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NAF Event

Save the Date!

The NAF is excited to announce our upcoming 9th Annual "Neuropathy Action Awareness Day!" This year, the NAF will be hosting the annual event

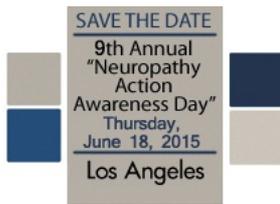
February 2015

As we head into 2015 many are faced with the challenge of resolutions made for the year to come. The NAF is committed to succeed as the premiere patient organization ensuring that neuropathy patients have access to individualized medications, IVIG and other treatments through patient empowerment and advocacy.

To achieve this goal, the NAF has a focus of increasing awareness among providers, the general public and public policy officials that neuropathy can be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided. To this end the NAF will take our Multifocal Motor Neuropathy (MMN) and Diabetic Peripheral Neuropathy (DPN) awareness to a new level in 2015. We will additionally provide increased resources to help patients explore alternative and complimentary remedies for their pain. And finally, we will actively work to support programs like our 9th Annual "Neuropathy Action Awareness Day" on June 18 to generate an even greater awareness of neuropathy.

We look forward to supporting you throughout 2015!

once again at the
**Intercontinental Los
Angeles/Century City** on
Thursday, June 18, 2015.



We are thrilled to announce that just as last year there will be two ways to participate in this year's event:

Attend In Person

The 9th Annual "Neuropathy Action Awareness Day" provides an exciting opportunity for patients to interact with other patients, providers and exhibitors. This year the morning consists of an Exhibit Area and educational sessions. There will then be a sit down luncheon. The afternoon consists of additional educational sessions and Exhibit Area with refreshments. The event features a celebrity speaker, elected officials and others. Just as in past years there will be a Silent Auction made up of fun trips, activities, events and other fun items!

Participate Via Live Broadcast (Live Stream)

Can't attend the conference in person? Don't worry since the NAF will be using the latest video Live Streaming technology that will allow you to participate FREE of charge from wherever you are! Yes, whether you will be in your home, office or your neuropathy support group you can still participate. All you need is a computer with access to the Internet! The entire day will be broadcast live. And since the entire day is being recorded you and others will be able to

MMN Campaign Success

MMN Awareness Campaign Huge Success

In 2013, the NAF launched a national campaign to raise awareness on Multifocal Motor Neuropathy (MMN). MMN occurs in approximately 1 in every 100,000 people and men are twice as likely as women to be affected. MMN can cause significant disability but does not shorten the lifespan of those diagnosed. The ability to control the progression of the disease is directly related to the speed and accuracy of correct diagnosis. Early and accurate diagnosis of MMN can mean the difference between MMN patients being successfully managed or permanently disabled.

To this end we created a [MMN Resource Center](#) on our website where patients can learn more about symptoms, causes, treatments and even read specific patient stories. The campaign ended in late 2014 and we are pleased to announce that to date we have had over 600 requests for our MMN Brochure and our MMN Public Service Announcement (PSA) aired in 74 total cities in 30 states. With nearly 11,000 views on YouTube and 9,598 clips played on national television stations the NAF is excited about the effectiveness of this campaign in spreading awareness on this rare disease! To view the PSA, [click here](#). To submit your MMN patient story please email us at info@neuropathyaction.org.

MMN Patient Story

Full of Hope with a Rare Disease

By Charles Wood

The best way to explain the onset of Multifocal Motor Neuropathy is like someone had flipped a switch and all the electricity containing those very important messages flowing from my brain to the muscles in my arms and legs slowed down; the lights were dimming; the motor was slowly shutting down.

In 2009 at the age of 68, I was still a "regular guy"-working, taking care of my family and home... trying to squeeze in a few moments each day to stay in shape. Little did I know that an insidious neuropathy diagnosis was going to change my life "forever" It all started with a reduction in my grip strength, then in 2010 at the age of 69 I noticed the first two fingers on my right hand beginning to curl under, My family doctor could not give me a diagnosis, so with a referral to a hand specialist and neurologist followed by a series of X-rays, MRI's, EMG's NCV's, (nerve conduction velocity tests), followed by an operation where the specialist reported finding a badly bent nerve. He straightened it and recommended electro stimulation therapy (no positive results ensued). Then a visit to yet another "Specialist" who ordered the usual battery of tests including a bone marrow biopsy this time, the prognosis was the same "it's so complicated."

By 2013 (now 72) the symptoms were getting worse, both hands were in fists, my wrists dropped, and my feet were beginning to drop making walking a problem. I could not even sign my name (thank goodness for ATM's) or button a shirt. All my hobbies were now challenges. Then the realization I could not even shave or feed myself. I was referred to another neurologist (my 4th) who, armed with my previous test results spent 90 minutes questioning and

watch long after the event is over anytime you want on the NAF website.

Registration information and agenda coming soon!

Colorado News

Colorado Insurance Commissioner Addresses Discrimination

On January 28 the Colorado Insurance Commissioner, Marguerite Salazar, issued a final Bulletin on Out of Pocket Costs for Specialty Drugs. This is a significant regulatory win for those who suffer from neuropathy in Colorado. The Commissioner has asked health plans to implement the following effective in 2016:

* CO will require that at least 25% of plans offered by a carrier cannot use a coinsurance structure - must use copayment structure for all tiers. Drugs in those plans cannot be subject to a deductible.

* For plans with the all-copayment structure, the highest allowable copayment for any of the drug tiers must be no greater than 1/12 of the plan's "individual" annual out-of-pocket maximum for that particular plan design. In practice, this could mean a max copayment for the specialty tier of about \$550 (based on a \$6,600 individual OOP max which is the limit in 2015).

* For no more than 75% of plans offered by a carrier, they can use co-insurance, but only in one or more of the highest tiers. Limiting the scale of co-insurance helps patients buffer their OOP costs.

examining me before telling me that I may have ALS or some form of peripheral neuropathy.

She referred me to another neurologist whom she considered to be "one of the best in this field". A couple of weeks later I secured an appointment, he examined me and rendered the diagnosis: I had "Multifocal Motor Neuropathy". He informed my wife and me that there was no cure, only a treatment that blocks the symptoms and that I should see significant improvement and eventually only need periodic booster infusions for the rest of my life or until a cure is found. I started my first two-day course of "intravenous immunoglobulin" (IVIG) treatment in January 2014. After some 4 treatments (16 weeks), improvements began to materialize, by August 2014 I was probably back to 80% of my abilities. By November I was at probably 95% and out on the golf course once again. My dosage is now being reduced and I am down to one day every 4 weeks until I reach the level of sustainable health with the minimal amount of treatment.

[Click here to read Charles' full story.](#)



Barb and Charlie Wood

Combating Rise in Out-of-Pocket Costs

Virginia General Assembly Should Act to Limit Rising Out-of-Pocket Costs for Vital Medications

By Dana Kuhn
President and Founder
Patient Services, Inc. (PSI)

Despite paying their monthly health insurance premiums, a growing number of vulnerable Virginians simply can't afford their prescription medications. Health insurers are increasingly driving up patient out-of-pocket costs by charging patients a percentage of the total cost of a medication rather than a fixed, manageable copay. Patients can be forced to pay between 25 and 40 percent of the total cost of their medications, adding up to hundreds or even thousands of dollars each month for a single treatment.

Although any Virginian can be subjected to unreasonably high out-of-pocket costs, those most likely to be affected are living with life-threatening or chronic conditions, such as cancer, hemophilia, hepatitis C, multiple sclerosis and HIV/AIDS. These patients need treatments to fight their diseases or manage their conditions, yet these Virginians are struggling to find the money to pay for them.

Several states across the country - including New York, Vermont, Maine, Delaware, Maryland, Louisiana and Montana - have already implemented copay limits for vital medications. Without similar

This bulletin is an important step forward in the efforts to end the practice of discrimination based on health status.



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legislation in Virginia, more and more patients throughout the state will face exorbitant out-of-pocket costs for the treatments they need. The reality is that health insurance exists to protect Virginians from the high costs of medical care in the event that they need treatment. Making sick people bear a far larger portion of their treatment costs undermines the very concept of insurance.

High out-of-pocket costs not only have harmful financial consequences for patients, they also damage patient health and drive up overall costs to our health care system through unnecessary hospitalizations. Patients who can't afford their medications often cut back or discontinue treatment altogether, making them more vulnerable to hospitalization and exacerbated conditions.

[Click here to read the rest of this article.](#)

Neuropathy Action Foundation

info@neuropathyaction.org

1950 Old Tustin Avenue

Santa Ana, CA 92705

[\(877\) 512-7262](tel:(877)512-7262)

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