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### Join Us in Los Angeles

## SAVE THE DATE!

The NAF is excited to announce our upcoming 11th Annual "Neuropathy Action Awareness Day!"

The NAF will be hosting the annual event once again at the **Intercontinental Los Angeles/Century City** on

February 2017

Thank you to all who have supported and continue to support the Neuropathy Action Foundation (NAF). With your generosity, the NAF continues to grow both nationally and internationally and is striving to bring help to neuropathy patients with obtaining the necessary resources, information and tools to access individualized treatment to improve quality of life.

We hope you enjoy this edition of the "Patient Voice" and that you will join us on June 23rd in Los Angeles at the 11th Annual "Neuropathy Action Awareness Day."

### Financial Assistance Resources

## Financial Assistance Programs for IVIG and Other Medications

**Friday, June 23, 2017.**

*Registration information is forthcoming.*



## California Patient Survey

### Act Now: Access to Medication Survey for California Patients

The California Chronic Care Coalition and the NAF are taking action to protect individuals from unexpected prescription coverage changes that keep you from the medication you need. Currently, insurers are free to put additional restrictions on pharmacy coverage, raise out-of-pocket costs, or even remove coverage of a treatment altogether at any time during the contract year. For many Californians, especially those with chronic health conditions, unforeseen insurance coverage changes are a growing reality - and they can be devastating. It is important for legislators and policymakers to hear the personal stories of how these coverage changes have negatively affected the health and livelihoods of individuals throughout the state.

We are searching for individuals whose lives have been negatively impacted by changing your health plan or mid-plan year prescription coverage changes. Please take our survey about your insurance coverage experience [HERE](#).

Additionally, if you or someone in your family would like to share your story with us, please contact: [\(916\) 444-1985](tel:9164441985).

## How Spouses Cope

When it comes to treating the over 100 different types of neuropathy, out-of-pocket costs can put medications out of reach for some patients. Worse, pharmacy benefit companies increasingly are restricting the list of drugs they will cover, leaving patients to pay the full cost of the medication they need. Consider, too, that neuropathy is a chronic disease, often requiring ongoing treatment. It's no wonder why the NAF receives so many calls from patients worried about access to their medications.

There is help. Most drug companies have various Prescription Assistance Programs. Additionally there are non-profit organizations that offer various types of assistance ranging from free medications to help with deductibles, coinsurance, loss of insurance, transportation and preservation of finances. The NAF recently created a document that lists various assistance programs that we help will allow you to continue or obtain your needed treatments and medications.

To read the newly created document [click here](#).

## DPN Survey Results Announced

### Neuropathy Action Foundation Announces Results from National Diabetic Peripheral Neuropathy (DPN) Survey

The Neuropathy Action Foundation (NAF) announced the results from a nationwide Diabetic Peripheral Neuropathy (DPN) Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, the impact of the disease on patient's quality of life and access to treatment.

The majority of the 978 patients completing the survey were from California (41%), Washington (9.5%), Oregon (6.7%), Nevada (6.5%) and Colorado (5.1%) with respondents from 23 other states also contributing to the results. Most patients reported that they were misdiagnosed multiple times before they were accurately diagnosed with DPN (59%). More than 52 percent reported that it took more than a year to be accurately diagnosed. Of these individuals, more than 49 percent reported that it took over two years to be accurately diagnosed.

"The long delay in proper diagnosis of DPN means that many patients receive multiple rounds of inappropriate treatments. As a consequence, their neuropathic pain is almost always under-treated. The challenge our Foundation faces is broadening Americans' awareness of DPN, including the early warning signs of it," said Jeffrey Ralph, MD, Board Member of the Neuropathy Action Foundation.

Sixty-four percent of survey respondents reported that they currently experience nerve pain. Nearly three-quarters (73.8%) of respondents said DPN impacts their overall quality of life. Basic tasks such as typing on a computer or phone, was reported to be either difficult or impossible for 55.7 percent of respondents. Sixty-six percent of patients reported having difficulty falling

## Caring for Those in Chronic Pain: How Spouses Cope

By Carol Bradley Bursack

Traditional marriage vows generally contain the words "through sickness and in health." For some couples, chronic sickness in the form of a painful disease can come close to defining their lives. I set out to see how these caregivers coped with this change, chronic pain, in their marriages.

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asleep at night and 59 percent of respondents reported more pain at night.

Over 61 percent of survey respondents reported that they have experienced step therapy. Step therapy occurs when an insurance company requires a patient to try and fail multiple DPN/pain medications before the patient is allowed to have the prescription originally prescribed by their provider. Of these patients, 36 percent were required to try two or more medications.

"The NAF is dedicated to ensuring neuropathy patients have unhindered access to treatment and therefore was disappointed to see the results of this survey show such a high use of step therapy," said Leslie MacGregor Levine, V.M.D., Ph.D., J.D., neuropathy patient and Board Member of the Neuropathy Action Foundation. "The impact of step therapy for patients in pain results in needless suffering - all because insurers have taken decisions about how to best treat patients away from providers," said Levine. "The good news is that elected officials have the power to make changes to eliminate this practice."

Neuropathy Action Foundation

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