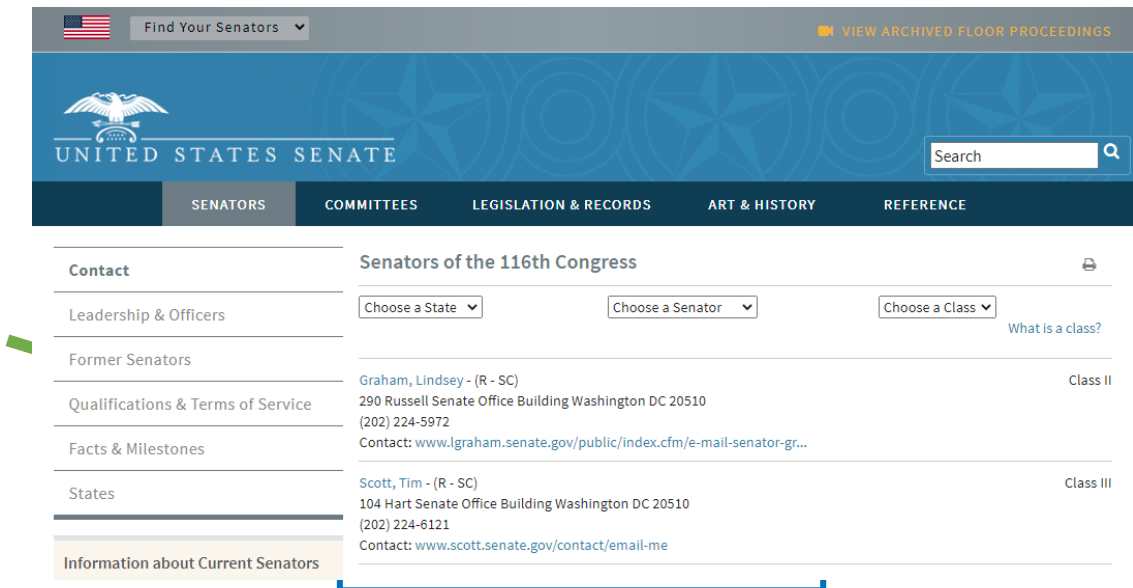
Please note, once you have located the official website for your representative, you will need to find the correct email and phone number for making contact. Each representative has his/her page set up differently, so if you need assistance, please email advocacy@iffgd.org

To find and contact your U.S. Senator:

1. Visit the Senate website www.senate.gov
2. Conduct a search using the **Find Your Senators** pull-down menu in the upper right corner (select your state and click Go).



3. On the results page is a link to the Senators' website, contact information, and links to an online contact form (forms vary by Senator).





FREQUENTLY ASKED QUESTIONS (FAQs)

Where do I go for questions?

Email advocacy@iffgd.org before, during, or after the event.

How much does the event cost?

This is a free event!

Who can attend IFFGD's 2020 Virtual Advocacy Event?

All are welcome to participate! Many people are impacted by gastrointestinal disorders and we invite everyone to attend.

How do I register for the event?

Registration is available [here](#).

What is available with registration?

You will receive a link to Sunday's educational portion prior to the event. [Advocacy training materials](#) will be emailed in advance of the advocacy event including a preparation packet, legislative information, and advocacy training videos.

Is Sunday's educational program being recorded?

Yes, all talks will be recorded.

Will the resources be available after the event, even without registration?

Yes! Educational videos from Sunday's program will be made available on <https://iffgd.org/> after the event. Advocate training materials, including videos and informational packets, will be made available [here](#).

How do I access the virtual event?

You will receive a link to the event if you have registered. You can use your laptop, desktop, cell phones, tablets, or other devices as long as you have an internet connection. A link to the educational portion will also be made available on the [Virtual Advocacy Event Page](#).

Will I be visible or heard by others during the event?

No, you will be watching the event as a viewer and will be muted at all times. There will be a chat box available for any questions or feedback during the event. As always, please email advocacy@iffgd.org with any questions or comments.

Will my data or internet affect by viewing ability?

Poor internet connection or cellular service can affect the quality of your connection to the live-streamed educational event.



What device should I use during the educational program?

You can connect using a computer, laptop, tablet, cell phone, or any other device with an internet connection. For the best possible experience, we recommend:

- For computers – You should be able to connect on any browser. Chrome provides the best quality experience
- For mobile devices – Download the Vimeo app for the highest quality and to ensure the chat box is available.

How long will the event last?

This is a two-day event beginning with a full educational day on Sunday and an advocacy call-in day on Monday. The event begins Sunday morning at 9a.m. EST and will conclude late afternoon that day. Calling and emailing of Congressional Offices will occur on Monday at the convenience of each participant.

Do I have to be actively participating during both days of the event?

No, but we encourage you follow the full day education program on Sunday if time permits. If you are unable to follow along the videos will be made available afterwards on <https://iffgd.org/>.

Do I have to be participating at a specific time on Monday, July 27th?

No, you can call and email at your convenience throughout the day. We ask that you try your best to complete your legislative contacts during the action day Monday. For most Washington D.C. offices, the best time to call is from 10 a.m. to 4 p.m. EST.

How do I locate my legislators if I am not familiar with them?

Visit [house.gov](https://www.house.gov) and [senate.gov](https://www.senate.gov), instructions are provided in the participant packet beginning on page 10.

How do I know if my legislator has already supported the legislation?

A list of current cosponsors is available on page 5 of this participant packet.

How long should my legislative contacts be?

Phone calls to legislative offices should be 20-30 minutes long at most but can be shorter. Follow the script on page 8 to help guide your phone calls and emails.

What should I be sending to my legislators?

The IFFGD Legislative Packet and H.R. 3396 Bill Text PDF documents. They can be downloaded [here](#).

Where do I find the documents to send my legislators?

Both documents will be sent to registrants as a link via email and made available on the Advocacy Training Materials page [here](#).



I am having trouble attaching the packet to send to my legislator, what should I do?

Email advocacy@iffgd.org and let us know the congressional office and email address you are trying to send it to, we will follow-up with that information for you.

What should I say for my call?

View the call and email script on page 8 of the participant packet to guide your contacts. Visit page 7 for guidelines and prompts to help you develop your story.

Should I follow-up with my legislator after the advocacy event?

Yes, you should follow-up with the office by phone or email within a few weeks of the event. Instructions on how to do so are available in a video recording [here](#).