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Message from the NAF President

October 2019

NAF Releases Three Brand New MMN Patient Videos



Recently when I was crossing a San Francisco toll bridge I heard what sounded like a party coming from

an upcoming toll booth. As I pulled up to it, I looked inside and saw a man dancing and singing. "What are you doing?" I asked. "I'm having a party," the tollbooth man replied. "What about everyone else?" I asked, feeling kind of embarrassed as I pointed to the folks in the other booths. "What about them?" the man said. "Each day I watch as they climb into their vertical booths...for eight hours a day, their brain is on hold and they are dead on the job until the end of the day when they re-emerge and go home."

Fascinated, I asked "what is different for you? You look like you are having so much fun." The tollbooth man laughed and said, "I do not understand why anybody would think my job is boring...I have a corner office with windows on all sides. I can see the Golden Gate Bridge, San Francisco, and the Berkeley Hills. Half of the Western world vacations here...and I get to stroll in and admire the view while I practice dancing every day!"

This recent conversation made me think about the neuropathy community and how over the past 14 years working with the NAF I have learned from so many of you about the power of attitude. I have learned that our lives are not determined by what happens to us, but by how we react to what happens; not by what life brings to us, but by the attitude we bring to life. So here's hoping that whatever may come your way in 2020 that you maintain a positive



Socorro King | Multifocal Motor Neuropathy

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! MMN occurs in approximately 1 in 100,000 people. 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

attitude which in turn causes a chain reaction of positive thoughts, events and outcomes. Happy 2020 and I hope you enjoy this edition of the "Patient Voice!"

*Dominick V Spatafora
Founder and President
Neuropathy Action Foundation*



SAVE THE DATE JUNE 19

The NAF is excited to announce the upcoming 13th "Neuropathy Action Awareness Day"!

The NAF will be hosting the annual event once again at the Intercontinental Los Angeles / Century City on Friday, June 19, 2020.

Registration and Agenda is forthcoming.



absolutely amazing individuals who agreed to share their personal journeys with MMN on video. Please take some time to watch the following three inspiring MMN patient stories.

- Deborah Zirpolo - <https://youtu.be/dd1iV8UOFHs>
- Socorro King - <https://youtu.be/YJgWv9nWpK4>
- Andy Klee - <https://youtu.be/dglaVtq0UA0>

Financial Assistance Programs for IVIG and Other Medications

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 NAF document [click here](#).



Find An Infusion Center Near You

The National Infusion Center Association (NICA) has created the largest publicly available database of infusion centers in the United States. The Infusion Center Locator was created to connect patients across the nation with infusion providers who are best able to meet their needs. Center staff can add and maintain listings to provide accurate information, including

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available medications, insurances accepted, office hours, amenities and more! Learn more or find your next infusion center by visiting locator.infusioncenter.org. For additional information please contact the NICA at INFUSIONCENTER.ORG or at (512) 402-6955.

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