

NeuroAdvocacy: Why Lobbying Matters

Advocating for patients and the specialty is a powerful way for physicians to make their voices heard.

By Janice F. Wiesman, MD

The United States is a representative democracy. Citizens elect local, state, and federal legislators who bring the views of their constituents to the job of governing. When a legislator considers a bill, or when an agency is tasked to make a rule inside legislation, individuals and organizations have the opportunity to make their stances known. This unique relationship does not exist in all countries throughout the world.

Active participation is essential to a successful democracy and is particularly important to the American Academy of Neurology (AAN) and its mission to advocate on behalf of patients and the profession. Advocacy through the AAN at both the national and state levels provides education, tools, and a logistic infrastructure that allow members to focus on the task at hand: improving the rules for our patients, colleagues, and practices.

Why Do We Advocate?

Member advocacy is one of the ways the AAN fulfills its vision to be indispensable to its members and its mission, which is “to promote the highest-quality patient-centered neurologic care and enhance member career satisfaction.” Much of this can be accomplished in our own offices and state neurology societies, but broader goals require involvement in national laws and regulations that govern health care. AAN members frequently reach out to their lawmakers to express their opinions and develop relationships. BrainPAC, the AAN’s political action committee, is another tool that members and staff can use to have direct access to the very lawmakers who make decisions that affect our patients and profession.*

When in Washington, we should visit the offices of our senators and representatives, speak to them at roundtables and fundraisers, and even also testify at hearings. To walk into the grand buildings that comprise the House of Representatives and Senate is awe-inspiring. Moreover, to be there as a partner in the “business of the people” is a privilege and a respon-

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sibility of our roles as citizens. But not all advocacy occurs inside the Beltway—we should also take the opportunity to visit district offices during Congressional recesses.

As a member of the AAN’s Government Relations Committee, I feel it is very important to make it clear to lawmakers that we are representing the AAN and not ourselves. As tempting as it is to address our personal issues with reimbursements, hassles with electronic health records, or maintaining certification, those discussions are not for this meeting. Of course, anyone can contact her or his representative or senator to discuss these matters on their own.

How Do We Advocate?

The most well-known form of advocacy is to propose or support a bill, which is called “legislative” advocacy. Importantly, legislative advocacy is very difficult; only about five percent of proposed bills each year become law.¹

Advocacy can also be “regulatory.” After a law is passed, the proper regulatory body is tasked with filling in the details. Consider this example from the Affordable Care Act: “The Secretary (of Health and Human Services) may by regulation adjust the number of beds described in paragraph....” At this point, organizations may lobby for how the number of beds

The AAN's Advocacy Team in Washington

The Academy has an active advocacy program based in Washington. The four members of the team include Mike Amery, Sr. Legislative Counsel; Derek Brandt, Sr. Congressional Affairs Representative; Natalie Pontzer, Manager, BrainPAC & Political Affairs; and Daniel Spirn, Regulatory Counsel. AAN members meet with senators, representatives, and their aides to give voice to the priorities of the AAN. This team also works with AAN members who go out to educate members of Congress and state legislators about health care policy that affects our patients and colleagues. Advocacy staff at the AAN office in Minneapolis coordinate congressional in-district office visits to reinforce messages discussed in the Washington office.

counted will be adjusted. This sounds like a small matter, but it may be important for the inclusion of a facility in some portion of the law. Regulatory advocacy takes the form of meetings with regulatory staff of the appropriate agency to discuss the method by which the Secretary fills in the details. Legislators can also be of help in the regulatory arena as organizations like the AAN circulate letters of support for their point of view that are then sent by members of Congress to the regulatory agencies. Because regulatory advocacy tackles smaller, but no less important goals, the path to success is often easier than that of legislative advocacy.

Given the challenges of advocacy, partnering with like-minded groups can be particularly beneficial. An example of this is the AAN's work with the American Heart Association (AHA) regarding issues related to stroke. At last year's Neurology on the Hill event, the AHA brought patients and their families affected by stroke to join AAN members at meetings in Congressional offices, to emphasize the importance of earlier treatment. This lent a personal touch to the proceedings and had a powerful effect on legislators.

With so many ways we can engage lawmakers through advocacy, physicians should always keep in mind that success often takes time and patience. Congress and regulators move slowly through a complicated maze of hearings, committee meetings, and votes. Achieving victory requires long-term planning and a commitment to principles.

What Do We Advocate For?

Advocacy efforts should focus on what is best for our patients and our members. These include giving voice to concerns about drug prices, supporting research funding, protecting patient access to neurologists, and relieving

administrative and regulatory burdens on neurologists.

One example of patient advocacy is support for the Furthering Access to Stroke Telemedicine (FAST) Act, a bill that would increase the reach of Medicare coverage for stroke telemedicine. Currently, only designated "rural" areas of the US are eligible for Medicare coverage for this service, but these areas account for only six percent of strokes that occur in the US.² As a physician who practices in New York City, I know that transferring a patient only a few miles through the city can take as long as a transfer across many miles of open highway. Time is of the essence after the decision to use tissue plasminogen activator (tPA) therapy after embolic stroke, which is why stroke telemedicine would benefit our patients throughout the country. Thus, stroke telemedicine services should be covered by Medicare, regardless of patient location.

An example of advocacy for our members includes our past support for abolishment of the Medicare Sustainable Growth Rate formula. After many years of work and support from numerous physician and healthcare groups, the formula was replaced in 2015 with the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). Although MACRA has its pros and cons, this change removed the previously threatened annual cuts to Medicare. Work is ongoing to ease the burden of regulation on physicians, including meetings with Health and Human Services staff regarding relief from the required measures under the Physician Quality Reporting System (PQRS). Of note, the AAN was instrumental in reducing the cuts made to reimbursement for needle electromyography in 2013.

For more examples of AAN advocacy efforts and successes, visit <http://bit.ly/2wk05UD>.

Getting Involved in Advocacy

Advocacy involves actions both small and the large. All AAN members can find a comfortable level of involvement. Ahead is a short list of events and initiatives that neurologists can join.

Action Alerts are emails sent to all AAN members requesting action, such as an email or a tweet, regarding a policy the AAN supports or challenges. The email is pre-written, but you may write your own. It takes three easy clicks and the email is sent. Action alerts represent a quick and easy way to make your voice heard in Washington. You may think that something this programmed and easy doesn't matter, but it does. Although congressional aides may not read each email or social media posting, they are counted, and numbers count in Washington!

Neurology on the Hill is an annual two-day event during winter in which AAN members from many different states convene in Washington to directly lobby their representative and senators. The first day is made up of educational sessions focusing on issues to be discussed during

Why Communicating with Legislative Aides Is Important

Sometimes we speak directly with the member of Congress; other times we talk with legislative aides. Aides are typically experts to the senator or representative for a given topic and are quite knowledgeable about our concerns. Each office will typically have a health care aide. They educate and advise the member regarding legislative decisions and we treat them with the same respect as we would a member. The purpose of our meetings is not to demand something. It is to “ask” for something. That something could be signing on as a co-sponsor to a bill or general support for increased research funding. Over many visits we establish a relationship with aides. We provide information, opinions, and answers to their questions in a timely manner. We get to know each other and this builds the mutual trust that is required in a good working relationship. If they know and trust us, they take us seriously, answer our calls, take our meetings and give us access to members. This dynamic is also true of our relationship with the in-district offices.

congressional visits, as well as background about the workings of advocacy and Congress. On the second day, we meet with our representative and senators (or their aides) in their offices to educate them about issues important to the AAN and to ask for their support or action on issues, as appropriate. This in-person meeting is meaningful to the offices and demonstrates our passion and commitment to ideas that benefit our patients and our profession. It is also exciting to see how Washington works and become part of the process in some small way. Over the course of the two days, physicians can also take a tour of the Capitol, sit in on a hearing, eat lunch in the Senate or House dining rooms, or watch a session of the House or Senate from the visitor balcony.

ADVOCACY QUICK TIPS

- Join your state neurological society. Advocacy can also be successful at the state level.
- Participate in AAN advocacy activities like Neurology on the Hill, Action Alerts, and read Capitol Hill Report.
- If you are planning to visit Washington, inform the AAN staff. They can alert you of any advocacy opportunities or events to attend.

The **Palatucci Advocacy Leadership Forum** is a four-day event, held in the spring, that trains members in advocacy and leadership skills at the local, state, and national levels. Each advocate comes to the Forum with an advocacy project. Advocates then learn how to put their projects into actionable steps that will lead to a successful outcome. Training builds confidence in advocates’ abilities to make positive changes for their patients and colleagues. Advocates are also taught about the workings of getting things done in Washington, how to give an “elevator speech,” and even testify before Congress.

Neurology Off the Hill is made up of individual in-district meetings with members of Congress or their staff during congressional recesses to discuss issues important to the AAN. These meetings are arranged by the AAN office in Minneapolis.

The Capitol Hill Report is emailed to all AAN members with updates on the latest legislative and regulatory developments. It also offers news tidbits about recent member visits to their elected officials, legislative and regulatory positions, and recent “wins.”

For more information about these activities and to keep abreast of policy issues, visit AAN.com/public-policy.

Advocacy: A Rewarding Pursuit

Advocacy with the AAN is both a rewarding and exciting experience. Not only are you working to benefit your patients and your colleagues, but, in the words of Alexander Hamilton, you are “in the room where it happens.” ■

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1. <https://www.govtrack.us/congress/bills/statistics>

2. http://www.heart.org/idc/groups/heart-public/@wcm/@global/documents/downloadable/ucm_493245.pdf