



American Brain Coalition

Capitol Hill Toolkit

The purpose of the American Brain Coalition (ABC) Capitol Hill Toolkit is to provide you, our ABC members, with advocacy tools to ensure a successful meeting with your member of Congress or legislative staff. Members of Congress and their staff want to understand the impacts of issues that are important to their constituents. This toolkit will help give guidance on how to conduct a visit and tips for success during and after the meeting, including pertinent information to enhance the content of your message. We have also included a section on Effective Advocacy Outside of Washington, DC. We hope this Toolkit will make advocacy for brain research and healthcare for our members as easy as possible.

- I. Identify Your Member of Congress** – Learn where they stand on legislative issues that affect the American Brain Coalition (ABC) and diseases of the brain, which committees/subcommittees they serve on, and their contact information. Information of this kind can be found [here](#) and [here](#).



II. Do Preparatory Research

A. Funding Environment:

1. For FY 2015, the [NIH Community](#) asked for \$32.0 billion, which is a 6.31% increase from FY 2014's \$30.1 billion;
2. The [Senate](#) proposed \$30.5 billion for NIH, which is an increase of 1.33% from FY 2014;
3. The [White House](#) proposed \$30.3 billion, a 0.66% increase;
4. However, the FY2015 spending bill only provided \$30.084 billion to NIH.
5. A [report by AAAS](#) gives a breakdown of funding for each of the R&D agencies;
6. An [NIH report](#) shows decrease of grant successes throughout the years.



B. Reasons to Increase Brain Research/Health Funding:

1. Biomedical research saves [lives](#) and decreases [healthcare costs](#):
 - Neurological disorders affect [50 million](#) people per year, cost the US [\\$760 billion](#) a year, and this number will [increase 3X](#) by 2030 if no cures are found.
2. Biomedical research stimulates the [economy](#):
 - Every dollar of research generates [\\$2.21](#) in economic output.
 - FY 2012, NIH funding led to the creation of [402,000](#) jobs across the US.
3. Biomedical research has provided the leading [innovative edge](#) in the world:
 - Currently, the US expenditures in research are falling while other countries' are [increasing](#).
4. Biomedical research helps to train for the next generation of medical researchers:
 - The percentage of NIH primary researchers under the age of 36 has dropped from [18 to 3](#) since 1982.
5. Neuroscience research leads to drug development:
 - For [brain disorders](#), the process to develop drugs to treat neurological and psychiatric conditions takes longer, is more costly and has higher failure rates than the development process for drugs to treat other conditions.



III. Schedule a Meeting (Congressional calendar for [House](#) and [Senate](#))

- A. Call or email the office where you would like to meet. For the House, click [this link](#) and enter your zip code to find your Representative. For the Senate, click [this link](#) and go to "Find Your Senators".
- B. Ask to speak to the scheduler to arrange an appointment.
- C. You will likely be asked what the intention of the meeting is. Kindly tell them you represent the American Brain Coalition and would like to meet to talk about support for brain research and healthcare.
- D. If you are unable to talk to someone, leave a clear message and check back every few days. You may also want to check the member's website in case there is a meeting request form online you can use. Don't be surprised if you have to make multiple requests. Be persistent but careful not to be overly aggressive, give them time to

respond.

- E. Once you secure a meeting, call to confirm a day or two prior to the meeting.

IV. The Meeting

- A. Know your audience – Remember where your member stands on legislative issues that affect the brain community
- B. Congressional members represent their constituents; enunciate the benefit of neuroscience funding to the local community.
- C. While members and their staff are educated, they are typically generalists, unless it pertains to issues within their Committees. Ask about the staff's background.
- D. Congressional staff are important, well informed and help provide direction to their boss' decision-making.
- E. Be positive and avoid partisanship.
- F. Prepare and practice a 5-10 presentation:



1. Briefly introduce yourself.
 2. Say that you are here on behalf of ABC. Describe [ABC's Mission, Vision and Goals](#).
 3. Describe your organization using nontechnical jargon and how it benefits society.
 4. Provide an "Ask" and support it with reasons why (see Preparatory Research). Tailor your speech to their background.
 5. Frame your message: What do you want and why? Who will it help? Why is it important in the broader health policy/national political context?
 6. Be prepared to be interrupted.
- G. Congressional staff are very busy, so keep the conversation concise (around 10 minutes long).

H. Meeting Logistics

1. Be prepared to not necessarily meet in an office - some meetings are held in the hallway outside of the member's or staffer's meetings.
2. Dress professionally, but wear comfortable shoes for walking around.
3. Bring your driver's license or state I.D.
4. Bring business cards and a camera just in case you see the
5. Congress member.
6. If you get lost, ask a Capitol Hill Police Officer – they are very helpful.
7. Allow time for long lines at the entrance of buildings for security screening.
8. If you are late, call the Congressional Office and let them know.
9. You will pass through metal detectors and go through security lines, so plan accordingly.
10. Mute your cell phone.

I. Tips for an Effective Congressional Visit

DOs

Do thank them for taking the time to meet with you.

Do thank them for considering your viewpoint.

Do be forthright and informative in your communications.

Do stick to an agenda.

Do keep it simple and brief.

Do provide an "Ask" - tell the legislator/staffer what you would like for them to do.

Do provide the legislator/staffer with a persuasive argument, allowing each group member to contribute to the conversation when appropriate.

Do cite specific issues and data.

Do offer to provide additional background information on the subject you are discussing.

Do offer to assist the legislator's staff in any way possible.

Do let the legislator/staffer know why you care about the issue - share personal stories.

Do tell the legislator/staffer how this subject affects their constituents.

Do expect your legislator to be responsive to your views.

DON'TS

Don't be narrowly ideological.

Don't be threatening or confrontational.

Don't be close-minded.

Don't be overly technical.

Don't lose track of time- legislators and staffers are extremely busy and you should respect their schedule.

Don't expect your legislator to drop everything and focus on your concerns.

V. Follow up with a Thank You Email within 1 Week after the Meeting

SAMPLE THANK YOU LETTER TO MEMBERS OF CONGRESS AND STAFF

[insert date]

The Honorable [Full Name]
United States House of Representatives
[Room and Office Building]
Washington, DC 20515

Or if Senate Office:

The Honorable [Full Name]
United States Senate
[Room and Office Building]
Washington, DC 20510

Dear Representative or Senator [Last Name],

On behalf of the American Brain Coalition, thank you for meeting with me on [date] to discuss biomedical research policy issues, in particular, those related to federal funding. The brain-related disease community is greatly appreciative of the time you spent understanding our positions and your interest in supporting research that lays the foundation for future medical breakthroughs. As I mentioned during our visit, we are grateful for the past Congressional support of the National Institutes of Health (NIH). As a patient advocate, I strongly believe that the NIH should receive the highest allocations possible in FY 2016 and beyond. Sustainable funding for the NIH is vital to the scientists in your district and across the country who are dedicated to preventing and curing diseases that affect millions of people. An adequate investment in the NIH will reap vast rewards – including, innovative medical therapies, better quality of life through disease prevention and early treatment, a strong economy, and better science education.

Please do not hesitate to contact me if I can be of further assistance.

Thank you again.

Sincerely,

VI. How to be an Effective Advocate Outside of Washington, DC

Advocacy that you do in your own community—week in and week out—is essential to creating positive change for diseases of the brain. The best way to become an effective advocate is to build strong relationships with all three people who represent you in Washington, DC, and with their staff who cover brain disease issues. You want them to recognize your name and to trust the messages that you deliver.

- A. Start regular, personal communications. That means you should contact them every month or two, by email or telephone. Do not rely on snail mail; it takes three to four weeks to arrive in DC because of testing for dangerous enclosures. Members of Congress expect to hear from their constituents on issues they are passionate about, so don't hesitate.
 1. Sometimes your messages will ask for something specific (e.g., a vote or co-sponsorship), but other times you should pass along information, ideas, and stories that you think will be helpful.
 2. When you receive an alert from the American Brain Coalition, please act promptly by sending emails as the alert requests, or personalize them with specifics relating to your experience and expertise.
- B. Write letters-to-the-editor about issues. Members of Congress always read the letters in their hometown newspapers. Editors like letters that respond to something that appeared recently in the paper. Keep your letter concise, approximately 150 words. Most newspapers prefer email submissions. Include your full name, address, phone number, and email.
- C. Go to town hall meetings that your members of Congress hold and ask questions about brain-related issues. Or make an appointment to meet with your member of Congress in the local office. Don't forget the state and county fairs, as well as parades that politicians frequent on weekends and during the August Congressional recess. Tell about the potential impact locally of proposed legislation (positive or negative), or tell about the ways that funding shortfalls have hurt at a local level.
- D. Invite your members of Congress to your organization. If one accepts, you can show off what your organization is involved in, but also ask some direct questions about what they are doing in Congress that supports your brain disease. Contact American Brain Coalition staff prior to the visit for possible questions and talking points.
- E. Build relationships with Congressional staff who work in the state or local offices (District Offices). They represent the member of Congress at local

meetings and events, and serve as caseworkers to help constituents with federal programs and benefits. Invite them to regular meetings and events on your calendar, and let them know how you can help them serve the community. Then when the Senator or Representative needs to know how legislation might affect constituents, local staff will know who to turn to for input.

- F. Share information and ideas with others in your community who care about brain disease issues.

VII. Become an American Brain Coalition Success Story

A number of American Brain Coalition members are working to increase awareness of brain-related diseases that have impacted themselves or their loved ones. One ABC member, Tremor Action Network, advocates for brain research in various ways. Recently, Tremor Action Network rallied their community members through social



media and asked them to send letters to Congress encouraging their elected officials to join the Congressional Neuroscience Caucus. As a result, they developed a substantial following of supporters which provoked the interest of both policymakers and the media. This grassroots advocacy activity translated into public attention of their organization, and importantly, neuroscience policy issues and their impact on people with tremor. To learn more about the successful outreach of this ABC member, visit the Tremor Action Network's [Blog](#) where [Nannette Hallowell](#), advocate and Blog Editor, shares her account of their numerous advocacy and policy activities.

The picture above is from the 2014 Rally for Medical Research Day when Nanette visited with her member of Congress.