



## Health Policy Tool Kit

Welcome to the Children's Cardiomyopathy Foundation Health Policy Tool Kit! The purpose of this tool kit is to prepare you for your upcoming visit to Capitol Hill. The information in this document will educate, inform, and encourage you to become more knowledgeable about the federal legislative process and become involved in health policy advocacy. Please use this information to take action to support children with cardiomyopathy and to improve the nation's health care system.

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## **Introduction**

**Welcome to the Children’s Cardiomyopathy Foundation (CCF) Health Policy Tool Kit.** The purpose of this tool kit is to educate and inform CCF members about health care issues, public policy, and the legislative process; encourage involvement in our government at all levels; and affect positive change in health policy for all children and families affected by cardiomyopathy.

This tool kit has been developed as an introductory guidebook that outlines the role of advocates in health policy, explains the public policy and legislative process, and provides tips and resources regarding how you can help bring about change.

Getting involved in the public policy process may seem intimidating, confusing, or just outside the realm of what you do. However, we believe that you will find—through the information provided in these pages—that having an impact on our nation's policymaking process can be easy, fun, and effective!

We hope you find this tool kit useful and will share it with your family, friends, and colleagues. Can one person help bring about change? Just think of the woman who started Mothers Against Drunk Driving (MADD) or the family that brought about Megan's Law. The creator of MADD lost a child to a drunk driver. She developed a grassroots movement that changed how the United States addresses drinking and driving. Megan's Law, which requires sex offenders to register and notify communities where they live, is another example of how one family turned tragedy into triumph. The family members' efforts after they tragically lost their daughter resulted in changes in both state and federal policies on public notification and potential risk. Elizabeth Smart’s father decided that no family should experience what his family did when she was abducted, so he took his idea for a nationwide Amber Alert system straight to the White House and President George W. Bush took action. Can one person bring about a result in one law? Absolutely!

**We appreciate your interest and thank you in advance for becoming involved in advocacy and health policy issues.**

## Chapter 1

### Advocacy Is Essential to Supporting and Advancing CCF's Priority Policies and Programs

**During the past 20 years, health and consumer-based organizations have incorporated public policy and advocacy into their missions and principal activities.** They have seen the gains that can be attained through such initiatives. For example, the HIV/AIDS activism of the 1980s and the breast cancer movement of the 1990s are well-known, tangible examples of what organizations and communities can achieve if they choose to allocate human and financial resources to affect public policies. Both causes have benefited from increases in research and programmatic funding for efforts to reduce and prevent the incidence, morbidity, and mortality of breast cancer and HIV/AIDS. For health issues to begin to receive the attention, public policy response, and funding they deserve, parents, guardians, loved ones, friends, and patients must engage in proactive and aggressive advocacy efforts to help drive the national health agenda.

- Policymakers and elected officials can positively and negatively influence issues that affect treatments, research prevention, early detection, etc.
- Lawmakers regularly make decisions that have an impact on patients, nurses, physicians, health insurers, hospital administrators, and researchers and these decisions may be made with limited substantive knowledge and understanding of the people and systems they are affecting.
- Your voice matters and we need your help to make a difference for children affected by cardiomyopathy.

Members of Congress are most responsive to people from their own states and communities, and they must hear from people that they represent about their priorities and concerns. Without hearing directly from those affected by this disease about priority problems and recommended solutions, policymakers either will fail to address such concerns or use information and expertise provided to them by others. Some of their sources may not share the views of the cardiomyopathy community. Policymakers must have your input, so they are aware of the needs in their communities and the ramifications of changes in policy. **A well-informed, articulate, passionate parent or patient can be a valued resource to elected officials and their staff, can raise issues of importance, and can help craft and implement necessary solutions.**

## Chapter 2

### What Is Health Policy Advocacy?

**Advocacy** is defined as the support or defense of a cause and the act of pleading on behalf of another person. Parents engage in advocacy every day on behalf of their children.

#### Turning Outrage into Action

Every day, people have experiences that are frustrating, unbelievable, or so outrageous that they think, "How can this be? There ought to be a law!"

Health policy advocacy means channeling this sense of outrage about inadequately conceived laws, policies, and regulations or about the absence of a law when the need for one is clear.

- Advocates let policymakers know what they, as citizens and constituents, believe elected officials should do.

Despite its simple definition, advocacy is multifaceted, and the types of advocacy activities are varied and diverse. The good news is that **health policy advocacy doesn't require new skills; it just involves applying existing ones in a new context.**

So, now that we have convinced you that advocacy can be easy and make a difference in the outcome of our nation's policy discussions, we will move forward into the nuts and bolts of the policymaking process and discuss how you, as someone affected by cardiomyopathy, can get involved.

#### Advocacy is a Right and a Responsibility

The McCormick Tribune Freedom Museum poll found that Americans' knowledge of television shows such as "The Simpsons" and "American Idol" far surpasses their familiarity with the First Amendment.

Only one of the 1,000 adults polled in the telephone survey could name all five freedoms granted under the First Amendment. Yet more than one in five (22 percent) could identify all five major characters in Matt Groening's cartoon family.

The First Amendment of the Constitution guarantees freedom of speech, the press, and religion, as well as the rights to peacefully assemble and **to petition the government for a redress of grievances.**

Think about it – the U.S. Constitution grants us the right to tell our elected officials our concerns and request them to take action to address them!<sup>1</sup> If we took the time, we all could come up with a list of grievances we would like our public officials to address.

**Remember: Policymakers work for the citizens.** Your tax dollars pay their salaries and for their health insurance, retirement benefits, and travel. After all, you are held accountable by your employers. Therefore, you have every right to hold them accountable for their actions, tell them what you want them to do, and give them feedback on how you think they are doing at their jobs. Entire systems are in place in Congress for the recording of your opinions. The ultimate job review you can give your public officials is by voting—either returning them to office or ending their service.

In the United States we have a participatory democracy and representative government. **Becoming involved is not only a right but also a responsibility.**

<sup>1</sup> United States Constitution, 1st Amendment, "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the government for a redress of grievances."

### Chapter 3

#### Advocacy Is Easy and Effective – Debunking the Myths

Numerous "myths" of advocacy exist that preclude people from becoming involved in the policymaking process, including the misperceptions that it takes a lot of time, doesn't make a difference, and requires great expertise. You may have questions, concerns, or preconceived notions about advocacy and health policy. To that end, we have compiled the 10 most pervasive advocacy myths and debunked them one-by-one.

<p><b>1. I am too busy—there is not enough time in the day.</b></p>	<p>Sending an email takes less than five minutes – only involves a few clicks – and does have an impact. Just look up your Member's Web site at <a href="http://www.house.gov">www.house.gov</a> or <a href="http://www.senate.gov">www.senate.gov</a> to locate their email address or an email form on their website. Remember: if you do not get involved, no one else will on your or your child's behalf.</p>
<p><b>2. I am a parent, not a lobbyist.</b></p>	<p>Perfect! Members of Congress are more likely to listen to you – you are an expert in what your family faces on a daily basis. You can provide the Member and staffers with substantive and valid information, as you know first-hand what occurs in today's health care system and what is needed to improve it. You are a "legitimate constituent voice" – not a hired gun.</p>
<p><b>3. Why should I bother? It doesn't seem to make a difference. I have written before and not received a response. When I have received a response, the letter didn't address the issue I wrote about or I totally disagreed with the views expressed.</b></p>	<p>It absolutely makes a difference, even though it may not feel that way. Offices count calls, emails, faxes, and mail. Staffers log opinions that are expressed and provide regular reports on constituent communications to the Member of Congress. If you have written and not received a response, write or call and let the office know. Sometimes, with the volume of mail, letters can get lost. Also, if you disagree with the views expressed in a response letter, write again and politely repeat your request and rationale and indicate you are disappointed in the Member's position on the issue. Usually if you bring it to their attention you get a prompt response.</p>
<p><b>4. My Member is a lost cause, doesn't sit on the relevant committee, or doesn't care about health care.</b></p>	<p>It is essential to weigh-in and go on record with your Member(s) of Congress. You never know when an issue will resonate with them or their staffers. Your stories will be very compelling.</p>
<p><b>5. My concerns or issues of priority are not being discussed in Congress.</b></p>	<p>Maybe that is because no one is writing/calling about them. You, your colleagues, and your patients can help elevate an issue to the national agenda by communicating with your policymakers about it. Sometimes it takes a grassroots movement to garner Congressional attention. People writing about their HMO horror stories stimulated the development of the "Patients' Bill of Rights."</p>
<p><b>6. I am not an expert in the issue you are asking me to weigh-in on.</b></p>	<p>You are an expert and understand first-hand what your child and cardiomyopathy patients like him or her face every day. Just be honest about your experiences.</p>

<p><b>7. The process is intimidating. I don't understand what a substitute amendment is, am unclear on how conference committees work, and cannot remember what a pocket veto means.</b></p>	<p>The details and nuances of the federal policymaking process are difficult to follow, but you do not need to know them all. Do not worry if you cannot remember 4th grade civics – no one can, not even Members of Congress. Just know who represents you in Congress – two Senators (<a href="http://www.senate.gov">www.senate.gov</a>) and a Representative in the House (<a href="http://www.house.gov">www.house.gov</a>), and read the information in this tool kit and you will be all set!</p>
<p><b>8. I am a Republican, and my Member is a Democrat. I am a Democrat, and my Member is a Republican.</b></p>	<p>Everyone consumes health care. Do not worry about your party affiliation; just identify yourself as a constituent and a parent – these are suitable qualifications for your views to be treated with respect.</p>
<p><b>9. I've done my part to support the cause. I've written and called before about cardiomyopathy issues and requested my Members' support. I don't need to write/call/email or meet with them again.</b></p>	<p>Every day Congress makes decisions that affect you. Writing, calling, emailing, or meeting with your policymakers regularly is essential. Each year Congress determines funding levels for the coming year. Nowhere is the adage – “the squeaky wheel gets the grease” – more true than Washington D.C. Policymakers often claim the reason for their inaction on matters is that they aren't “hearing (enough) from home” on the issue. Don't give them an excuse!</p>
<p><b>10. I cannot make it to Washington to meet with my Member.</b></p>	<p>Members and staffers will tell you that developing a relationship with your policymakers and their staffers “back-at-home” is more effective since you can see them in your own community. Coming to Washington is effective but communicating from and at home is even better. Emails, calls, and faxes from you to your Members of Congress sent to their Washington office are great. Visiting the district office or attending a town hall meeting is terrific.</p>

## Chapter 4

### A Quick and Simple Refresher on United States Civics

For most of us, the last time we really needed to understand the process of how a bill becomes a law was in our elementary school civics lessons. In fact, most Members of Congress and their staffers don't have much more formal education about the process than that. You do not need to have a PhD in political science to become involved and bring about change in the public policy process. You only need to understand the basics. Although the information contained here uses the U.S. Congress as the example, most state legislatures are structured and function similarly. For more specifics on state public policy processes, visit the National Conference of State Legislatures at [www.ncsl.org](http://www.ncsl.org).

#### The United States Congress

The U.S. Congress consists of two bodies, called chambers or houses: the Senate and the House of Representatives.

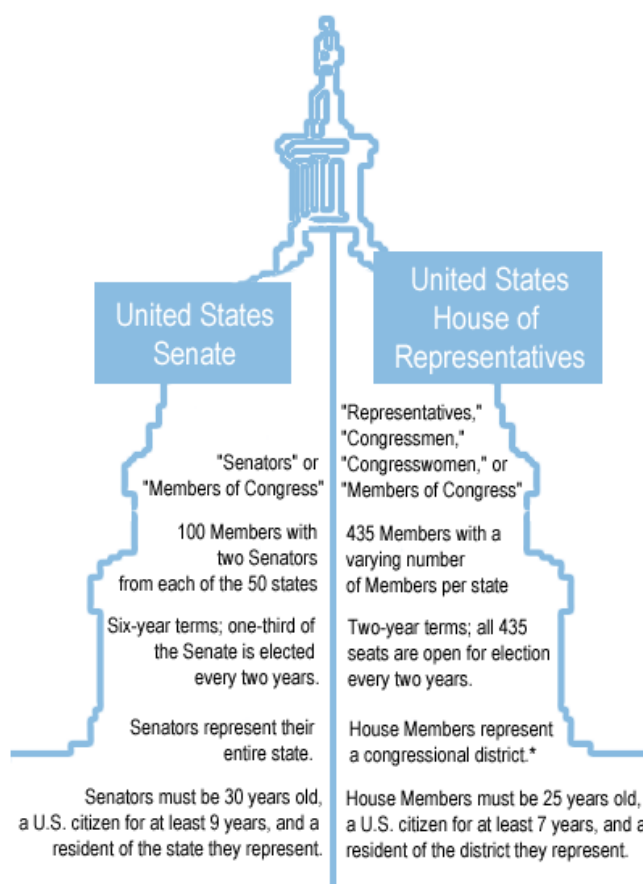
- National elections are held every two years on the first Tuesday of November in even numbered years (2012, 2014, 2016, etc.).
- The next national election will be held in November 2014.
- In every national election there are 33 Senate seats whose six-year terms are expiring and all 435 seats in the House of Representatives are open for election.<sup>2</sup>
- Elections held in non-Presidential election years (e.g., 2010, 2014) are known as "mid-term elections" because they are held in the middle of a President's four-year term.
- The next Presidential election is in 2016.

Congressional districts for each state are created by the state legislature and based on population. Districts may be parts of a city, multiple cities or towns, or entire counties. The total number of House Members per state is determined by the Federal Census and is reviewed and changed every 10 years when the new census results are available. The calculation to determine the number of Representatives per state is made by dividing 435 (the total amount of Representatives set by the Constitution) into the total U.S. population. Alaska, Delaware, Montana, North Dakota, South Dakota, Vermont, and Wyoming do not have enough people to qualify for one Representative; the Constitution addresses this by stating that every state must have at least one. Representatives from these states are referred to as "At-Large."

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<sup>2</sup> Every six years, 34 Senate seats are up for re-election.





Every person in America (except residents of the District of Columbia) is represented in the U.S. Congress by two Senators and one Member in the House of Representatives. In other words, everyone has a "Congressional delegation" consisting of three Members: two Senators and one Representative.

### Timing and Schedule

A "new Congress" begins the January following a November election, lasts two years, and has two sessions. For example, the first session of the 113th Congress began in January 2013 and the second session of the 113th Congress will begin in 2014. When policymakers are working in Washington, D.C., Congress is referred to as being "in session." When policymakers are in their home states and districts meeting with their constituents and conducting business locally, Congress is referred to as being "out" or "on recess." Although the Congressional schedule is different each year, some regularly scheduled breaks, or recesses, occur each year. These usually coincide with special weekends, holidays, and the election cycle. Typical Congressional recesses fall during the following holidays: Martin Luther King Day, President's Day, Easter, Passover, Memorial Day, the Fourth of July, Labor Day, and Thanksgiving. Additionally, Congress is out usually the entire month of August.

### Leadership

Because the United States principally has a two-party system consisting of Democrats and Republicans, each chamber has two groups: a majority party and a minority party. The party with the greatest number of Members in a chamber is considered the "majority" party and the party with the smaller number of Members is called the "minority" party. The few Members of Congress who are not affiliated with a national political party and identify themselves as "Independents," typically choose one of the two parties to affiliate with for organizational purposes.

112th Congressional Make Up <sup>3</sup>	
United States Senate	United States House of Representatives
53 Democrats 47 Republicans 2 Independents who caucus with the Democrats	232 Republicans 200 Democrats 3 Vacancies
Senate Leadership	House Leadership
Senate Majority Leader Harry Reid (D-NV) Senate Majority Whip Richard Durbin (D-IL)  Senate Minority Leader Mitch McConnell (R-KY) Senate Minority Whip John Cornyn (R-TX)	Speaker of the House John Boehner (R-OH) House Majority Leader Eric Cantor (R-VA) House Majority Whip Kevin McCarthy (R-CA)  House Minority Leader Nancy Pelosi (D-CA) House Minority Whip Steny Hoyer (D-MD)

Like most large organizations, Congress does much of its work by committee. Most Members of Congress are assigned to one or more committees. Typically, committee assignments, leadership positions, and party ratios remain the same throughout the two-year session of Congress. However, occasionally, Members retire, die, or are indicted, which then requires changes to be made. The following committees have jurisdiction over the majority of programs and issues of importance to health care:

Key Committees	
United States Senate	United States House of Representatives
<b>Appropriations Committee</b> Labor, Health and Human Services, and Education (LHHS) Subcommittee	<b>Appropriations Committee</b> Labor, Health and Human Services, and Education (LHHS) Subcommittee
<b>Health, Education, Labor Pensions (HELP) Committee</b>	<b>Energy and Commerce Health Subcommittee</b>
<b>Finance Committee</b> <b>Health Subcommittee</b>	<b>Ways and Means Committee</b> <b>Health Subcommittee</b>
	<b>Education and Labor Committee</b>

<sup>3</sup> As of March 4, 2013.

## Chapter 5

### Key Types of Legislation

In general there are two main types of legislation: authorizing and appropriations legislation.

An **authorizing bill or authorizing legislation** provides a federal agency with the general authority to conduct programs and obligate funds. This type of bill does not guarantee funding; rather, Congress needs to appropriate funds as part of the annual appropriations process. For example, Congress enacted the Nurse Reinvestment Act in August 2002 to support loan repayment, scholarship, and other Nursing Development Workforce programs. This legislation “authorizes” the Health Resources and Services Administration (HRSA) within the U.S. Department of Health & Human Services (HHS) to operate such initiatives. In other words, by enacting this legislation Congress authorized – or permitted – funding to be allocated by Congress over the course of five subsequent fiscal years to support this effort.

However, unless Congress provides a specific allocation each year for the Nurse Reinvestment Act programs in the **appropriations bill** that contains funding for HHS and HRSA, the nursing workforce programs will not receive any resources for the coming year. Just because the funding has been authorized does not mean it will be appropriated. There are numerous programs that have been created by an Act of Congress but have failed to secure appropriations for their implementation and support. In these cases, in particular, it is critical for advocates to take action to help secure much-needed funding to have important programs enacted and implemented.

**An analogy:** an authorizing measure is like being approved to utilize the services at your bank but not actually being given any checks to draw funds out of your checking account. An appropriations measure is the actual check being written to draw funding out of the U.S. Treasury and allocated to particular agencies and programs.

The information in Chapter 6, “How a Bill Becomes a Law,” applies generally to both authorizing and appropriations legislation.

## Chapter 6

### How a Bill Becomes a Law

The chief function of Congress is the making of laws. While Congress is in session, any Member of Congress can draft and introduce a bill. Below are the specific steps a bill goes through to become a law.

**Step 1: Bill language or legislation is drafted.** An individual Senator or Representative may develop original legislation. The President of the United States, a private citizen, a business or trade association, or an organization may request that a bill be prepared and may even assist in drafting the proposed legislation.

**Step 2: Legislation is introduced.** A bill is introduced in the Senate by a sponsoring Senator or in the House by a sponsoring Representative and assigned a number. In the Senate, all bills start with "S." followed by a number, e.g., S. 1234; all bills in the House start with "H.R.," e.g., H.R. 5678. The bill's title, sponsors and cosponsors (i.e., Members who join with the sponsor in official support of the measure), and introductory remarks are published in the *Congressional Record*, an official account of the daily proceedings of the House and Senate chambers (<http://www.gpoaccess.gov/crecord/index.html>).

**Step 3: Legislation is referred to committee and subsequently to subcommittee.** The Secretary of the Senate and the Clerk of the House assign, or refer, a bill to the committee(s) with the appropriate jurisdiction. Senate and House committees have subcommittees, or smaller groups of Members who focus on policy matters in particular issue areas. A bill usually is referred to the subcommittee with the most appropriate jurisdiction under the committee rules. For example, a bill that assures private health insurance coverage of colorectal cancer screening might be referred to the House Energy and Commerce Committee and subsequently referred to its Health Subcommittee.

**Step 4: Subcommittee hearing and mark-up are held.** Subcommittees have the option to hold hearings on a bill and invite testimony from public and private witnesses. Individuals or organizations may make their views known by testifying before the subcommittee, submitting a written statement to be included in the official record of the hearing, or disseminating a press statement or other materials at the hearing. Once subcommittee hearings are completed, the subcommittee usually meets to "mark-up" a bill; that is, to consider changes and amendments to the text of the legislation. The subcommittee Members literally go through the measure, line-by-line, "marking it up" with the adopted changes. The Members then vote on whether to report the bill favorably to the full committee. If not favorably reported, the bill usually dies.

**Step 5: Full committee hearing and mark-up are held.** Once a bill is reported to the full committee, or, if the subcommittee has abdicated its jurisdiction and deferred to the full committee, the full committee may repeat any or all of the subcommittee's procedures, which include hearings, mark-up, and a vote. Advocates again have the opportunity to testify or otherwise express their views, as at the subcommittee level. If the committee votes favorably on a bill, it is "reported" out of committee and sent, along with the committee report, to either the full Senate or full House for consideration by all of the Members in the chamber. The committee report includes the origin, purpose, content, impact, and estimated cost of the legislative proposal.

**Step 6: Floor consideration and full chamber vote are held.** Once the bill is reported out of committee, it is placed on the calendar for consideration and additional debate. Prior to reaching the House or Senate floor, Members of the leadership in the chamber discuss and determine the parameters for debate (e.g., how long the debate will last, how many amendments may be offered). Once the debate parameters have been determined, the measure is brought before the chamber for consideration by all the Members. At this stage, the bill may be amended, voted up or down, referred back to committee, or tabled. Should either of the two latter options occur, the bill typically dies. A majority vote (half of all Members present voting in the affirmative, plus one) is necessary for the legislation to be passed, or enacted, in a chamber.

**Step 7: Legislation is considered in the other chamber.** After a bill is passed by the Senate or House, it is referred to the other chamber. Each chamber considers the legislation under its respective parameters and rules. (For more information about how each chamber handles legislation, visit [www.house.gov](http://www.house.gov) or [www.senate.gov](http://www.senate.gov).)

**Step 8: Legislation is sent to conference committee.** To be sent to the President for enactment into law, a bill has to pass both the House and Senate in *identical form*. If differences exist between the Senate and House versions of a bill, an ad hoc "conference committee" usually is appointed by the President of the Senate and the Speaker of the House to resolve the differences. Conference committees usually are composed of Senators and Representatives on the committees that originally considered the legislation. If conferees are named, they meet to discuss and debate the differences between the two bills and develop uniform legislation. However, if the conferees are unable to reach agreement, the bill dies. If the President of the Senate and the Speaker of the House fail to name "conferees" to the conference committee, the bill dies.

**Step 9: Uniform legislation is considered by the House and the Senate.** If the conferees reach agreement on the bill, the revised bill, now a uniform measure, and a conference report are sent back to the Senate and the House for a final vote. For the measure to be sent to the President, both the Senate and House must approve the compromise conference committee bill (without any modifications) by a majority vote.

**Step 10: The legislation is sent to the President.** If the bill has made it this far it then goes to the President for consideration. The President has four options: (1) sign the bill, which will make it a law; (2) take no action for 10 days while Congress is in session, which also will make it a law; (3) take no action either when Congress is adjourned or at the end of the second session of a Congress, which will result in the bill being "pocket vetoed" and therefore dying; or (4) veto the bill. If the President vetoes a bill, Congress may attempt to override the veto. This requires a two-thirds vote by both the Senate and House. If either chamber fails to garner a two-thirds vote, the bill is dead. If both succeed, the bill becomes law.

Thousands of legislative proposals are introduced in the Senate and House during each session of Congress. However, typically fewer than five percent of the bills introduced in Congress are enacted into federal law. Bills not acted upon over the course of the two-year session of Congress die at the end of the session, and must be reintroduced in the next session of Congress. Any cosponsors of the bill must be re-collected when the measure is reintroduced.

The following two charts illustrate varying ways bills may go through the legislative process.

#### Example 1: Nurse Reinvestment Act in the 107th Congress

*The Nurse Reinvestment Act is an authorizing bill. It creates new programs, expands existing programs, and grants authority to the Health Resources and Services Administration within the U.S. Department of Health and Human Services regarding activities in which it can engage to address the nursing shortage. The legislation does not contain any funding, so separate appropriations are necessary to support the programs and activities contained in the new law.*

House	Senate
H.R. 3487, the "Nurse Reinvestment Act," was introduced in the House of Representatives.	S. 1864, the "Nurse Corps Recruitment Act," was introduced in the Senate.
The House passed H.R. 3487 by voice vote on December 20, 2001 at the close of the first session of the 107th Congress.	The Senate passed S. 1864 by unanimous consent on December 20, 2001 at the close of the first session of the 107th Congress.

The two versions of the legislation differed in many aspects. A formal conference committee never was convened, but Members and staff of House and Senate Republicans and Democrats met for approximately six months in the beginning of the second session of the 107th Congress to craft a single, consensus measure on which all Members could agree. In late July 2002, a revised, consensus version of the "Nurse Reinvestment Act" (H.R. 3487) was developed and sent to both chambers for consideration.

Upon receipt of H.R. 3487 from the Senate, the House agreed to the measure by voice vote on July 22, 2002.

The Senate passed the consensus version of H.R. 3487 by unanimous consent on July 22, 2002. The measure then was sent immediately to the House for consideration.

H.R. 3487, the "Nurse Reinvestment Act," was sent to the White House on July 30 for presentation to the President. The President signed the measure into law on August 1, 2002, and it became Public Law No. 107-205. Subsequently, funding has been included in each of the LHHS bills from fiscal year (FY) 2003-FY 2013 to support federal nursing development programs.

### Example 2: Patients' Bill of Rights in the 107th Congress

*"Patients' Bill of Rights" legislation seeks to ensure patients – particularly those in Health Maintenance Organizations (HMOs) – have access to and coverage of certain types of care and health care providers. Examples of such guarantees or "rights" include: direct access to specialists; continuity of care protections so that patients will not have to change doctors in the middle of their treatment; and access to a fair, unbiased, and timely internal and independent external appeals process to address health plan grievances.*

#### House

The House passed H.R. 2563, the "Bipartisan Patient Protection Act," by a vote of 226–203 on August 2, 2001 (during the first session of the 107th Congress).

#### Senate

The Senate passed S. 1052, the "Patients' Bill of Rights/ Bipartisan Patient Protection Act," by a vote of 59–36 on June 29, 2001 (during the first session of the 107th Congress).

Although identical in many aspects, the House bill contained provisions regarding patients' right to sue their health maintenance organizations (HMOs) that differed from those in the Senate-passed bill. Therefore, the bills needed to be sent to a conference committee so a single, uniform measure could be crafted. For the legislation to be sent to the President for enactment or veto, both the House and Senate must pass an identical version of the "Patients' Bill of Rights" legislation.

The House named conferees – Members of the House who serve on committees with jurisdiction over the legislation. These conferees were to be the House's Democratic and Republican Representatives to the conference committee.

The Senate did not name conferees. Unless conferees are named by both chambers, a conference committee cannot be convened.

Therefore, because a conference committee never was convened, both versions of the "Patients' Bill of Rights/Bipartisan Patient Protection Act" died at the close of the 107th Congress, which ended in November 2002. If consensus had developed, the new uniform bill would have been sent back to both the House and Senate for a final up-or-down yes/no vote, with no amendments allowed. If passed by both chambers, the measure would then have been sent to the President for his signature or veto.

## **Chapter 7**

### **How to Get Involved in Health Policy Advocacy**

If you can write a letter, send an email or leave a brief phone message - just like you do for your friends or family - you can "do" health policy advocacy. It's that easy. Being involved in advocacy is important - if elected officials do not hear from the cardiomyopathy community, they and their staff will not be aware of our issues or concerns. With a brief phone call, email note, or letter, parents and others affected by cardiomyopathy can educate Congress about the issues impacting our children.

You have already taken the first step in becoming a health policy advocate. After reading this manual you can continue to take action on priority issues by visiting the Children's Cardiomyopathy Foundation website.

You also can continue to reach out to your Members of Congress. Continue to build relationships with the health staff in those offices. Consider visiting the district or state offices of your Members when you return home to build relationships at the local level. Offer yourself as a resource to the offices on health care issues.

If you are not registered to vote, the League of Women Voters Web site allows men and women to register online at <http://www.vote411.org/>.



## Chapter 8

### How to Communicate With Members of Congress

**Many ways to communicate with policymakers exist: letters, postcards, email, phone calls, faxes, and face-to-face meetings.** Advocates often wonder which method is most effective and whether all are counted equally. Each Congressional office has its own calculus and system for handling and “counting” different communications. Generally, each policymaker gets a regular report from staff regarding how many letters, postcards, emails, phone calls, and faxes have been received on various issues and what positions constituents are advocating. No matter what method you use, the most important thing is to ensure your voice is heard.

**All offices handle constituent communication differently. Therefore, you might want to call each of your Members' offices and inquire on their preferred method of constituent input.**

For the most part, the information below and the tips and guidelines found in the next chapter apply to all forms of written communication, including faxes, emails, and regular letters.

#### Proper Forms of Address for Members of Congress

##### Members of the United States House of Representatives

The Honorable [First Name Last Name of Member of Congress]  
 United States House of Representatives  
 Washington, DC 20515

Dear Representative [Last Name of Member]:

##### United States Senators

The Honorable [First Name Last Name of Member of Congress]  
 United States Senate  
 Washington, DC 20510

Dear Senator [Last Name of Member]:

Also, you can reach your Members of Congress in the following ways:

- Phone through the U.S. Capitol Switchboard at (202) 224-3121.
- Email your U.S. Representative through: <http://www.house.gov>;
- Email your two U.S. Senators through: <http://www.senate.gov>
- Look in the “Blue” pages of your phone book, which have local, state, and federal government contact information.

## Chapter 9

### Top Ten Tips for Writing a Letter, Fax, or Email

Writing to Members of Congress is one of the easiest and most effective ways for constituents to communicate with policymakers on issues of interest and priority. Written communication can be done by email or by sending a letter to the Congressional office by fax. Such written correspondence, if done correctly, can result in garnering support for public policy priorities of the cardiomyopathy community.

When writing to policymakers, be sure to use your personal stationery and email account, as your employer might not share your views on the topic. For all forms of communication, be sure to include your full name, return mailing address, email address, and phone number. If you are a federal or state employee, you must use personal email and your personal computer.

Be sure to keep a hard copy of what you send, as sometimes faxes, emails, or letters are lost and you may need to send a second copy to ensure a response.

1. **Always be polite.** When addressing correspondence to any government official, be sure to use the proper forms of address (See Chapter 8). Even if you are angry, frustrated, or disappointed, be sure to use a polite tone and appropriate language; be sure not to be threatening, confrontational, or rude. The most effective way to communicate with your Members of Congress is the way you communicate with your colleagues, neighbors, patients, family and friends – clearly, concisely, and with respect and honesty.
2. **Identify yourself and why you are writing.** In the opening sentence, make your request up front and identify yourself as a registered voter, constituent, and your connection to cardiomyopathy. For example: “*As a parent of a child of cardiomyopathy and a constituent in your district, I am writing to request your support for the HEARTS Act.*” If you know the Member or staff aide, say so at the beginning of your message; this may alert the aide reading your correspondence to give your message special attention.
3. **Be concise and informed.** To the degree possible, try to keep your letter to a single page. You do not need to be an expert on the issue, but you should be familiar with the basic facts and points (e.g., name of the legislation and the associated bill number and why it should be supported or opposed). If you are requesting that the policymaker cosponsor a particular measure or are writing to express disappointment at a particular vote the policymaker cast, check the list of cosponsors and the vote record first at <http://thomas.loc.gov/> to ensure that you have the most up-to-date information and all of your facts correct.
4. **Personalize your message.** Remember, you are an expert in what it is like to deal with cardiomyopathy – and as such, you have many experiences to share. Tell your own story and explain the relevance to the issue at-hand. Although form letters and postcards are “counted,” they often do not elicit a response from a Congressional office. Personal stories and illustrations of local impact are more easily remembered by policymakers and their staff than statistics and generic examples. Moreover, personal stories often are what spur policymakers to action – not statistics. The reality is that our policymakers often legislate by anecdote. Your own words are best and can influence the legislator’s response or vote. If you are using a template letter, take a few moments to personalize it with your own experience. Also, you should include relevant state or local information to explain how the issue affects your family and community.
5. **Be honest and accurate.** If you are including statistics or other scientific information, be sure to verify your sources and have them handy if the Congressional office wants additional information. Also, be sure not to exaggerate the situation or issue you are discussing; do not oversell the policy solution you are advocating or overstate the consequences if the policymaker does not do what you request.
6. **Be modest in your request.** Although you may wish to address multiple issues, it is best to focus on only one or two issues of top priority. Your communication will be clearer and policymakers or staffers will be more receptive because you have not overwhelmed them with too many requests.

7. **Offer assistance and serve as a resource.** Policymakers and their staffers are overworked and overwhelmed, so offer your assistance; they will appreciate your input and help. If you have an article of interest, be sure to include it with your correspondence, or refer to it and indicate that you would be happy to provide it should they be interested.
8. **Express appreciation.** Too many times we forget to thank Members of Congress and their staff. If you receive a letter informing you that the Member shares your views or took the action you requested, write back expressing your thanks for the response and support. Or, if you learn that the policymaker recently cosponsored a bill you support or voted the way you hoped, send a letter expressing your pleasure at his/her action. At the close of your correspondence, be sure to acknowledge and thank the Member for his or her attention to your concerns.
9. **Ask for a response.** Because policymakers and their staffers work for you, you have every right to (politely) ask for a response and hold them accountable if your communication goes unanswered. In fact, entire systems, processes, and staff exist in Congressional offices to respond to constituent input. It is important to note, however, that because of the volume of constituent input, it could be weeks or months before you may receive a response. Be clear in your correspondence that you are requesting a written response regarding the policymaker's views on the issue or legislation you addressed.
10. **Make sure to follow-up.** If you do not receive a response in a timely fashion (a month for most offices, a bit longer for large states like California and Texas), be sure to follow up with the office by phone or with another letter (fax is best) with your original attached (make sure you keep or print a copy for your records before you send it off) and indicate you have not received a response and would like one. Follow up with a phone call to ensure that your fax has been received. If you receive an unsatisfactory response to your correspondence, write or call again to express appreciation for the response and be polite, yet firm, in communicating that the response was not what you anticipated or requested. Reiterate your points and address any concerns or points the policymaker has made on the issue in the correspondence. Also, if a Member of Congress does not take an action on your request, it is your right to (politely) request the office to provide an explanation.

### **Other Tips**

Keep in touch with the offices of your Members of Congress to establish a relationship and make yourself available as a local resource on cardiomyopathy and heart issues. There are times when you and an elected official will have to “agree to disagree” but over time, you also may find that the policymaker may be supportive and helpful on other matters.

### **Specific Tips About Regular Mail Service on Capitol Hill**

As a result of anthrax attacks in fall 2001, the U.S. Postal Service mail is handled differently by Congress. Most incoming mail is irradiated to ensure it is safe for handling. This process takes quite a while and often damages the contents. Therefore, for time sensitive communication, sending written correspondence by email or fax is advised – or make a quick phone call (see Chapter 10). Also, enclosing items such as photographs, originals of articles, or other documents is not recommended; it is best to save these items for hand delivery when you have a meeting in the office – either in the local office or in Washington, D.C.

### **Specific Tips About Email**

Each Congressional office maintains a different policy about how email from constituents is handled. Most Members of Congress have an email form on their website. To access the form, visit the individual Member's Web page ([www.house.gov](http://www.house.gov) or [www.senate.gov](http://www.senate.gov)), find your Member's website, and click on “contact”. Many Congressional offices provide a generic, automatic acknowledgement that your email has been received but then will follow-up with either a specific email response to your issue or a letter via regular U.S. Postal Service. A

handful of offices still do not respond individually to email but count the input and inform the policymaker how many people have written about the particular topic and what position they are advocating.

Some Congressional offices have instituted computer-based “algorithms” to ensure that email messages they receive are from legitimate constituents. Typically, all this entails is a requirement that the constituent to answer an easy math equation (e.g., what is two plus two?), or to copy a word or phrase from one place on the screen to another. This helps them weed out any computer-generated or “spam” messages, and allows constituent communications to get through. It is best to contact your Members’ offices to learn about their individual policies about constituent correspondence. You can call the Capitol Switch Board at 202-224-3121 to be transferred to your Members’ offices, or look in the “blue pages” of your local phone book, and your Members of Congress should be listed under the Government section.

## Chapter 10

### Top Ten Tips for Calling Your Members of Congress and Their Staff

Calling the offices of Members of Congress is one of the easiest and most effective ways for constituents to communicate with policymakers on issues of interest and priority. Such a phone call, if done correctly, can result in garnering support for your public policy priorities.

When calling policymakers, be sure to do so on your own time and with your own phone, as your employer might not share your views on the topic. While calling the local offices of your Members of Congress does not involve a long-distance call, it is best to contact their Washington, DC offices as they are better equipped to handle a greater volume of constituent calls and most policy staff are located in the Capitol Hill office, not in the district.

To reach the offices of your two Senators and your Representative in the House, look up your Member's contact information on [www.house.gov](http://www.house.gov) or [www.senate.gov](http://www.senate.gov), or call the U.S. Capitol Switchboard at 202-224-3121 and ask to be transferred to their offices. If you are not sure who represents you, just visit [www.senate.gov](http://www.senate.gov) and [www.house.gov](http://www.house.gov) to learn your policymakers' names, or ask the Capitol Hill Operator to assist you.

Be sure to keep a record of the date and time of your call(s), and the person with whom you spoke or for whom you left a message. Sometimes the phone logs are lost and you may need to follow-up with the office to ensure a response.

**1. Once connected to your elected official's office, identify yourself as a constituent to the receptionist.**

Clearly state your first and last name, your hometown, and why you are calling. If you know the name of the health legislative assistant, be sure to ask for them directly. If not, ask for the staffer's name and request to be transferred. Sometimes, the receptionist will indicate that you will need to leave your comments with him/her. If that is the case, you still should ask for the name of the health legislative assistant so that you have that information and record it for future reference.

*"My name is Jessie Johnson. I am a parent of a child with cardiomyopathy from San Francisco, and I would like to speak with the health legislative assistant about a cardiomyopathy issue."*

**2. If transferred to the health legislative assistant personally or if you are put into the staffer's voicemail, reintroduce yourself and immediately identify the topic you are calling to discuss. If you are instructed to leave a message with the receptionist, repeat your name and continue with your message that you wish to deliver.**

*"My name is Jessie Johnson. I am a parent of a child with cardiomyopathy from San Francisco and I am concerned that Congress is not providing adequate funding for cardiomyopathy education and awareness. I urge the Senator to sign on to S. 254, the Cardiomyopathy Health, Education, Awareness, Risk Assessment and Training in the Schools Act, also known as the HEARTS Act."*

**3. Make a few brief points** as to why the issue is of concern to you, your community, and the nation and why the Member should take action. You may want to use written notes to help you stay on topic and remain clear while articulating your case.

**4. Be clear as to what you are asking the Member to do** (e.g., cosponsor a particular bill, vote for or against a specific measure, sign a "Dear Colleague" letter).

*"I urge the Senator to call for increased funding for children's cardiomyopathy research and awareness efforts through the Centers for Disease Control and Prevention by cosponsoring the HEARTS Act."*

**5. Be polite in your tone and language.** The staffer on the other end of the phone is overworked, overwhelmed, underpaid, and receives dozens – if not hundreds – of calls a day. In fact, in some offices, you may be speaking

with a junior staffer or a college intern, so be sure to be patient and forgiving. Also, be sure not to use any “lingo” or “slang” (e.g. do not use acronyms in your speech). You should not assume the person on the other end of the phone is familiar with the issue you are discussing so be as clear and concise as possible.

6. **Keep it brief.** Limit your call to no more than five minutes unless the staffer asks you questions and seems engaged in the discussion. Offer to send additional or follow-up information to the staffer and request their preferred mode of communication (e.g. email, fax).
7. **Specifically request a written response** from the office on the Member’s position or action on the issue you addressed.

*“I would like a letter from your office detailing the Senator’s views on this issue and what she is doing specifically to address the cardiomyopathy issues.”*

8. **Provide your full name, mailing address, email address, and phone number.**

*“My name is Jessie Johnson. 123 Main Street, San Francisco, CA 94123. My phone number is (415) 555-1234. I look forward to hearing back from your office.”*

9. **Thank the staffer** for his/her time and indicate that you appreciate his/her willingness to listen and record your comments. Be sure to record the name of the staffer and the day and time you spoke, so you can have it for future use and in case you need to follow up.

*“May I have your first and last name for my records? Thank you very much for your time and for recording my views and seeing that I receive a response from the Senator. Goodbye.”*

10. **If you do not receive a response within a reasonable timeframe** (approximately a month), either call or write to follow-up and request a response. Reference your phone call and mention with whom you spoke and the topic to help facilitate a meaningful reply.

### Other Tips

If you receive the voicemail for a staffer or the office, be sure to leave a brief, clear message for the staffer (noting his/her name down for future reference) – providing your full name, contact information, and the nature of your call and specific request (e.g. become a cosponsor of the HEARTS Act); be clear that you would like a return call and/or a letter from the Member on the topic about which you are calling.

*“Hello. This is Jessie Johnson from San Francisco I am a parent of a child with cardiomyopathy and would like to request that the Senator sign onto the HEARTS Act, in support of increased funding for pediatric cardiomyopathy education and awareness programs. I would appreciate knowing the Senator’s position on this issue. I can be reached at 123 Main Street, San Francisco, CA 94123. My phone number is (415) 555-1234. I look forward to hearing back from your office. Thank you very much for your attention to my request.”*

Again, be sure to keep in touch with the offices of your Members of Congress to establish a relationship and make yourself available as a local resource on cardiomyopathy. There are times when you and an elected official will have to “agree to disagree” but over time, you also may find that the policymaker may be supportive and helpful on other matters.

**Also, you can reach your Members of Congress in the following ways:**

- Email your U.S. Representative through: <http://www.house.gov>.
- Email your two U.S. Senators through: <http://www.senate.gov>.

- For tips about writing to your Members of Congress, see Chapter 9.

## Chapter 11

### Top Ten Tips for Meeting With Your Members of Congress and Their Staff

Meetings with Members of Congress and/or their staff are terrific ways for constituents to communicate with policymakers on issues of interest and priority. Such meetings can be conducted at Congressional offices in Washington, DC or “at-home” in district offices and if done correctly, can result in garnering support for your public policy priorities. Visiting with them enables you to educate them about your concerns, offer yourselves as a resource, and establish a relationship that can prove mutually beneficial over time. It is best to build a relationship before you need it.

Prior to arriving in Washington, DC or at the district office, be sure to schedule a meeting with the staffer or through the appointment secretary/scheduler for a visit with the Member of Congress. For instructions regarding how to schedule such meetings, see your NIWI participant email that you received with details about the event. Be clear who will be attending and what issue(s) will be discussed. The week before, confirm the appointment as the Congressional schedule changes very often — and such changes often are beyond their control.

**In advance of the meeting**, be sure to put together some “leave-behind” materials from the advocacy section of the CCF website that you will provide to the Member/staffer at the end of your discussion.

If you have arranged for a Member of Congress to attend your chapter meeting/conference, inform your colleagues and make all the appropriate logistical arrangements. Be sure to have someone present who can take pictures and make certain to give copies of the photos to the Member and his staff, as well as to CCF.

1. **Prepare and be on time.** Members of Congress and their staff are very busy and often have to be in more than one place at a time. Be respectful of their time by giving yourself plenty of time to go through security, find your way to the office, and announce yourself to the receptionist. If you will be attending in a group, discuss with your colleagues in advance what you will be covering in the meeting. Be sure to select a primary spokesperson and determine who in the group will raise which points and requests. You should be clear about your roles and who will cover the different topics in the meeting. Open by thanking the Member/staffer for his or her time. Be sure that everyone in the group identifies herself/himself – first and last name and connection to cardiomyopathy – and remember to mention that you are a voting constituent and provide some context about where you live/work in the district/state. If the Member/staffer has been helpful in the past or has taken action that you appreciate, be sure to say thank you up front. Prior to your meeting with the Member/staffer, it is best to get a sense of what matters currently are pending before the Congress, and the committee(s) on which the Member sits. For resources that list this type of information visit [www.house.gov](http://www.house.gov) and [www.senate.gov](http://www.senate.gov).

*“I am Jessie Johnson from San Francisco, and I am the parent of a child with cardiomyopathy. We very much appreciate your time today, and want to thank you for your past support of children’s health issues.”*

2. **Be brief and clear**, as you typically will have only 10–25 minutes for the entire meeting. Cover only a few (one to three) topics. It is best to prepare talking points beforehand to ensure that you and your colleagues “stay on message.” Anticipate the kinds of questions you may be asked from both supporters and opponents. Do your best to be prepared to answer such questions in the meeting. If you do not know the answer, acknowledge the question and indicate since you are not certain of the answer that you will follow-up with them later (and remember to do so). Do not assume that the Member/staffer is very knowledgeable about the issue you are discussing – be sure to provide them with some background. If you are not discussing a specific piece of legislation, explain that you want to provide background information or provide your perspective on an issue of importance to you and your community.
3. **Provide a personal story or real-life illustration** of the problem, as personal stories are more easily remembered and more compelling than statistics. As necessary, briefly cite evidence or statistics to support your position, particularly any local, regional, or state data. However, be sure not to overwhelm the policymaker or staffer with too many statistics or references to studies (this kind of information can be in the



materials you leave behind or can be sent with your thank-you note). Discuss how the policy change (e.g. education programs through the HEARTS Act) will have an impact on your family and community. Be concise and honest about the issue(s) and the solution(s) and make clear the relevance of the issue(s) to their constituents.

4. **Be polite and listen carefully** to the policymakers' or staffers' views and comments. Even if you disagree, it is important to be courteous. Be flexible and consider the opposing view. Do not be argumentative or threatening. You may agree to disagree on an issue today and find that you can agree and work together on another matter tomorrow. Much of health policy advocacy is about building and maintaining relationships. Some of the best friends of the community were not always allies but become supporters over time.
5. **Make sure to get a response – in a nice way.** Ask directly, and politely, for the policymaker's views and position on the issue. Do not let the policymaker or staffer distract you with other issues (gently steer the conversation back to your issue), avoid responding, or dismiss your specific concerns with a broad statement such as, "Of course, I support pediatric health." Stay on message and the topic as politely as possible. It is your Constitutional right to "petition Congress for redress of grievances" – so take this opportunity to do what you can to get a commitment from the Member to take action on your request(s). However, if the Member truly is undecided or the staffer is not familiar with the Member's position on the issue, do not force a response – reiterate your interest in knowing the Member's position, offer to answer any additional questions/provide additional information, and request a follow-up letter once a decision has been made on your request. Ask politely for a good day in the next week to 10 days for you to follow up on your request(s).
6. **Bring a concise set of materials with you to leave behind.** However, do not hand over the materials until the close of the meeting, or the Member/staffer may choose to start reading the material and only listen to you with one ear. Early in the meeting indicate that you have materials to leave on the topic(s). Be sure to follow-up and follow through on any promises of additional information.
7. **Leave your contact information.** If you leave a business card, make it clear that you are visiting on your own time and not representing your employer unless you have received such clearance. Be sure to get a business card from the Member/staffer so that you know how to reach them. Be sure to ask the Member/staffer their preferred mode of communication (e.g. email, faxes, voicemail/phone).
8. **Summarize your requests of the Member/office** and any responses the Member/staffer have given to ensure you are clear on where they stand on the issues. Summarize the Member's/staffers' requests and indicate how you plan to respond. Express thanks and appreciation for their time, interest, and courtesy.
9. **Report back to CCF** so others can follow-up with the office with additional information and reinforce the message(s) you delivered.
  - ✓ Fill out a "Report Back" form on the CCF advocacy website.
10. **Follow-up with a thank you note** to the Member/staffer referencing the date of your meeting, who was in attendance, and the issues discussed. Your follow-up letter should express appreciation for the time and consideration extended to you during your meeting, reiterate your request(s), and ask for a written response from the office. Be sure to call/email/write with answers or information the Member/staffer requested. Be sure to keep in touch with the Member/staffer to maintain and strengthen the relationship and make yourself available as a local resource on children's cardiomyopathy. Again, there are times when you and an elected official will have to "agree to disagree" but over time, you also may find that the policymaker may be supportive and helpful on other matters. Great ways to keep in touch are sending an article of interest from the local paper or inviting the Member/staffer to a relevant at-home when they next are visiting.
  - ✓ You will receive a template thank you letter is provided on the CCF advocacy website.

**Other Tips**

When visiting Capitol Hill or a federal building in which your Member of Congress maintains an office, you could encounter long lines to get through security (bags and all contents from your pockets must be put through the X-ray machines and you must step through a metal detector). Be sure to allow yourself plenty of time to get through security.

Since your initial meeting is in Washington, DC, be sure to schedule a similar meeting with the staff in the district or state office and check in with your policymaker when s/he is at home visiting to reinforce the relationship and follow up on your issues of priority.

The Congressional schedule is very fluid and Members and staffers often are pulled away for various events and activities that are not known in advance (e.g. last minute press conference, meeting with the Chairman of a committee the Member sits on, etc.) and, as such, your meeting could be delayed or bumped (the Member may not be available and you instead may meet with staff). Also, space on Capitol Hill is at a premium so your meeting could occur in the reception area in the office, in the hallway, or downstairs in the coffee shop. Do not take any last minute meeting changes personally and make sure you always are gracious and flexible.

## Chapter 12

### Congressional Offices: The Real Deal and Who's Who

Because legislators spend a great deal of time out of the office, their staff may well be considered the invisible force in U.S. lawmaking. In fact, most people do not realize that most of the work on Capitol Hill is done by 20- and 30-year-olds who are bright, hard-working, and devoting their time and energy to the public policy process. They advance the interests and priorities of the Members of Congress for whom they work and the states and districts they represent.

All Members of Congress have staff to assist them during their term in office. The legislator's staff, often referred to as "personal staff" (as opposed to "committee staff," as discussed below), includes both the district (at home) and non-district (Washington, DC) offices. The personal staff handles constituent needs and drafts legislation, works with the media, coordinates scheduling, and meets with advocates, constituents, and lobbyists. There is quite a bit of turnover in Congressional offices among the staff, especially at lower levels, which contributes to the challenge of staffers maintaining expertise in a particular issue area and advocates developing and sustaining relationships with staff. To be most effective in communicating with Congress, knowing the titles and principal functions of key staff is helpful.

**Administrative Assistant (AA) or Chief of Staff (CoS):** The AA/CoS reports directly to the Member of Congress. She or he usually has the overall responsibility of evaluating the political outcome of various legislative proposals and constituent requests. The AA/CoS usually is the person in charge of overall office operations, including the assignment of work and the hiring and supervision of staff.

**Legislative Director (LD):** The LD usually is the staff person who monitors the legislative schedule and makes recommendations regarding the pros and cons of particular issues and proposals. The LD works with the Member of Congress and the CoS to determine legislative priorities, oversee the development of legislative proposals, and direct the work of legislative staff.

**Legislative Assistant (LA):** Most Congressional offices have multiple LAs who are responsible for a portfolio of issues. For example, depending on the responsibilities and interests of the Member, an office may have a different LA for health issues, environmental matters, homeland security, or taxes. **The majority of your interactions with most Congressional offices will be with LAs. It is important to note that the average Health LA is a woman in her mid-to-late twenties with an undergraduate degree in Political Science and little, if any, formal knowledge or education about health care concerns.**

**Legislative Correspondent (LC):** More common in the Senate than in the House as a result of the volume of mail received in Senate offices, LCs work closely with a particular LA focused on a portfolio of issues. LCs principally are responsible for sorting, reviewing, and responding to constituent correspondence and monitoring and reporting on the issues of importance to constituents. LCs also do research and some writing for the LAs (e.g., background issue memos, talking points for the Member of Congress) with whom they work and also conduct meetings with constituents, usually when the LA is unavailable.

**Press Secretary or Communications Director:** The Press Secretary's responsibility is to build and maintain open and effective lines of communication between the Member, the constituents, the media, and the general public. The Press Secretary serves as the Member's spokesperson and works to promote the Member's profile, inform the public of the Member's views on specific issues, and help advance the Member's legislative agenda.

**Scheduler, Appointment Secretary, or Personal Secretary:** A Scheduler, with counsel from the CoS, maintains the primary responsibility for allocating a Member's time among the many demands that arise from Congressional responsibilities, staff requirements, and constituent requests. Schedulers also are responsible for making travel arrangements and arranging speaking dates and visits to the district. Some Members have one scheduler in DC who maintains their entire schedule, whereas others have one scheduler in DC and one "at home" in the district or state who keeps the calendar for all local events.

**State or District Director:** State or District Directors are the highest-ranking staffers in the Member's state or district. In essence, this person serves as a CoS for all the activities and staffers in the local office(s). District Directors work closely with the CoS in DC to ensure coordination of activities, priorities, and awareness of what is going on locally of relevance to the Member.

**Caseworker:** Caseworkers are the staff Members in a district office assigned to help with constituent requests. Caseworkers' responsibilities may include helping resolve problems constituents present in relation to federal agencies (e.g., Social Security and Medicare issues, veteran's benefits, immigration concerns, passports). A Congressional office may have several caseworkers.

#### *Other Relevant Staff*

In addition to staff who work in individual Members' offices, Congressional committees and subcommittees all have their own staff. The committee and subcommittee staffs are broken down into majority staffers and minority staffers, with the ratio usually reflecting the ratio of the committee and subcommittee Membership. These staffers typically have expertise in the issues for which the committee or subcommittee has jurisdiction and often have law or other advanced degrees. These staff Members draft legislation, investigate issues of importance to the committee chairman and ranking Member, organize hearings and mark-ups, and develop policy. Committee and subcommittee staffers are principal players in the development of legislation. Much less turnover occurs among committee and subcommittee staff, and these staffs have a greater depth of expertise than personal staff. Therefore, establishing and maintaining relationships with key committee staffers is a worthwhile investment of time and energy.

**Committee Chairs and Ranking Members typically have staff in their personal offices as well as on the committees and subcommittees on which they sit.** For example, Senate HELP Committee Chairman Tom Harkin (D-Iowa) has a significant set of staffers who work for the committee as well as personal staffers who also may work on health care matters. When contacting Congressional offices of Members who are part of committee leadership, finding out whether the staffer responsible for your issue of concern is a Member of personal or committee staff is important.

For your Members' Washington, DC, and local office information, visit [www.house.gov](http://www.house.gov) or [www.senate.gov](http://www.senate.gov).

## Chapter 13

### How to Work With Congressional Staff

When working with Congressional staffers, please keep the following points in mind:

- (1) **Remember who they are.** Staff members will be key figures in developing policy that can have an impact on you and others in your state and district.
- (2) **Do not overestimate what they know.** Staff members often require outside expertise. Yet, it is important not to be condescending or use jargon. It is smart to ask staff how familiar they are with a particular subject so you can tailor your remarks to their knowledge level.
- (3) **Do not underestimate their influence.** Legislators trust them, depend on them, and act on their suggestions. These 25-year-old staffers have direct access to Members of Congress and will make recommendations and help direct their positions and actions. Junior staffers often are promoted to more senior positions, so it is important to treat all staffers with respect.
- (4) **Be honest.** Provide accurate, complete information to maintain your credibility. Be reliable; do not over-promise or under-deliver. If you do not know an answer, that is fine, but be sure to indicate that you will follow up. Always follow-up if you have promised additional information.
- (5) **Provide summarized, useful information.** Information should be concise, brief, focused, and have references, as appropriate. More information always can be requested/provided.
- (6) **Visit them before asking for assistance.** If possible, introduce yourself and get acquainted before you request something from a staffer or Member.
- (7) **Do not attack ideas.** Oftentimes staffers reach out to stakeholders for input on a draft proposal. This is an honor and should be handled as such. Even if you disagree, be respectful in your constructive criticism and be prepared to offer an alternative idea or proposal. Express your appreciation for their interest in the issue and thank them for asking for your viewpoint.
- (8) **Follow Up.** Be a tenacious advocate. Congressional staff are overworked and could easily forget your issue unless you follow up. Be persistent and polite – it will pay off.
- (9) **Be a Resource and Stay Connected.** Maintaining regular contact is important; be a local resource on whom the staffer can rely. You should make sure that the staffers for your Members receive newsletters, updates, or articles you think may be of interest and assistance to keep them up to speed on key issues in your community. Be sure not to inundate or overwhelm them, though, as they receive a lot of information and are very busy.
- (10) **Express thanks to the Member of Congress and staff.** Sometimes, we forget to thank Members of Congress and their staff. Express your appreciation whenever appropriate.

Getting to know staff Members can be very beneficial; they have the capacity to influence the decision-making process. Even if you cannot travel to Washington, DC, you can develop relationships with the local district staff and get to know the DC staff via phone and email. DC staffers often make special trips to the district or state to meet with constituents, so be sure to check occasionally with the Health Legislative Assistants to see when they might be visiting your area—let them know you would like a few minutes to see them on their next visit.

## Conclusion

**Your active participation in health policy advocacy is essential to ensuring that the children's cardiomyopathy community's priorities are received and addressed by policymakers from a parent's and patient's perspective.** Parents and patients can and must become involved in health policy advocacy. This Health Policy Tool Kit provides all the tools necessary to be effective health policy advocates at the national, state, and local level. We thank you for taking the time to review and use this resource and encourage you to involve your colleagues and others in the cardiomyopathy community in your efforts.

Good luck in your advocacy endeavors; do not forget to have fun!