



In This Issue

[MMN Patient Story](#)

[New at the NAF](#)

[8th Annual "Neuropathy Action Awareness Day"](#)

[NAF President Wins McDowell Award](#)

[Patient Advocacy](#)

August 2014

MMN Patient Story



Hunt for the Elusive Cure

Imagine being told for 23 years that you have a deadly, incurable neuromuscular disease, only to discover one day that you do not. I lived for



Thank you to the all that joined us this year in making the 8th Annual "Neuropathy Action Awareness Day" a success! This year over 600 patients attended in person and through live online streaming for this exciting educational event in Los Angeles, CA at the Intercontinental Hotel Century City.



Educational Exhibitors

years with a diagnosis of ALS, also known as Lou Gehrig's disease, anticipating only living 3-5 years. This quirky miracle of sorts has come about through an odd combination of medical misdiagnosis and advancing medical discoveries.

When I was about 19 years old I began developing several baffling physical symptoms. My hands would cramp up for no reason, my legs grew stiff and tired very easily, in turn causing me to trip and stumble. Maybe it was the crazy dessert diet I concocted to lose 5 pounds from my midsection, though I only weighed 110 pounds! In a search for answers I spent the next several years journeying from doctors to specialists in search of answers that would come much later in my life.

[To read Gigi's full story click here.](#)

New at the NAF

NAF Board Member



Please join the NAF in welcoming Leslie MacGregor Levine to the Board of Directors! Leslie is a patient advocate. She runs a large support group for neuropathy patients in the Boston area, and provides counsel to and shares resources with patients from many regions of the country. She works with patients at the Massachusetts General Hospital. Leslie is on the Advisory Board for a Patient Centered Outcomes Research Institute (PCORI)- funded national data networking program, and is a PCORI grant reviewer.

After graduating from Princeton University with an A.B. degree in biology, Leslie attended the University of Pennsylvania, where she completed a veterinary medical degree and a Ph.D. in physiology. She then worked for several years doing research on diabetes at Harvard Medical School. Leslie then obtained a J.D. from Harvard Law School, then trained as a biomedical patent attorney. She practiced patent

During this information packed day patients, caregivers, and professionals in the field were provided with multiple educational sessions, a sit down luncheon, and a lesson in comedy. The NAF looks forward to hosting another successful event next year! If you missed the event this year or just want a recap of the information you learned [click here](#).



Guest speaker Judy Carter speaks with a patient



Sprinkles Cupcakes sporting NAF logo



Exploring the exhibits

NAF President Wins 2014 McDowell Pain Awareness & Advocacy Award

McDowell Pain Awareness & Advocacy Award

August 1, 2014 - The Power of Pain Foundation presents the *Melanie McDowell Pain Awareness and Advocacy Award* annually. The recipient is a pain patient or provider who has demonstrated outstanding commitment to assisting and advocating for people with neuropathy pain diseases. Nominations are solicited in the pain community for people who are making a significant contribution within the field of research, education, awareness, or patient assistance.

Mr. Dominick Spatafora is the 2014 recipient of The Power of Pain Foundation's Melanie McDowell Pain Awareness and Advocacy Award. This is in recognition of his outstanding work and advocacy for people in pain. Mr. Spatafora's awareness contributions to the neuropathy and chronic pain communities are outstanding. Mr. Spatafora is the president of the Neuropathy Action Foundation (NAF). Dominick was diagnosed with multifocal motor neuropathy at the age of 30. Shortly after being diagnosed Dominick became a patient advocate because of his personal struggles accessing appropriate treatment. Dominick's neuropathy is not typical and does not fall neatly into the treatment guidelines established by his managed care company. At one point Dominick went three months without his IVIG treatment before he lost the use of his right hand. After working cooperatively with his physician and others Dominick finally prevailed and resumed treatment which gave him back the use of his hand. Dominick founded the NAF because of his commitment to educate the public on what neuropathy is and most importantly to help other neuropathy patients obtain and maintain appropriate individualized care.

Barby Ingle, POPF Chairman, said, "Dominick Spatafora is making a difference in people's lives by telling his story and encouraging others to be their own best advocate. The inspiration and energy Dominick provides to neuropathy patients helps to keep us positive as we deal with our own chronic pain issues and learn how to become our own best advocate. Dominick is truly active and making a difference in the lives of patients throughout the United States. Thank you to Mr. Spatafora for all you do to put a spotlight on neuropathy diseases and other chronic pain conditions."

The award will be presented to Dominick Spatafora on November 14th, 2013 at the 8th annual Comic Pain Relief show held at Chandler Center for the Arts, in Chandler, Arizona. This year's Comic Pain Relief show will feature entertainment hypnotist Tom DeLuca. "Tom DeLuca is not your average entertainer. He's known as the best in his business and Tom's hypnosis show is appealing to the entire community. DeLuca's show is very original and not cookie-cutter material. "For every show, there are at least one or two people who show the beauty of their imaginations," said DeLuca. "When you get people who are so deep into imagination, the show is spontaneous and sparks intense creativity. It really turns out to be a novel show."

The Power of Pain Foundation's programs are focused on assisting those affected by neuropathy diseases involving chronic pain such as diabetic neuropathy, post cancer pain, lupus, lyme, neuro-muscular dystrophy, multiple sclerosis, and reflex sympathetic dystrophy (RSD). Chronic pain affects over 37% of the population according to the latest Institute of Medicine report. That's over 100 million Americans, or 1 in 3 people. Currently, there is not cure for many of the neuropathy diseases but these are treatment options that can help patients manage their conditions. Through efforts such as Mr. Spatafora's we see improvements made for patients dealing with access to proper and timely care challenges.

[Click here to visit the Power of Pain Foundation.](#)

Patient Advocacy

State Legislative and Policy Update on Specialty Tiers, Co-Insurance and Discrimination

law first at two law firms, then joined a succession of biotechnology and pharmaceutical companies before becoming Director of Intellectual Property at Harvard University.

One day while at Harvard, Leslie developed acute neuropathy, which left her unable to walk and in great pain. The neuropathy forced her to go on disability from her much valued position. It took about nine months before she was diagnosed with autoimmune small fiber neuropathy, and another year before she started treatment with IVIG. This treatment almost totally relieved her symptoms. Leslie played a lead role in her medical care to obtain appropriate diagnosis and therapy. This process made her realize how hard it must be for people without her background to self educate, advocate and effectively work within the medical system when faced with the debilitating and typically painful symptoms of neuropathy. At that point she became involved with helping other neuropathy patients to gain knowledge and to help facilitate their effective diagnosis and treatment.

[Click here to learn more about NAF Board Members](#)

Follow the NAF on Twitter!

The NAF is now on Twitter!

Follow us on 

Coming Soon

Check out the NAF on Facebook soon for exciting patient information, resources, and upcoming awareness events.

Thanks for sharing the excitement in these growth opportunities for our foundation!

Stay Connected



The NAF continues to be concerned about how health plans have been targeting certain chronically ill patients by charging them more for their lifesaving and limb-saving medications and therapies. Many health plans have created "specialty tier" cost structures, a form of coinsurance that dramatically increases prescription copayments for chronically ill patients. Rather than paying a flat co-pay for medication, patients with medications on specialty tiers can pay co-insurance of up to 50 percent of the total cost of the drugs.

Specialty tiers and co-insurance are prescription drug formulary management tools that insurers use to limit their liability and increase the beneficiaries' share of the costs of certain prescription drugs. These specialty drugs are typically used to treat complex, chronic conditions and are either injected or infused. They may require refrigeration, compounding or other "special" handling. These drugs often do not have generic alternatives and are the only drug available, leaving patients with no effective alternative therapy.

Although any patient might be affected by coinsurance, those patients most affected include those living with specific conditions such as cancer, multiple sclerosis, hemophilia, primary immune deficiencies and certain neuropathies. Health insurance is a means by which health risk is spread across a pool of payers. Yet, when certain serious illnesses like the ones mentioned above strike, patients are singled out or discriminated against for much higher out-of-pocket costs.

Specialty tiers are discriminatory because they apply a totally different benefit structure to certain medicines that patients with particular diseases need. By selectively applying high cost-sharing requirements to these drugs, while requiring lower, fixed copayment requirements for other drugs, plans that use specialty tiers force certain patients who suffer from certain diseases to pay much more.

There have been several favorable developments thus far in 2014 that will hopefully help neuropathy patients:

- A new 2014 law in Louisiana (SB 165) limits co-pay or co-insurance to \$150 per specialty drug up to a 30 day supply.
- A new law in Maryland (HB 761) limits patient co-pay or co-insurance to \$150 per specialty drug up to a 30 day supply and defines criteria for what is considered a specialty drug.
- The National Health Law Program (NHeLP) and the AIDS Institute filed a complaint with the Office for Civil Rights at the U.S. Department of Health and Human Services (HHS OCR) alleging that four Florida insurers are violating the Affordable Care Act (ACA) and federal civil rights laws through the use of discriminatory cost-sharing practices.
- In California, the Neuropathy Action Foundation and 30 otherpatient and provider groups have asked the state's Insurance Commissioner to investigate whether specialty tier cost structures violate federal and California law.
- A new 2014 law (HB 308) passed in Virginia states that insurers are required to provide affected enrollees 30 day notice of a modification to a formulary that moves a prescription drug to a tier with higher cost sharing requirements.

The NAF will keep you updated on this important access issue in future editions of our Patient Voice Newsletter.

Stay Connected

Follow us on 

View our profile on 

Join My Mailing List

Forward To A Friend

Copyright © 2014. All Rights Reserved.



Neuropathy Action Foundation | 1950 Old Tustin Avenue | Santa Ana | CA | 92705