Neuropathy Action Foundation

Awareness • Education • Empowerment

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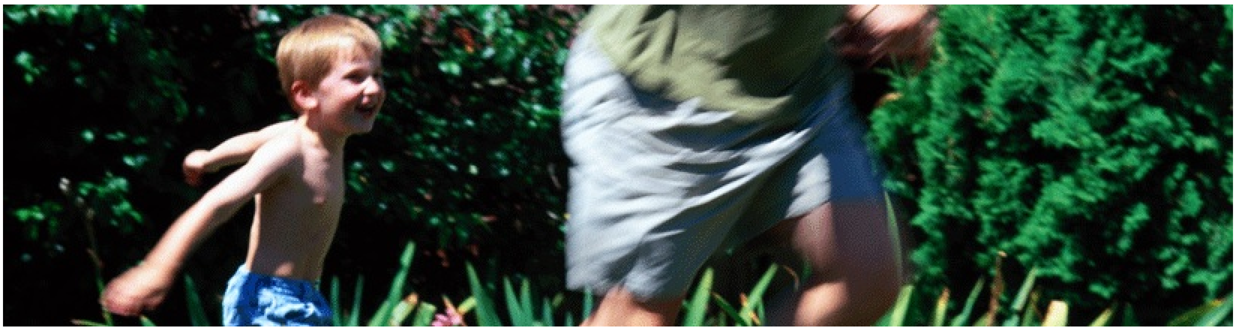

In This Issue of the Patient Voice

This Is The Story of My Journey With MMN

By Michael Aylward

In late October 2013 was my first sign of muscle weakness in my right arm. I didn't think much of it at the time. A couple of weeks after that, I couldn't extend my fingers on my right hand. This was the first time I was concerned that something was wrong. I thought it would be nothing more than carpel tunnel becaus e of my work.

As Christmas approached, and I was losing more arm function, I tried not to be afraid of what it could be.

January 2014 - I was told that I had ALS. So, went for a second opinion, but still had that nugget of doubt and fear that ALS could be a possibility. This is when we met the amazing Dr. Barboi who let us know by the end of the visit that it was not ALS. More tests needed to be done to determine the correct diagnosis.

While I was going through all the tests to get a confirmed diagnosis, I tried acupuncture, meditation, massage, and traditional physical therapy. The physical therapy was working because I was regaining strength and endurance.

June 2014 - I got the confirmed diagnosis Multifocal Motor Neuropathy (MMN) and boy that

May 2018

The NAF invites you to attend the 12th Annual "Neuropathy Action Awareness Day" on Friday, June 22nd at the Intercontinental Hotel in Los Angeles. This event will be the largest neuropathy gathering in the United States this year and will bring together patients and caregivers from across the country to learn about neuropathy, strategies for managing the painful condition, and empowering patients to become advocates for their own health care.

"Neuropathy Action Awareness Day" provides an opportunity for patients to interact with other patients, providers and exhibitors. The event consists of a full day of educational presentations, luncheon, exhibit area and silent auction.

The event is free of charge; however, the NAF requests a $25 donation from patients and caregivers and $125 from others who attend the luncheon. Register today at (877) 512-7262 or www.neuropathyaction.org.

Don't want to miss this important patient opportunity but can't attend in person? Register for our free online streaming! You can participate anywhere you have access to the internet - at home, the office, your support group - anywhere!

12th Annual "Neuropathy Action Awareness Day" - Friday, June 22, 2018

Program and Agenda

was a large weight lifted off my shoulders because it's not fatal and it is treatable. The treatment is an IV infusion.

August 2014 - My first infusion treatment. I still didn't have any fear , but I knew it was not going to be an easy fight. I kept working during this time and was able to drive until November. Tom our son had moved home at this point. He gave up his apartment and put aside his career because he saw Jeannie couldn't physically do it all anymore. If I fell, she couldn't pick me up and it was getting harder on her helping me to get up and down the stairs. So, Tom started to drive me to work every day and pick me up. It was an hour drive each way, just so I could keep working.

Click to continue reading.

NBC Los Angeles - Are Your Prescriptions Cheaper Without Insurance?

The NAF has been attempting to bring awareness to an issue since last year when we first learned of a practice that harms neuropathy patients on NBC Nightly News called "Prescriptions May Be Cheaper Without Insurance." The story highlighted a practice occurring throughout the U.S. where a patient goes to their pharmacy to fill a prescription and is charged a co-payment through their insurance that may be more than if the patient were to pay cash. When this happens pharmacists are prohibited from disclosing the price discrepancy. The pharmacist is reimbursed at the normal rate, but is contractually obligated to send the over-charged money to the Pharmacy Benefit Manager (PBM).

Last month on April 5, the NAF's 2017 "You Are Our Hero" award recipient, Carolyn Johnson, Co-Anchor, NBC4 Southern California News at 4 p.m. and 6 p.m., aired the following piece on this very topic: https://www.nbclosangeles.com/news/local/Paying-a-Price-for-Prescriptions_Los-Angeles-478938663.html This piece coincides with two pieces of legislation in California (AB 315 and AB 2863) along with several other bills in various states across the country trying to address this issue.

As always, the **NAF wants to hear from you on this topic. Are you or your family members**

9:00 - 9:30 Registration & Exhibits

9:30 - 9:40 Welcome

9:40 - 10:15 The Whole Body Experience: Neuropathy from Head to Toe

10:15 - 10:55 Understanding a Neurologist's Approach to the Diagnosis and Treatment of Peripheral Neuropathy

10:50 - 11:20 Non-Opioid Treatments for Neuropathy

11:20 - 11:45 Ask the Experts - Your Chance to Ask Questions of Top Neurologists

11:45 - 12:15 Break & Exhibits

12:15 - 1:15 Food As Medicine: Improve Health, Increase Vitality & Live Longer!

1:15 - 1:45 Putting YOU into the Cargiving Equation

1:45 - 2:15 Refreshments & Exhibits

2:15 - 3:00 Understanding and Championing Healthcare Rights for Yourself and Others

Click here to see the full agenda.

A Patient Guide to Sudoscan Testing

Neurologists today may order many different tests to better understand and provide answers about your neuropathy. One of the newer tests available is Sudoscan. But what is it, do you really need it, how is it performed, and what will it tell you about your neuropathy?

What is a Sudoscan test?
Sudoscan is a test of the sweat function on the palms of your hands and the soles of your feet.
Sweat glands are activated by some of the thinnest and longest nerves in the body. These nerves are of the C-fiber variety and are sympathetic nerves, so they are considered to be part of the autonomic nervous system.

experiencing this? What are you told when you ask your pharmacist what the cost of your medication would be if you were to pay cash? Let us know at info@neuropathyaction.org.

The soles and palms contain the highest density of sweat glands on the body; if those sweat glands are not functioning correctly, it may signal a problem with either or both small fiber neuropathy or autonomic neuropathy.

How do I need to prepare for a Sudoscan test?

- You will need to review any medications you take with your physician. Some medications which affect acetylcholine, the nerve transmitter for sweat glands, can alter your test results.
- Avoid bulky jewelry such as rings or bracelets which may not allow good contact of your palms with the test plates.
- Wash off any lotion, ointment, or other residue from your feet and hands prior to testing.

How is the test performed?
A Sudoscan device consists of a computer with a touch screen, and 2 sets of stainless steel plates on which your hands and feet will rest during the test. The test cycle lasts about 3 minutes, and for best results, should be performed in the standing position.

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Action Foundation

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