



RARE TOOLKITS

Building Relationships with Your Representatives



So you want to build relationships with your government representatives?



Thank you for including us on your journey! Most likely you have a need for this toolkit **Building Relationships with Your Representatives** because you or a loved one has a rare disease. As you prepare to use the tools in this kit, we want you to know that you are not alone. We are in this together. It is our hope that the personal stories, resources, tips, and suggestions for self-reflection in this guide will make the road to advocacy for your rare disease more manageable.

We know, all too well, that a lack of information and support for people living with RARE diseases can lead to feelings of dis-ease. Please know, it's not just you—feeling depressed, anxious, and isolated are common conditions in the RARE community. Fortunately, RARE Advocates see these challenges as opportunities to take control back from their disease by filling the void with support groups, knowledge, and advocacy.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. We've included a table of contents to make it convenient for you to find the information you are most interested in at this time. ■

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Paper and pen indicate an interactive exercise



Jean's Journey



The Advocate's Role



Overview of Advocacy

Talking the Talk

You don't have to become a political "wonk" to be a successful advocate; but knowing the basics makes it easier to navigate the road ahead. Like the medical industry, the legislative field has its own language. Don't be afraid to ask a legislator or their staff member to define a legal term you don't understand; they will appreciate your desire for clarity.

We've included glossaries at the end of each section to make it easier for you to become familiar with basic legislative terminology often used by lobbyist, policy experts, and seasoned advocates. Knowing these terms prepares you to talk the talk when the director shouts "ACTION!" and the spotlight is on you to educate a government representative about your rare disease advocacy goals.

All legislators have the same job: to represent their communities (constituents), including the 1 in 10 Americans who are impacted by rare diseases. This toolkit provides an overview of what it means to be an effective advocate. It highlights the minimal differences between the state and federal legislative systems. ■



What's In a Title?

Legislators are referred to by a number of titles. Listed are some of some of the most commonly used titles:

- Lawmaker
- Representative
- Elected official
- Legislator
- Policymaker
- Member (federal)
- Congressman/Congresswoman (federal)



The Road to Advocacy: Jean's Journey

Like Dorothy and her three amigos on the road to Oz, there are other advocates on the path with you. Which is why, through a compilation of their reports from the field, we are able to provide you with a toolkit companion, Jean Jergens. We believe "*Jean's Journal Notes*" from her road to advocacy will motivate and inspire you to use the information in this Building Relationships with Your Representatives toolkit.

Squeaky Wheel on the Road Less Traveled

With the exception of your grocery store shopping cart, the squeaky wheel does get the oil. Sharing your story with legislatures can have a huge impact on rare disease awareness. It can help spark the development of new treatments, therapies, and policies that promote a better quality of life for you, other rare patients, and caregivers.

Advocating for the creation and passage of good policies and supporting existing policies is equally as important as defeating bad policies that reduce funding for: research, clinical trials, and impose restrictions or changes to healthcare coverage. ■

Meet Jean



Jean's journey to advocacy began when she was 33 years old. She is married to Danny and they have a 4-year-old daughter, Charlotte. The first symptoms of Jean's rare disease were identified more than six years ago. She is currently managing her disease with an experimental medication, holistic therapies, life-style changes, and her faith.

Fortunately, Charlotte does not have Jean's rare disease; but the probability is high for Jean to give birth to a child with genetic markers for the disease. Jean and Danny want to have more children; but Jean's doctor advised them not to until they know more about her disease. Jean's motivation to become a RARE advocate is twofold: her desire to have more children and the allocation of additional government funding for more pharmaceutical trials for rare diseases.

Getting to Know All About Your Member

Like the grand poobah of a small country, it is helpful to have strong allies who will have your back when troubles a brewin'. Fortunately, you don't have to host a State Department dinner to meet potential allies. Experienced advocates know that legislators at every level of government are ally-worthy; which is why Jean joined her neighborhood action group. The group's monthly meetings often include guest speakers who are city-level politicians and local civic leaders representing special interest groups.

At the end of the meetings Jean introduced herself to the speakers. She told them her rare disease advocacy goals and she asked them to support her efforts. Jean's involvement with the neighborhood action group allowed her to meet potential allies and to share her advocacy goals with people outside of the RARE community.

Friended!

Jean was not looking for a new BFF, but she knew building relationships with local politicians could lead to introductions to legislators up the ladder. Other advocates told her that having a good rapport with legislators increases the odds for her to help them get bills introduced, to help draft bill language, to shape the debate on the issues, and to get legislation signed into law. She was also told that it is extremely helpful to have a legislative champion in her corner who can knockout bad policies and amend weak legislation.

The Internet makes it easy to find out who your legislators are and where they stand on healthcare issues. Ideally, you want to find representatives who have a record of supporting unique issues like rare diseases. Legislators who work on these types of issues likely have a personal connection to them. But don't let that stop you from sharing your story, you never know who it touches.

It is most beneficial to establish and maintain a consistent relationship with legislators in between sessions. Use this, less busy, time to remind your legislators that you want to be actively involved when action is needed for legislation in the new session.

Jean's Journal Notes

Marching Orders



Jean's journey to advocacy began with many of the questions you are likely pondering.

Where do you start? Can you really make a difference?

After putting Charlotte to bed, Jean and Danny had many late night discussions about whether Jean should pursue advocacy. They, eventually, decided it would be her "job" in the approaching New Year.

A few weeks later Jean was preparing dinner while Charlotte watched a Christmas special on the TV. Jean's ears perked up and when Charlotte began to sing along, the lyrics of the song that engaged little Charlotte suddenly had new meaning for Jean.

***"If you want to change your direction,
If your time of life is at hand,
Well, don't be the rule, be the exception
A good way to start is to stand.
Put one foot in front of the other
And soon you'll be walking 'cross the floor.
You put one foot in front of the other
And soon you'll be walking out the door
You never will get where you're going
If ya never get up on your feet..."***
(*"SANTA CLAUS IS COMIN' TO TOWN,"*
RANKIN/BASS, 1970, ANIMATED CHRISTMAS
SPECIAL.)

The lyrics are a pick-me-up for Jean when she feels overwhelmed with her advocacy efforts.

You can find out who your representatives are at the state and federal level with a Google search. You will need to enter your address when searching. There are also resources at the end of this toolkit on how to get information on your representatives.

Sessions:

Each Congress lasts two years and is comprised of two sessions for legislators to work daily on government legislation. Since 1934, the first session convenes on January 3rd of odd-numbered years and adjourns on January 3rd of the following year; the second session runs from January 3rd to January 2nd of even-numbered years. Congress traditionally takes vacation for a month in August.

Homework First

Do your homework first and it will be easier to build rapport with your representatives. Jean knows politics are about people, so she did research to find information about her representative's family, hobbies, achievements, and politics. It helps to know what issues your representatives are passionate about. Look for things you may have in common with them: education, sports affiliations, hobbies, charitable activities, or who knows, even fly-fishing for large mouth bass.

Legislators are often active on social media (Facebook, Twitter, and LinkedIn) and/or have their own campaign websites. Read their bios and PR releases, and check their voting record on your state's government website. Use a magnifying glass to get in close on the people and objects around them in the photos on their campaign website. The 100-pound large-mouth bass mounted on the wall, trophies, diplomas, and photos of them in grip and grins with other, hopefully recognizable, people can be useful rapport building information.

Remember to keep an open mind if the information you uncover is unfavorable or not relevant to your cause. While, Jean didn't have any shared interest with her representatives, she did discover something useful. She was happy to learn that her state senator, Wallace Smalls, supported an unpopular piece of legislation that provides students in her district with free, off campus, WIFI.

Jean's Journal Notes

Legislative Titles



In the beginning Jean, like most advocates, had many questions about the players and the process of government business. One of the first things she needed clarity on was legislative titles. Here's what she found:

The United States legislature is bicameral, and there are three different titles for legislators.

1. Representative (member of the House of Representatives)
2. Senator (member of the United States Senate)
3. Congressman/Congresswoman (an individual member of the House of Representatives, synonymous with "representative")

"Building and nurturing lasting relationships with legislators is so key in this process. You will find that they will be your champion, help you navigate and provide guidance through this journey. While there are people who are incredibly supportive, you may also find support in the most unlikely people through this process. At the end of the day, whether you reached your goal or not, building relationships is a success and milestone in of itself."

-SHARON KING, PRESIDENT, TAYLOR'S TALE

Crush It!

Now that you know who your legislators are and also some basic background on them, it's time to introduce yourself. It's natural for this step to feel like the preteen jitters you had the first time you called your junior high crush. After Jean made her first, sweaty palm, call to Representative Smalls, calling his office on a regular basis became easier.

Ongoing communication is important; and it takes only a few minutes to convey your feelings about an issue on a phone call, in a handwritten note, or an email. Time and location allowing, face-to-face meetings are the most effective way to influence your legislators.

Mind your manners! Remember, you are one of many constituents clamoring for support from your representatives. When you establish a relationship with the legislator ask him or her how they prefer to be contacted.

Unless you have really bonded with your representatives, avoid sending their home baked goodies for the holidays or birthday bouquets. You should be persistent about your advocacy goals, but you don't want to be "unfriended"! When you get a legislative win it is appropriate to send the representative a heartfelt letter of gratitude; it's also a good idea to include in the letter how the legislation will positively affect the rare disease community.

Field Tip : No Assumptions

Jennifer Bernstein of Horizon Government Affairs has counseled rare disease advocates on how to talk to representatives. She offers a cautious tale about prejudging the way a representative may respond to your goals. She advises advocates to keep an open mind about the person they will be meeting with.

Bernstein shared that during a counseling session with a rare advocate who had lost a child to cancer, she was aware that the representative they were preparing to meet with was a member of the Tea Party. Because of the representative's past voting history and political platform (the intentions and principles of a political party), Bernstein expected the meeting to be a waste of time. She thought he wasn't going to support anything that involved government spending no matter how worthy.

As it turned out, his wife had recently given birth and he began to cry as the advocate told her story. When the meeting was over, he told her "Whatever you need, I'll get it for you. If it's money, that's fine." Bernstein was shocked and said, "I'd never seen anything like that."

This is just one example of the potential impact you can have. One in 10 Americans are impacted by a rare disease; which suggests the odds are in your favor that talking about a rare disease will build a connection with your legislator.



No Place Like Home

Representatives primarily work in their state capitol offices, on Capitol Hill, in Washington, D.C. But, like Dorothy's desire to return to Kansas, representatives also like to go home. During session breaks they are often "in-district," which means they are home in the jurisdiction they represent as a legislator. Contact their capitol office to see if you can get an appointment with them the next time they're home. Also ask if the representative has any town hall meetings scheduled during his in-district time.

Legislators usually have staff members who work in different policy areas: healthcare, economics, workforce development, and other specializations. They have expertise in these areas and are generally the legislator's go-to resource for policy recommendations and related information. They can be a great resource for information and for building rapport with your representative.

Call these experts and give them your "elevator pitch," and request a meeting with them. They may ask you to follow-up the discussion with an email. Do

this follow-up promptly and send a duplicate copy of the email communication to the staff that handles the specific issues (if this information isn't on the representative's website call his office and request it).

"When I was first writing my letter to my representative, I made sure to include some key tactics. I kept my letter logical and I was specific in what I was asking for. And I made sure what I was asking was also do-able. But the key point of my letter was to share my son's story. I included a picture of him and conveyed emotion through his story. But I did not ask for sympathy, I asked my representative to be that someone who can help him because we had already tried other options."

-NICOLE DRYER, PARENT ADVOCATE

Jean's Journal Notes

How to Write an Email or Letter to Your Legislator



Sharing your rare disease story and advocacy goals with your state and federal representatives can be very satisfying. Don't worry! You do not have to be an Oprah's Book Club author to write a letter to your legislators; but, you do want it to be professional. More importantly, you want your letter to grab the attention of your legislator.

Start the letter with who you are and why you are writing. In the opening sentence clearly state your request. Let them know you are a registered voter, you are a constituent, and you are also someone with a rare disease or a caregiver.

An easy way to outline your letter is the "hook, line, and sinker" method:

- The "hook" is your opening statement. Jean's salutation and hook statement is "Dear Representative Wallace Smalls, a rare disease is hindering my ability to have another child."
- The "line" gives the details of the hook: these details are the name of your disease and other related info. In Jean's case this includes the 50-50 odds of her having a child with markers for the same rare disease.
- The "sinker" is asking the representative to help you with your specific advocacy goals. Jean's primary goal is getting more funds allocated for rare disease clinical trials in hopes that she will get the data she needs to make an informed decision about having more children.

Remember, communicating with your representatives is a marathon not a sprint. Therefore, you should expect to write many letters about why you're advocating for rare disease legislation. Use the items on this list as a guide for writing your letters.

1. Personalize your message. Tell your story and explain its relevance to your advocacy goals. If you are using a template letter personalize it with your own experience.
2. Be polite. Communicate with members of Congress clearly, concisely, and with respect. Even if you are angry, frustrated, or disappointed, be sure to use a polite tone and appropriate language.
3. Be honest, accurate, and clear. If you are including statistics or other scientific information, be sure to verify your sources. It is best to avoid lengthy questions, jargon, acronyms, and abbreviations.
4. Be of assistance and serve as a resource. Policymakers and their staffers are often overworked and overwhelmed, so offer them your assistance. They will appreciate your input and help, especially if there is no current legislation regarding your issue.
5. Express appreciation. At the close of your correspondence, be sure to acknowledge and thank the member for his or her attention to your concerns. You should also send a handwritten thank you note after an in-person meeting. Thank you notes are appropriate, and they also serve as a reminder of your conversation with the representative. Send a thank you note in a small envelope to increase the odds of it being placed on top of other larger mail where the representative will see it.
6. Ask for a response. At the close of your correspondence politely ask for a written reply regarding the representative's views on the issue or about the legislation you discussed.
7. Send a follow-up note if you do not receive a response in a few weeks.

Come on Down!

Getting a meeting with Representative Wallace Smalls was easier than Jean thought it would be, maybe he connected emotionally with the letter she sent him. The appointment was set and Jean felt like a contestant on the “Wheel of Fortune,” who had much more to gain than winning a new car.

Jean wanted to make the most of their meeting, so she wrote a short to-do list that included: pre-meeting preparation and a reminder to send a thank you card with a short summary of what they discussed. Remember, legislators work for you! This first meeting is a small, but important part of an ongoing process.

Script Rehearsal

Do your homework, review your notes, and if you have to, make a cheat sheet on your disposable coffee cup. It is important to make a credible, first impression when you meet with your representatives and their staff. Look at their personal website or your state’s website for information regarding your legislators stand on rare diseases or related issues; what committees they belong to; bills they have sponsored; and how they have voted in the past on similar issues.

Subscribe to their newsletter and monitor their activity on Facebook, Twitter and in the local media to get current news on their legislative activities. You will feel more confident about meeting with them when you know their voting record on legislation relevant to your advocacy goals. You may not know all of the details of the legislation that is important to you, but it helps to know the basics.

If numbers will help tell your story and make your case stronger, have that data ready. But, beyond the legislation and the numbers, the most important thing is to tell your story with passion and conviction.

The most experienced public figures practice what they’re going to say, even when they’ll have the assistance of a teleprompter. They know practicing a speech helps them to appear confident and prepared. While practice doesn’t always make perfect, it can help you share your story and advocacy goals in a more confident and organized manner.

You are advocating for healthcare legislation because you or someone you love is in physical, emotional, and possibly financial distress because of a rare disease. Healthcare is a very personal issue to each



one of us. You want the representative to make an emotional connection to your story.

Moved by heartbreaking images on television, usually in the wee hours of the night, people generously donate money to worthy causes all around the world. Give your representative a photo of your family or a drawing from your child. The power of meeting and seeing the faces of the people affected by their legislation can influence lawmakers to take action.

Lastly, know what you want the representative to do; this is your “ask.” State it clearly and succinctly. You can put together a summary of the issue on a one-pager to share with your representative and then give it to the rep at the end of the meeting. Representatives have many meetings throughout the day. Make it easier for them to process your information by hearing it first, and then being able to read and process it second. Also, providing a typed summary allows them to refer back to your key points and your ask after you leave.

“When I first decided to begin my journey into advocacy, I knew the first thing I had to do was research my state legislatures and get to know their opinions and views. But instead of taking this information and thinking how do their views fit my cause, I looked at my cause and figured out, based on their views, why they would care. I used research and statistics to bring my cause to life and presented a win-win situation.”

-SHARON KING, PRESIDENT, TAYLOR’S TALE

Lights Camera Action!

You'll want to feel confident and ready for your close up when the spotlight is on you. So what to wear? There are many things a meeting with your representative is not, the least of which is: a tailgate party, a day at the beach, or casual Friday at the office. Conventional wisdom is to dress appropriately for the person and the place; which in this circumstance is a government official, in a government office—enough said!

Typically, you'll have about 15 minutes to introduce yourself, tell your story, and make your ask. You should be prepared to do most of the talking during the meeting. The critical thing is to connect your ask to your story. Tell the representative how the particular legislation, funding, and/or other action you are seeking will impact you, your child, or other people with a rare disease. Also, ask to have your picture taken with the representative. Get permission to share it on social media (remember to tag them) and other materials.

That's a Wrap!

If you take a photo with your representative and have permission to share it on social media, link it to the representative's Twitter account and Facebook page. Raise awareness for your cause by including a comment about your meeting when you post the photo. Check out the Global Genes' toolkit "How to Promote Your Rare Disease Story Through Social Media" for more ways to share your rare disease story.

Whether you meet with the representative or a staff member, send a thank you note or email right away.

More specifically, send your thank you email in the evening or on weekends when legislators and their staff are less busy. When you send a thank you, also include: a summary of the meeting, your ask, and any other information you promised to share with them.

When there is an upcoming vote connected to your advocacy efforts send your representative a message as soon as possible. Be clear in your subject



line and email closing about the issue (example: "Thank you for supporting bill number 8888 on rare diseases--Please vote yes!"). Remind your representative of your concerns and that you hope they will use this opportunity to support your goals. Keep your issue on their radar and get updates on the status of legislation by touching base with your representatives regularly.

Continue to communicate with the staff members and/or the representatives throughout the year; and keep track of the representative's actions on your issues. When your representative sponsors a piece of legislation you agree with, send them a thank you email. Providing positive feedback goes a long way. If your representative is passing on opportunities to act on the issues you discussed during your meeting, make a follow-up call or write an email reminder about the importance of the issue. ■

"When you meet with your representative, remember that their time is pressed, so make it easy for them. Come prepared having done research on your representative and bring materials such as contact information, fact sheets, or in my case, a copy of the old legislation. Remember you're trying to educate them on this matter so be confident, to the point and clear about your needs. You are the expert and they work for us and they want to help, if you keep that in mind it gets easier each time."

-NICOLE DRYER, PARENT ADVOCATE

Box Office Review



Jean's experiences have taught her that her advocacy efforts and expertise are a benefit to her representatives and the entire rare disease community. Take steps to build rapport with your legislators before you need them to take action. Ultimately, you want them to see their relationship with you as a win-win; that you're as valuable a resource to them as they are to you.

To-Do List:

- ✓ Follow your representatives on social media.
- ✓ Subscribe to your representatives' newsletters.
- ✓ Monitor websites affiliated with your representatives for legislative news about healthcare and rare disease issues.
- ✓ Invite representatives to your rare disease support group and related events.
- ✓ Ask representatives and their staff to subscribe to your newsletter (if you have one).
- ✓ Send representatives information about RARE awareness days or milestones for your rare disease community.

Tips for Meeting with Your Legislator

- ✓ Do your homework. Be informed about your representative's position on rare diseases.
- ✓ Stay on message. Make your message personal, be specific, and be courteous.
- ✓ Make an outline of the issues in order of importance you want to cover.
- ✓ Practice your presentation.
- ✓ Be prompt and responsive.
- ✓ Convince your legislator that you are a reliable resource for rare disease information.
- ✓ Remember the "ask." Be clear and precise about why you're meeting and what you want the representative's help with.
- ✓ Help representatives remember the focus of your meeting, after you leave, by giving them a one-page outline of how your issue affects rare diseases.
- ✓ Take pictures. Politicians love to have their picture taken.

Tips and Tricks to Remember from Rare Advocates like You

1. There is power in numbers.
2. Ask for help. You are the constituent, government legislatures work for you. They want to hear what you have to say. They may not be able to solve all of your problems, but they do want to help.
3. Attend meetings, make phone calls, and send letters to your representatives or their staff; you never know who will take interest in your cause.
4. Don't be discouraged if someone isn't on the same page as you.
5. If it's your first time navigating the system, don't be afraid to ask questions or ask for help. The network of advisors and supporters are the building blocks of your success.
6. Know where your representatives stand in their issues and make your cause relevant to them.
7. When meeting your representative: come prepared, keep it simple, and give them a reason to care.
8. Bring your cause to life, use numbers, stories, and photographs to make it real; remind them of the financial and human cost.
9. Connect your cause to the big picture; show the social impact of how legislation affects the rare disease community.
10. Make connections and hear their feedback.
11. Nurture your relationships with your representatives; they may be your biggest supporter and champion.





It may take several attempts before the legislation you're advocating for makes it through the system. No matter the outcome, you are a winner! By building relationships, sharing your story and bringing awareness to your disease and the rare community, you are helping to move mountains. Jean knows legislative change is a marathon not a sprint, and she will continue to share her journey to advocacy at the state and federal level. ■

***"You have brains in your head.
You have feet in your shoes. You
can steer yourself any direction
you choose. You're on your own.
And you know what you know.
And YOU are the one who'll
decide where to go."***

-DR. SEUSS

Legislative Glossary

Act: a formal decision, law, or the like, by a legislature, ruler, court, or other authority; decree or edict; statute; judgment, resolve, or award.

Advocate: to speak or write in favor of or against; support or urge by argument; recommend publicly.

Amendment: a change or addition to legislation.

Bill: a form or draft of a proposed statute presented to a legislature, but not yet enacted or passed and made law.

Bicameral: a legislative body with two branches or chambers (i.e. the U.S. Congress is comprised of the House and Senate).

Bipartisan: representing, characterized by, or including members from two parties or factions (i.e. supported by Democrats and Republicans).

Caucus: a meeting of party members within a legislative body to select leaders and determine strategy that pursues its interests through the legislative process.

Committee: groups of legislators who are assigned, on either a temporary or permanent basis, to examine matters more closely than the full legislative chamber can.

Constituent: a citizen who authorizes another to act on his or her behalf, as a voter in a district represented by an elected official (i.e. you are a constituent of your local district congressional representative).

Grassroots: general population or individuals, who are the main body of membership for a group or interest.

Incumbent: currently holding an indicated position, role, office, etc.

Legislation: laws, both approved and proposed, that are decided upon by a legislative body.

Lobby: to campaign for the purpose of influencing members of a legislature to act according to the group's or individual's special interest. Lobbying can influence votes, decisions to appoint or appropriate dollars, etc. Asking any elected official outside one's own legislative district to take any action is considered lobbying.

Lobbyist: a person who tries to influence legislation, rules, regulations, appointments, appropriations, and more on behalf of special interest issues; a member of a lobby.

Rare Disease: a disease is considered rare if it has a prevalence of fewer than 200,000 affected individuals in the United States. There are approximately 7,000 rare diseases currently identified.

Senate: an assembly or council of citizens having the highest deliberative functions in a government, especially a legislative assembly of a state or nation.

Unicameral: a legislative body with a single branch (in many countries, a parliament is unicameral).

Resource Guide

Rare Disease Legislative Advocates

<http://rareadvocates.org/>

A program of the EveryLife Foundation for Rare Diseases, provides support for the advocacy of rare disease patients and organizations. This resource provides information and news about rare disease legislation, a list of members of the rare disease caucus, and a rare disease scorecard on the voting records of members in the House and Senate.

National Organization of Rare Disorders

<http://rarediseases.org/advocate/>

The advocacy page of NORD provides links to policy issues and policy statements, as well as information tailored to patients and their families, patient organizations, and researchers.

American Planning Association: Tips for Successful Legislative Meetings

<http://bit.ly/Advocates-Toolbox>

American Psychological Association: Advocacy Information

<http://bit.ly/APA-Advocacy>

National Association of Social Workers: Advocacy Resources

<http://bit.ly/NASW-Advocacy>

University of California, Riverside-Government and Community Relations: Tips for Effective Lobbying

<http://bit.ly/UCR-EffectiveLobbying>



An Overview of State Legislatures

Jean's three years of library science courses help her to make light work of researching the legislative process; but if you thought high school civics' classes were a snooze fest, you're not alone! Hopefully, your need for this toolkit and Jean's journey to advocacy story makes this information on how government lawmakers do their jobs more interesting.

United We Stand!

Fast Fun Facts:

- State legislature is the governmental body that presides over each of the 50 United States and its territories.
- The formal name varies from state to state, for example, in two states, the legislature is simply called the Legislature, or the State Legislature; in nineteen states, however, the legislature is called the General Assembly.
- In Massachusetts and New Hampshire, the legislature is called the General Court, while North Dakota and Oregon designate the legislature as the Legislative Assembly.
- Every state, except Nebraska, has a bicameral legislature, meaning that the legislature consists of two separate legislative chambers or houses.
- The smaller chamber is called the Senate and is usually referred to as the Upper House.
- Of the two chambers, members of the Senate typically represent a larger geographical area and a higher number of citizens and usually serve longer terms, generally four years.
- In 41 states, the larger chamber is called the House of Representatives.
- Five states designate the larger chamber the Assembly (California, Nevada, New Jersey, New York and Wisconsin) and three states (Maryland, Virginia and West Virginia) call it the House of Delegates.
- Members of the larger chamber usually serve two-year terms.
- Some states, like Missouri, have enacted term limits for their legislative chambers restricting the number of years either a representative or a senator can serve.

It's difficult to generalize about state legislatures, since they vary so greatly from state to state. If you are not sure who your representatives are or if you want to learn about your members' actions on rare disease legislation check out the resources at the end of this section to find more state specific information

And review the "House Names by State" in the Resource Center to see what each of the two chambers are called in your specific state. ■



How a Bill Becomes a State Law

Stately Ideas

The following represents the typical procedure for transforming a bill into law. It is important to note, however, there is some variation in the legislative process from state to state. The steps here describe the passage of general bills not resolutions.

A resolution is not an official bill but is passed with the goal of demonstrating consensus on a topic and/or for administrative purposes. The procedures for local bills or budget bills are also different. In California, the budget bill is legislation that presents the governor’s proposal for spending authorization for the next fiscal year. It is then prepared by the Department of Finance and submitted to each House of the Legislature in January (accompanying the governor’s budget). The budget bill becomes the Budget Act upon signature by the governor, after any line-item vetoes. Like California, every state legislature has a website with information about their legislative process. Consult your state legislature’s website for additional procedural guidance regarding budget bills.

Jean's Journal Notes

Face-to-Face



Really excited and nervous to meet Representative Wallace Smalls this morning!

To-do, do, do list...

- ✓ Elevator pitch is ready
- ✓ Copies of family photos
- ✓ Research notes
- ✓ Thanks for school district vote
- ✓ Firm handshake
- ✓ Spin the wheel, remember the “ask”
- ✓ Selfie with Rep. Smalls
- ✓ Breathe!

HOW A BILL BECOMES A STATE LAW



Bill Drafting

How many legislators named Bill does it take to draft a bill? If you guessed one, move to the head of the class! A legislator, named Bill, may develop an idea for a bill by listening to his constituents, some of whom are likely named Bill, and then he works to solve the issue.

A bill concept may also grow out of the recommendations of an interim committee study conducted when the legislature is not in session. The idea is researched to determine which state law needs to be changed or to be created to best solve a problem. Unfortunately, some bills may be introduced that are bad for rare disease causes. As a rare disease advocate it is equally important to educate your representatives about how a bill may negatively impact your cause.



The Advocate's Role

- As an advocate, you can visit a legislator and request that a bill be drafted to fund services, address a problem, or change a policy.
- Getting to the bill drafting phase does not typically happen overnight. It can often take months (or even years) of educating your member depending on the policy itself and the member's priorities.
- This is the main reason why building a relationship with your member is so important. You want your representative to regard you as an expert on your disease.

Bill Introduction

After a bill is drafted and before it gets the bum's rush by those who oppose it, the bill is dressed up like a rooster in a tux and introduced by way of the listed protocols:

- A legislator may introduce the bill in the body of which he or she is a member by filing it with the appropriate clerk.
- A bill is given a caption/title and a number. The bill number allows the legislator and the public to track the progress of the bill.
- Some states have bill filing deadlines, so be sure to consult with your legislator on the timing of filing and introduction of any bill.

Your state government's website may offer a way to sign up to receive alerts on specific bills. After a bill is introduced a short description of it is read aloud while the chamber is in session; this ensures that all the members are aware of the bill and its subject. This step is called the first reading, and it is the point in the process where the chamber leadership assigns the bill to committee(s).

How often a session occurs, the schedule of votes, and the process varies by state. The committees, comprised of a small group of assigned legislators, are often topic specific and standing or ad hoc in nature. The committee assignment is announced on the chamber floor during the first reading of the bill. In some states, depending on the issue, bills are assigned to several committees.



The Advocate's Role

- When favorable legislation is introduced issue a press release, write a letter, and/or post a message on your personal website, Facebook, or Twitter accounts applauding the bill's introduction.
- Likewise, if it is a bad bill, you can use the same social media tools to oppose the legislation in whole or in part.
- Advocates can also express neutrality or ambivalence on a bill if it is neither harmful nor ideal for your advocacy agenda.
- Whatever your position, as an advocate, it is important to use your voice to draw awareness to the issues you care most about. You want the legislature to recognize you as an expert and someone they can reach out to you about rare disease legislation.



Committee Process

The governor of your state appoints committee leadership, or chairs. So, pull up a 3-legged chair and stay awhile!

1. The committee process allows a bill to be thoroughly discussed and debated by the legislators, the public, and those who will be directly impacted by the bill.
2. The chair of each committee decides when the committee will meet and which bills will be considered.
3. The committee leadership often has great influence over the direction and the activities of the committees.

Committees have several options when considering a bill.

They can:

- ✓ Approve the bill language as is.
- ✓ Amend the bill language draft.
- ✓ Defeat or “kill” the bill.

If a bill is defeated in committee, the bill is generally considered “dead” for the rest of that session. For reconsideration a dead bill would need to be reintroduced during the next legislative session.

Committee chairs and ranking members play a key role in the legislative process and should be targeted in your advocacy efforts, even members who do not represent your district. Information regarding standing committees and subcommittee membership can be found on your legislature’s website.

It is also important to know that in many states bills can be assigned to multiple committees and often in both Houses of the legislature. This means that even if a bill fails in one committee, it may still make it out alive in another committee.

Rules regarding this process vary by state. So, you’ll want to learn more about this process as it applies to your state. When a bill escapes the hatchet and is passed by the committee(s) to which it was referred, the bill is available to be voted on by the entire body of members.

“If you live in a country run by committee, be on the committee.”

-UNKNOWN



The Advocate’s Role

During the committee process advocates should:

- Write to committee members and encourage a hearing on the bill(s) important to them.
- Prepare oral and/or written testimony for committee hearings.
- Notify the committee of their opposition/support or share any general information they would like to provide by checking a “for information only” box upon attendance of the hearing.
- Recruit fellow advocates and allies to show a strong presence during hearings on key legislation.

“It is important to prepare for a committee presentation! Prepare your elevator pitch and bring any helpful handouts or visuals. Having different perspectives is always helpful. I remember a young woman who has PKU came with her two roommates and they spoke on her behalf and attested to how PKU affects not only her, but also those around her. It was a powerful moment.”

-NICOLE DRYER, PARENT ADVOCATE

Floor Action: Dance-A-Thon

Before teams take to the floor for a dance marathon they are usually given the following rules: participants can only leave the floor when nature calls and they cannot fall asleep; although some marathons allow one member of the team to sleep as long as the other member continues dancing while keeping the sleeper vertical.

Floor action for a bill can also become a marathon. And when it does, it is the likely cause of why members get caught on camera snoozing while in session. The day a bill appears “on the calendar” it is open to debate and amendment by the entire body considering it. The bill is then called up for passage, and after being considered the third time and debated (eyelids getting heavy), it may be passed with or without amendment by a majority of the (awake) members to which the body is entitled.



The Advocate’s Role

- You can contact key legislators in advance of a floor vote to ask them to speak either in favor of or in opposition to a bill. And advocates may want to provide talking points for legislators who support their position, especially when amendments are being made to the bill.

Bill Is Engrossed and Enrolled

The bill, passed by the originating chamber, then goes to the office of the clerk where it is retyped, without errors or erasures, and is transmitted to the other chamber for consideration. The bill is engrossed or reproduced with any amendments inserted in the proper places. The other chamber then goes through a similar process of considering the bill.

After being passed by both chambers, the bill is enrolled (retyped) without errors or erasures, by the clerk in the chamber of origin. This step involves preparing the bill in the exact form passed by both Houses.

Conference Committee Process

The 24-hour dance-a-thon continues—“18 hours left to go, swing your partner to and fro!” If a bill is passed with amendments, it may need to return to the originating chamber in its modified form.

- That chamber can either agree or disagree with the amendments.
- If the amendments are agreed to, the bill is enrolled and sent to the governor.
- If the amendments are not agreed to, a conference committee can be requested to work out differences between the versions.
- In this case, conferees are assigned, generally comprised of an equal number of legislators from both chambers.

Once the conference committee reaches agreement, a conference committee report is prepared and must be approved by the conferees. Conference committee reports are voted on in each chamber and must be approved or rejected without amendment. If approved by both chambers, the bill is sent to the governor.

The conference committee process can vary considerably from state to state, so it is important to consult the rules for your legislature.



The Advocate’s Role

- Advocates may ask legislative leadership to appoint legislators who are champions for your cause to the conference committee.

Amendment: There are several types of amendments. A bill is subject to amendment as soon as the Senate begins to consider it. Committee amendments are considered first; then senators can offer amendments to any part of the bill, generally, in any order. Senators may debate each amendment without limit unless the Senate (1) agrees to a motion to table (kill) the amendment, (2) agrees to a unanimous consent request to limit debate on the amendment, or (3) invokes cloture, limiting debate on the amendment or on the bill and all amendments to it.

Governor's Action

Upon receiving a bill, the governor has a set number of days in which to:

- ✓ Sign the bill
- ✓ Veto it
- ✓ Allow it to become law without a signature

If the governor vetoes the bill and the legislature is still in session, the bill is returned to the chamber from which it originated with an explanation of the governor's objections. A certain number of votes are required by each chamber to override a governor's veto.



The Advocate's Role

- If a governor seems hesitant about signing a bill, you can write letters, op-ed essays, and/or issue press releases urging the governor to sign the bill.
- When a governor signs a bill, advocates may issue a press release about the signing.
- When there is a bill signing ceremony encourage other advocates and your supporters to attend.
- Show appreciation. Give an award to the legislators or other elected officials who support your cause.
- Advocates can also take action against a bad bill. Use press releases, a petition, an in person meeting, and other communication tools to ask the governor to veto the bill. ■

"Talk with your representative and share your story often - two keys to successfully cultivating champions. A representative from the House spoke on behalf of our cause on the floor even though I only remember just meeting him at a breakfast I held. I am still surprised about this but it goes to show you never know who will be interested in your cause and become a champion for you when it matters."

-SHARON KING, PRESIDENT, TAYLOR'S TALE



The following table describes the outcomes of two policy areas in three different states.

State	Bill Number	Process	Outcome
Step Therapy			
California	AB-374	<ul style="list-style-type: none"> In Assembly, read three times in committee with amendments and passed In Senate, read three times in committee with amendments and passed Bill passed on the Senate and Assembly floor 	This bill was presented in February 2015 and approved by the governor in October 2015, having passed through each part of the process with overwhelming majority.
Illinois	HB-3549	<ul style="list-style-type: none"> In House, assigned to committee, passed with short debate Passed through second and third reading, arrived in Senate In Senate, assigned to committee, currently postponed 	This bill was presented in February 2015 and while it successfully passed in the House, once arriving in the Senate, it was assigned to the Committee on Insurance, where it has been postponed since October 2015.
Florida	HB-963	<ul style="list-style-type: none"> Filed and referred to three committees in House 	This bill has been introduced to the House, while a similar bill is being introduced in the Senate. Both are currently in progress.
Newborn Screenings			
California		<ul style="list-style-type: none"> In Assembly, read three times in committee with amendments and passed In Senate, read three times in committee with amendments and passed Bill passed on the Senate and Assembly floor 	This bill was presented in the Assembly in April 2014 and passed through each phase up to approval by the governor with a unanimous vote of "ayes" each time.
Illinois		<ul style="list-style-type: none"> Introduced in Senate and passed through three readings Arrived in house and assigned to committees Bill passed in both houses 	This bill was presented in the Senate in February 2011 and successfully passed through each phase, being approved in August 2011.
Florida	CS/SB-632	<ul style="list-style-type: none"> Filed and introduced in Senate Favorable in two committees Moved to Appropriations, died here 	This bill was introduced in the Senate and passed two committees but died in Appropriations. In the House, the identical bill was introduced and was favored in two committees but died as well in appropriations.

RARE Community: Tips for Success

Nicole Dryer, PKU Parent Advocate

Nicole's son was diagnosed with Phenylketonuria (PKU), a metabolic disorder. His disorder is the reason she is a rare disease advocate. PKU requires medical formulas and a strict diet, which Nicole was able to receive for her son through the hospital and its funding program.

Unfortunately, as funding decreased this benefit was moved to insurance with some additional barriers and challenges. These new obstacles motivated Nicole to drive change for her and her community. Nicole, along with other advocates and supporters, looked to reform the current bill where the coverage cap for medically necessary food would be raised. With a supportive team and a clear goal in mind, Nicole found success on a state level and continues to work for change on the national level.

"I started my journey in advocacy because I had to fight for my son and I had to figure something out for him. I reminded myself on the journey that I had to keep fighting to give my son and others like him a voice. As a parent you don't ask for this and you feel out of control; but advocating for him gave me some control back. I felt empowered that I can do that for him."

-NICOLE DRYER, PKU PARENT ADVOCATE



* Photo provided and approved for use

Sharon King, Batten Disease Parent Advocate, President, Taylor's Tale

Sharon co-founded Taylor's Tale in honor of her daughter, who was diagnosed with Batten disease in 2006. The organization funds groundbreaking research and supports all rare disease patients through legislative action. Sharon was the catalyst for the passage of Taylor's Law, North Carolina legislation that established a state-level advisory council for rare disease housed within the University of North Carolina School of Medicine. Sharon's determination and her ability to bring this cause to life for others outside the rare disease community made her successful in her advocacy efforts. ■

"When I was advocating, I chose to advocate for the rare disease community as a whole. I used Taylor's story as a way to make this community feel real. But I didn't want my story to be a sob story or just another example of a family fighting the system. I wanted to show, with Taylor's story, how many people really exist in this community and everyone that it affects."

-SHARON KING, BATTEN DISEASE PARENT ADVOCATE,
PRESIDENT, TAYLOR'S TALE

“Who’s Who” in Your State’s Politics

Advocate: This is you! The person who is supporting, recommending, or defending your cause or policy.

Assembly Member: Any member, representative, or delegate of the legislature in states that have a Legislative Assembly.

Committee Chairperson: The person who presides over the legislative members assigned to particular legislative issues. In most cases for rare diseases it would be a Health Committee.

Conference Committee: A committee, composed of members of the majority and minority parties according to the demographics of the legislature, assigned to resolve disagreements between the two houses of the legislature.

House or Senate Clerk: An officer who keeps records and organizes affairs for the state House or Senate.

House Delegate: Any member of the legislature in states that have a House of Delegates.

House Member: Any member of the legislature in states that have a House of Representatives.

Legislator: The person elected to represent you in your district or state that makes the laws as part of the legislative body.

Legislature: Elected officials who make, change, and repeal laws for your state.

Governor: Elected official in charge of the executive branch of government in your state.

Ranking Members: The second-most senior member of a legislative committee. This term is often also used to refer to the senior-most member of a legislative committee from the minority party.

Representative: Elected official who acts or speaks on your behalf in a House of Representatives. This term can be used in both the state and federal legislature.

President of the Senate: Title given to the organizing officer who oversees the Senate.

Senator: Elected official who acts or speaks on your behalf in a Senate. This term can be used in both the state and federal legislature.

Speaker of the Assembly: Title given to the organizing officer who oversees the State Assembly.

Speaker of the House: Title given to the organizing officer who oversees the House of Representatives.

Speaker of the Legislature: Title given to the organizing officer who oversees a unicameral state legislature.

House Names by State

State	Lower House	Upper House
Alabama	House of Representatives	Senate
Alaska	House of Representatives	Senate
Arizona	House of Representatives	Senate
Arkansas	House of Representatives	Senate
California	State Assembly	State Senate
Colorado	House of Representatives	Senate
Connecticut	House of Representatives	Senate
Delaware	House of Representatives	Senate
Florida	House of Representatives	Senate
Georgia	House of Representatives	State Senate
Hawaii	House of Representatives	Senate
Idaho	House of Representatives	Senate
Illinois	House of Representatives	Senate
Indiana	House of Representatives	Senate
Iowa	House of Representatives	Senate
Kansas	House of Representatives	Senate
Kentucky	House of Representatives	Senate
Louisiana	House of Representatives	State Senate
Maine	House of Representatives	Senate
Maryland	House of Delegates	Senate
Massachusetts	House of Representatives	Senate
Michigan	House of Representatives	Senate
Minnesota	House of Representatives	Senate
Mississippi	House of Representatives	State Senate
Missouri	House of Representatives	Senate
Montana	House of Representatives	Senate
Nebraska	Legislature (unicameral)	Legislature (unicameral)
Nevada	Assembly	Senate
New Hampshire	House of Representatives	Senate
New Jersey	General Assembly	Senate
New Mexico	House of Representatives	Senate
New York	State Assembly	State Senate

State	Lower House	Upper House
North Carolina	House of Representatives	Senate
North Dakota	House of Representatives	Senate
Ohio	House of Representatives	Senate
Oklahoma	House of Representatives	Senate
Oregon	House of Representatives	State Senate
Pennsylvania	House of Representatives	State Senate
Rhode Island	House of Representatives	Senate
South Carolina	House of Representatives	Senate
South Dakota	House of Representatives	Senate
Tennessee	House of Representatives	Senate
Utah	House of Representatives	Senate
Vermont	House of Representatives	Senate
Virginia	House of Delegates	Senate
Washington	House of Representatives	State Senate
West Virginia	House of Delegates	Senate
Wisconsin	State Assembly	State Senate
Wyoming	House of Representatives	Senate

Resource Guide

Finding your local legislators, bills, reports, votes, etc.:

- The Library of Congress
<http://bit.ly/SLW-Library-of-Congress>
- National Conference of State Legislatures
<http://bit.ly/NatCongressStateLegislatures>
- Open States
www.openstates.org

Watch live broadcasts or webcasts of your state legislature:

- National Conference of State Legislatures
<http://bit.ly/NCSL-Broadcasts>

General information of governors and update on policy and issues in the US:

- National Governors Association
<http://www.nga.org/cms/govstaff>

Publications on policies and advocacy stories, opinions and updates:

- National Health Council - Medical Innovation
<http://bit.ly/NHC-Medical-Innovation>
- National Health Council - Publications
<http://bit.ly/NHC-Publications>



Why Advocating at the Federal Level Matters

Inside-Outside Voice

When children use their playground “outside voices” indoors, a teacher may admonish them to use their less headache inducing “inside voices.” Like children on a playground, Capitol Hill is a place where it is appropriate to use your outside voice. Legislative history suggests that the way funding is distributed amongst different topics and priorities, often depends on who has the loudest voice and is causing the most headaches.

If other members of Congress are not getting a headache about a problem, it’s unlikely that your representative is aware of it and, consequently, its need for funding. This is why you may have to use your outside voice or a bullhorn to educate your members about RARE legislation that affects you.

And because they are uninformed about the complex legislative or regulatory issues that patients in the rare disease community face, your representatives may assume the problem isn’t big enough to merit attention or buying a barrel of aspirin from Sam’s Club to cope with.

“When I was on The [Capitol] Hill, no one came in and talked to me about rare diseases, I worked on the Hill a long time and never once dealt with a rare disease group. If no one out there talks about it, no one knows what’s going on. Members on the Hill are in a bubble. They can’t focus on anything unless you make them focus.”

-JENNIFER BERNSTEIN, EXECUTIVE VICE PRESIDENT,
HORIZON GOVERNMENT AFFAIRS

The Orphan Drug Act of 1983

The Orphan Drug Act of 1983 is an example of the potential change that rare disease advocates can promote at the federal level. This legislation put incentives in place to motivate the pharmaceutical industry to focus their efforts on therapies for smaller disease populations.

Prior to the passage of the act, there were only 38 approved orphan drugs. Now there are more than 400 approved orphan drugs and more than 450 drugs in development. Patient advocates played a critical role in the creation and passage of the legislation. When rare disease advocates work together on issues of common interest we all win. To learn more about the drug development process, take a look at the Global Genes’ Toolkit 3-part series “Molecules to Medicine.”

Remember, your elected officials are there to represent you. They want to hear from constituents and understand what issues matter to them. That is their job and being responsive to constituents is how they keep their jobs. They are in Washington to work for you.

Rare disease patients and their families are in a unique position to tell their powerful stories and to affect change. Unlike many of the people who call on representatives, rare disease families and patients have a high level of credibility, and their stories are capable of moving lawmakers to take action.

Through advocacy you have the power to help direct funding to where it is needed or to enact laws that can change the lives of rare disease patients. Although the legislative process can sometimes take a long time, it is important to stay the course. Know that each meeting you have makes your policymaker more aware and more knowledgeable of rare diseases, and that's a big deal! ■

The Difference Between Federal & State Policymaking

From a practical point of view, there's not a lot of difference in dealing with lawmakers at the state and federal levels. Depending on the state in which you live, state legislatures may be full or part-time, but federal legislators are full-time. Nevertheless, it is important to determine whether your issue should be handled at the state level or the federal level.

Either way, you are the expert on your rare disease and building relationships with both your state and federal policymakers before you need their help is important. And consistent communication is key at both levels of government. There can be a difference in the time it takes to draft, pass, and enact a piece of legislation. Historically, it can take years to move a bill through the process and into law at the federal level; so be prepared to dig deep into your reservoirs of patience and persistence as you move through the process. ■



Determining if a Policy Topic is Federal or State

It is important to know the differences in federal legislation versus state legislation, but it is equally important to determine if your policy topic is better addressed on the federal or state level. Here are examples of each.

State Level

- State Medicaid programs.
- Insurance regulation.
- Don't seek support for federal legislation from state representatives.

Federal Level

- Increasing research funding at the National Institutes of Health.
- Addressing U.S. Food and Drug Administration regulations that could accelerate the drug development process or increase access to experimental therapies for rare disease patients these are the types of issues that should be addressed by the House and Senate.
- Don't go to your congressional representative or U.S. senator to seek support for a state bill.



Self-check Interactive: Building Relationships with Your Representatives

List 3 of your advocacy issues and which level of government (federal or state) you think is appropriate to address each issue.

Jean's Journal Notes

Capitol Action



While Jean continues to build rapport with her state representative, she has accepted that even small legislative changes require equal doses of time, patience, and aspirin. Nearly two years have passed since she and Danny decided that advocacy would be her new job. With Charlotte, now six and in school, and Danny's solar panel business on solid ground, their desire to have another baby while her health is still stable has become more urgent. So, when Jean is invited to join a group of other rare disease advocates for the annual Walk a Mile in My Genes rally on Capitol Hill, she eagerly accepts.

Jean knows part of the job of the advocate is to call for specific actions, but she has also learned that advocates play a crucial role in educating elected representatives and their staffs about:

- What it's like to have a rare disease
- The challenges patients face in getting access to treatments
- What can be done to accelerate research
- How investment in rare disease research produces benefits to patients with more common diseases, and more

Jean and other advocates agree that sharing this information is an effective way for representatives to learn how legislative and regulatory changes can impact the lives of the people they represent.

"I'm an idealist: I don't know where I'm going but I'm on my way."

-CARL SANDBURG

Understanding the Federal Process: How a Bill Becomes Law

Rock Star

Jean uses Schoolhouse Rock's "I'm Just a Bill" episode to explain to Charlotte, mommy's work as an advocate. While Charlotte doesn't really understand it, the iconic video has street cred for teaching generations of American children how a bill starts out as an idea, before it becomes a scroll of paper, rapping and chillin' on the steps of Capitol Hill, with aspirations of being a music video star.

And who knew?! Years after Schoolhouse Rock's beloved video, Vox Productions created "How a bill really becomes a law: What Schoolhouse Rock Missed." The Vox video includes explosive details that Schoolhouse Rock overlooked about bills seeking fame, fortune, and approval on Capitol Hill.

There are several stages of debate, revision, and voting before a bill becomes a law. Jennifer Bernstein, executive vice president, of Horizon Government Affairs, offered this overview:

HOW A BILL BECOMES A LAW



* Figure adapted and modified from National Association of Realtors



Drafting

An idea is generated in the form of a bill. Ideas can come from anywhere—lobbyists, Political Action Committees (PACs), grassroots political movements, or citizens. Anyone may draft a bill; but only members of Congress can bring legislation to the floor and those who do become a sponsor.

A member of Congress (either a senator or a representative) chooses to sponsor the bill.



The Advocate's Role

Before approaching members of Congress to sponsor your bill try to get community support in the form of letters or from patient organizations. Going in with community support can make it easier to show that the issue is important to the community.

Referral to a Committee

The bill is introduced on the floor of either the House or Senate, where it is referred to an existing committee or subcommittee. 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 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 the possibility of these changes while your bill is being reviewed. Once the bill is in a committee, it is placed on the official calendar. After review, passage will be determined. The committee may defer, amend, or vote on the bill.



The Advocate's Role

Regardless of which committee hears the bill or which congressional office supports your bill, you may not get movement on the bill unless you can show how the cost associated with the legislation will be covered. Find ways to offset the cost of the bill, so it is cost-neutral, before or during its passage through Congress to become a law.

Subcommittee Review

Bills can be referred to a subcommittee for a hearing. During a hearing there is an opportunity to put views on record. The views and testimony of experts, public officials, supporters, and opponents can be submitted in person or in writing.

Mark Up

Once the hearings are complete, the subcommittee may meet to make revisions and amendments before recommending the bill to the full committee. The bill can die if the subcommittee votes to not report the legislation to the full committee.

Committee Reports a Bill

Once the bill is received from the subcommittee, the full committee can have further hearings or vote on the recommendations of the subcommittee. Then the full committee votes on its recommendations to the House or Senate.

Publication of a Written Report

Once a bill is voted on to be reported, staff members prepare the report. The report details the bill's intent and scope, impact on existing laws and programs, position of the executive branch and the views of the dissenting members of Congress.

Scheduling Floor Action

The bill is then reported back to the originating chamber and is placed on the calendar.

Debate and Vote

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. It can get reintroduced, though, as soon as the new Congress starts.

Referral to Other Chamber

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.

Conference Committee

If significant changes or alterations to the bill occur by the other chamber, a conference committee is formed to reconcile the differences. If unable to reach a compromise, the legislation dies; but if they agree a conference report is prepared with recommended changes. Both the House and Senate must approve the conference report for the bill to move forward.

Final Actions

If a conference report occurs and is approved by the House and Senate, it is sent to the president to sign or veto the legislation. If the president does not sign after 10 days, it can become a law without the president's signature; but if Congress adjourns during the 10-day period, the bill is pocket vetoed and will not become a law.

Overriding a Veto or Becoming a Law

If the president approves the legislation, the bill becomes a law. The president can also veto the bill. If the president vetoes the bill, Congress can override the veto if at least two-thirds of the House and Senate vote to do so. ■





What's Happening in Government

The In-Crowd

As an advocate, you want to be in the know about government doings. Unless you desire a life of intrigue, getting intell about legislation does not, usually, require wearing a black trench coat and giving unmarked currency to a stranger on a park bench.

Thanks to the Internet, most advocates can catch up and stay current with what's happening in state and federal legislative matters while seated on a comfy sofa at home instead of a park bench. Fortunately, there is a wealth of resources online that you can use to stay in the loop about issues related to your cause.

It's a good idea to bookmark agency websites (like Department of Health) and sign up for any newsletters they offer. Listed are a few suggestions of the types of websites that make staying current on government legislation easier:

- Follow nonprofits!
- Follow news outlets!
- Follow legislators on social media!
- Google Alerts!

Understanding what is happening with federal legislation and on Capitol Hill can make you a more qualified spokesperson, caregiver/patient, and advocate. When you don't know the policy change landscape, it can be hard to understand how to get the help you need and to know what programs and services, and clinical trials exist. AND knowing what is happening on The Hill makes you an expert on the issues, which is how you want lawmakers to think of you. As your relationship with them evolves, they may even reach out to you for your opinion and advice on policy efforts! ■

"The man who wishes to keep his respect for sausages and laws should not see how either is made. With reference to the laws, a knowledge of how they are made may increase our respect for them and their makers; and if it does not, we are at least able to express our dissatisfaction in an intelligent manner."

-OTTO VON BISMARCK



My Rare Disease Week on Capitol Hill

Janet Mills, CADASIL Patient Advocate,
cureCADASIL.org

What were you lobbying for? And what goal did you want to achieve on The Hill?

I was lobbying for continued funding for the NIH and other government supported programs that can help with treatments for all rare diseases, including my own of CADASIL. I also asked my House representative to join the Rare Disease Committee. She said she would consider it.

What was successful for you in DC?

I learned that I can effectively tell my rare disease story in a short amount of time, and advocate for all rare diseases with legislators. Before this, I was unsure how I would feel doing this. I wanted to share facts and a compelling story while trying not to cry. I did get emotional, but I was able to control it enough to get my messages across.

If you could have been given any advice before going to DC your first time, what advice would you have liked to hear?

Ask to be paired with someone who has experience in lobbying. Plan what you're going to say in a short amount of time. Then speak with confidence. You DO know what you're talking about!

Any tips or advice for first-timers?

Be sure to send a thank you acknowledgment to the legislators with whom you met. They will appreciate it and will more likely remember you.

Why is important for advocates to lobby on the federal level?

I believe it is vital for our state senators and representatives to hear from their constituents in person. Once you get to know them, your cause is more likely to be viewed as important to them as well. I hope to go to DC again, as there are only a few people in the state of Wyoming who can or will go. ■

Rare Disease Week Overview

Rare Disease Week on Capitol Hill is held annually around the end of February. During the week advocates and disease groups from around the nation gather in Washington, DC, to learn about legislative procedures; advocate for their communities; meet and work with other advocates; and to share their stories. It is a unique opportunity where you can meet new advocates or learn from experienced advocates on how to fight for the Rare Disease community on the federal level. Check out the EveryLife Foundation to learn more about Rare Disease Week on Capitol Hill (<http://everylifefoundation.org/events/>).

** Photo provided and approved for use*

Federal Legislative Glossary

Appropriations bill: In order for the government to spend money on a specific program created in a piece of legislation, it must authorize the funding for it through an appropriations bill. It's not enough to get a program enacted. Money must be allocated for it to operate.

Authorization bill: This is legislation that establishes or calls for the continuation of a program, sets the parameters under which it operates, and specifies how funding for it will be used.

Budget resolution: This is created each year to describe, in broad terms, a framework for the various parts of the budget.

Caucus: A caucus is a group of members of the House, Senate, or both who share a common interest in a specific issue and who meet to discuss ways to address that. There is a rare disease caucus that involves member of the House and Senate. You should check to see if your representative is a member ahead of meeting with your representative or the representative's staff.

Cloture: In the Senate, there is no limit on debate. However, if at least 60 members vote on cloture, it can end a debate and bring a matter to a vote.

Conference committee: This is made up of appointed members of the House and Senate to resolve differences between versions of a bill passed by both chambers. Once resolved, the final bill must be passed by each chamber.

Co-sponsor: A Senator or representative who adds his or her name to the list of supporters of a specific bill.

Fiscal Year: The United States government operates, from a financial point of view, on a year that begins October 1 and ends September 30.

Mark-up: This is the process of a committee or subcommittee reviewing, debating, amending, and voting on a bill. Once it passes out of this process, it goes to the floor of the House or Senate for a full vote.

Scoring: A process conducted by the Congressional Budget Office to determine the fiscal impact of a piece of legislation.

Resource Guide

The Congressional Record

<http://bit.ly/CR-DailyDigest>

Provides a daily digest of the proceedings of the House and Senate. You can use this website to find comments on the floor made by your representative.

House.gov

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

The website of the U.S. House of Representatives. It provides links to committees, members, and legislation.

Senate.gov

<http://www.senate.gov/index.htm>

The website of the U.S. senate. It provides links to committees, members, and legislation.

The Library of Congress

<https://www.loc.gov/>

A rich resource of information. You can use this website to access Congressional Research Service Reports on pending legislation. These are unbiased analyses that in the past were available only to congressional staff.

Federal Register

<https://www.federalregister.gov>

Is billed as the “daily journal” of the United States government. It provides a way to track proposed regulations and to learn about public hearings and opportunities for public comment. Information is organized by major topics and includes an area on health and public welfare where issues pertinent to the rare disease community would likely appear.

Congress.org

<http://bit.ly/VisitingCapitolHill>

Has an advocacy section that provides a useful introduction to first-time advocates. Although it is written for a broad audience, members of the rare disease community will find it a useful resource.

The Hill

<http://thehill.com/>

Is a publication covering the daily developments of national politics with a special eye on policy.

Politico

www.politico.com

Is a publication about the national political scene with a focus on the politics driving the issues and the players.

Federal Register

<https://www.federalregister.gov>

Provides a way to track proposed regulation. Information is organized by major topics and includes an area on health and public welfare where issues pertinent to the rare disease community would likely appear.

The Capitol.Net

<http://thecapitol.net/>

Provides knowledge on the legislative and executive branches of government and how to work with them. This site is a great resource of terms and glossaries for the first-time advocate.

Resource Guide Continued

Congress.gov

<http://congress.gov>

Includes the text of bills, as well as where they are in the legislative process. At this website you can also gain access to the Congressional Record (<https://www.congress.gov/congressional-record#daily-digest-house-of-representatives>), which provides a documentation of the proceedings of Congress, including remarks made by your representative. You can also use this resource to find your congressional representative or senator's website, as well as track the activity of individual committees. Each member of the Senate and House of Representatives maintains their own websites. Their websites are an easy way to learn about your representatives and to track your members' legislative activity.

House Energy and Commerce Committee

<https://energycommerce.house.gov/>

Is one committee that rare disease advocates will want to follow. This committee is responsible for overseeing health related legislation including matters that concern the National Institutes of Health and the Food and Drug Administration. A link on the home page allows you to sign up for email updates from the committee.

The Senate Committee on Health, Education, Labor & Pensions

<http://www.help.senate.gov/>

Is the counterpart to the House Energy and Commerce Committee in that health-related legislation would likely begin its life here. The website offers agendas, legislative summaries, information about hearings, and more.

Rare Disease Legislative Advocates

<http://rereadvocates.org/>

This resource provides information and news about rare disease legislation, a list of members of the rare disease caucus, and a rare disease scorecard on the voting records of members in the House and Senate.

Google

<https://www.google.com>

It's easy to forget about the power of Internet searching, but Google is very reliable for finding information about your representative or about a particular piece of legislation. Remember to make use of this popular resource.

Video Resources

Schoolhouse Rock: I'm Just A Bill

<http://bit.ly/SchoolhouseRock-Bill>

A child-friendly, animated video that explains in very basic terms how a bill becomes a law.

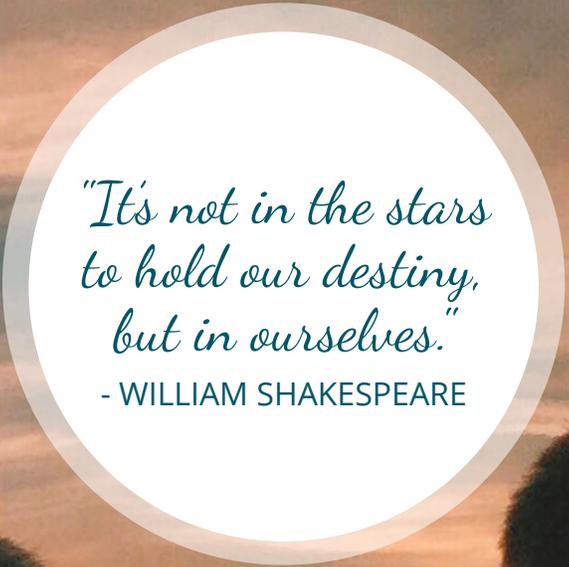
Vox: How A Bill Really Becomes A Law: What Schoolhouse Rock Missed

<http://bit.ly/VOX-SRMissed>

A animated breakdown of the classic Schoolhouse Rock: I'm Just a Bill cartoon that lays out more details of how a bill becomes a law on the federal level.

**Welcome to
Something Bigger!**





*"It's not in the stars
to hold our destiny,
but in ourselves."*

- WILLIAM SHAKESPEARE

You are a part of something bigger—THE RARE COMMUNITY! Building connections within your specific disease community is absolutely the most vital part of your efforts. Members will tell you that the depth of the connection they feel with others in their rare disease community is hard to describe. There is an innate sense of closeness and empathy that comes with a rare disease diagnosis.

Like we said in the beginning you are not alone. You are part of an estimated 30 million Americans and 350 million people worldwide that are affected by a rare disease. While the diseases and the symptoms may be different, people in the rare community often share the same challenges and fight for the same changes. This is a powerful thing! Rare is everywhere and is frankly not-so-rare.

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Let's Stay Connected!

Global Genes is invested in collecting and then sharing best practices and lessons learned as well as devoted to celebrating successes of the rare disease community.

Submit questions, feedback and your action steps here:
www.globalgenes.org/toolkitfeedback

Follow us @globalgenes



If you are interested in contributing to a future toolkit topic, please email:
advocacy@globalgenes.org.

You can view upcoming toolkit topics and access past titles here:
www.globalgenes.org/toolkits

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www.globalgenes.org/give



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