Patient Voice - August 2021 Issue **Visit our Website**

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Dear Member,

The NAF invites you to share your personal stories, experiences, questions, news and tips, with our readers and the neuropathy community. Your story may be published in an upcoming “Patient Voice” newsletter! Simply email us at **info@neuropathyaction.org**.

Best Wishes,

Dominick V. Spatafora
Founder and President

NAF Announces CIDP Patient Survey Results

The Neuropathy Action Foundation (NAF) announced the results from a Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, efficacy of treatment, and the impact of the disease on patient's quality of life. "Early and accurate diagnosis can mean the difference between CIDP patients being successfully managed or becoming permanently disabled," said NAF President Dominick Spatafora. "Timely treatment can make a big difference in patients' lives." The NAF believes these survey results will increase awareness and action among providers, the public and public policy officials.

The majority of the 297 participants completing the survey were males (62%) from the United States (88%) with respondents from five other countries contributing to the results. While 70% of respondents reported that they were diagnosed between the ages of 41 and 65 years old, more than 54% of those completing the survey reported that it took more than one year to be accurately diagnosed. The majority of the misdiagnoses were made by Neurologists (60%) and Family Care Providers (21%). "It is very clear that we need to do a better job at accurately diagnosing these patients. The sooner we can identify CIDP, the sooner we can start individuals on the proper therapy, alleviate their symptoms and improve their lives," said Jonathan Katz, Chief of Neuromuscular Services at California Pacific Medical Center.

When asked about treatment options, 76% reported receiving intravenous immunoglobulin (IVIg) and 11% reported receiving subcutaneous immunoglobulin (SCIg). A reduction in symptoms was reported within three months of their first Ig treatment by 68% of respondents. Only 7% reported that Ig did not help them manage their symptoms. If recommended by their Neurologist, 67% would consider SCIg treatment. Interruptions in treatment due to COVID-19 were experienced by 39% of the respondents.

Nearly 30% of all participants stated that CIDP often or always interferes with their employment and 51% said it impacts their quality of life. Loss of balance (51%) and weakness in legs (49%) were the most common symptoms before starting treatment. CIDP has a direct impact the participant's emotional wellbeing. Fatigue was reported by 43% of the respondents. Some 46% reported feeling depressed and 28% of those completing the survey said they had time when they felt hopeless. Feeling embarrassed by their physical limitations was a concern for 49% of respondents.

"The survey results illustrate the complexity of CIDP and the impact it can have on people's lives," said Spatafora. "The good news is that the data also shows that treatment helps many individuals."

Are You Receiving Ig?

Register today for a the Immunoglobulin National Society's (IgNS) 2-day FREE conference for patients and caregivers.

The IgNS Patient 360 is an educational and support conference for patients with a variety of diagnoses, taking place August 28-29, 2021.

AAN Issues Formal Position Statement on COVID-19 Vaccine

Based on existing evidence, neurologists should recommend COVID-19 vaccination to their patients, a newly released American Academy of Neurology (AAN) paper said.

The objective is to provide a deeper understanding of Ig therapy, improve communication with the healthcare team, provide patient advocacy and support solutions, and myriad other benefits.

Some topics covered will include: improving SCIg/IVIg infusions and side effects; interactions with immunoglobulin; food and inflammation; and safety and efficacy of alternative medicine.

If you would like to learn more or attend please visit: https://ignsconference.com/ignsp360/.

"Barring the rare circumstance of an absolute contraindication to available vaccine formulations, it is the American Academy of Neurology's formal position that eligible patients should be offered the COVID-19 vaccine," wrote Elisabeth Marsh, MD, of Johns Hopkins University School of Medicine in Baltimore, and members of the AAN Quality Committee, in ***Neurology***.

According to the AAN Committee, “vaccine benefits outweigh risk of post vaccination complications.”

Based on all evidence the Neuropathy Action Foundation (NAF) also recommend that neuropathy patients received COVID-19 vaccinations.

To read more about the AAN’s statement hit the following link: **Read more.**

DPN Awareness Poster in English and Spanish

The NAF has many outstanding patient and caregiver resources on its website. One such resource is poster in both English and Spanish to be hung in providers' offices in hopes of bringing awareness to Diabetic Peripheral Neuropathy (DPN). Our goal is to bring additional awareness to DPN and help the general public better recognize the symptoms and warning signs of DPN. We also hope the flyer sheds light on the importance for patients to have meaningful conversations with their healthcare providers about how to better recognize and manage DPN symptoms.

The poster can be viewed in English and Spanish below.

English Version **Spanish Version**

Multifocal Motor Neuropathy: Is There Hope?

Aug 9, 2021 | **Patient Blog** - Multifocal Motor Neuropathy (MMN) is a rare disease affecting the body’s motor nerves and occurs in **less than 1 in every 100,000 people.** While this disease is rare, it is not fatal, and there is approved treatment that can slow symptoms. There is hope. Below, you’ll find information on MMN symptoms, treatment, and financial assistance for high MMN medical costs.

What is MMN?
MMN is a progressive, auto-immune disorder that affects motor nerves, which help control the muscles. Men are twice as likely to develop MMN as women, and it is typically diagnosed between the ages of 35 and 70.
While the cause is unknown, it is known that the immune system mistakenly attacks the body’s own nerve cells as if they were invaders. Researchers continue to try to find out why this happens.
MMN is a progressive disorder, which means that the signs and symptoms tend to worsen slowly over

time, with no remission.

Symptoms of MMN

The main symptom of MMN is progressive muscle weakness of the arms and legs. While this disease is not fatal, it can cause a great deal of dysfunction and disability for a person. Unlike other neurological disorders affecting the arms and legs, there are usually no sensory deficits, meaning feelings of tingling or numbness and pain are not associated with the disorder. MMN also affects the **right and left** sides of the body differently. Muscle weakness often begins in the hands, causing hand weakness. Affected individuals may drop objects frequently or have difficulty performing tasks that require fine motor skills such as turning a key in a lock. Some individuals have trouble **extending or bending** their wrist upward (wrist drop).

Sometimes, muscle weakness starts in the legs. Foot drop is the first sign in a **third** of MMN patients, which causes reduced mobility of the toes. Foot drop occurs when weakness of the muscles involved in lifting the foot causes the foot to drop or drag when attempting to walk. Symptoms also include muscle wasting, cramping, and involuntary contractions or twitching of the leg muscles. Patients with MMN can have fasciculations, which are the spontaneous firing of a motor unit. Fasciculations are also characteristic of ALS (Amyotrophic lateral sclerosis), which is why many patients with MMN are initially misdiagnosed with ALS. The similarities can cause delays in diagnosis, therefore a delay in treatment.

MMN Treatment

While there is no cure, treating patients with intravenous immunoglobulin (IVIg), an infusion-based treatment, benefits patients with MMN. IVIg treatment can reverse the conduction block, which allows nerves to reach the proper muscles. It can also reduce the chances of developing new nerve lesions and slow the progression of deficits. **Researchers** believe that the conduction block in multifocal motor neuropathy is reversible.

Financial Assistance for MMN

Patient Services, Inc. has a newly established fund to help patients with MMN. PSI provides financial assistance with copays, infusion and nursing costs, and travel expenses.
To see if you qualify for assistance, check out our **prescreening tool and apply today**. You can also call us at 1-800-366-7741.

Virtual Program: Learn about ATTR (hATTR) amyloidosis

You are invited to register for a virtual program to learn more about hereditary ATTR (hATTR) amyloidosis. There is no cost to attend this event.

PROGRAM: hATTR Amyloidosis: Educational Overview.

DATE: Thursday, September 09, 2021 at 4:00 PM PDT

This Program Will Cover:

- Disease Overview
- Genetics and Inheritance
- Resources and Support

Sponsored by: Alnylam Pharmaceuticals, Inc.

REGISTER NOW

Visit: http://bit.ly/hATTRvirtualprogram909

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