



the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

FPN | News

FALL 2019



FROM THE
EXECUTIVE
DIRECTOR

Greetings!

Thank you for your continued, generous support which enables *the* Foundation for Peripheral Neuropathy to sustain an extraordinary caliber of education, research, and services. In short, your support helps us improve the lives of those living with peripheral neuropathy.

Everything we do—from patient education and conferences to research and advocacy—is designed to improve lives and hasten scientific discoveries. We couldn't do this work without you. We deeply appreciate your financial support of our mission and hope you will continue being a valued member of our organization in the years to come.

In this issue of our Newsletter, I am pleased to share learnings on acupuncture, driving tips and new charitable giving opportunities. I'm also excited to report on several new research findings from the annual Peripheral Nerve Society's Meeting, which was held in Italy in June 2019, to demonstrate the quality of research that our community is helping to achieve. And lastly, I'm pleased to highlight a remarkable woman's story. I think you will agree that she has learned a simple recipe for life that we should all adopt!

I hope that you find our resources helpful and inspiring. Thank you again for your support.

Kindest regards,

Lindsay Colbert



FPN Premium Member and Texas native, Dana Delgado is a retired educator who served as a special education teacher, school counselor, principal, and college professor. Although retired, Dana still works as a free-lance journalist, college planning coach and writing tutor.

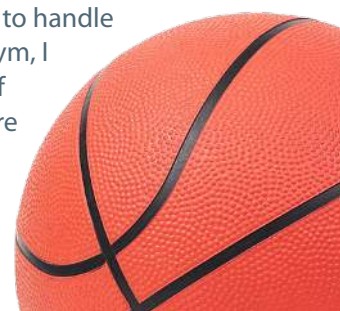
Dana is no doubt busy with her work, her students and her community. She also has a claim to fame that few of us have: Dana is a national basketball champion.

Dana and her fellow teammates on the basketball team, the Chicago North Stars, won gold in the National Senior Games. The event was held in Albuquerque, New Mexico in June of this year, featuring more than 14,000 athletes participating in team and individual competitions in over twenty sports.

The Foundation for Peripheral Neuropathy recently had the opportunity to chat with Dana about life, sports, and peripheral neuropathy.

What is your connection with peripheral neuropathy? My story with peripheral neuropathy is a familiar one. After battling mysterious leg pain for over 40 years, I was finally diagnosed around 2012. What started as leg weakness, pain, and severe leg cramps had progressed to burning, tingling, and numbness in both legs resulting in mobility issues and extended into my hands and arms. In 2018, I was diagnosed with autonomic neuropathy.

How did you get involved with sports? When my body began to hurt more than ever and began to significantly limit my life's activities, I felt like I needed to become more active. I joined the gym but found that to be too much for me to handle by myself. One day at the gym, I was invited to join a group of ladies playing volleyball. Before long, I was competing in the National Senior Games



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PN BIOMARKER STUDY

During the June 2019 Peripheral Nerve Society (PNS) annual meeting in Genoa, Italy, new results from the “Biomarker study” were presented. This study is **searching for biomarkers associated with neuropathic pain in patients with idiopathic peripheral neuropathy**. Blood samples from 60 patients were analyzed for over a thousand biomarkers, including lipids, proteins, metabolites and other components. All analyzed samples were obtained from patients enrolled in the Peripheral Neuropathy Research Registry (PNRR), which is sponsored by *the Foundation for Peripheral Neuropathy*.

Half of the 60 patients reported intense neuropathic pain, while the other 30 did not report any pain symptoms associated with their neuropathy and did not take daily pain medications. The data was then analyzed for differences in the two groups, not only in the measured levels present for each analyte, but also for interactions between them, e.g. correlations and different interaction patterns between individual biomarkers.

While the team did not find highly significant differences in the expression of certain biomarkers, they found several differences in interactions and are currently investigating these

findings further. **The team hopes that these differences in the expression profiles might provide some explanations into why some people develop neuropathic pain while others do not, and may potentially point towards new future targets for therapy.**

The preliminary findings were presented at the PNS meeting by Perry van Doormaal, a neurologist from the Netherlands who served as a postdoctoral researcher at Johns Hopkins School of Medicine in 2018. “It is always exciting and a great pleasure to present our findings for the first time to a large audience,” Van Doormaal stated. “There was quite an interest in this study from fellow researchers.” PNRR Project Manager, Simone Thomas, agreed. “These gatherings provide great opportunities to catch up with all other experts in the field and discuss the findings of these studies. Often new research ideas originate from such meetings.”



PNS MEETING 2019

The annual Peripheral Nerve Society (PNS) meeting took place in Genoa, Italy from June 22-25, 2019 with a record 1200 attendees. The purpose of the PNS annual meeting is to bring together clinicians and scientists from across the world interested in peripheral neuropathy and the neurobiology of the peripheral nerve to present on the latest findings and explore new opportunities for learning and research. For a second consecutive year, *the Foundation for Peripheral Neuropathy's*

Executive Director was present at this conference to learn about the latest in research and serve as a valuable resource for clinicians.

The meeting is typically focused on four categories of peripheral nerve disorders: **Inherited neuropathies, Immune-mediated neuropathies, Diabetic neuropathy, and Toxic/Chemotherapy neuropathy**. Below are some highlights that our clinicians want you to know about:

- Amyloidosis is a condition in which the body does not properly manage the production of the amyloid protein, causing damage to many organs, including, in some cases, the nervous system. For hTTR amyloidosis and certain other types of amyloidosis that affect the nervous system, peripheral neuropathy is often one of the earliest manifestations of the condition. Recently, there has been a breakthrough in treatment of peripheral neuropathy caused by hereditary TTR amyloidosis, including tests to diagnosis and pharmaceuticals to test for the condition. The new pharmaceuticals do not cure the ailment, but can help the body better manage the amyloid protein, which can reduce the symptoms and help the patient and the

patient's doctor better manage the disease. Several talks and posters were dedicated to present and discuss data from studies focusing on treating patients with TTR amyloidosis. Questions such as when to start treatment, potential markers of treatment success and how to monitor response to treatment were discussed by Dr. Teresa Coelho, MD (Portugal), Dr. Laura Obici, MD (Italy) and Dr. Isabel Conceicao, MD (Portugal) among others.

- Exciting developments were also reported in the more common form of **inherited neuropathies**, also known as Charcot-Marie-Tooth, or CMT. Presented by Dr. Marina Kennerson, PhD (Australia), three new genes that can cause CMT were discovered in the past year. Additionally, there was a major development in understanding mechanisms of disease caused by TRPV4 gene at Johns Hopkins University. The research community is also preparing to test new medications expected to slow the progression of symptoms. Some of the trials are expected to start recruiting participants in early 2020 and FPN will offer information to our constituents when known.

- **Guillain-Barre-Syndrome (GBS)** is an acute form of polyneuritis, causing weakness and often paralysis of the limbs. GBS is routinely treated with IVIg infusions over several days. One study presented by Dr. Bart Jacobs, MD, PhD (Netherlands) evaluated the benefits to the patients who were treated with a second round of IVIg infusions, when those patients continued to worsen following a first round. The data revealed that there are actually no significant benefits to a second round of IVIg. Also notable is the ongoing analysis of the data collected by the “International GBS Outcome Study”, which collected data from over 1000 patients diagnosed with GBS over the

past few years. The findings (which will be discussed in several upcoming papers) were presented by Dr. Michael Lunn, FRCP PhD (United Kingdom) and are broadening our knowledge of GBS.

- **Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)** is a rare neurological disorder marked by inflammation of nerve roots and peripheral nerves and destruction of the fatty protective covering (myelin sheath) of the nerves. It, also, is treated with IVIg infusions. The “hot topic” was treatment evaluations – more specifically, how frequently IVIg infusions should be given, the benefits of IVIg breaks and how often treatment breaks should be planned. The development of CIDP treatment guidelines is definitely something the PNS community is currently working on, highlighted by Dr. John England, MD, FAAN (Louisiana State University). Several medication trials for new CIDP treatments are also in different planning stages and some of them are going to start patient recruitment within the next year.

- **Diabetic neuropathy** is another area of current research focus. In the past few years, metabolic syndrome has received a lot of attention. One of the clear messages of the 2019 PNS conference discussions was that many patients with diabetic neuropathy also have metabolic disease. It also appears that the type of obesity has some influence on the severity of the metabolic syndrome—patients with metabolic syndrome as the

suspected underlying medical conditions for their neuropathy seem to commonly have a larger waist measurement.

- Similarly, many patients with diabetic neuropathy have **small fiber neuropathy (SFN)**, and the research focus in that area was that the sodium channel mutations many of the patients with very painful SFN have had and their treatment.

- And last but not least, several ongoing studies were presented to the research community. Of particular interest is the **IMAGiNe** study which investigates IgM anti-MAG-induced neuropathies—a very rare form of neuropathy which occurs when the body’s own immune system develops antibodies against a key glycoprotein (MAG—or myelin-associated glycoprotein), which is essential to maintaining a healthy peripheral nervous system. FPN is currently supporting this study by funding patient recruitment in the United States, and we are working together with several academic centers in the US. Johns Hopkins (Baltimore, MD) is already actively enrolling, and other sites such as the Mayo Clinic (Rochester, MN) and Cedars-Sinai Medical Center (Los Angeles, CA) have also expressed interest in getting involved.

Next year’s PNS annual meeting will occur in Miami, Florida in June 2020 and the Foundation is expecting to join the top researchers and clinicians from around the world, once more, to identify opportunities for collaboration, research and funding.

Bringing Home Gold (continued)

traveling to first volleyball and then basketball tournaments around the country. Besides being fun, I met some wonderful and courageous women who were trying to cope with their own health challenges.

Tell me about your team, your league, and sports competition. I’ve been fortunate to play with a most supportive and fun-loving Chicago team during the past year; although all other teams, from New Jersey, to Canada, to New Mexico and Texas on which I have competed have been equally inspirational and motivating over the past 11 years. This year, my Chicago North Stars team reeled off five straight wins after starting 1-3 to win the National Women’s Basketball Championship in Albuquerque, NM this past June in the 70-74 age division. It was our first national title and a real triumph for a group dealing with a host of health issues including Parkinson’s disease, brain aneurysms, cancer, knee and leg injuries, peripheral neuropathy, traumatic brain injuries, and heart surgery. Each of my teammates has a story to tell and is amazing in her own right.

How has being involved with the team helped you, your health, your life? The Chicago North Stars have been my family since 2013 when we first played together. We lost every game that year but a bond was formed and the benefits, physically, emotionally, and socially, were immense. Most of us are not athletes, nor possess great talent or skill, but we have each other while sharing an unyielding determination.

What would you say to people who are looking for inspiration to live their best life, despite their PN? Change and improvement is within all of us but we need a network of support. Find or build your network, set goals, and have fun. Become as active as possible and stay connected. It is not easy and there are still challenges for me, but no matter the curve

balls thrown at you, there is hope and relief within reach. You just have to believe there is hope, reach for it, adjust as you need to, but do not succumb to the challenges. Seek the best options for you. For me, it has been the National Senior Games Association which has been much more than just competition. There is still a glorious world to be experienced. Embrace it.

What would you love people, with and without PN, to know? PN, like other health issues, is a real challenge but should never define us. It pains us unmercifully at times and distracts us but we cannot let it consume us. We are about much more than just neuropathy. We are about school, careers, family, and the loving and caring spirit we bring to this world. When I taught school, many of my students thought I was a superhero when they learned I had no sensory feeling in my legs and feet. They thought it was amazing. I guess it’s all on how you perceive your challenges.

When the challenge becomes overwhelming, surround yourself with people that will support you and allow you to grow and not just rescue you. In life, we are all learners and teachers. Learn when you need to understand and teach when others need mentoring and support.

You are such an inspiration—what motto do you live by? I’ve learned that I am never alone nor I can achieve anything without others. I live by the principle of perpetual motion by constantly exploring new opportunities, seeking activities that provide movement and exercise and stimulate the mind, and network with positive minded people. Surprisingly, it’s a rather simple recipe for life and not a magic potion.

Thank you, Dana, for inspiring us all!

ACUPUNCTURE *for the* TREATMENT *of* NEUROPATHY



Acupuncture has been utilized in the East for centuries and thought to balance “Chi”, one name for our vital life force energy. In the West, acupuncture is growing in popularity for the treatment of a variety of issues, including but not limited to headaches, digestive issues, neck and back pain, fatigue, anxiety and hormonal imbalances. Research studies support the use of acupuncture for a variety of chronic pain syndromes including chronic pain from diabetic neuropathy and carpal tunnel syndrome.^{1,2}

A recent article published in 2014 in the Journal of the American Medical Association (JAMA), Acupuncture for Chronic Pain, performed a large analysis of acupuncture in 29 clinical trials involving 17,922 subjects. It was concluded that acupuncture is associated with improved pain outcomes in a variety of pain syndromes as compared to controls.²

Although there are various approaches that can be utilized by the experienced acupuncturist in the treatment of neuropathy, the procedure most commonly utilized in medical acupuncture involves inserting very thin needles into acupuncture “points” which are located along the pathway of the affected nerves and muscles. Additionally, a small electrical current is often applied to the tips of the needles to augment the pain-relieving effect. Generally, the procedure does not cause discomfort. The needle insertion should and can be felt as the needle contacts the “Chi”, but it is generally not a very strong sensation and is typically well-tolerated. Some individuals find the sensation of the needles and the added electrical current calming to the nerves and emotions.

There are multiple theories for how acupuncture exerts its therapeutic effects, many of which are relevant to the nerves and neuropathy. Some of the proposed mechanisms of action include the promotion of the release of the body’s own pain-relieving chemicals and nerve growth factors and changes in the brain’s perception of pain.

Generally, a course of 6-12 acupuncture treatments, lasting from 30 minutes to one hour, 1-3 times per week is recommended to determine if acupuncture will be of benefit to any one individual. The results tend to be cumulative, and the benefits sometimes cannot be appreciated until after several weeks of treatment. Once benefit is noted, less frequent treatments may be sufficient to maintain the therapeutic effect. Some of the potential benefits of acupuncture for neuropathy include reduced aching, burning, prickling, numbness and hypersensitivity of the nerves.

Common side-effects of acupuncture can be bruising and soreness at the site of needle insertion. Very rarely, there are serious complications such

as skin infection or organ puncture, complications which are avoidable by the proper technique and utilization of sterile, disposable needles by the practitioner. As long as the acupuncture is performed by a qualified practitioner, the procedure is safe. I would recommend seeking a physician (MD or DO) trained in medical acupuncture and board certified by the American Board of Medical Acupuncture (DABMA). The American Academy of Medical Acupuncture keeps a list of trained medical acupuncturists at their website: <https://www.medicalacupuncture.org/Find-an-Acupuncturist>

Acupuncture is not taught in the standard medical school training curriculum in the U.S. Therefore, your doctor may not be familiar with acupuncture as a safe and potentially effective alternative or complement to standard medical practices. Additionally, medical insurance does not always cover the costs of acupuncture. Fortunately, this situation continues to evolve and improve as more insurers and insured alike are turning to acupuncture as a safe, affordable alternative or complement to prescription medications.

Julie Rowin MD is a Neurologist, Neuromuscular Specialist and Medical Acupuncturist in Westchester, Illinois. She is board certified by the American Board of Medical Acupuncture and works with several modern adaptations of traditional acupuncture techniques for the treatment of neurological disorders including: Neuroanatomical acupuncture, Chinese scalp acupuncture and Auriculotherapy.

1. Dimitrova A, Murchison C, Oken B. Acupuncture for the Treatment of Peripheral Neuropathy: A Systematic Review and Meta-Analysis. Journal of alternative and complementary medicine (New York, NY). 2017;23(3):164-179.

2. Vickers AJ, Linde K. Acupuncture for chronic pain. JAMA. 2014;311(9):955-956.

Living Well with PERIPHERAL NEUROPATHY

On September 14, in collaboration with the Neuropathy Alliance of Texas (NATX), FPN hosted a Patient Conference in Austin, Texas. The presentations centered around the topic of living well; namely how to maintain your independence at home and on the road, integrative approaches to thriving with chronic illness, exercising through all stages of PN, and an update on clinical trials for treatment for neuropathy.

Following this half-day conference was a networking luncheon which allowed patients to mingle with each other, the speakers and staff of FPN and NATX.

If you were unable to attend this event and would like to watch the presentations, the recording can be accessed through our online Media Center, exclusive to FPN’s Premium Members.

A BIG thank you to our sponsors for supporting this event!

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Driving and Neuropathy

The ability to drive is an integral part of our daily lives and holds a lot of meaning to all of us as we age. Driving enables us to access the community, provides us with independence, and is intimately tied into our idea of self-worth. Some people might be concerned that, as we age or our neuropathy symptoms worsen, we will lose the ability to drive.

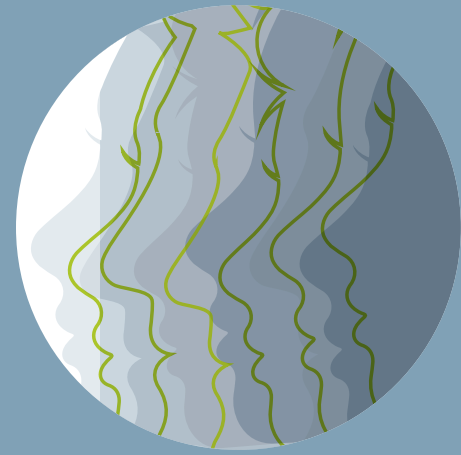
Megan Frazier, MS, OTR, DRS, owner of Functional Stability and Mobility, spoke at both a PN Support Group meeting as well as our Austin Patient Conference, and provided various resources for driving safety and information on potential driving options. Her company provides driving evaluations and training focused on keeping clients safely on the road for as long as possible. Symptoms such as foot and hand numbness, slowed response time, loss of balance, and difficulty knowing how much pressure you are putting on the pedal can significantly impact your ability to safely drive.



Medications and related side effects are also an important consideration when evaluating your driving safety. You can check how your medications may impact driving at roadwiserx.com. It is important to speak regularly with your doctor about how your symptoms are progressing and if you notice them affecting your driving.

And if you're concerned, your physician can recommend a referral to an Occupational Therapist Driver Rehab Specialist (OT DRS), who can complete a Comprehensive Driving Evaluation to determine how your specific symptoms are impacting your driving. You may find that you could benefit from adaptive modifications such as hand controls, a left foot accelerator, and/or steering wheel modifications to increase your safety, help you continue driving longer and help you live your best life.

If you found the information from Megan beneficial and/or want to learn more, watch her presentation from our September 14 Austin Patient Conference, where she provided more modification tips for driving to make your life more accessible. Go to: www.foundationforpn.org/living-well/fpn-media-center/



The Faces of Peripheral Neuropathy

The Foundation for Peripheral Neuropathy aims to raise awareness of peripheral neuropathy among patients, physicians, research scientists, and the general public. While raising awareness is something we do all year, we focus particularly on greater knowledge and recognition of peripheral neuropathy during National Peripheral Neuropathy Awareness Week, which FPN sponsors each May.

This year, we initiated an effort to expand the general perception of what peripheral neuropathy is and who is afflicted through our Faces of Peripheral Neuropathy campaign. During the campaign, we collected stories from hundreds of patients, young and old, from around the world, on their peripheral neuropathy history and how they manage their lives with peripheral neuropathy.

We are bringing these stories to our members and readers through our newsletters and our website. Keep a lookout for them in our upcoming newsletters, or read them for yourself on our website section Patient Testimonials.

Have a story to tell yourself? Please submit your story at www.foundationforpn.org/share-your-story/

Charitable Giving in the New Tax Age

2019

At FPN, we have the utmost gratitude for you, and all of our donors, who make the work we do to improve the lives of people living with peripheral neuropathy possible. We also understand that new tax regulations have changed the tax implications of these gifts. In order to help us all understand what these changes mean, we recently hosted a presentation with a panel of experts in the areas of planned giving, wealth management, and charitable gift accounting.

Mark Friese, Senior Vice President, Wealth Management with Menick, Friese, Phillips, Bock Group/Merrill Lynch & Co provided an overview of some of the gift planning tools you can use that allow you to both support our mission and also provide benefits to you and your loved ones.

For instance:

- You can make a gift using appreciated securities and realize larger tax savings than if you donated cash or cashed in those securities;
- You can make a donation directly from your IRA fund that supports our education and research programming;
- You can structure any number of trusts or giving formats that can meet your requirements, even provide tax benefits or income to you and your family, yet can also help advance our mission;

- You can leave a lasting impact by taking actions now through bequests and directed funds.

This presentation, as well as other charitable giving tools, are available on our website.

If you would like help locating these resources, or would like to schedule a conversation with Mark Friese to learn more about the options available to you personally, please contact:

Nancy Frohman at 847-808-4374.



Did you know you can shop at Amazon and support the FPN mission to improve the lives of patients with peripheral neuropathy?

By doing your online shopping through AmazonSmile, and selecting the Foundation for Peripheral Neuropathy as your designated charity, you can shop to your heart's content—and know that Amazon will donate 0.5% of the price of your eligible purchases to the Foundation for Peripheral Neuropathy, with no additional cost to you.

How do I shop and support FPN? Go to <https://smile.amazon.com/ch/26-1195248> to be taken the AmazonSmile website, and your purchases can help the millions of patients living with peripheral neuropathy.



Like us on [Facebook.com/FoundationForPeripheralNeuropathy](https://www.facebook.com/FoundationForPeripheralNeuropathy) and join the conversation.



The Foundation for Peripheral Neuropathy newsletter is published two times a year—Spring and Fall.

The information contained in this newsletter is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.



the FOUNDATION for PERIPHERAL NEUROPATHY®

485 Half Day Rd., Suite 350
Buffalo Grove, IL 60089
info@tffpn.org
847-883-9942

For the most up to date news and information, visit our website:

WWW.FOUNDATIONFORPN.ORG

The Foundation for Peripheral Neuropathy hopes our mission is important to you and that, by supporting us, we help you fulfill your personal objectives for charitable giving.

MAKE A DIFFERENCE TODAY

Please use the enclosed donation envelope (or donate online at www.foundationforpn.org) to support the ongoing work of the Foundation.

Contact Nancy at 847-808-4374 or at nancy@tffpn.org

For more information about giving, including bequests and sponsorship opportunities

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