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## Current News

**New York Based "The Neuropathy**

December 2014

## Happy Holidays!

Thank you to all who have supported the Neuropathy Action Foundation (NAF) this year! With your generosity, the NAF continues to grow both nationally and internationally. The NAF has been able to assist patients by providing resources, education and awareness regarding this widespread and disabling condition. Best wishes during this Holiday season from all of us at the Neuropathy Action Foundation!

## Donate Today

### Please Support the NAF This Holiday Season

Neuropathy is a disease of the nerve that impacts over 20 million Americans. Despite this astronomical number, neuropathy continues to be most common disease many have never heard of. While there are over one hundred different types of neuropathy the NAF has dedicated 2014 to advancing our national campaign for Multifocal Motor Neuropathy (MMN). Why MMN? Easy! Early and

## Association" Dissolves

New York based "The Neuropathy Association" is dissolving according to a letter sent to the neuropathy community last week signed by their Chairman of the Board. Since 1995, TNA has focused its efforts on helping and healing people with peripheral neuropathy through awareness, education, support, advocacy and research. According to the letter, TNA recently concluded that the best course of action was to dissolve and 'pass the torch' to the Foundation for Peripheral Neuropathy (Foundation) based in Chicago.

The NAF has partnered with the Foundation in various ways over the years and is excited about the increased role they will hold in the neuropathy community. The NAF has absolute confidence in the Foundation and pledges to help them in any way we can. The Foundation's mission is to dramatically improve the lives of people living with Peripheral Neuropathy. According to their website, the Foundation will be the catalyst for advancing innovative therapeutic developments and accelerating a cure for painful neuropathies by funding collaborative efforts of leading scientists and physicians.

The Foundation strives to raise awareness of peripheral neuropathy through outreach programs to patients, their families and healthcare professionals. To learn more about the Foundation please visit [foundationforpn.org](http://foundationforpn.org). The NAF wishes the Foundation the best of success and hopes to continue partnering with them to provide the greatest support for those who suffer from neuropathy.

accurate diagnosis of MMN can mean the difference between MMN patients being successfully managed or permanently disabled.

The ability to control the progression of MMN is directly related to the speed and accuracy of correct diagnosis. I know this because I was originally diagnosed with ALS and told I only had three-to-five years to live. It took over a year before I was correctly diagnosed with MMN and began receiving treatments that continue to allow me to lead a productive and active life today. In addition to our current MMN Campaign we hold an annual "Neuropathy Action Awareness Day" and provide quality education via brochures, public service announcements, newsletters and website material - all free of cost to patients.

Through our patient programs we have become a premiere patient advocacy organization ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve quality of life. Please support the NAF and millions of neuropathy patients this holiday season by making a tax deductible contribution. The mission of the NAF can only be sustained through the generosity of people who share our commitment to improve the lives of those living with neuropathy.

Happy Holidays,

Dominick V. Spatafora  
Founder and President

## Patient Education & Resources

### Do You Have Your Copy?

We would like to inform you of a new patient resource called "Coping with Chronic Neuropathy" which is a DVD filled with information, hope, humor and challenge. Having lost the full use of both legs from undiagnosed and untreated neuropathy for decades until 2004, the seminar features Eugene B Richardson, BA, MDiv, EdM, MSM, MS, a retired Senior Army Officer who has lived with neuropathy for 45 years and recipient of the NAF "You are our Hero Award" in 2010.

The DVD is endorsed and recommend by Alan Berger MD FAAN, Professor and Chairman, Dept. of Neurology, UF Health@Jacksonville who writes "For four decades Gene has struggled with the challenges and relentless symptoms of neuropathy and now as a professional counselor and teacher he proactively shares his insights both as a professional and patient." Endorsed by Thomas Brannagan MD FAAN, Professor and Chairman, Department of Neurology, Columbia University, NYC; and by practicing Neuromuscular Neurologist Waden Emery MD FAAN of Lighthouse Point, FL, Dr. Emery writes: "When it comes to neuropathy, having the right support is critical and this DVD is a great place to start."

Surviving beyond the challenges of the disease is the theme throughout, with insights shared on how to use anger as power, while facing the question of "why me", yet holding onto the fun from your inner child. Discussed is the power of faith, increasing your neuropathy knowledge, getting and giving patient support, and learning to adapt to the changes neuropathy brings to lives while remaining focused on getting help for your neuropathy. Critical issues such as getting support from the doctor, family and from the

## NAF President Featured in New MMN Video

Over the years the NAF has partnered with various organizations to benefit as many neuropathy patients as possible. One such group that we have a considerable amount of respect for and continue to collaborate with is the GBS|CIDP Foundation International. The GBS|CIDP Foundation International is proud to present a recently produced video about Multifocal Motor Neuropathy (MMN). Other newly created videos highlight: adult and pediatric GBS and CIDP. All of the videos can be found on YouTube as well as on the GBS/CIDP Foundation International website, GBS-CIDP.org.

The video on MMN features NAF President (and MMN patient) Dominick Spatafora and, Dr. Richard Lewis, from Cedars-Sinai Medical Center. Dr. Lewis describes the symptoms and characteristics of MMN. In addition to Dr. Lewis, Dr. Carol Lee Koski, the GBS|CIDP Foundation International Medical Director, also speaks about MMN and Centers of Excellence. Dominick talks openly about this very rare disease, initial miss-diagnosis, and finally, the discovery a neurologist who was informed and knowledgeable about this rare neurological condition. To view the video please visit: [www.gbs-cidp.org/variants/mmn-overview](http://www.gbs-cidp.org/variants/mmn-overview).

work place are topped off with a chapter on the reality of a patient's world and the importance of finding a secret place of peace. The seminar leaders poem "When is it Enough?" inspires us as it is read to the music from "You Lift Me Up" while his two supporting doggies bring the DVD to a close.

## Be the Source of Hope

Recently the NAF partnered with BloodSource to help bring awareness to the importance of plasma donation. BloodSource, not-for-profit since 1948 and based in Mather, CA, recently opened the first voluntary plasma donor center in the U.S. where collections are designated solely for further development into plasma-based medicines, such as immunoglobulins. Plasma-based therapies give enormous hope to people who struggle with more than 80 diseases, including autoimmune diseases, bleeding disorders, and neurological disease, such as multifocal motor neuropathy (MMN) and chronic inflammatory demyelinating polyneuropathy (CIDP). With more than 65% of the world's plasma coming from the U.S., the global need for plasma shows no sign of abating. BloodSource is proud to be on the leading edge of voluntary plasma donation dedicated to helping patients close to home and around the world.



Patients rely on plasma-based medicines for a one-time need - or perhaps a lifetime - with access and availability critical to their health, well-being, productivity and personal fulfillment. There is only one source for plasma and it's another human being who rolls up his/her sleeve, gives an hour and a precious gift, impacting the smaller world of a patient surrounded by family and friends, and the larger world of many thousands of patients in need. Together, we do save lives. The following link illustrates a new national video featuring NAF President Dominick Spatafora discussing how he relies on plasma to help treat his MMN: <http://youtu.be/SiLKbk5PVDMA>

Please learn more about your eligibility to donate plasma at [bloodsource.org/sourceplasma](http://bloodsource.org/sourceplasma)

## PolyNeuroExchange - An Online Source for Expert Information about Peripheral Neuropathies

The PolyNeuroExchange website is an online education resource that provides up-to-date information on inflammatory neuropathies. The platform makes high-quality information about neuropathies accessible to those interested to learn more about symptoms, diagnosis, and treatment options for peripheral neuropathies. Experts in the field share information about the pathogenesis and mechanism of action of inflammatory neuropathies, as well as the results and implications of clinical trials for new treatments.

Although various neuropathies may be discussed, particular attention is given to Chronic Inflammatory Demyelinating

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Polyneuropathy (CIDP) and Guillain-Barré Syndrome (GBS). New content will be added to the PolyNeurExchange website over time, in particular new information on latest developments in the neuropathy field and outcomes of recent clinical trials.



[www.polyneuroexchange.com](http://www.polyneuroexchange.com)

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