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

In this Issue

- ► NAF Completes Five Year Multifocal Motor Neuropathy Campaign
- ► My CIPD Story
- ► Your Legislators Are On Social Media. Are You?
- ► National Diabetic Peripheral Neuropathy (DPN) Survey

Dear Member,

As you know we cancelled our 13th "Neuropathy Action Awareness Day" in June 2020. Although we were looking forward to seeing everyone in Los Angeles, it was simply not possible to move forward with the in-person meeting given the pandemic. We were hopeful that the event would be rescheduled for some time in 2021, but after conducting an informal survey of past attendees and neuropathy community members it became apparent that our community is not ready for an in-person event yet. However, we do have some good news! The NAF will hold our 13th "Neuropathy Action

Awareness Day” in June 2022. As in the past the event will be available for individuals to attend in person as well as virtually and will include top neurologists from across the country as well as numerous exhibitors and sponsors. Please stay tuned for more information as it becomes available and in the mean time we hope you stay well and healthy.

Best Wishes,
Dominick V. Spatafora
Founder and President

NAF Completes Five Year Multifocal Motor Neuropathy Campaign

While there are over one hundred different types of neuropathy the NAF has focused our education and awareness quite heavily over the years on Multifocal Motor Neuropathy (MMN). Why MMN? Easy! Early and accurate diagnosis of MMN can mean the difference between MMN patients being successfully managed or permanently disabled. Some highlights of the NAF's efforts include:

In 2014, the NAF conducted a nationwide campaign raising MMN awareness and facilitating a dialogue on the value of early diagnosis and available treatments via the creation of a MMN brochure and a 60 second MMN Public Service Announcement (PSA). The PSA aired in 74 total cities in 30 states and currently has nearly 50,000 views on YouTube.

In 2016, the NAF announced the results from the first ever international MMN 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.

In 2018, the NAF conducted a targeted digital advocacy campaign in to increase awareness of MMN among three key audiences: patients living with neuropathy who know it; patients living with neuropathy who don't know it; and practitioners in the field. The campaign generated 1,153,057 impressions and 67,098 clicks to the NAF website.The campaign has more than doubled the amount of MMN patients in NAF database.

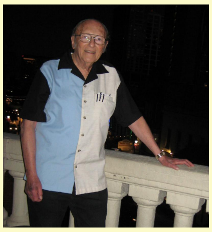
In 2019, the NAF conducted a Digital Army and Email List Acquisition Campaign focusing on MMN. The MMN campaign generated nearly 6,000 new users to the NAF database. The campaign reached over 160,000 unique people and generated nearly 360,000 impressions. The campaign also generated 2,153 new Facebook followers and 335 new Twitter followers. Through email responses and online forms over 100 patients submitted their stories to the NAF. The NAF identified three amazing individuals who agreed to share their personal journeys with MMN. Please view the following inspiring MMN patient stories: Deborah Zirpolo - https://youtu.be/dd1iV8UOFHs; Socorro King - https://youtu.be/YJgWv9nWpK4; and Andy Klee - https://youtu.be/dgIaVtq0UA0.

In 2020, the NAF continued to educate around MMN and raise awareness of the impact of the disease to neurologists, potential patients, as well as the general public. There were three components to the campaign:

- Increase Awareness of MMN Through Creative Content - The NAF launched a digital campaign across Facebook and Twitter to educate and raise awareness of MMN. The campaign included ads featuring animation and first-person video testimonials that were created from three MMN patients. NAF served animation and first-person video testimonials to explain MMN and highlight its impact. The campaign reached 581,093 people and generated 2,773,053 impressions, 1,938,729 three-second video views, and 11,679 clicks, with an overall click-through rate of 0.42%.

- Create an Email Series to Educate and Engage New NAF Members - NAF engaged subscribers that were acquired from the 2019 digital acquisition campaign through a series of emails. Subscribers received three emails that encouraged them to spread awareness of MMN. The emails were sent to 3,300 readers and generated an average 15% open rate and an 11% click rate.

- Map and Engage Online Influencers to Share MMN Content with Their Online Audience - Collaborated with two diverse influencers in the health space to raise awareness of MMN to their online audience. The influencer campaign reached 37,600 people and generated 490,339 impressions and 2,518 engagements, including 2,065 clicks and 84 comments, with an overall click-through rate of 0.40%. The campaign also reached 20% of users between the ages of 18-44 and 80% of users between the ages of 45 plus.



My CIDP Story

By Fredrick P. Shell

In May of 2013, we spent a glorious week walking all over Philadelphia and adjacent areas. Occasionally at night I felt a stabbing Ice Pick type of pain in my back, which was only momentary, so I ignored it.

Fortunately, my wife did not ignore it. Without my knowledge she made me an appointment in the Physical Therapy area of the clinic we frequent.

My first PT session, the middle of June, was uneventful with various exercises, some involving standing on my toes. All were accomplished without difficulty. I went home, did my daily exercises, and returned to PT three days later.

However, this time when I was asked to stand on my toes, my heals would not move off the floor. My Therapist became alarmed and immediately had me schedule an appointment with a Neurologist.

By the end of June, I had progress from walking unassisted, to a cain, then to a walker, finally in a wheel chair. My legs were becoming weaker and weaker by the day. I started my initial series of IVIG Infusions the first week of July 2013. My Neurologist thought I had ALS, but sent me to USC for additional tests.

At USC I was diagnosed with CIDP and started on a three week cycle of IVIG, with Physical Therapy between visits. In August I traded in my wheel chair for a walker.

In September I moved up to a cain, and got rid of the cain in October. I was quite fortunate to have been diagnosed early in the process. The IVIG Infusions are a Miracle for me. I have experienced no side

Your Legislators Are On Social Media. Are You?

The number of individuals using social networking sites such as Facebook, Twitter, LinkedIn, and YouTube is growing at an astounding rate. Facebook has 2.85 billion active monthly users and Twitter sees approximately 500 million Tweets per day.

Given the numbers, social media mobilization has become an integral part of any successful advocacy effort. It's an effective way to engage and coalesce the neuropathy community and opinion leaders from across the U.S. around a single subject. Social media offers opportunities for rapid knowledge exchange, dissemination and response among many people. It can direct communication at a particular user, and it can turn up the volume on a particular topic by sheer numbers of engagement.

Tweets, retweets, posts, likes, and shares have added another layer of communication and influence to public policy debates.

At the NAF, we've been working hard to harness the potential of social media with our community during critical debates. We believe our social advocacy - and especially yours - during this year's legislative sessions made a big difference.

Moving forward we see it as a valuable communication and influencer tool and hope to see more of our community engage. Targeting legislators and opinion leaders with a consistent message from the neuropathy community can make a big difference in the outcome of a vote or position statement.

The NAF team is thankful for our community, that has created a growing effects, and at one time the interval between Infusions was eight weeks.

However, when we tried to reduce the amount of IVIG, I did experience a minor set back, and am currently on a four week cycle between infusions. Except for afternoon fatigue, and some ankle weakness, which results in occasional minor foot slap when I walk, I feel I can do anything that is considered normal for a 78 year old.

If you are just starting your Journey, and fearful of the future- so was I.

After turning in my wheel chair and walking again, I consider my minor limitations to be not worth discussing.

I am now five years and three months with CIDP. Life is good and the future is Bright.

Wishing anyone with CIDP, the same success at managing this problem as I am having.

presence for neuropathy patients across social media with 1,535 followers on Twitter and 3,532 likes on Facebook. The NAF thanks you for your due diligence and engagement with social media on behalf of the neuropathy community. This will be an increasingly important advocacy tool and we appreciate your time and willingness to engage and share pertinent information with your networks.

Happy Independence Day!

National Diabetic Peripheral Neuropathy (DPN) Survey

The Neuropathy Action Foundation (NAF) conducted 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 1,348 patients completing the survey were from California (40%), Washington (7%), Colorado (6%) and Texas (5.1%) with respondents from 27 other states also contributing to the results. Most patients reported that they were misdiagnosed multiple times before they were accurately diagnosed with DPN (60%). More than 50 percent reported that it took more than a year to be accurately diagnosed. Of these individuals, more than 40 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 (71%) 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 54 percent of respondents. Sixty-six percent of patients reported having difficulty falling asleep at night and 61 percent of respondents reported more pain at night.

Over 62 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, 39 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 Dominick Spatafora, 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 Spatafora. "The good news is that elected officials have the power to make changes to eliminate this practice."

To learn more about DPN please download a copy of the NAF’s DPN brochure at **fpn_naf_brochure.pdf (neuropathyaction.org)** or view our Public Service Announcement (PPSA) featuring Jerry Mathers at **Diabetic Peripheral Neuropathy (DPN) PSA Featuring Jerry Mathers (The Beaver) - YouTube**.

Support the Neuropathy Action Foundation.
When you shop at **smile.amazon.com,** Amazon donates.
Go to smile.amazon.com
amazonsmile

Share Tweet
Share

Donate Today

Neuropathy Action Foundation | http://neuropathyaction.org

Neuropathy Action Foundation | 1950 Old Tustin Avenue, Santa Ana, CA 92705

Unsubscribe oldweirdharold@hotmail.com

Update Profile | Constant Contact Data Notice

Sent by info@neuropathyaction.org powered by

Constant Contact
Try email marketing for free today!