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# Neuropathy Patient Champions Justice for All

By Dan Bennett

Like so many people, Dominick Spatafora's illness took him by surprise.

"I was a 29-year-old, healthy guy," Spatafora said. "I was a regular Generation X kind of a guy who thought of himself as a consumer, not a patient. I was often looking at life and asking, 'What's in it for me?'"

Spatafora's perspective changed when he began experiencing a serious tremor in his right hand. By the time he decided to visit a doctor a year later, atrophy had set in.

"I was misdiagnosed by two different neurologists," he said. "One diagnosed me with Lou Gehrig's disease, and gave me three to five years to live. The next diagnosed me as needing an ulnar nerve transplant."

Finally, Spatafora was diagnosed correctly—with multi-focal motor neuropathy, a condition caused by deterioration of the peripheral nerves, disrupting the body's ability to communicate with its muscles, organs and tissues, according to the definition provided by The Neuropathy Association ([www.neuropathy.org](http://www.neuropathy.org)).

"I was fortunate in that my employer paid for a second opinion, and the diagnosis was reconfirmed," Spatafora said. "I went on monthly IVIG treatments, and my condition improved dramatically."

Then one day, Spatafora received a phone call that would change his life a second time. It was his physician, telling him there was a national shortage of IVIG, and that he would no longer receive the product. Going months without treatment, Spatafora lost the use of his right hand.

"I was a 30-year-old guy who had completely lost the use of his right hand, and I needed that IVIG to live my life," he said.

It was then that Spatafora's career background in the public-policy industry paid off. Spatafora had long been involved in public healthcare efforts. While working for former House Speaker J. Dennis Hastert, Spatafora was part of sweeping healthcare reform efforts, and later became one of the leading healthcare policy advocates in Arizona, as an employee of the state's medical association.

"Being involved in public-health policy, I knew where

to go," he said. "I appealed the decision by my health insurance company, and won that appeal."

It was the letter that followed that prompted an already angry Spatafora to realize that patients with neuropathy needed an advocate.

"The letter informed me that I had won my appeal, but then asked me not to tell anyone I was getting the IVIG, because other patients would not receive it," he said. "That made me irate. I knew that other patients without my background and experience would not be able to navigate through this complex system."

Spatafora began planning and developing the San Francisco-based Neuropathy Action Foundation.

"It's about awareness and empowerment," Spatafora said. "We want to educate the general public on what neuropathy is. Most people don't realize that it is one of the most debilitating kinds of pain, and that 20 million Americans suffer from this."

The foundation also seeks to better inform physicians, as a good number of cases go undetected.

"The third goal may be the most unique and powerful, and that is patient empowerment," Spatafora said. "With the high cost of prescription drugs, insurance companies are often limiting access. We will have a patient hotline where people can seek solutions. We want to establish an appeal process or regulatory body that will help patients. At the top of the website, we have a favorite quote of mine from anthropologist Margaret Mead: 'Never doubt that a group of small, committed citizens can change the world. Indeed, it is the only thing that ever has.' Patients need to step up to the plate and share their voice."

Meanwhile, Spatafora continues his own career as a consultant for DVS Governmental Consulting Solutions, a company he founded.

"The most powerful coalition I have seen is that which teams patients and care providers," Spatafora said. "No health plan or government entity can beat that. And so many patients with chronic illnesses have such passion and energy, but they don't know where to go. This foundation will help them funnel that energy." ■

*For more information about the Neuropathy Action Foundation, visit [www.neuropathyactionfoundation.org](http://www.neuropathyactionfoundation.org).*

