

## Silence Is Not Golden

Advocating for awareness, research, and treatment of neurological disorders.

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ccording to the *World English Dictionary*, advocacy is defined as "active support, especially of a cause." The *Merriam-Webster's Dictionary of Law* defines advocacy as "the action of advocating, pleading for, or supporting a cause or proposal." I serve as editorin-chief of *Neurology Now* because I am a strong advocate of bringing the best information about neurological disorders and their treatment to patients and their fami-

lies. My reasoning is that when people are well-informed, they are able to make better choices about their own health. And, they are better equipped to advocate for themselves—with their physicians, hospitals, insurance companies, and even Congress.

Advocacy for patients with neurological disorders is a crucial activity for the American Academy of Neurology (AAN). The AAN has made major investments in advocacy and continues to increase these efforts. For one, the AAN publishes *Neurology Now* and makes it available without cost to anyone who requests it. Their new book series, Neurology Now Books<sup>TM</sup>, launched September 1. In addition, the AAN provides tools, training, and assistance to neurologists as they work to change

American health policy for the better. This is especially important in light of today's health care reform agenda.

Many people—patients and neurologists alike—question whether they can really make a difference on their own, particularly in relation to something as massive and complicated as health care reform. An article in *Neurology Today* (August 19, 2010), which is a newspaper published by the AAN for neurologists, describes the experience of Melissa Ko, M.D., assistant professor of neurology and ophthalmology at the State University of NY Upstate Medical Center in Syracuse, NY. (You can read the article online at http://bit.ly/NTadvocacy.)

Dr. Ko has had success in making advocacy work—one conversation at a time. She participated in the AAN's Neurology on the Hill event in 2009. This is a yearly daylong event that brings together neurologists from all over the country to talk with their congressional representatives and senators about the most pressing issues for neurological patients. Dr. Ko and others spoke for 15 minutes

with Ronald Hikel, senior staff and health policy aide to former New York Representative Eric Massa, about the need to develop a registry for patients with Parkinson's disease and multiple sclerosis (MS). They requested that Representative Massa co-sponsor legislation to make this happen. Dr. Ko received an e-mail from Hikel several hours later saying that Massa agreed. One 15-minute conversation set the stage for an important initiative with

great potential to impact patients with Parkinson's disease and MS.

"Ultimately, I find people in positions of authority or power who care enough about this issue to be on board," Dr. Ko told *Neurology Today*, "and they see that you're doing this because you genuinely care about your patients—there's no billing code for 'I advocated for my patients today.' It actually does matter, and our voice has a great deal of credibility."

There are many things that neurologists and patients with neurological disorders need to "plead for," such as increased awareness of various neurological disorders, more funding for research, and better coverage for diagnostic testing and treatment. As Dr. Ko told *Neurology Today*, "Our lawmakers

assume the silence means that neurologic patients and the neurology specialty are just fine, and there isn't a need for additional funding or research. That would be a travesty."

One of the most powerful ways to advocate for neurology patients, in my experience, is for neurologists and patients to join in the conversation with our law-makers. Give us your ideas about specific issues you believe need more support, and share your experiences with advocacy with us. Whatever your views are on the issue of health care reform, silence is not golden and action is required.

Take good care,



Robin L. Brey, M.D. Editor-in-Chief