



**GBS | CIDP**  
Foundation International

**2019 ADVOCACY TOOLKIT**  
GBS-CIDP FOUNDATION INTERNATIONAL





## What is Advocacy?

Your journey matters, and you have the power to use your voice and tell your story to empower informed decisions by federal, state, and local government officials!

Advocacy is when a person or a group of people communicates with a government official or their staff to influence bills and laws that reflect the needs, wishes, or wants of a certain community. Advocacy involves bringing the community voice into the lawmaking process by:



- Writing letters to Senators, Congresspersons, and state legislators to educate them about a particular topic
- Calling the offices of your elected officials and making your opinion known on a particular bill, law, or proposal
- Meeting the staff elected officials at their offices on Capitol Hill or in their home state to share your story and ask for the elected official to take a particular stance on an issue

The GBS-CIDP Foundation International works with the community to make positive policy changes for patients affected by GBS, CIDP, or related syndromes. We work to ensure that patients will have access to appropriate healthcare, treatment, and insurance, that research at the National Institutes of Health and other government agencies is appropriately funded, and that lawmakers are educated about what it is like to live with a rare disease. To accomplish this goals, we participate in the following advocacy activities:

- **Action Alerts** – where we ask members of the GBS-CIDP community to contact their elected officials and inform them of a current issue
- **Hill Day** – where we bring members of the community to Capitol Hill and schedule meetings with Members of Congress to discuss current policy issues and raise awareness of GBS, CIDP, and related syndromes (by invitation only! If you are interested in attending, email [Advocacy@GBS-CIDP.org](mailto:Advocacy@GBS-CIDP.org))
- **Advocacy Toolkit and Action Center** – where we help you write a letter or make a phone call to your elected officials to educate them on your current situation and concerns



**Legislative Agenda: About the Issues**

Every year, the GBS-CIDP Foundation International outlines a legislative agenda that describes asks we will make to our federal government to improve the lives of the patient community. In 2019, we are asking Senators and Congresspersons to:

- **Support legislation enacting a Medicare Part B Home Infusion Demonstration Project for patients with CIDP and MMN**
  - How does this help the community?
    - Many affected individuals and families struggle with accessing infusion centers, which may be hours away, for infusions that can take an entire day (leading to skipped-treatments and progressive disability).
  
- **Continue to include Guillain-Barre Syndrome as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2020.**
  - How does this help?
    - Military service members, particularly those stationed abroad, are at a higher risk for infection. Two-thirds of GBS cases occur following an infection and most commonly these infections include gastroenteritis or respiratory tract infections; two prevalent illnesses amongst those that frequently travel abroad.
    - Through this program, research into the cause, treatment, or cure of GBS can be studied. Researchers are able to submit proposals to this program, which is generally less competitive than typical federal grant programs.
  
- **Provide the National Institutes of Health (NIH) with at least \$41.1 billion in FY 2020, a \$2 billion funding increase**
  - How does this help GBS & CIDP patients?
    - NIH coordinates a modest-but-meaningful research portfolio in peripheral autoimmune neuropathies. Additional funding will ensure this important research portfolio can expand and advance to help improve treatment and diagnosis and ultimately finds cures.
    - The NIH held the clinical trial that showed the effectiveness of IVIG treatment for CIDP patients!
  
- **Provide the Centers for Disease Control and Prevention (CDC) with \$7.8 billion in FY 2020, a \$500 million funding increase**
  - How does this help?
    - Zika virus is a leading trigger for peripheral autoimmune neuropathies and CDC is leading federal efforts to contain and combat outbreaks. Additional resources will enhance these important and timely public health activities, particularly in at-risk areas like Puerto Rico.



### Does Advocacy Work?

YES!! Many communities have had laws passed because of grassroots advocacy, and the GBS-CIDP Foundation has had its own successes in advocating to the federal government, including:

- HR 4724
  - GBS CIDP Foundation has worked with legislators to introduce a bill that will take the necessary steps to ensuring the IVIG home infusions are covered by Medicare comprehensively.
  - The bill was first introduced to the 115<sup>th</sup> Congress, and we received critical feedback on how to make the bill better. We are now getting ready to have our foundation champions in the House of Representatives re-introduce the bill to the 116<sup>th</sup> Congress.
- DOD PRMRP
  - The Department of Defense (DOD) supports a research program- called the Peer Reviewed Medical Research Program – where grants are given to researchers studying diseases from an approved list.
  - Every year, diseases are added to the list. Through Advocacy, GBS has been a disease that is eligible to be studied under this program since 2016.
  - This creates more (less competitive) research opportunities for the community.
- NIH Funding has continued to increase
  - GBS-CIDP Foundation International has advocated along with many other advocacy/medical groups to ensure that the NIH is properly funded each year. We have been successful in securing increases each year since this effort began.
- Through grassroots advocacy, the rare disease community was able to secure essential patient protections during the healthcare reform process:
  - Eliminated discrimination of pre-existing conditions.
  - Banned lifetime or annual caps of coverage.
  - Secured dependent/child coverage through parents' policies until age 26.
  - Created systems to reduce out-of-pocket costs.
- Report language to communicate GBS-CIDP priorities to appropriate federal research agencies, as seen below

*Peripheral Neuropathies.*—The Committee is pleased at the continued progress of ongoing research into Guillain-Barre syndrome, chronic inflammatory demyelinating polyneuropathy, and related conditions. The Committee encourages NINDS to work with NIAID and stakeholders on a state of the science conference on evolving research and scientific mechanisms.

*Autoimmune Neuropathies.*—The Committee continues to encourage NIAID and NINDS to collaborate on a state-of-the-science of autoimmune neuropathies research into conditions like Guillain-Barre syndrome and chronic inflammatory demyelinating polyneuropathy. The Committee is pleased that NIAID and NINDS are working with stakeholders on the importance of the patient perspective.



### Talking to Members of Congress

- General rules!
  1. Meeting in-person? Dress in business attire.
  2. Calling? Make sure there is no background noise.
  3. Writing? Type your letter.

- What to tell your Senator / Congressperson
  1. Your name
  2. I am a constituent in your state/district
  3. Your story (*PRO TIP: type this out and save it*) :

Sentence 1: I was diagnosed with \_\_\_\_\_ in \_\_\_(year)\_\_\_ at the age of \_\_\_\_\_, a time of my life when I was \_\_\_\_\_.

Sentence 2: Share a detail about the diagnosis process.

Sentence 3: Share a detail about the treatment you received and whether you still receive treatment or experience side-effects.

Sentence 4: Share how your life is impacted now as a result of your diagnosis.

Sentence 5 : My story is unique, but there are thousands of other people with similar stories and struggles, so I hope that you will work with me and the GBS-CIDP Foundation International to make policy changes that will help others impacted with this or similar diseases.

4. Ask for support of the GBS-CIDP Foundation International's Legislative agenda:
  - Please consider co-sponsoring legislation that will allow for a Medicare Part B Home Infusion Demonstration Project, securing this medically necessary treatment for individuals with CIDP.
  - Continue to include GBS on the list of conditions eligible for study through the DoD PRMRP
  - Provide the NIH with \$41.6 billion. The NIH continues a modest-but-meaningful portfolio of essential research for these rare neurological conditions.
  - Provide the Centers for Disease Control and Prevention (CDC) with \$7.8 billion in FY 2020, a \$500 million funding increase
5. Thank the Congressperson/Senator/Staff member for their time – even if you were just talking on the phone or writing a letter!



### **Advocacy Dos and Don'ts**

- **Do** feel confident and professional.
- **Don't** argue! If the staff member (or Senator or Congressperson) doesn't agree with your asks, spend time sharing your story and educating them on what it is like to live with a rare disease.
- **Do** use printed materials to help guide your meeting - visual aids may be helpful for you and the person you are meeting with.
- **Don't** make up facts! If you don't know the answer to a question, let the person know that you will follow up with them.
- **Do** be efficient - meetings will likely only be 15-20 minutes, phone calls may be shorter, and your letter needs to be read quickly! Make sure you get to the point quickly, no matter how you are communicating.
- **Do** be prepared by visiting the "All About Advocacy" Section on GBS-CIDP.org ahead of your meeting, call, or letter writing session.
- **Do** follow up with the person that you met with by sending them an email a few days after your meeting or phone call. Check back in regularly, and share your story each time you each out!





### Advocacy Vocabulary

- Advocate
  - Someone who supports a cause.
- Action Alert
  - A message that the Foundation will send asking for members of the community to take an action, usually to contact their legislators about a specific policy issue.
- Appropriations
  - When the government sets aside funds for a specific, defined purpose. Appropriations is the budget for the government and government-sponsored programs.
- Bill
  - A written, proposed law
- CDC
  - The Centers for Disease Control, the national agency that monitors, does surveillance on, and reports on disease outbreaks, disease distribution, and other public health topics.
- CMS
  - Centers for Medicare and Medicaid Services, the federal agency that oversees Medicare and Medicaid funding and distribution
- Committee
  - A group of legislators that develops bills on a specific topic, such as health or veterans' affairs.
- Cosponsor
  - A legislator that supports a given bill, but did not necessarily take part in writing the bill.
- DoD
  - Department of Defense
  - PRMRP - Peer Reviewed Medical Research Program. This program exists under the DoD, and includes an opportunity for researchers to apply for funding to study a particular condition. GBS is a condition that may be studied under this program.
- FDA

The Food and Drug Administration, the national agency responsible for approving new drugs / medical devices and monitoring the safety of food, medical devices, and medicines.



- H.R. xxxx
  - This designation means that a bill was introduced in the House of Representatives
- L.A.
  - Legislative Assistant - a staff member on a legislator's team that reviews, summarizes, and recommends legislative activity to the Senator or Congressperson. L.A.'s usually become experts on a certain topic, like healthcare.
- Legislator
  - A person, elected by the public, that writes and votes on proposed laws. Legislators include Congresspersons and Senators at the federal level and State Representatives and State Senators at the State level.
  - The legislative branch of federal government includes the Senate and the House of Representatives.
- NIH
  - National Institutes of Health, the national medical research center. The NIH is comprised of several specialty research centers, such as :
    - NINDS - National Institute of Neurological Disorders and Stroke
    - NIAID - National Institute of Allergy and Infectious Diseases
- Rules Committee
  - A committee in the House that assigns each bill a "rule", which determines how much the bill will be debated.
- Speaker of the House
  - The leader of the House of Representatives. The Speaker controls the calendar of the House of Representatives.
- Sponsor
  - The primary writer (or writers) of a bill. There may be several sponsors on any given bill, and each bill has to have at least one sponsor. Sponsors must be legislators.





### Who's Who in Congress

- Senator
  - Each state has 2 Senators. The Senate is one chamber of Congress, and Senators vote on bills in the Senate.
- Representative/Congressperson
  - Each state has a different number of Representatives, and this is determined by the population size of your state. The federal courts draw districts within each state, and then each district elects a Congressperson. Representatives vote on bills in the House of Representatives, a chamber of Congress.
- Congress
  - The legislative branch of the government – they write the laws. The two chambers of Congress are the House and the Senate.
- Speaker of the House
  - The leader of the House of Representatives
- Vice President
  - The leader of the Senate
- Key Committees for the Foundation
  - House Committee on Ways and Means
    - This committee is responsible for reviewing and making recommendations to bills that are related to revenue-raising measures. Bills related to Medicare, unemployment, Social Security, and other similar programs fall under this Committee's review.
  - House Committee on Appropriations
    - This committee is responsible for reviewing and making recommendations to bills that are related to government spending. Bills related to agriculture, Health and Human Services, Defense, and other similar programs fall under this Committee's review.
  - Senate Defense Appropriations Subcommittee
    - This Subcommittee within the Appropriations Committee (Senate) is responsible for reviewing and making recommendations to bills related to spending within the Department of Defense (DOD).
      - This is important for the foundation because Guillain-Barre Syndrome is a condition eligible for study through the DOD Peer Reviewed Medical Research Program, and needs to be added to the list of eligible conditions every year.
  - Rare Disease Caucus
    - A congressional caucus is a group of members of the United States Congress that meets to pursue common legislative objectives. Caucuses are formed in the House of Representatives and can hold briefings or hearings with the patient community to raise awareness on issues. While no bills can be introduced or created through a caucus, the caucus may choose to vote similarly on issues related to Rare Diseases.