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Power of Pain Challenge

NAF Accepts #painPOP Challenge!

The NAF recently participated in the Power of Pain Foundation's #painPOP Challenge in an effort to help bring awareness to neuropathic

November 2015

Since 2006 the NAF has been helping neuropathy patients obtain the necessary resources and information to access individualized treatment to improve their quality of life. The NAF's patient advocacy for the protection of accessible health care is essential in today's cost driven environment. Without such advocacy our nation's health care debate will be focused on measures that are designed to provide short term savings, at the expense of patient health and long term costs.

The NAF has accomplished more than we ever imagined possible since our inception. Let me share with you just a few of the NAF's accomplishments:

- Provided comprehensive online neuropathy resources that have been viewed by millions of neuropathy patients and their caregivers from around the world annually.
- Provided patients with our bi-monthly "Patient Voice" e-newsletter.
- Helped 507 patients with access issues obtaining IVIG

pain. The #painPOP Challenge is an activity involving popping a balloon on camera to promote awareness of chronic pain diseases. The challenge encourages nominated participants to be filmed talking about how chronic pain affects them and then nominating others to do the same.

After being challenged, participants must record a video of themselves. First, they are to announce their acceptance of the challenge and give a fact or tell how pain affects them or their loved one. Then the participant can nominate a minimum of three other people to participate. Whether people choose to donate, perform the challenge, or do both varies. Participants can participate or donate at powerofpain.org and end the video with #painPOP. The natural reaction to the noise of the pop is a reminder of what pain patients go through on a daily basis.

[Click here to watch the short video clip.](#)

Patient Resource Now Available in Spanish

NAF Creates Diabetic Peripheral Neuropathy (DPN) Educational Brochure in Spanish

The NAF and the Foundation for Peripheral Neuropathy have joined together to create a DPN educational brochure in Spanish. DPN is nerve damage caused by chronically high blood sugar and diabetes. The brochure is being released nationally and is intended to help Spanish-speaking patients and medical professionals identify, treat and manage the progressive and often painful condition.

Diabetes mellitus (DM) continues to be a heavy burden on health and health resources

and other medications.

- Held the largest neuropathy education event in the U.S. annually called the "Neuropathy Action Awareness Day." For the past nine years thousands have attended in person and thousands more have watched on the NAF website.
- Created a Diabetic Peripheral Neuropathy (DPN) public service announcement (PSA) featuring celebrity Jerry Mathers from the classic hit sitcom Leave it to Beaver. The PSA has aired in 39 cities in 23 states.
- Created the first ever multifocal motor neuropathy (MMN) brochure and PSA. The PSA has aired in 74 cities in 30 states and has received over 15,000 views on YouTube.
- Featured on ABC, NBC, CNN, IG Living, Neurology Now and many other publications and broadcasts bringing increased awareness to neuropathy.
- Advocated for access to IVIG and other medications via press conferences, legislative hearings, letters of support, newsletter articles and traditional and social media

In 2016 the NAF will be celebrating our 10 year anniversary and thanks to the past support of individuals like yourself the NAF has never been stronger. However, the mission of the NAF can only be sustained through the generosity of people who share our commitment to improve the lives of those living with neuropathy. Please support the NAF this holiday season by making a tax deductible contribution at http://www.neuropathyaction.org/support_naf/donate.html.

Thank you!

California Lowers Out-Of-Pocket Costs



CA Governor Jerry Brown Signs AB 339 Reducing Out-Of-Pocket Prescription Drug Expenses for Millions of Californians

AB 339 was signed into law which will help Californians with chronic conditions like neuropathy afford their medications by capping the amount an individual pays out-of-pocket (OOP) for medications at \$250 for a single 30-day prescription. The NAF applauds Governor Brown and the bill's author Assemblyman Rich Gordon for addressing specialty tiers and high OOP costs which has been the NAF's number one policy issue for years.

Californians with neuropathy, HIV/AIDS, hemophilia, multiple sclerosis and other serious conditions can face costs of thousands of dollars for necessary medications and can pay as much as \$6,600 OOP. AB 339 will make it easier for Californians to afford vital treatments. AB 339 does the following:

- Establishes caps on copays/co-insurance pre-deductible for patients. Most patients would see copays capped at \$250 for a 30-day supply.
- Defines tiers to prohibit plans from moving a drug from a lower tier to a higher tier, but allows plans to move a drug from a higher tier to a lower tier.

throughout the world. In the U.S. the burden is borne disproportionately by ethnic minorities such as Hispanics. In the state of California, there are approximately 2 million diabetics and this is expected to increase to 4 million by 2020. Therefore, getting information to the Hispanic community about the seriousness of diabetes and DPN, its risk factors and those who may be at risk, and way to help manage the disease is essential.

DPN is often painful and a debilitating condition that is caused by damage to the peripheral nervous system-the complex web of nerves that connect the central nervous system (the brain and spinal cord) to the rest of the body. About 60% to 70% of all people with diabetes will eventually develop DPN. Studies have shown that people with diabetes can reduce their risk of developing nerve damage by keeping their blood sugar levels as close to normal as possible. The first sign of DPN is usually numbness, tingling or pain in the feet, legs or hands. As the nerve damage increases, the loss of sensation in the feet can reduce a person's ability to detect temperature or to notice pain.

To view the DPN brochure in Spanish and English please visit www.neuropathyaction.org.



- Prohibits health plans from having more than 4 tiers.
- References federal guidance which prohibits discriminating against patients who must take expensive drugs. This will allow state regulators to enforce federal provisions.

This success follows an earlier win this year on OOP costs when Covered California made history by becoming the first health benefit exchange in the nation to set caps on how much patients have to pay for specialty drugs. The vast majority of Covered California patients will see their specialty drugs capped at \$250 per month, per prescription. Overall, the caps will range from \$150 to \$500 beginning in 2016.

Special thanks to all of you that have supported the numerous bills in California on this topic over the years. This historic legislation once again proves that one should "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

Letters to the Editor

After the September 2015 Newsletter

I just read your article about applying for disability benefits. A well done article, but there is one thing it seems everyone forgets about--....PASSION!!

I'm a 7-8 year sufferer of Peripheral Neuropathy and have finally been approved for benefits after a 4 year wait. I went through all of the formalities of filling out stacks and stacks of papers that seemed so far away from who I am. That is until I said "Forget this, I'm going to give them ME!" And I have to say that's what got me over the hump!

Through the process, I started writing to our Congressman and state Senate members (TN.) and told them how this really is and feels and has taken away my life--....Misery on Earth! That got me some great responses from them and a good deal of support! Why? I skipped the "robot talk" and showed how angry and passionate of how myself and 20+ million people are suffering this disease and how it wasn't NEWropathy. This has been a disease that's been around forever but not paid attention to!

Like I said--...It's an awesome article, but sometimes you have to tell them to give MORE....Give them the pain, the anguish and how their world has been limited, and I mean dig deep into their hearts and tell them how it is, living with this terrible disease! And like I did in trying to tell the WORLD! I'm still trying to make some noise to make life easier for us. Maybe YOU can do an article on the subject I write about? This is what people need to read....Thank You for all that you do!

Cliff Powell, Nashville, Tennessee

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