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Action
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In This Issue of the Patient Voice

Seeking MMN Patients to Tell Their Story

The Neuropathy Action Foundation (NAF) is searching for three Multifocal Motor Neuropathy (MMN) patients willing to be interviewed on camera to discuss their journey
with MMN from the sign of first

symptoms to diagnosis to treatment while focusing on the impact MMN has on quality of life.

August 2019

National IVIG Shortage Update

Patients across America receive regular phone calls about their intravenous immunoglobulin (IVIG) treatments. Typically, these calls are to confirm scheduled treatments. However, in recent months, the calls are causing distress by relaying messages such as: "Due to the nationwide IVIG shortage, we need to cancel your appointment" or "You must switch to subcutaneous treatment." This shortage has understandably caused panic among patients who depend on IVIG to function normally and live productive lives. The NAF has heard from 117 neuropathy patients having access issues to IG products. Nearly fifty percent of the communications have been from the states of New Jersey, Massachusetts, California and Colorado, however we have heard from neuropathy patients in 21 total states.

We are hearing these stories in alarming frequency from patients, government agencies like the US Food and Drug Administration (FDA) in the following alert https://www.fda.gov/vaccines-blood-biologics/safety-availability-biologics/information-about-immune-globulin-human-product-shortage, and in the media like the following August 19 Wall Street Journal article: https://www.wsj.com/articles/drug-shortage-leaves-patients-without-immune-disorder-treatment-11565343023?shareToken=st0b79367b7dbc4126abd02e43f29f4ac4.

The NAF has recently learned that other patient organizations are

The videos will be used on the NAF website and promoted nationally through social/digital media in hopes of increasing awareness among researchers, providers, the general public and public policy officials that MMN is a serious yet treatable condition when diagnosed quickly and accurately.

It is our sincerest hope that by better understanding the MMN patient journey we will gain a better understanding of what is needed to help MMN patients. If you are interested please contact us at info@neuropathyaction.org or at (877) 512-7262.

Beware of Scams and Expensive Neuropathy Treatments

Peripheral Neuropathy patients are typically under the care of a physician such as their neurologist, family practitioner, or in some cases a podiatrist. Unfortunately for some, the treatment of peripheral neuropathy which usually includes prescription drug therapy is unsuccessful.

These patients often suffer from debilitating neuropathy pain, are desperate and are searching for relief. There are many bad actors out there that try to take advantage of these patients through direct mail advertising, TV, full-page newspaper ads, free dinners, invitation only seminars, and the internet to gain the attention of those who suffer from neuropathy. The typical ad will utilize provocative pictures of feet standing on sharp tacks or pictures of feet on fire.

One marketing tactic frequently used includes a free dinner lecture

attempting to recommend the "prioritization" of IG products. In other words, they are recommending that only on-label medications used for primary immune deficiencies should be covered during this shortage, whereas other off-label indications (like some neuropathies, MS, etc) not be covered. This is shameful and just wrong. Many neuropathy patients rely on IVIG to function and get through life. There are no other options for many in our community. Patients with one disease should not be prioritized over patients with another disease. Physicians are in the best position to know how to treat a patient - not a bureaucrat or an Executive Director of a patient organization. It is the physician that knows a patient's medical history, how the patient responds to treatment, and any other biological factors that could impact the success or failure of a medication. Decisions about how to treat patients should not be made based on an algorithm, what is most profitable for a health insurance company or what is best for one patient community. No two patients are alike and one-size-fits-all approaches simply do not work.

Nobody is at fault for the current shortage. In fact, the FDA, the Plasma Protein Therapeutics Association (PPTA), patient organizations like the NAF, manufacturers and many others are all working cooperatively to assist as many patients as possible during these difficult times. Should you or a loved one have any IG access issues please contact us at info@neuropathyaction.org or contact the FDA at CBERshortage@fda.hhs.gov or (240) 402-8380.

NAF Supports Zero-Dollar Co-Payments for Medicare Part B Biosimilars

Last month the Arthritis Foundation sent a letter to the Senate Finance Committee and Energy and Commerce Committee that the NAF signed onto. The NAF and multiple other national patient organizations support a policy proposal to incentivize uptake of biosimilars through a zero-dollar co-payment for beneficiaries enrolled in Medicare Part B. The NAF believes that biosimilars hold great promise to lower drug costs and increase patient access to medications, however a lack of uptake threatens the realization of this promise.

Many Medicare beneficiaries struggle with high out-of-pocket costs, and for those with chronic diseases like neuropathy this is a problem that confronts them year-after-year. Patients should have access to the right drug at the lowest possible cost. Biosimilars cost on average 30% less than the reference product and some analyses show they could save the U.S. as much as $54 billion over the next decade. A zero-dollar copay structure for these medicines under Medicare Part B is a key element of the larger policy discussions around high drug costs.

Despite this potential for savings to both patients and the health care system overall, usage rates remain low. While there are myriad factors contributing to this, we believe moving patient cost sharing to zero can help spur adoption. We believe strongly that the value of biosimilars to patients lies in lower costs and easier access.

Therefore, proposals that would result in no cost sharing to the patient could help deliver that value and, importantly, save money to the health

at a local restaurant to sell their treatment or services. Oftentimes patients will be asked to buy expensive machines or equipment with a claim that the machine will cure their neuropathy. The NAF wants you to be on high alert of these schemes. To this end, we would like to share a recent NBC Los Angeles story by former NAF "You Are Our Hero" award recipient, Carolyn Johnson, titled "Some patients Say SOCAL Chiropractic Business Has Drained Their Bank Accounts and Their Hope." This piece can be viewed at: http://4.nbcla.com/7SqziL3
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care system overall. In fact, an Avalere analysis estimates implementing this proposal would result in $1.9 billion to $5.2 billion in savings to Medicare over 10 years. Further, the policy would be voluntary to the beneficiary, providing incentives to patients who choose biosimilars, rather than mandating the use of biosimilars. During this time of increased attention on drug prices and the high cost of medications, we believe there is a window of opportunity to positively impact the discussion through the above mentioned proposal.

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Neuropathy Action Foundation
1950 Old Tustin Avenue | Santa Ana, CA 92705
(877) 512-7262 | info@neuropathyaction.org