

THE ASK (What do you want?)

All successful advocates have one thing in common: they came to the table with a clear “ask” or goal in mind. While the end goal for all of you is to see the disease your child suffers from eradicated, this is a specific legislative goal.

- Are you seeking a disease-specific bill that would authorize research funding?
- Do you want to recruit members of Congress to sign a letter to the National Institute of Health (NIH) asking for stronger investment in research and grants for the illness?
- Are you trying to partner with a university to seek a congressional earmark for research or secure appropriations committee report language?

You have to know this (and know why) before you begin to advocate. Telling the story of your child and the disease they struggle with is absolutely compelling, but when you get to the end of the story, you need to be able to clearly articulate what you need from the member or Senator. You must be driven and persistent, almost single-minded in your focus, unified with others who seek the same goal, and prepared to face the obstacles and bureaucratic red tape that come with dealing with the federal government. You have to understand the challenges that come with fighting a disease-specific battle and realize the limitations of your efforts to best maximize your effectiveness.

How Do You Start?

The most logical place to start your advocacy is with your own federally elected representative and Senators. These people represent you and your family. Do not underestimate this relationship. Members of Congress and Senators are particularly sensitive to constituent needs because, obviously, they need their constituents' support in order to continue to be elected to Congress. Therefore, they or their staff should be willing to meet with you to discuss your child's disease and consider helping with your requests. These relationships are vital and working hard to cultivate them will be a key to success. That said, how do you engage your representatives? Before you begin contacting them, do your homework! You should find the answers to several questions:

- What bills have they introduced? This can be easily found by going on the Library of Congress website. Introduction of a bill indicates that this is either a personal priority for the Congressperson or Senator or that it is overwhelmingly supported by their constituents. Pay special attention to any health-related bills that they might have introduced.
- Next, look at other which bills they have co-sponsored. Are they co-sponsors of any bills funding or supporting disease research?
- What committees do they sit on? I'll address committees in more depth later, but be aware that if they are on the House Energy and Commerce Committee or Senate HELP Committee, they and their fellow committee members have jurisdiction over most health-related legislation.

- Visit their websites: Locate the issues page and see what (if anything) they list under health or related categories.
- While on their website, pay close attention to their press releases. How they promote their work, both on Capitol Hill and back at home, speaks volumes about their priorities. Press releases (especially those from more seasoned Members of Congress) are statements about accomplishments that they are championing, what they value, and what they are working towards. Pay close attention to any health related press releases.
- A note about the websites: Keep in mind that while some of the content may be partisan, you should focus on the issues based material on the website. For your advocacy purposes, it does not matter if you and your representative are not in the same political party: they are your voice in Congress and you cannot afford to allow partisanship to dampen your enthusiasm for building a relationship with the member or senator.

Visiting Your Representative in the District

So... once you've done your homework, what next? You should begin by making plans to meet with your representative.

All members of Congress have at least one district office (and in many cases, several). Your efforts should start there. **It is not scary or overwhelming: these people were elected to serve YOU!**

- Make an appointment to meet with the representative or his staff at the district office. (Be aware that when Congress is in session, members are only in the district on weekends, so a meeting with staff may be all that is feasible.) Be prepared to speak with them about your family, the disease, the status of research, and what you are asking of them.
- When possible, bring your affected child. The impact of seeing the effects of a devastating disease firsthand cannot be overstated. Especially given that many diseases make long distance travel difficult, a district office visit with your child, where you might take photos with staff to bring to a later Washington, DC visit, is a good step.
- The expression is there is safety in numbers. When it comes to advocacy, there is POWER in numbers. Find other families in your district and work together to schedule joint meetings. This will demonstrate a community need for action and a sense of voter unity around the issue. Help recruit more families to your cause: Every voice makes an impact, and the more who speak as one and demand action, the louder the call is in Washington.

Once you've had your initial meeting there, maintain contact. The district staff is your preliminary link to the member. Their primary job is to provide constituent service and their office is much more convenient than the office in Washington, D.C.

- In August, during the month long recess, most members have open houses or town hall meetings. Attend these and make an effort to speak briefly to the member, always thanking them for the “good work” they do on your behalf throughout the year.
- Continue to make appointments a few times a year to update them on any new developments regarding your efforts, the status of research funding, and any new breakthroughs regarding the disease.
- Make sure to invite the office (member and staff) to any fundraising events that you host or participate in for the disease. While they may not be able to attend, part of your argument to Congress, particularly when asking for new or increased research funding, is that you are not asking for a handout. Demonstrating an active fundraising base within the disease community (and within the member's district) will allow you to argue that you are asking the government to partner with your efforts, rather than underwrite the entire cause.

Remember that relationships in politics matter. In addition to your own outreach to the office, it is important to identify friends, colleagues, neighbors, acquaintances (anyone you might even tangentially know) who have a personal relationship with the member or Senator. Ask them to assist by putting a word in on your behalf, sending a letter of support, or helping you to set up meetings. If you do not know anyone who has this sort of relationship with the member, find the most politically active (donors, local elected officials, party activists) members of the official's

party and ask them for assistance. As cynical as it might be, money and influence play a role in getting Congressional attention. Being able to identify those who already have influence with a member of Congress can be key in translating a meeting into support.

THE DC OFFICE

While you are solidifying your relationship with the district office, you should be making inroads with the DC office as well. Members of Congress and Senators get far more meeting requests than they can possibly accommodate, even if they didn't have to spend any time voting or in committees (both of which you need them to be doing, or else why would you be in Washington to ask for their help!). It is not the end of the world if you are assigned to meet with a staff member. Think of the representative or Senator as the CEO of a small office. They need to know about any issue that might come up for a vote, so their staffs are charged with learning all the minutiae of a given subject area and making sure their boss is well-informed when the subject comes up.

- Staffers in Washington primarily focus on legislative policy. You will need the staff member who handles health care to become your champion, particularly if you are looking to pass legislation. While the disease you are speaking about is obviously not something cheerful, you should come into the office with a smile on your face and a positive attitude.
- Bring a one-page fact sheet that outlines both the important facts about the disease and the request you are making of Congress. Yes, just one page. Staff members have so many meetings about different subjects within their issue area that they really need the basic facts. More than a page and they simply won't be able to digest the main thrust of

your argument and the information they need to understand the disease. You need to hook them and gain their support before bogging them down with pages of information. They'll make time to explore your cause in depth once they are on your side.

Brevity also applies to your talking points. You should be prepared to speak for about 15 minutes and know all of the salient points that you MUST hit in order to leave the staff or member with a clear impression of why you came. While you may get a full half-hour (the standard block of time for sit-down meetings), the staff member may have limited time and you could end up with 10 minutes outside the office in a hallway. Regardless, you should appear grateful for any time they give you and use it wisely. Be prepared to answer typical questions:

- Is the federal government doing anything currently for the disease? Has the government done anything in the past? If so, what was the cost?
- What is your organization's main goal? Are you dedicating any of your organization's financial resources to research (or whatever you are asking the government to do)?
Demonstrating a commitment by private and non-profit sources to the cause will emphasize collaboration, rather than a government hand-out.
- Does research for this disease have farther reaching impact on any other diseases? (This is a strong selling point, particularly to conservatives who like to see "more bang for their buck," and members who are wary about supporting "disease-specific" projects or legislation.)

Be aware of something we refer to in Washington is “compassion fatigue.” With so many requests for help on different diseases, it can be difficult for staff members to connect to one, to “pick one among the many,” for their bosses to support. Especially with budget concerns and the economy, many staff members will repeat the standard answer that “disease-specific legislation just isn’t moving right now.” It may be true that disease specific legislation is harder to move, but there are a handful of disease-specific bills that HAVE moved, and you still need to tell them your story, emphasize their important role in changing the course of the disease, and challenge them to help you fight.

After you leave the office, FOLLOW UP.

- Remember that you were probably not the only meeting that staff member had that day, and certainly not the only issue they dealt with on behalf of their boss.
- Make sure to send an e-mail as soon as possible with a quick thank you note. If you have a blackberry, send it that day. Otherwise, note the date you had the meeting when sending the thank you note.
- Retain the business card of the staff member for future contact. Call to remind them of the discussion you had and what you hope to achieve.
- Just as with the district staff, keep the staff member in Washington informed of any developments in the district or nationwide with regard to the disease. If you host or attend fundraisers or benefits for the cause, send them photos and information about the event, particularly if the event occurs in your district. The more emphasis that you can place on this being an issue of importance in the district community, the more likely you are to gain their support.

Beyond your Member or Senators' offices, what can you do? Contact members on the key committees. Identify celebrities who are somehow affected by the disease (whether living with it themselves or as a parent) and invite them to join you (or a national organization you are affiliated with) to advocate.