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Awareness

New NAF Partnership Reaches 3 Million Patients A Month in U.S.

Patient Voice May 2014

The NAF invites you to attend the 8th Annual [Neuropathy Action Awareness Day](#) on **June 11th** at the **Intercontinental Hotel in Century City, Los Angeles**. This educational event is packed with important information and is FREE for neuropathy patients to attend. The day consists of an Exhibit Area, sit down luncheon, and educational sessions, including Judy Carter, world renowned Comic & Author as well as some of the top treating physicians of neuropathy.

The event is open to patients, caregivers, and others in the community who want to learn more about neuropathy, and policy/health care issues impacting patients and patient advocacy. Patients attend for FREE with the option to participate in the sit-down luncheon for \$20. Register to reserve your spot today!

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

The NAF is committed to reaching patients with education, aiming to ensure the ability to obtain the resources and information necessary to access individualized treatment to improve quality of life. The NAF has recently chosen to partner with Chicago based ContextMedia:Health (CMH), a mission-driven organization, committed to patient education.

CMH is currently installed in approximately 4,500 physician offices and hospitals and is seen by over 3 million patients a month. CMH strives to bring awareness to specialized organizations, such as the NAF. Through CMH's broad reach and NAF's programming, the partnership will allow us to spread the word about neuropathy, and make a difference in the lives of people all over the US. This new partner is currently helping the NAF reach more patients by showing our Multifocal Motor Neuropathy (MMN) and Diabetic Peripheral Neuropathy (DPN) Public Service Announcements throughout the U.S.

Healthy Living

Summer Tips

As the weather warms up and spring turns to summer, we must remember a few important health tips to maintain wellness through the hottest months of the year.

Drink water - the recommended amount of water for adults is 6-8 8oz glasses per day. If you are physically active, drink more to alleviate dehydration. Water also helps to keep skin clear and flush toxins from the body.

Wear sunscreen - the American Academy of

[Click here to register!](#)

8th Annual "Neuropathy Action Awareness Day"

Program & Agenda

9:30 - 10:00 *Registration & Exhibits*

10:00 - 10:05 *Welcome*

10:05 - 11:00 *Understanding a Neurologist's Approach to the Diagnosis and Treatment of Peripheral Neuropathy and Treatment Options for Painful and Non-Painful Neuropathies*

11:00 - 11:30 *Guillain - Barre Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) 101*

11:30 - 12:00 *Break and Exhibits*

12:00 - 1:15 *Lunch Program*

1:15 - 1:50 *Sleep Disorders 101 for the Patient with Neuropathy*

1:50 - 2:30 *Diabetes and Neuropathy*

2:30 - 3:00 *Refreshments and Exhibits Break*

3:00 - 3:30 *Alternate Options in Treating Neuropathy and Achieving Optimal Health*

3:30 - 4:15 *The Whole Body Experience: Neuropathy from Head to Toe and Medical Laws: From the Courts to Your Nerves*

[Click here to see the full agenda](#)

Patient Advocacy

Advocates Seek to Curb Patient Bills for Specialty Drugs

Patient advocates want California's insurance commissioner to investigate specialty tiers, a pricing structure insurers use to require patients to pay a larger share of the cost of specialty drugs. As a dedicated patient advocate, the Neuropathy Action Foundation (NAF) was one of several groups that signed a letter to the CA Insurance Commissioner to provide support to this important cause.

KPCC-FM (NPR)
May 8th, 2014

Patient and provider advocacy groups are accusing California's health insurance companies of discriminating against people with certain diseases by requiring them to pay more for their medications.

The groups want California's insurance commissioner, Dave Jones, to investigate a pricing tool known as specialty tiers. Those

Dermatology recommends using broad-spectrum protection of at least 30 SPF to protect your skin from sunburn, early aging, and skin cancer. Wearing protective clothing can also protect skin from harmful exposure to the sun.

Don't skimp on sleep - 6-8 hours of sleep at night will keep you happy, healthy, and ready to take on the world!

Skip the soda - not only does soda cause dehydration. It has added sugars, artificial sweeteners, and calories that can add to your waist.

Take a walk - Just 15 minutes can burn up to 100 calories.

Neuropathy & Active Lifestyle

Neuropathy patients suffer from a variety of symptoms that can be debilitating and painful; it is especially important to maintain an active lifestyle. It is recommended that adults achieve at least 150 minutes of moderate physical activity each week; that is just 30 minutes a day 5 days a week. The type of exercise isn't the focus - getting up and moving is!

Physical activity plays a key role in cardiovascular health, maintaining blood sugar levels, and provides an instant mood boost. Another benefit of physical activity is that it promotes stronger muscles, joints, and bones which lead to a decrease in falls among older adults. This is an especially important benefit for neuropathy patients. For optimal health results incorporate both aerobic activity and strength training in an exercise regimen. Two days per week should integrate strength training such as push-ups, sit-ups, or

set the higher prices that insurers require consumers to pay for costly drugs to treat certain diseases, such as cancer, hemophilia and multiple sclerosis.

For many drugs, patients are responsible for just a standard co-pay. But for drugs that insurers move onto a specialty tier, patients may have to come up with as much as one-third of a drug's cost. The patient could end up paying "thousands of dollars" for a monthly prescription, said Liz Helms, president of the California Chronic Care Coalition.

Some states have already put limits on this practice. The coalition of 23 patient and provider advocacy groups, including the Neuropathy Action Foundation (NAF), wrote a letter to Jones asking him to investigate whether specialty tiers might violate a state law banning discrimination based on medical condition.

The advocates' letter states that California's Unruh Civil Rights Act (Section 51 of the Civil Code) specifies that all people must be treated equally regardless of their "disability, [or] medical condition."

Noting that HIV/AIDS, hepatitis, epilepsy, seizure disorder, diabetes, clinical depression, bipolar disorder, multiple sclerosis and heart disease are defined as "disabilities" under Section 12926.1 of the California Government Code, the letter says, "it is our opinion that certain patients with certain medical conditions on certain medications are being forced to pay much higher OOC [out-of-pocket costs] and are being discriminated against."

A spokesman for commissioner Jones said he has not yet reviewed the request.

Health plans have generally opposed efforts to regulate specialty tiers. They say forcing insurance companies to spread the cost of specialty drugs among all their customers would raise the underlying problem is the soaring cost of specialty drugs, said Nicole Kasabian Evans, a spokeswoman for the California Association of Health Plans.

"We can't just look at the price of insurance," she said. "We have to look at the costs of these medications and really bring those companies to the table if we want to talk about fair pricing for these medications."

According to some estimates, specialty drugs account for just one percent of all prescriptions in the US, but 25 percent of all drug spending.

[Click here for more information](#)

Maryland Patients Score Specialty Tier Victory

Across the country, members of the neuropathy community are burdened with mounting prescription drug costs as their insurers move vital medications into specialty drug tiers. Last week, the Maryland neuropathy community scored a tremendous victory when Maryland's governor signed HB 761 into law, capping the amount that insurers can charge for specialty tier prescription drugs at a maximum of \$150 per month!

Specialty tiers are discriminatory because they apply a totally

weights. Days between strength training should target cardiovascular exercise including brisk walking, jogging, swimming laps, or riding a bicycle.

Don't forget to stretch! Dynamic stretching is used at the beginning of a workout to warm the muscles and prevent injury. This is stretching while moving without an extended hold - swinging arms, rotating your ankles, and shallow squatting. Static stretching - or holding a deep stretch should be utilized at the end of a workout when your muscles are the warmest and most pliable.

Please consult with your physician before starting a new exercise regimen.

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.

The financial burden of paying for prescription drugs could be a strain for anyone, but it has a potentially devastating impact for those living with chronic conditions. The increased financial burden jeopardizes the financial solvency of entire families and jeopardizes the ability of some patients to take their necessary medications. No one should have to choose between taking life-sustaining medication and paying rent or providing food for their children.

The NAF will continue to monitor and provide assistance when able to additional efforts in other states as issues arrive around Specialty Tiers.

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