A personal journey in advocacy

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Summary

Over the past decade, neurology advocacy has caught the attention of neurologists feeling increasingly frustrated about the health care environment in which they practice. We describe our experience in practicing advocacy at the national and local levels. Neurologists can participate in many levels of advocacy to benefit their patients and their profession.

Advocacy in neurology has steadily gained momentum over the last decade as neurologists feel increasingly frustrated about deterioration in their practice environment. Neurologists are working with their state societies, patient advocacy groups, and the American Academy of Neurology to support their profession and their patients.

We write from the standpoint of a neurologist and a neuro-ophthalmologist with large multiple sclerosis (MS) practices in the metropolitan Seattle area. Our involvement in advocacy began with participation in the Palatucci Advocacy Leadership Forum (PALF), the American Academy of Neurology (AAN)'s advocacy skills training program now in its 10th year.¹ Named after the late Donald Palatucci, MD, this intensive leadership training forum allows up to 30 AAN members a year to focus their advocacy interests by teaching media, grassroots legislation, and action planning skills.² PALFers learn how to be interviewed on camera so they can increase public awareness of key issues. They learn about how each level of government works, how issues impact legislation, and how to develop relationships with legislative targets. They learn how to work on their action plans by breaking down their ideas into smaller tasks and mapping out the steps needed to accomplish their goals. The PALF has graduated 300 neurology advocacy leaders who are working on neurology-specific issues throughout the United States and 16 other countries. Two-thirds of PALF graduates now serve in leadership roles throughout the Academy. Over 80% of graduates have reported that professional advocacy has become a greater priority. Many describe

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Figure 1 Neurology on the Hill 2012

The principal author Dr. Henson, with Mike Amery, Esq., Legislative Counsel of the American Academy of Neurology (AAN), and John W. Henson, MD, an AAN member.

the importance of communication training. Others describe the sense of empowerment gained from being able to impact legislation. PALF has also resulted in the development of a large international neurology advocacy network with members supporting one another by sharing resources and ideas.

One of the authors has also been a regular participant of the AAN's annual Neurology on the Hill (NOH), a 2-day event in Washington, DC.³ This event allows neurologists to quickly learn about issues important to neurology, and then meet with their legislators to educate them and request assistance on these issues. At the 2012 NOH, 142 neurologists representing 42 states and 110 districts participated in over 220 Congressional office visits, providing education about the critical role of neurology, requesting recognition of cognitive care services as payment reforms are considered and increasing NIH funding. Most importantly, our annual visits to the Hill have allowed us to become familiar to our legislators and their staffers, so that we become a reliable resource for them to come to when they have questions about issues that may impact us, their constituents (figure 1).

For those who thrive on being at the heart of the action, the AAN in conjunction with the American Neurological Association and the Child Neurology Society offers the Kenneth M. Viste, Jr. Neurology Public Policy Fellowship.⁴ Each year, a fellow is chosen to work as a staff member in a congressional office and works with constituents, lobbyists, and congressional staff, participates in hearings related to policy, and helps draft health care-related legislation. Currently 14 neurologists have successfully completed the fellowship.

Busy clinicians who are unable to spend that much time inside the Beltway can easily support the profession by responding to Vocus, the Academy's online advocacy tool which helps to identify issues and aid communication with congressional representatives via personalized e-mail form letters.⁵ Neurologists can submit an e-mail regarding a relevant issue on behalf of themselves or their patients in less than 5 minutes. Since the AAN first started using Vocus, the number of members who have responded has exceeded 3,000. Almost 20,000 congressional contacts were made in 2011.

The Academy's efforts in advocacy have also resulted in the formation of the BrainPAC in 2007.⁶ The BrainPAC is the only political action committee dedicated solely to neurology. Since its inception, more than 1,100 AAN members have invested over \$500,000 toward bipartisan

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candidates who support neurologists' efforts. During the 2010 congressional election, over 90% of candidates supported by BrainPAC were successful in winning seats. One of the key lessons learned by serving on the BrainPAC's board of directors has been the recognition that political affiliation is not as important as having access to, and therefore, influence on the federal legislators who decide on issues that affect neurologists and their patients, and the critical role of having a political action committee in opening doors to which we have not previously had access.

Underscoring the value of advocacy, the Neurology Residency Review Committee (RRC) has made advocacy training a priority for neurology residency programs. In the RRC guidelines, it is specifically stated that "residents are expected to advocate for quality patient care and optimal patient care systems."⁷ This trend of junior neurologists becoming involved in advocacy is consistent with the fact that almost 20% of all PALF graduates are neurologists in training.⁸

All politics is local

The Washington State Neurological Society (WSNS) was founded after we and several other colleagues identified at the Palatucci forum our action plan as the need for a state neurologic society. WSNS has grown in size since its inception to about 100 members and has served as a nidus for state level advocacy, such as the NeuroAlliance. The NeuroAlliance was established by the WSNS to improve communication and cooperation between patient advocacy organizations and neurologists in the state. The activities of the NeuroAlliance were coordinated by one of the authors. The members of the NeuroAlliance included a variety of patient advocacy groups that represented the spectrum of neurologic conditions, ranging from the local chapter of the American Stroke Association to the Tourette Syndrome Association. Meetings with legislative and other governmental leaders resulted in a WSNS-led NeuroAlliance Advocacy Day at the State Capitol, with an educational session with the Governor's Health Care Aide and legislative visits. Budget constraints have limited administrative support for the NeuroAlliance, making it difficult to find neurologists committed to the time necessary to maintain the success of the program.

Because of our large MS practices, we work closely with the Greater Northwest Chapter of the National Multiple Sclerosis Society (NMSS) in its advocacy functions. We participated in MS Day in Olympia, our state capitol, by accompanying Society staff, volunteers, and our patients to educate our legislators and their health aides about the disease and the toll it takes on people (figure 2). As a result of these visits, we became known to our state legislators as a source of reliable information when they had questions about bills which might impact our patients and we knew who to contact when we had specific legislative concerns. The presence of physicians with their patients lent credibility to our presence in Olympia, and showed that we were not looking out just for our own personal gain.

We participated in the chapter's Insurance Advisory Committee, which consisted of neurologists, individuals with MS, insurance company executives, attorneys, community volunteers, and chapter staff to respond to problems with insurance payment for medications and medical services and procedures. An early success of the committee included negotiations that led to the elimination of tiering of MS disease-modifying therapy within one of the major insurance carriers in Washington State. The committee developed educational forums about employment issues relevant to MS for regional human resources administrators. The committee also coordinated testimony at the state's Medicaid Formulary meetings. Our participation at these meetings allowed us to help our patients get the treatments they needed.

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We have both also participated in the Society's annual Public Policy Conference in Washington, DC, where thousands of patients with MS, family members, volunteers, and staff lobby on national issues relevant to people living with MS. One of the successful initiatives included funding over \$20 million in MS research through the Congressionally Directed Medical Research Program since 2008.⁹ We have also been active in the Federal Advocacy Council and the State Advocacy Council of the NMSS. One of the more significant accomplishments for one of us was working on the NMSS's Health Care Reform Principles, which have served as a blueprint for the Society's advocacy efforts.¹⁰ Some of the concepts were also part of the Affordable Care Act, including prohibiting discrimination against an individual based on preexisting health conditions, obviating limitations on out-of-pocket costs, providing access to long-term support and services, expanding Medicaid, providing subsidies to those who cannot afford coverage, and eliminating lifetime limits on the amount of coverage a person may receive.

Another exciting accomplishment was working with NMSS staff and Social Security Administration to add aggressive forms of MS to qualify for the "Compassionate Allowances Initiative." This initiative allows individuals to receive Social Security Disability Insurance quicker than the average applicant.

The work that we as neurologists have done advocating on behalf of our patients with MS has helped with reciprocity from the NMSS for neurologists to be included in the primary care bonus payment. Our patients have gone to Capitol Hill to explain the importance of the cognitive care services that we provide to them, and why those services should be paid for. Advocacy has been a deeply satisfying activity for both of us as we recognize that our efforts have helped make the lives of our patients better and our practice of neurology more sustainable and rewarding.

Figure 2 Multiple Sclerosis Day 2010 in Olympia, Washington

The authors with Eileen Cody, State Representative and a nurse.

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L. Jung Henson is a current National Board member of the Board of Directors of the National MS Society, a member of the Executive Board of the BrainPAC, and a member of the Government Relations Committee of the American Academy of Neurology. She previously served as the Advocacy Editor of the AAN Web site and was a founder and board member of the Washington State Neurological Society. E. May is the chair of the Government Relations Committee of the Greater Northwest Chapter of the National MS Society. He was previously a board member of the Washington State Neurological Society. Go to Neurology.org/cp for full disclosures.

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