



the FOUNDATION for
PERIPHERAL NEUROPATHY®

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FPN | News

SPRING 2021



FROM THE
EXECUTIVE
DIRECTOR

Despite COVID-19 impacting many of our lives in a less-than-ideal way, *the* Foundation for

Peripheral Neuropathy (FPN) has found the last year to be extremely fruitful.

Thanks to our grassroots efforts, our advocacy program was a huge success! For the first time ever, peripheral neuropathy is included in the Department of Defense's Appropriations Bill as an eligible condition to receive up to \$370 million in research dollars. The Foundation was instrumental in the approvals, and our researchers are more than eager to submit applications for funding in 2021. (Read more on page 3.)

The Peripheral Neuropathy Research Registry has also grown this year, with the addition of a new enrollment site in the University of Michigan. FPN looks forward to this new partnership and eagerly invites our readers to meet the new Principal Investigator who will lead this site in this program—Dr. Amro Stino. (Read interview on page 1.)

And why stop this momentum? So much more is in store this year, with more virtual educational programming being made available to allow people to access more information from their homes during the COVID era. (See page 2.)

I hope that you will enjoy this issue, which will highlight some of our key researchers and volunteers within. This newsletter will hopefully offer plenty of answers on other topics that our readers find to be helpful too and, with your continued support, we will be able to provide more answers for you and other patients in the foreseeable future.

Thank you for being a part of our community. Keep staying safe!

Lindsay Colbert



THE PNRR WELCOMES THE UNIVERSITY OF MICHIGAN AND DR. AMRO STINO

The Foundation for Peripheral Neuropathy (FPN) is pleased to welcome the University of Michigan as a new site for patient enrollments into the Peripheral Neuropathy Research Registry (PNRR). Lindsay Colbert, FPN's Executive Director, recently sat down with Dr. Amro Stino, the site's Principal Investigator (PI) in this research project, to learn more about him and his interest in PN and learn why this new partnership will be beneficial for the peripheral neuropathy research community.

Q Dr. Stino, how long have you been a neurologist and focusing on peripheral neuropathy?

A For eight years now.

Q What areas of research are you most interested in in the field of PN?

A Autoimmune neuropathy, GBS, CIDP, anti-MAG neuropathy, but also cryptogenic and metabolic syndrome neuropathy reversal as well as pain management.

Q We're excited that the University of Michigan is a new enrollment site in

the PN Research Registry as of February 2021. How did you learn about FPN and the PNRR?

A Dr. Gordon Smith, a former Principal Investigator for the PNRR at the University of Utah and a current Board Member of the Foundation, is a friend and mentor. I had also been aware of the work being done in the FPN space and was eager to be part of it.

Q What excites you most about the PNRR and your partnership in the consortium?

A The ability to rub shoulders with experts in the field and to partake in cutting-edge research through impressively large-scale questionnaires and biospecimen data. Very excited!

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PROFILE | Simone Thomas



Simone Thomas is the Project Manager for the Peripheral Neuropathy Research Registry (PNRR).

Here, we give some insight behind the person who is responsible for managing this important FPN program that serves as a cornerstone for research programs and studies in key academic research institutions across the U.S.A.

the PERIPHERAL NEUROPATHY | Research Registry

Why did you get involved in the field of peripheral neuropathy?

Until 2015, I worked as a Project Scientist in the space flight program. When the government contract I worked under was cancelled, my choices were to move back to Houston or to reinvent myself new. I like living on the East Coast, love to have four seasons, the hills and mountains and walking through the woods – all things you cannot find in Houston. Thus, it was a difficult decision, but in the end, I decided that I will try to find new employment at a large research institution and my first choice was Johns Hopkins University (JHU). I ended up finding a position in the Neurology Department in the Neuromuscular Division, and my first clinical research assignment was the PNRR. Getting involved in neuropathy research was rather by chance than by design, but I am glad I did.

How did you learn about FPN?

I work with Dr. Ahmet Höke, who is the lead investigator for the PNRR, and my first work assignment was to be the JHU liaison for the project. That is when I learned about the Foundation and the work the Foundation is doing.

Why is your role as PNRR Manager so important?

With any research project, the quality of the data is important – you need to make sure that your results are real and accurate. As the Project Manager, I ensure that all PNRR data records are of high quality. That is accomplished by reviewing the data set of each new enrollment record and checking that all data seems to be consistent with a diagnosis of PN and with the PNRR guidelines.

What excites you most about the PNRR?

The PNRR is a very powerful research tool. When conducting clinical research, it takes the longest time to collect data and samples. The PNRR collects both data and samples for researchers “ready to use.” Similar database projects have boosted research for other medical conditions in the past. I hope that the PNRR will accomplish that for the subtypes of peripheral neuropathies we investigate in the database. Right now, we have just over 2000 patients enrolled, which sounds like a lot, and can meet some research needs, but for some of the research applications we plan to do, we still need more patients to join the registry.

Do you think that peripheral neuropathies will ever be cured?

I am optimistic that we will find better treatments for peripheral neuropathies as we learn more about the underlying conditions that are causing the nerve impairment to begin with. Slowing down or even stopping disease progression and finding better relief for the most daily-life impairing symptoms, such as neuropathic pain, should be feasible in the not-so-distant future.

Do you have any suggestions for patients who want to be a part of the research solution?

There are multiple ways to be part of the research solution: agree to participate as a subject in clinical research, or become a lobbyist to advocate for research by increasing public awareness, or by donating to organizations like *the Foundation for Peripheral Neuropathy*. Funding is the constant critical denominator for research, because it takes time (lots of man-hours) and the required laboratory equipment and agents are expensive.

What is unique about the PNRR for you and other researchers?

Having medically-relevant information for the evaluation of PN from over 2000 patients by itself is already a powerful research tool, but the PNRR also collects blood samples from the majority of the enrolled patients. Thus, if we see trends and mechanisms during data analysis, we will then be able to immediately investigate this further by having blood samples for microbiologic analysis readily available. That is priceless.



Building on the success and positive feedback from our educational webinars in 2020, we are planning another full year of educational programming designed to bring presentations from experts—all online and all viewable from the comfort of your own home.

Here is what we have in store

- Trends in Charitable and Planned Giving
- Supplements for Nerve Health (Sponsored by LivOn Labs)
- Ask the Expert: Your Questions on COVID-19 and PN Answered!
- Nutrition and Health (Sponsored by LivOn Labs)
- Physical Therapy for PN
- Chair Yoga for PN Patients
- Healthy Meal Prep
- Diabetic Peripheral Neuropathy: The Patient's Experience
- Peripheral Neuropathy and Mental Health
- Foot Health for Peripheral Neuropathy Patients
- Infrared Light and Physical Therapy for PN
- Ask the Expert: Your Questions on Living Well Answered
- Hereditary Peripheral Neuropathy: What is it? How to deal with it

Check our website (www.foundationforpn.org/events) for dates and times. We will also send details on all sessions through our email announcements. Sign up for announcements by emailing us at info@tffpn.org.



ADVOCACY

PN IS FINALLY ELIGIBLE FOR FUNDING FROM THE DOD!

In December, FPN applauded action taken by Congress to designate “peripheral neuropathy” as a condition eligible for research funding from the Department of Defense’s (DoD) Peer Reviewed Medical Research Program (PRMRP). Language designating the condition eligible for funding is included in the fiscal year 2021 Omnibus Appropriations Act cleared on December 21, 2020, by the House and Senate.

“Enactment of this legislation opens new doors for our research community to apply for critical research dollars to study a condition that affects 30 million Americans,” stated Lindsay Colbert, Executive Director of FPN. “The PRMRP funds innovative high-risk, high-reward research that leads to new treatments and cures, and we are delighted that our researchers will now have an opportunity to compete for this funding.”

Every year, Congress designates dozens of specific conditions that are eligible for research dollars from the PRMRP, which is funded at \$370 million in the Omnibus legislation. Prior to the enactment of this legislation, peripheral neuropathy was never included by Congress as a PRMRP research topic. Thanks to a national advocacy program initiated by the Foundation that engaged grassroots advocates across the country, Congress took an interest in the disorder, particularly as it relates to members of the U.S. Armed Services, and their families.

“As our veterans population continues to age, peripheral neuropathy will grow in prevalence, and new breakthroughs are needed to treat this population, as well as current members of the U.S. Armed Forces,” stated Lou Mazawey, President of FPN’s Board of Directors. “Including peripheral neuropathy in the PRMRP will significantly augment the amount of research that the DoD currently funds, and will greatly accelerate our research community’s efforts to find a cure for this debilitating condition.”

University of Michigan (continued)

“...every disease has a cure, and we just need to find it.”

Q Dr. Stino, are you hopeful that we will find cures for peripheral neuropathy in the future?

A I am. I personally believe every disease has a cure, and we just need to find it. I think data regarding dietary and exercise impact on metabolic syndrome early and small fiber neuropathy reversal is very encouraging.

Q When seeing patients, what is the most common complaint you hear?

A Burning foot pain is the single greatest complaint. Numbness comes second. Interestingly, weakness is not always reported, but often incidentally noted on exam, and then patients will mention it.

Q When seeing patients, what is the most helpful thing you can tell them?

A I always advise patients to establish goals of care in any clinical visit. Is their goal to run? Get pain relief? In general, if there is a fall risk, I counsel them extensively on the fact that fall risk (while not as noticeable as pain) is the greatest risk to health.

Q Is there anything else that the FPN community should know about you, Dr. Stino?

A I am someone who enjoys collaborating with investigators, clinicians, and teams both nationally and internationally. I enjoy traveling (my parents are from Egypt, so I often enjoy going overseas and visiting and documenting historic and cultural landmarks), which spurs an interest in international-based research. I am an avid sports fan (a Michigan Wolverine at heart), although I also have a special place in my heart for The Ohio State University, as it was my first job.

Thank you, Dr. Stino, and welcome to the FPN research team!

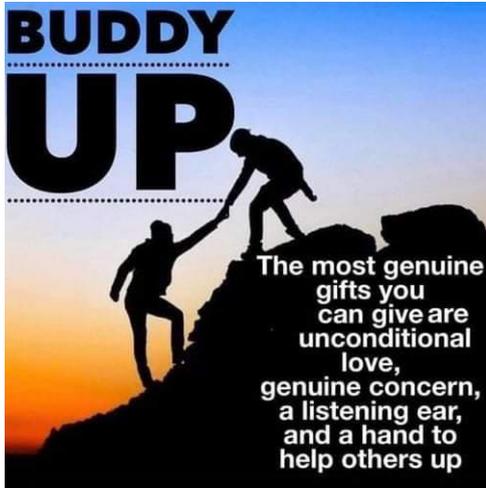
If you are interested in getting involved in this research project, please contact FPN.

CLINICAL TRIALS AMIDST COVID-19

COVID-19 put a halt on many activities; however, thankfully most clinical trials are back up and running. Dr. Ahmet Höke, the Foundation’s Scientific Advisory Board Chair,

reiterates that the best way that patients can get involved in trials is through the website, www.clinicaltrials.gov and following up with the Foundation or the performing site if they have questions about the particular trial they’re hoping to participate in.

Many trials are *not* offered to patients virtually, as much of the participation requires physical examinations and tests, states Dr. Höke. There are, however, some research studies that allow patients to fill out a questionnaire form so that travel outside of their home is not necessary.



Written by Michael Wright, founder of **Peripheral Neuropathy Success Stories!**, shares his new program, **Buddy Up!**

"I am writing to advise you that my buddy has been chatting with me for about two weeks now through the Buddy Up! program. She has helped me a lot through this difficult time, and I greatly appreciate what she's doing for me. She's patient and listens and provides great advice. I am grateful for this service."

That feedback was recently sent to me in reference to our Buddy Up! program, which is part of our Facebook group, Peripheral Neuropathy Success Stories!. I started this group a short while ago so that neuropathy patients would have a positive support group that inspires and educates. We now have nearly 11,000 members in over 100 countries.

Sometimes, our members need some extra support, a little push, and this was the genesis of "Buddy Up!" Members can request to be paired with people who have been certified to be a Buddy. Communication is done through Facebook Messenger, so it's convenient. Dozens of members have benefited, and we've had rave reviews!

Come join our group, if you haven't already, and let us know if you too could use a BUDDY!

You can be a Buddy or find a Buddy through the Buddy Up! program.

Join the Facebook group, Peripheral Neuropathy Success Stories!, and message Michael Wright through that group. Or email FPN through info@tffpn.org, and we will make sure you are connected!



FPN VOLUNTEER SPOTLIGHT

Alex Feigenbaum

Google Grants and Search Advertising

Alex Feigenbaum has lent her expertise to *the* Foundation for Peripheral Neuropathy to allow us to publish ads on Google. Through Google Ads, FPN is able to reach more patients and spread awareness for peripheral neuropathy. Here, Alex gives us a lesson on advertising in the digital world.

Q: What is a Google Grant and who qualifies for one?

A: The Google Ads Grant program provides qualifying non-profit organizations with up to \$10,000 a month in subsidized advertising dollars. In other words, qualifying nonprofits can run ads on Google free of charge, up to \$10,000/month. To qualify, a nonprofit must hold valid charity status in its country of origin, and cannot be a governmental entity or organization, hospital, school, or university.

Q: What is Search Advertising? What are Google Ads?

A: Search advertising is when a business or organization pays for ads to be placed in front of users based on their search engine queries. For example, we may show an ad to someone searching for "information on neuropathy." We get charged a fee every time someone clicks on our ad.

Google Ads refers to ads specifically configured and deployed on the Google Search Network. You may notice that when you search for something like "Dentist Near Me," many of the initial results have an "Ad" icon next to them. This indicates that they are ads paid for and run on the Google Search Network.

Q: Why Search Advertising?

A: Search advertising can be very effective because it matches people who are searching for something on an engine with resources or products and services that meet that need. When people search for something on Google, they are effectively telling Google what they need or are looking for. When configured correctly with appropriate keywords (specific words that trigger a Search ad), advertisers can identify and meet that need with their own services.

Q: How can search advertising benefit nonprofits?

A: Grants can be leveraged in many ways to benefit the goals of each nonprofit! At FPN, our Grant efforts have focused mainly on disseminating relevant information to those who may be in the process of searching for information on neuropathy.

Q: Are there requirements for maintaining a Grant account?

A: Yes, there are! This can get a bit technical and is not an exhaustive list of the requirements. Each account must maintain at least two Ad Groups (a group of ads with a common goal), and each Ad Group must contain at least two ads. Each account must utilize location targeting provided by Google in order to ensure that they are only targeting those within their service area. Additionally, there must be a negative

Volunteer Spotlight (continued)

keyword list (keywords that exclude certain searches) to keep targeting relevant.

Q: What about performance?

A: Performance tracking is a huge part of any successful marketing campaign, and is also a requirement of maintaining Grant status. While setting

up a campaign, it is essential to identify the purpose of the campaign and how performance will be measured, both in terms of hard and soft goals.

Every organization has different goals, and therefore their campaigns will have different goals. Common goals would be phone calls, emails, form submissions and app downloads. These are best tracked with a Google Analytics, which

can be linked back to the Google Ads account.

We thank Alex for offering her expertise which has enabled FPN to expand our reach to more people who need or want information about PN. Do you have a skill, expertise, or interest in areas such as technology, public relations, fundraising, marketing, writing, medical research or review that can help FPN advance its mission? Let us know!

SUPPLEMENTS for Nerve Health

Because so many factors from diabetes to cancer to liver failure to vitamin deficiency affect nerve health, dietary supplements vary in their effectiveness. While most supplements for nerve health are safe, it's important to research any interference they may have with medications, and talk to your doctor or pharmacist.

Poor nerve health is often accompanied by inflammation and oxidative stress, which exacerbate challenges to attaining optimal nerve health. Many of the supplements that support nerve health have anti-oxidant properties.

Supplements should be taken to address potential nutritional deficiencies. "Nutritional gaps" do not take into account absorption challenges. Stress, alcohol, medications, and aging can deplete minerals, vitamins, and antioxidants.

Getting all your nutrients from food may not work for everyone in today's day and age. Supplementing the nutrients you need in the correct doses in forms you can absorb is an easy way to take a proactive role in supporting nerve health.

B12 | Vitamin B12 deficiency can manifest itself in the nerves.

While too much B12 won't hurt, more B12 doesn't mean more benefits. Your body has a limited capacity for B12 absorption. Strict veganism and chronic inability to absorb B12 can cause deficiency.

B6 | Vitamin B6 is associated with poor nerve health when you have too little and when you have too much. B-Complex supplements usually contain appropriate doses.

B1 | Vitamin B1 (thiamine) is critical for healthy nerves. Deficiency is rare in the developed world, but can occur in alcoholics and people who have had gastric bypass surgery. Thiamine is found in most B-Complex supplements.

ALPHA-LIPOIC ACID | Oxidative stress can damage tissues and nerves. It's a feature of obesity and related conditions like diabetes. Some studies have found positive effects in taking alpha-lipoic acid due to its ability to mitigate oxidative stress damage. Alpha-

lipoic acid also supports insulin sensitivity and healthy blood glucose levels.

N-ACETYLCYSTEINE | The supplemental form of amino acid cysteine, NAC has shown promise in supporting nerve health by improving liver function.

Cysteine is the most important building block of the master antioxidant glutathione, which helps your liver remove foreign substances from your body.

GLUTATHIONE | Alpha-lipoic acid, NAC, l-carnitine, selenium, and vitamin C have shown promise in supporting nerve health. Is that because these nutrients increase glutathione?

Excessive oxidative stress and depressed glutathione levels are often experienced by people looking to improve their nerve health. Researchers believe the aforementioned nutrient combination can support nerve health, possibly by its effects on glutathione.

Glutathione is difficult to absorb from pills, which is why it's a staple in IV clinics. Liposomal glutathione may enable superior absorption.

FISH OIL | Inflammation is a characteristic of damaged nerves, and the anti-inflammatory effects of the omega-3 fatty acids in fish oil are well known. Researchers examined this supplement's effects on diabetic mice who had fewer nerves in their paws, and found the rats showed improved nerve health.

MAGNESIUM | Magnesium is critical in glucose metabolism and maintaining healthy insulin sensitivity. Low magnesium is correlated with oxidative stress. While results are mixed, research indicates a possible association between magnesium and healthy peripheral nerve function.

How to supplement for nerve health

The most effective way to supplement for nerve health is to understand what is compromising your nerve health. Get tested for nutritional deficiencies and biomarkers of oxidative stress. The only way a supplement will work is if you need it.

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MAKING AN IMPACT TODAY AND INTO THE FUTURE

You can help us continue to improve the lives of people with peripheral neuropathy and inspire future scientific research and discoveries with a legacy gift.

The Foundation for Peripheral Neuropathy has teamed up with experts from Merrill Lynch to bring you information on charitable planned giving and planned giving structures.

To learn more, contact Nancy at **847-808-4374** or go to our website at **www.foundationforpn.org**.



Like us on **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.



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