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NAF Event

Save the Date!

Winter 2014

As we head into 2014 many are faced with the challenge of resolutions made for the year to come. The NAF too is determined to succeed as the premiere patient advocacy organization. To achieve this goal, the NAF has a narrow focus to ensuring neuropathy patients across the nation have access to individualized treatments with the current health care changes. Within this objective, the NAF will strive to assist neuropathy patients with self-advocacy and education. And finally, actively work to support programs that generate an even greater awareness of neuropathy among providers and the general public to improve patient care.

We look forward to supporting you throughout 2014!

Patient Information

Specialty Tiers: Discrimination Against Chronically Ill or Cost Control Measure?

The NAF is excited to announce the upcoming 8th Annual "Neuropathy Action Awareness Day!" This year, the NAF will be hosting the annual event at the **Intercontinental Los Angeles/Century City on Wednesday, June 11, 2014.**



We are thrilled to announce that after listening to the neuropathy community over the years there are now two ways to participate in this year's event:

Attend In Person

The 8th 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. This year, the NAF will be awarding our 2014 "You Are Our Hero Award" to Jerry Mathers, American television, film, and stage actor. Best known for his role in the television series *Leave It to Beaver*, in which he played "Beaver" Cleaver. 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

By Dominick V. Spatafora, President, Neuropathy Action Foundation

I am writing today as a multifocal motor neuropathy (MMN) patient who is prescribed intravenous immune globulin, as well as the founder and president of the Neuropathy Action Foundation (NAF). The NAF is dedicated to ensuring neuropathy patients obtain the necessary resources and tools to access individualized treatment to improve their quality of life. I am extremely concerned about how, in recent years, health plans have been targeting certain chronically ill patients by charging them more for their lifesaving and limb-saving medications and therapies.

Many health plans have created "specialty tier" cost structures, a form of coinsurance that dramatically increases prescription copayments for chronically ill patients. Rather than paying a flat rate for medication, patients with medications on specialty tiers can pay coinsurance of up to 35 percent of the total cost of the drugs. For some patients, that can cost up to \$3,000 per month.

Specialty tiers are prescription drug formulary management tools that insurers use to limit their liability and increase the beneficiaries' share of the costs of certain prescription drugs (sometimes referred to as specialty drugs). These specialty drugs are typically used to treat complex, chronic conditions and are either injected or infused. They may require refrigeration, compounding or other "special" handling. These drugs often do not have generic alternatives and are the only drug available, leaving patients with no effective alternative therapy.

Although any patient might be affected by coinsurance, those patients most affected include those living with specific conditions such as cancer, multiple sclerosis, hemophilia, primary immune deficiencies and certain neuropathies. Health insurance is a means by which health risk is spread across a pool of payers. Yet, when certain serious illnesses like the ones mentioned above strike, patients are singled out or discriminated against for much higher out-of-pocket costs. This practice is appalling and negates the very reason they had been paying for insurance in the first place: to be protected from financial hardship should they become ill.

Specialty tiers are discriminatory because they apply a totally 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.

What are your thoughts in this issue? Have you been impacted by Specialty Tiers? We want to hear from you. Please email your story to info@neuropathyaction.org.

The PATH study - CIDP Treatment With Subcutaneous Immunoglobulin (IgPro20)

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. You will even be able to ask the speakers questions and receive an instant answer real time. And since the entire day is being recorded you and others will be able to watch long after the event is over anytime you want on the NAF website. Register soon for FREE to receive the link to watch live!

Registration information and agenda coming soon!

Awareness

PSA Success



To date, the MMN Public Service Announcement produced in collaboration with the GBS/CIDP Foundation International has aired in over 41 different cities throughout 22 states. With over 4,000 views on YouTube and 3,400 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](#).

MMN Awareness Campaign

In 2013, the NAF launched a very successful campaign to raise awareness on

CSL Behring is currently recruiting patients for the PATH study, an international clinical trial designed to evaluate the effectiveness of IgPro20 compared with placebo in the treatment of chronic inflammatory demyelinating polyneuropathy (CIDP). The study will also look at the safety and tolerability of two different doses.

Intravenous immunoglobulins (IVIG), steroids and plasma exchange are recommended treatment options for CIDP. IVIG have to be administered by intravenous injection (through a needle inserted in your vein). In contrast IgPro20 is a subcutaneous immunoglobulin (SCIg), which means that it can be administered by injection under the surface of the skin. It may, therefore, offer another treatment option for CIDP, possibly allowing patients to administer the medication at home, or wherever and whenever it suits them, and to integrate the treatment into their lifestyle.

What does the study involve?

The study is made up of 4 different periods that all together will last about 52 weeks. The study doctor will decide if you are eligible to continue in the study at the end of each study period.

1. Screening period

In the Screening period some medical assessments and a blood draw will be done. The study doctor will use the results of these tests to decide if you are eligible to participate in the study.

2. Ig dependency period

Some patients do not need the same amount of IVIG throughout their treatment of CIDP, and some may not need IVIG anymore because they are in remission. The purpose of the Ig dependency phase is to be sure patients still need IVIG treatment before treating them with the study drug. To do this the study doctor will ask you to delay (pause) your next regular IVIG treatment and closely monitor you to look for signs of IgG dependency. You will be trained to check your own symptoms at home by using tools to measure any change in your ability to perform certain daily activities. You will be asked to come into the office as soon as your symptoms start to get worse. If your symptoms do not worsen after 12 weeks, you may not need IVIG anymore or only a reduced dosage.

3. IVIG Re-stabilization period

You will quickly be treated with IVIG again as soon as the study doctor confirms that your symptoms do get worse during the Ig dependency period. In this case you will continue in the study and receive IVIG over a period of 10 to 13 weeks to improve your symptoms.

4. Subcutaneous (SC) treatment period

For the final period of the study, you will receive either the study drug IgPro20 or placebo as weekly subcutaneous infusions over 25 weeks. The study team will teach you how to administer the subcutaneous infusions at the beginning of this period, after which you can do the weekly infusions yourself.

To make the comparison between IgPro20 and placebo as fair as possible, this study is "double blinded." This means that neither you nor the study doctor will know which treatment you are taking. The study doctor will closely monitor your symptoms during this period. If there is any sign that your symptoms get worse, you will again be given IVIG and will stop with the study.

Who can take part?

To be eligible for the study, patients diagnosed with CIDP should:

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. Visit the NAF's [MMN Resource Center](#) to learn more about symptoms, causes, and treatments for MMN.

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- Definite or probable CIDP according to the EFNS/PNS 2010
- Have had repeated treatment with IVIG (≥ 4 infusions) within the last 9 months prior to enrollment.
- Have had an IVIG treatment during the last 8 weeks prior to enrollment.
- Be ≥ 18 years of age.

Patients with any of the following are not eligible to participate:

- Any polyneuropathy of other causes
- Any other disease (mainly neurological or chronic orthopedic) that has caused neurological symptoms or may interfere with treatment or outcome assessments
- Severe diseases and conditions that are likely to interfere with evaluation of the study product or satisfactory conduct of the study
- History of thrombotic episodes within the 2 years prior to enrollment

Known allergic or other severe reactions to blood products including intolerance to previous IVIG

Where can I find more information about taking part in the study?

You can find more information about the study and where we are currently recruiting patients published on the US website www.clinicaltrials.gov.

To find out if there will be a study site open near you, you can also send an email to clinicaltrials@csllbehring.com and the study team will provide you with information on how to contact a participating investigator.

Patient Resources

[Multifocal Motor Neuropathy \(MMN\) Brochure](#)

[Diabetic Peripheral Neuropathy \(DPN\) Brochure](#)

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