



**This RARE Toolkit was made possible by the generous support  
from the member companies of the RARE Corporate Alliance -  
Patient Advocacy Committee**

Alexion  
Amylin  
BioMarin  
Feinstein Kean Healthcare  
Genzyme  
GlaxoSmithKline  
Parabase Genomics  
Pfizer  
Shire  
Sigma Tau Pharmaceuticals  
Siren Interactive  
ViroPharma

# BRINGING RARE DISEASE TO CAPITOL HILL: ADVOCATING FOR YOUR CAUSE



## Introduction

Capitol Hill may seem like an enigma to some. Shrouded in mystery, its activities may seem elusive and arcane. How does it function? How can it benefit you? Many are not aware what an incredible resource Capitol Hill can be for the rare disease community.

Laws and bills go before Congress and the Senate every day that can directly impact the rare disease community—as a result of advocates like you! From diffusing just how a bill becomes a law to understanding the intricacies of Congress, this toolkit will help integrate you into the public's role in government.

# SECTION 1:

## BACKGROUND INFORMATION



Patient representatives, especially among the rare disease community, can frequently find themselves feeling lost. But they have the capability to get involved and affect great change! Advocates bring both personal and practical feedback to government, relaying what many people dearly need.

### Know your Congress: The 113th Congress

**Congress**, the legislative body of the United States government, is divided into two houses: the House of Representatives and the Senate.

**The House of Representatives** has 433 total members who serve two year terms, representing districts across the nation. These districts are apportioned to states based on population size, and each state has at least one Representative. In the 113th Congress (the current one), there are 200 Democrats, 233 Republicans and zero Independents. 78 Representatives are women, while 355 are men.

**The Senate** is more stagnant, always having 100 members at any given time. Regardless of population, each state has two senators which serve six year terms. Of the 113th Congress (the current one), 53 senators are Democrats, 45 are Republicans and two are Independents. 20 senators are women; 80 are men.

### How Does a Bill Become a Law?

Getting a bill passed may seem like a lofty or unattainable goal. Can the general public even

partake in the process? It may be surprising for some to learn that the first step originates with you, the people! By proposing an idea or bill first, you are laying the ground work for passing a law in Congress.

“When thinking about approaching members of Congress about an issue that you would like them to address, it is very important to remember that doing so is a fundamental right and responsibility of each citizen of the United States of America. The right to petition is expressly set out in the First Amendment and it allows citizens to ask government at any level to right a wrong or correct a problem.”

—**Heather Long**, Co-Author of HR 2671 CAL Undiagnosed Diseases Research and Collaboration Network Act, and Parent Advocate

There are several stages of debate, revision and voting before a bill can turn into a law:

1. An idea is generated in the form of a bill. Ideas can come from anywhere—lobbyists, PACs, grassroots political movements or **citizens**.
2. A member of Congress (either a Senator or a Representative) chooses to sponsor the bill.

Insider tip: When approaching members of Congress to sponsor your bill, consider getting support from the community first. When going in with support from the community (such as signatures from patient organizations), it proves how important the issue is to the community.

3. The bill is introduced on the floor of either the House or Senate, where it is referred to an existing committee or subcommittee.

## SECTION 1: BACKGROUND INFORMATION

Note: Most issues relevant to the rare disease community are under jurisdiction of the **House Energy and Commerce Committee** or **Senate, Health, Education, Labor and Pensions (HELP) Committee**. Every couple of years, the members of these committees may change (with each election, a shift may occur), so make sure you are aware of these while your bill is being reviewed.

Insider tip: Regardless of which committee the bill is heard or which Congressional office supports your bill, you will not get anywhere unless you cover the cost. Consider offsetting the cost before or during the bill's passage through Congress to become a law.

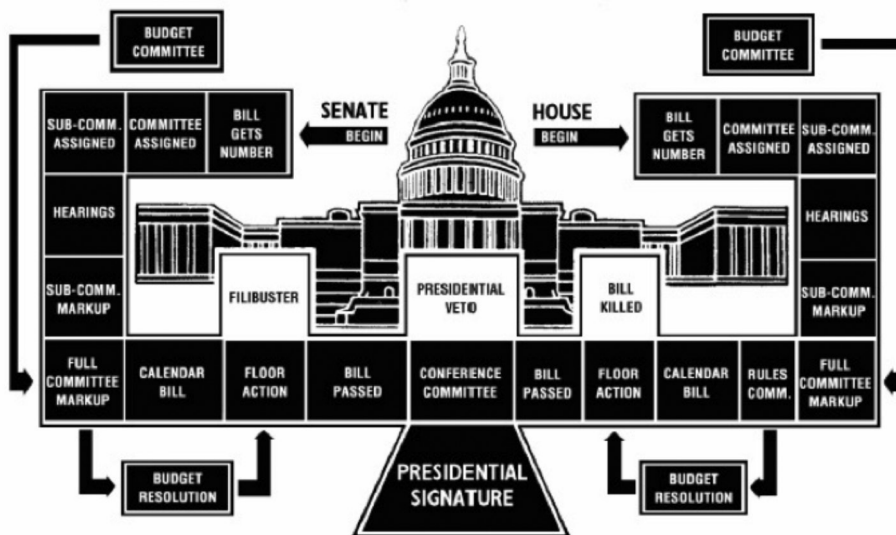
- Once the bill is in a committee, it is placed on the official calendar. The committee may defer, amend or vote on the bill.
- If the bill returns successfully from the committee or subcommittee, the Senate and the House will debate the bill separately, offering amendments and casting votes. If the bill is defeated in either the House or the Senate, the bill dies.

- Following the passage by the House or Senate, the bill is passed to the other chamber, where it follows the same route from committee to floor action. The bill may be received, rejected, ignored or changed.
- If the bill passes both chambers, it can then go to the President for signature. If the President approves the legislation, the bill becomes a law. The President can also veto the bill.

Insider tip:

“Patience is a necessity—very rarely will anything be accomplished during one legislative cycle. It might take two or more cycles before you even gain any traction, but just stick with it.”

—Jennifer Bernstein, Vice President, JC White Consulting.



## SECTION 2: REACHING MEMBERS OF CONGRESS



United States Representatives, like their Senator counterparts, are elected by the people, and it is a part of their job to listen to you. So you should always feel entitled to reach out to them, be it through sending an email, mailing a letter, placing a telephone call or visiting their offices.

### Finding your Representative

Although there are two houses of Congress, consider contacting a member of the House of Representatives first. With fewer constituents, they have more time to directly engage with the public and hear issues. If you are unsure who your representative is, use this easy search engine:

<http://www.house.gov/representatives/find/>.

This search engine uses zip codes to generate the district you are in, targeting the Representatives in your area (i.e. your possible Representatives). You can then access the websites of those listed to track down their contact information.

### Calling a Member of Congress

You can access your Representative's telephone number by calling the **US Capitol Switchboard** at (202) 224-3121. A staff member will typically transfer calls directly to the office, where a legislative assistant will answer. Here are a few tips to remember before you call. Advance research can go a long way! We recommend identifying which staff member is responsible for your particular issue before calling.

In addition, it is important to articulate why you are calling and what issue(s) you are calling about. Sometimes, you will be able to speak directly to the Senator or Representative, but more often you will speak to a staff person in the member's office. This person will provide a summary of all those who called and their positions on issues to the Congressman or woman later.

### Writing to a Member of Congress

Getting your voice heard by a member of the United States government is a liberating experience! And you shouldn't wrongfully assume that members of Congress pay little attention to constituent mail. Concise, well written letters are one of the most effective ways Americans can influence law-makers.

But the fact is these members do receive hundreds of letters and emails on a daily basis, so it is important to compose a letter of substance! Below are some helpful tips to ensure this:

- Pick one subject and try not to deviate from it.
- Be brief, factual, personal and courteous—and include examples, if possible.
- Don't be afraid to ask for action!
- Although a response may not come instantly (since it takes about a month for Congressional offices to receive letters), it is always great to respond to these, even if it is just a thank you note.
- A personal letter (handwritten) will send a stronger message than a letter on a generic form.
- When writing to a Committee Chair, it is proper to address him/her as Mr. or Madam Chairman.

View a **sample letter template** in the **Appendix**.

## SECTION 2: REACHING MEMBERS OF CONGRESS

### Emailing a Representative

Writing an email is just like writing a letter! However, you should note that some members do not respond to emails. Although there is no central listing of members' email addresses, you can find their individual contact information through their websites. The U.S. House of Representative's Directory (<http://www.house.gov/representatives/>) can help you locate these.

When addressing an email to a member of Congress, a couple of things to consider include:

- Include your address in the top left corner under your name.
- Address the member of Congress as Representative/Senator (last name).

### Meeting with a Member of Congress

If you have the means to travel and speak directly with a member of Congress, this would perhaps show the most of tenacity. Individuals and groups can arrange meetings with Senators and Representatives in their Washington or local offices. Check their website, get on their mailing list or call their office directly to arrange a meeting.

All Congressional offices in Washington require a written appointment request. Although some members do offer walk-in meeting times in their local offices, an appointment request is highly recommended.

Insider tip: It is a misunderstanding that in order to meet with your member of Congress, you must travel to their Washington D.C. office. Talking to your legislator in his district office creates a more relaxed environment.

Here are a few other thoughts to keep in mind before, during and after your meeting:

- Plan your visit carefully. What do you want to achieve? Think about who would the

best person in the office to meet with. Bring materials and information to support your position.

- Come prepared. Learn everything about your issue in advance. Also research where your legislator stands on these issues (especially through past votes). Use **CSPAN's search engine** to learn legislators' past votes: <http://www.c-spanvideo.org/congress>. Another great resource to explore is **Project Vote Smart** (<http://votesmart.org/>), which provides information on how your representative has voted on issues.

Insider tip: Try to be seen as a resource for staff members. Congressmen and women have over 50+ issues that they need to stay abreast of. When you are willing to do the "legwork" and provide information on your issue, you are laying the foundation for a personal relationship with this important contact.

"Be sure to visit your member of congress's website to familiarize yourself with their background and history. It is also important to learn more about their legislative priorities and voting record. You want to know as much information about the member as possible in order to be able to establish a relationship and connection. You can find most of that information on the member's website or by visiting **The Library of Congress** (<http://thomas.loc.gov>)."

—Allen Todd, Director of Patient Education & Advocacy, Global Healthy Living Foundation

- *Be prompt.* Punctuality to an appointment is a courtesy—and a must! Congressmen and women often have very crowded schedules. If interruptions occur, try to be flexible and patient.
- *Be respectful and responsive.* It's important to demonstrate the connections between your interests and the larger community. There is a good chance you will be asked

## SECTION 2: REACHING MEMBERS OF CONGRESS

questions; try to answer these honestly, and if you don't know an answer, offering to follow-up is very professional. Don't be afraid to leave behind a one-pager with a summary of your issue.

“Localize the issue. Be sure you connect the idea you are there to discuss with the state/district of the office you are visiting. Members of Congress always want to know how legislation affects their constituents and you have the opportunity to provide that information in these meetings.

You often see advocates meet with members of Congress or staff members and just talk about problems. It is very important that advocates come to a meeting to discuss solutions and ask that member to support your solution.”

—**Allen Todd**, Director of Patient Education & Advocacy, Global Healthy Living Foundation

- *Be brief.* Meetings should be kept to a maximum of 20 minutes, so plan to discuss no more than two issues.

“Be prepared to make a short “elevator pitch” (2 minutes) that gets to the heart of your issue. Anything longer than that and people will tune you out. If you can capture their attention in the first two minutes, you can discuss it in more detail.

It may or may not be extremely useful to talk about the detailed science or pathology of your disease. Talk more about its impact on your family and focus on the human experience. Remember they talk to many people in one day, and your story needs to be easily understood.

But you can't just tell a sad story. There are plenty of those. Identify some actionable issues and make specific requests that you think would be meaningful.”

—**Roy Zeighami**, Board Member, National MPS Society

- *Send a thank you letter.* This gives you the opportunity to outline the points you covered in the meeting and share additional material. It also shows your dedication to your cause!

Refer to a **checklist** for meeting with a member of Congress in the **Appendix**.

Pressing your cause forward may be difficult and watching it move slowly through the process may be frustrating, but remember how important it is to not abandon your convictions. One patient advocate reflects on bringing the issues important to the rare disease community in front of Congress:

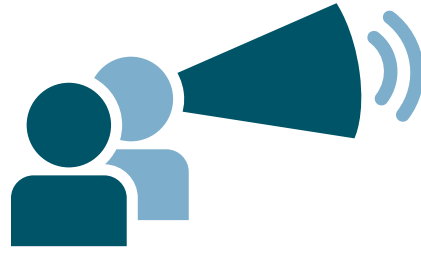
“Trying to get a Member of Congress to take on a cause, propose legislation and see it through to the end is difficult, but not impossible. You do not need to have a political background, nor do you need to know all of the nuances of playing in the political arena. Accept the fact that inevitably you will make mistakes. Also remember that your representatives are human too and that they are in Congress to represent you. They work for you. Always remain respectful and courteous when working with them or their staff. They have a lot of things to deal with so they may not always get back to you quickly. You will need to follow-up regularly.

Getting legislation passed is very difficult. However, remain confident that with perseverance and your passion for your cause, you will succeed in bringing the issues of the rare disease community to the forefront of awareness so that the people who make up this community will reap the same benefits afforded to those who have common diseases even if you never get a piece of legislation passed.”

—**Heather Long**, Co-Author of HR 2671 CAL Undiagnosed Diseases Research and Collaboration Network Act, and Parent Advocate



## SECTION 3: SPECIFIC WAYS TO ADVOCATE



There are several ways to advocate; a couple of which are listed below. These serve as great first steps to get involved, learn about the legislative process and watch your efforts set things into motion.

### Joining the Rare Disease Congressional Caucus

Some noteworthy Representatives include those who specialize in rare diseases, participating in the **Rare Disease Congressional Caucus**: <http://www.rarediseases.org/advocacy/initiatives-updates/caucus>. This forum allows members to voice their constituents' concerns, exchange ideas and build support for legislation that will improve the lives of those with rare diseases. Co-chaired by Joseph Crowley (NY-7) and Leonard Lance (NJ-7), this caucus consists of more than 50 members. A full list is available in the **Rare Disease Legislative Advocates** website (<http://rareadvocates.org/rarecaucus/>).

A great way to start advocating for rare diseases is by imploring your Representative to join this Caucus! To do so, access an Ask Letter on the **Rare Disease Legislative Advocates** website (<http://www.congressweb.com/kaki/21>) that, once you add your address, will automatically generate and send to your member of Congress.

View a **Rare Disease Congressional Caucus One Sheet** that you can leave behind in the offices of your members of Congress in the **Appendix**.

### Participating in Rare Disease Lobby Day

Rare Disease Day is an annual event, observed worldwide on the last day of February, to raise awareness of rare diseases as a public health issue. The **Rare Disease Legislative Advocates Lobby Day** on Capitol Hill corresponds with Rare Disease Day. In 2013, Lobby Day was held on February 27th. Open and free to the public, Lobby Day aims to:

1. Educate patient advocates about the legislative and appropriations process
2. Inform Congress about rare diseases and the many different needs of the patient community
3. Build lasting relationships with members of Congress and their staff
4. Ensure that the needs of rare disease patients are considered in future legislation and policy
5. Empower patient advocates to take an active role in the democratic process

In addition, patient advocates will take away lessons and experiences. During Lobby Day, they will have the ability to:

1. learn more about the regulatory and legislative process
2. meet with their local legislative members
3. interact with other advocates

## SECTION 3: SPECIFIC WAYS TO ADVOCATE

One parent advocate, who participated in the Rare Disease Legislative Advocates Lobby Day, shares his experience and offers advice to others who are considering participating in future events:

“I felt Lobby Day was extremely effective to get a good sense of the importance of coming together as a united front amongst all rare diseases, and it was great to show strength in numbers. I learned that there are a number of legislative initiatives affecting the rare disease community. It is important to remain aware of these and rally support.

I would advise others to definitely bring a bullet pointed 1-pager about their story/disease and rare diseases in general. Also relax. Yes, these are politicians (or their aides), but they are human beings. Your stories will touch them (we even made the men cry). Finally, remember to follow up afterwards. Politicians and their aides meet thousands of people each year. Most never follow up from their visits. The ones that do, get attention”

—**Jeff Wuchich**, Co-Founder & President, Cure AHC

If you are interested in learning more about Lobby Day or attending the 2014 Lobby Day, please contact [Julia@RareAdvocates.org](mailto:Julia@RareAdvocates.org) with **Rare Disease Legislative Advocates (RDLA)**, (<http://rareadvocates.org/>) a great resource that equips individuals with informational meetings, legislative resources, advocacy tools and specials events.

The **RDLA** has a list of all legislation that is relevant to the rare disease community and holds monthly calls/meetings for advocates to learn more about legislation or ways to help promote their own legislation.

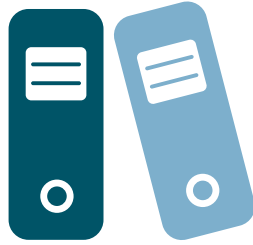
### Capturing Your Lobby Day Experience

Not every rare disease patient advocate is able to attend Rare Disease Legislative Advocates Lobby Day each year, so sharing your experiences with others who were unable to attend is very kind.

Here are a few ideas to “capture” your experience:

- Be sure to take photos at the meetings and events with fellow advocates and with your Representatives.
- Snap photos of the Genes Ribbons™ and post to Facebook, Instagram or Google+ pages. Tag @Global Genes and @RareAdvocates.
- Post pictures, quotes and snippets from your experiences to Global Genes |RARE Project (<http://www.facebook.com/globalgenesproject>) and RDLA (<http://www.facebook.com/rarediseaselegislativeadvocates>) Facebook pages.
- Send tweets. Include @RareAdvocates and @GlobalGenes in your tweets and hashtags #RareLobbyDay and #CareAboutRare. During your meetings, learn the Twitter handles of the Representatives you are meeting with and thank them for the meeting in your tweets.

# APPENDIX



## Sample Letter for Contacting Members of Congress

January 1, 20XX

Name

Address

Dear Mr. \_\_\_\_\_:

My name is \_\_\_\_\_, and I'm writing to you on behalf of the rare disease community, specifically \_\_\_\_\_. I am affiliated with \_\_\_\_\_, a nonprofit that \_\_\_\_\_.

I am writing to you about an issue that is very important to me: \_\_\_\_\_.

This issue affects me personally because \_\_\_\_\_. It is also important to the

community that you represent because \_\_\_\_\_.

I urge you to consider the following actions:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

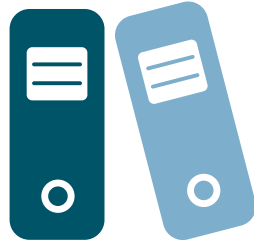
We must do all we can to \_\_\_\_\_. Thank you for your time.

Sincerely,

Your name

Your address

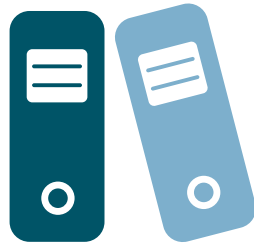
# APPENDIX



## Checklist for Meeting with Members of Congress & Staff

- Arrive on time, not more than 10 minutes early
- Thank them for agreeing to meet with you
- Share your personal story, explaining why the issue is important to you
- Make a specific “ask” – to protect the NIH & FDA Funding and join the Rare Disease Caucus
- If unsure how to answer a question, write it down and tell them you will follow up—you don’t have to be an expert on the legislation
- Leave behind a one-pager with a summary of your issue and your contact information
- Respect the Staffer’s time, so cap the meeting at 20 minutes
- It’s ok to ask for a photo with a Member of Congress, but try to make it a group shot and do it quickly
- Report back to RDLA staff on how the meeting went
- Follow up with a thank you note that reinforces your ask

# APPENDIX



## Rare Disease Congressional Caucus One Sheet



### Please Join the Rare Disease Congressional Caucus

The bipartisan Rare Disease Congressional Caucus is led by Representatives Leonard Lance (R-NJ) and Joseph Crowley (D-NY) to promote awareness of rare disease issues. Our goal for the Caucus is to grow House membership and formalize the Caucus in the Senate

**Background:** There are more than 7,000 rare disorders that together affect more than 25 million Americans and their families. One in 10 Americans has a rare disease. The Orphan Drug Act was enacted in 1983 to encourage pharmaceutical companies to develop drugs for diseases that have relatively small patient populations. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the U.S. More than 80% of rare diseases are considered “ultra rare,” affecting fewer than 6,000 people, some diseases affect fewer than 100. Rare diseases include rare cancers, tropical or neglected diseases, genetic diseases and many pediatric diseases and cancers. Many of these diseases are life threatening and have no treatment options.

Despite the success of the Orphan Drug Act there have been fewer than 450 treatments for less than 300 diseases approved for marketing by the FDA in the last 30 years. The science exists for many of these diseases to be treated; however, treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. Additionally, while a few treatments have become available for some, patients struggle with insurance companies and government programs to afford these lifesaving treatments.

**Solution:** A Rare Disease Congressional Caucus will help bring public and Congressional awareness to the unique needs of the rare disease community - patients, physicians, scientists, and industry, and create opportunities to address roadblocks in access to and development of crucial treatments. The Caucus will give a permanent voice to the rare disease community on Capitol Hill. Working together, we can find solutions that turn hope into treatments.

**To join the Caucus, please contact:**

Helen Dwight, Office of Rep. Lance (R-NJ): [Helen.Dwight@mail.house.gov](mailto:Helen.Dwight@mail.house.gov) (202) 225-5361

Nicole Cohen, Office of Rep. Crowley (D-NY): [Nicole.Cohen@mail.house.gov](mailto:Nicole.Cohen@mail.house.gov) (202) 225-3965

# RESOURCE GUIDE



## Learning your Legislator's Previous Votes

**CSPAN Search Engine (<http://www.c-spanvideo.org/congress>):** This search engine can help educate you into your legislator's stance on important issues. When approaching members of Congress, it is essential to come prepared. Learning their position on certain issues is a part of this process.

**Project Vote Smart (<http://votesmart.org>):** A nonprofit research center, Project Vote Smart provides abundant, accurate and relevant information to the public. Access this resource to read easy-to-understand summaries of legislators' voting records.

## Locating Members of Congress

**U.S. House of Representatives Directory (<http://www.house.gov/representatives>):** This directory can help you locate your United States Representative. From there, you can access their websites to learn their contact information in case you want to send an email, mail a letter or visit their office.

## Preparing to Advocate

**Global Healthy Living Foundation (<http://www.ghlf.org/about/>):** A 501(c)(3) non-profit advocacy organization, the Global Healthy Living Foundation advocates for improved access to care, educating the community about the importance of diagnosis, early and innovative medical intervention, long-term lifestyle improvement and therapeutic compliance.

**National Health Council (<http://www.nationalhealthcouncil.org/>):** The National Health Council provides a united voice for the millions of people with chronic diseases and disabilities and their family caregivers. The NHC is committed to advocating for health care that will cover everyone, curb costs and abolish exclusions for pre-existing conditions.

**Rare Disease Legislative Advocates (<http://rareadvocates.org>):** A collaborative organization designed to support the advocacy of all rare disease groups, Rare Disease Legislative Advocates provide informational meetings, legislative references, advocacy tools and details on special events. This resource has a list of all legislation that is relevant to the rare disease community and holds monthly calls/meetings for advocates to learn more about legislation or ways to help promote their own legislation.



**Contributors:**

**Jennifer Bernstein**

Vice President  
*JC White Consulting*  
<http://whiteandassociatesdc.com>

**Julia Jenkins**

Rare Disease  
*Legislative Advocates*  
<http://rareadvocates.org>

**Heather Long**

Co-Author of HR 2671 CAL Undiagnosed  
Diseases Research and Collaboration  
*Network Act, and Parent Advocate*

**Allen Todd**

Director of Patient Education & Advocacy,  
*Global Healthy Living Foundation*  
<http://www.ghlf.org>

**Jeff Wuchich**

Co-Founder & President,  
*Cure AHC*  
<http://cureahc.org>

**Roy Zeighami**

Board Member,  
*National MPS Society*  
[www.mpssociety.org](http://www.mpssociety.org)



**Global Genes Project**  
Siren Interactive  
Rare Disease Legislative  
Advocates