



the FOUNDATION for  
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

# FPN | News

FALL 2021



FROM THE  
EXECUTIVE  
DIRECTOR

Dear Friend:

Another year is almost complete, and I am thrilled to be writing

to you today with a healthy mind, body, and soul. I hope you are also staying strong amidst the pandemic and trust you are finding peace and new opportunities to stay connected with your communities during these unusual times!

The Foundation for Peripheral Neuropathy (FPN) continues to strive for success and new ways to engage with our loyal supporters and newly-diagnosed patients during the pandemic. At this time, I'd love to highlight three updates which demonstrate our organization's commitment to you and our closest supporters in 2021.

1. In the new year, we are launching a new website which we hope will offer the continued excellence you have grown to expect and appreciate. Our website will offer important updates on research developments, much-needed resources for our patients and caregivers, and a new look and feel that will be user-friendly and beautiful for our friends! Visit us at [www.foundationforpn.org](http://www.foundationforpn.org).
2. Since gathering together continues to prove difficult in 2021, we will continue to grace your home on a monthly basis with our educational programs. We hope you can participate in our webinars. Some exciting programs coming up in November and December that I would like to highlight include Updates on PN Research, Ask the Expert, and Nutrition and Supplements.

(continued on page 3)



## NEW RESEARCH PROJECT UNDERWAY

In collaboration with the Kelly Laboratory, Protego Biopharma recently accessed 40 biosamples from FPN's Peripheral Neuropathy Research Registry<sup>1</sup> to develop a new treatment option for PN patients. Researchers from Protego informed FPN of the development of an ELISA<sup>2</sup> specific for non-native transthyretin that is being proposed to use as a diagnostic/prognostic assay in patients with Familial Amyloidotic Polyneuropathy (FAP) related to transthyretin deposition and carriers of mutations responsible for the disease.

This study will probe the biochemical mechanisms of amyloid diseases with 40 plasma samples, studying idiopathic, chemotherapy-induced, and diabetic peripheral neuropathy patients between the ages of 30 and 70, half male, half female.

The study, which is anticipated to be completed at the end of 2021, will also use the assay to determine target engagement by various therapeutics either in use or in development for the treatment of these disorders.



<sup>1</sup> Learn more about the PNRR on Page 3

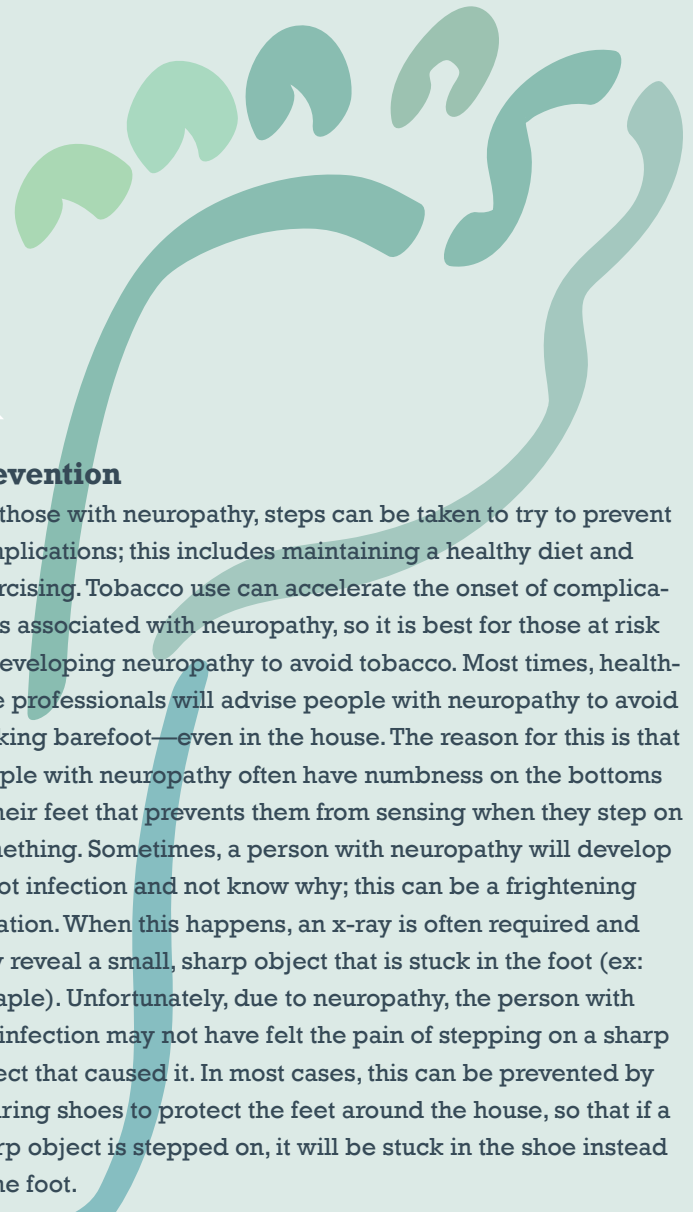
<sup>2</sup> What is an ELISA? ELISA (enzyme-linked immunosorbent assay) is a plate-based assay technique designed for detecting and quantifying soluble substances such as peptides, proteins, antibodies, and hormones. In an ELISA, the antigen (target macromolecule) is immobilized on a solid surface (microplate) and then complexed with an antibody that is linked to a reporter enzyme. Detection is accomplished by measuring the activity of the

reporter enzyme via incubation with the appropriate substrate to produce a measurable product. The most crucial element of an ELISA is a highly specific antibody-antigen interaction.

### INSIDE

- PN and Foot Care
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# Peripheral Neuropathy & Foot Care



People with neuropathy are at increased risk to experience problems with their feet. This risk involves the potential for skin changes, ulcers that don't heal, infection, and other complications. As a result of this increased risk, it is suggested that people with neuropathy take special care of their feet to try to avoid problems. While specific directions can only be provided by your healthcare provider, this article will provide general recommendations that apply to most patients with neuropathy.

by: Jeffrey Lehrman, DPM

## Types of Neuropathy

There are three main types of peripheral neuropathy: sensory, motor, and autonomic. Sensory neuropathy affects the nerves that allow you to feel things. This commonly involves the feet and can result in numbness, tingling, burning, sensitivity to touch, as well as other symptoms. Motor neuropathy affects the nerves that control muscles and can result in lack of coordination, falling, and/or weakness. Autonomic neuropathy affects nerves that function automatically and can result in excessive sweating, low blood pressure, dizziness, and more. The most common of these types of neuropathy is sensory neuropathy.

## Foot-Related Neuropathy Complications

Neuropathy is a nerve disease and, often, the smallest nerves of the body are most susceptible to damage caused by neuropathy. Typically, as nerves travel farther away from the center of the body, they become smaller; some of the smallest nerves are found in the feet. As a result, symptoms of neuropathy are often experienced in the feet. People with neuropathy may experience foot discomfort, loss of sensation, dry skin, and skin ulcers that do not heal properly.

## Prevention

For those with neuropathy, steps can be taken to try to prevent complications; this includes maintaining a healthy diet and exercising. Tobacco use can accelerate the onset of complications associated with neuropathy, so it is best for those at risk of developing neuropathy to avoid tobacco. Most times, healthcare professionals will advise people with neuropathy to avoid walking barefoot—even in the house. The reason for this is that people with neuropathy often have numbness on the bottoms of their feet that prevents them from sensing when they step on something. Sometimes, a person with neuropathy will develop a foot infection and not know why; this can be a frightening situation. When this happens, an x-ray is often required and may reveal a small, sharp object that is stuck in the foot (ex: a staple). Unfortunately, due to neuropathy, the person with the infection may not have felt the pain of stepping on a sharp object that caused it. In most cases, this can be prevented by wearing shoes to protect the feet around the house, so that if a sharp object is stepped on, it will be stuck in the shoe instead of the foot.

## Shoes

Wearing appropriately-fitting shoes is important for people with neuropathy. It is suggested that people go shoe shopping later in the day. This helps to account for any swelling during the day when the feet are measured. Furthermore, when shoe shopping, both feet should be measured, as many people have different-sized feet. It is typically best for people with neuropathy to avoid shoes that have any rough seams or creases that could rub on their skin and cause problems.

## Shoe Inserts

Not only is shoe selection important, but so is the selection of the shoe insert. Shoe inserts should be the appropriate softness, have the correct arch height, and fit well (both in the shoe and to the person's feet). Now there is a smart shoe insert which monitors the feet and is capable of detecting increases in pressure and temperature (both signs of developing problems) and communicating this information to both the person wearing the smart inserts and to their healthcare provider. These smart shoe inserts can help to prevent the formation of foot ulcers. Readers can learn more about these at: [www.orpyx.com](http://www.orpyx.com).

## Conclusion

People with neuropathy are at risk of developing foot problems. Following the guidance provided here, when appropriate, and discussing these things with a healthcare professional can help prevent these problems from occurring, or manage them if they have already begun.

# What is our Research Registry all about?

The Foundation for Peripheral Neuropathy's Peripheral Neuropathy Research Registry (PNRR) is a set of patient data and samples intended for research use. These samples and data are from peripheral neuropathy patients with diabetic, chemotherapy-induced, HIV/AIDS, and idiopathic neuropathies.

*the* PERIPHERAL  
NEUROPATHY Research  
Registry

The intent of this program is for new research projects and clinical studies to start, so we can learn more about the characteristics of painful vs. non-painful neuropathies and better diagnose this condition. With new research, there is always new opportunity for advancements in treatment and prevention strategies.

More information about the PNRR can be found at:

[www.foundationforpn.org/research/research-registry/](http://www.foundationforpn.org/research/research-registry/).

*From the Executive Director (continued)*

3. Our commitment to research has not swayed amidst COVID, rather it has gotten stronger!
  - a. FPN will soon be funding the IMAGiNe Study for anti-MAG peripheral neuropathy patients (a rare autoimmune variety of PN), to identify and predict disease progression and treatment response for sufferers of the disease.
  - b. This year, FPN increased its funding to our unique biobank program, the Peripheral Neuropathy Research Registry (to develop treatments for chemo-induced, diabetic, idiopathic and HIV/AIDS neuropathies). We continue to work closely with new researchers who want to gain access to this data to advance research.
  - c. And lastly, FPN continues to push its agenda on the Hill, to advocate for PN patients and continue receiving government dollars for peripheral neuropathy research into 2022.

More updates on these research initiatives can be found within this newsletter.

As always, I thank you for your continued support and loyalty to FPN. In return, I promise nothing short of excellence and outstanding service provided by my staff and the organization's esteemed boards and volunteers! We do this for YOU!



Last year, *the* Foundation for Peripheral Neuropathy secured a significant milestone victory in its federal advocacy efforts. Thanks to the efforts of our grassroots advocates, Congress for the first time included the designation of “peripheral neuropathy” as an eligible condition for study under the Department of Defense’s Peer Reviewed Medical Research Program (PRMRP). This designation was included in the final enacted version of the fiscal year 2021 Defense Appropriations Act.

In response to this action, on March 15, the PRMRP issued a program announcement inviting researchers to submit applications for funding. We understand that a number of researchers from the peripheral neuropathy community have submitted applications, and we should know at the end of this year or early next year if any of them are funded.

Throughout 2021, as Congress continues to cope with response and recovery to the COVID-19 pandemic and complex budgetary decisions, FPN has been working to ensure that the peripheral neuropathy designation is renewed in the fiscal

year 2022 Defense Appropriations Act. Throughout the winter and spring, our advocates sent dozens of emails to their senators, asking them to submit our request to the Senate Committee on Appropriations. We also continue to receive support from veterans’ organizations like the Vietnam Veterans of America and Veterans for Common Sense, given the prevalence of peripheral neuropathy in veteran populations.

As of the writing of this report, the Senate Committee on Appropriations has not yet begun “marking up” its version of the fiscal year 2022 Defense Appropriations Act. The majority and minority parties in Congress have been in a stalemate over larger budgetary questions about how much funding should be appropriated for defense and non-defense programs. Until this dispute is resolved, it is unlikely that the 2022 Defense Appropriations Act will move forward in the Senate. However, these disputes are not out of the ordinary, and are often resolved in November or December. In the meantime, FPN will continue advocating before the Senate to ensure that the peripheral neuropathy designation is renewed.

## FPN Welcomes New Board Member



The Foundation for Peripheral Neuropathy is pleased to welcome our newest member of our Board of Directors, Kristy Townsend, Ph.D, effective June 1, 2021.

Kristy holds a Ph.D. in Neuroscience and has been investigating the brain and nervous system in the regulation of energy balance and metabolism for the past 20 years. Townsend is now Associate Professor in the Department of Neurological Surgery at The Ohio State's Wexner

Medical Center and founded the Townsend Lab for Neurobiology and Energy Balance. Research in the Townsend Lab focuses on neural plasticity (or, remodeling and regeneration), and how the brain and nervous system impact appetite, metabolism, and energy expenditure (or, calorie burning).

The Townsend Lab is involved in neuropathy research in three ways:

1. The laboratory investigates how nerve endings can die back into adipose tissue (or, fat tissue) under the skin in conditions of

small fiber neuropathy and how this impacts metabolic health;

2. The laboratory researches mechanisms of neuropathy and potential treatments in cases of diabetes or aging;

3. Townsend and colleagues are working on a medical device for the functional diagnosis of small fiber neuropathy through an academic spin-out company called Neuright, Inc.

**Please join us in welcoming Kristy Townsend to our team!**



## MAKE 2021 THE YEAR FOR GIVING

**While the past year has been a challenging one for many reasons, we at FPN continued to be busy with new programming, new research opportunities, and continued advocacy for more research dollars.**

**And while this year has been unique in many ways, the CARES Act and other legislative and tax regulations makes 2021 a good year to give.**

HERE ARE A FEW WAYS:

### **1 Take advantage of favorable charitable deductions permitted in 2021.**

The CARES Act, passed by Congress at the end of last year permits charitable donations to be deducted from your income taxes as a way to encourage charitable giving.

If you itemize, any of your cash donations up to 100% of your adjusted gross income (AGI) can be deducted. If you represent a corporation, up to 25% of the adjusted gross income can be deducted.

If you don't itemize, you can claim up to \$300 as a deduction for cash donations if you file as an individual. If you file jointly, you and your spouse can claim up to \$600.

These deductions, at least for the moment, are applicable only through the 2021 tax year.

### **2 Make gifts of appreciated securities.**

Although we don't know what future capital gains tax rates will be, we do know that current rates make it a favorable time to donate appreciated securities, such as publicly traded stock or mutual funds that have been owned for more than a year. By donating appreciated shares, the donor can get a deduction on his or her income taxes and is not charged the capital gains tax on the appreciated shares.

### **3 Qualified Charitable Distributions from your IRA.**

Individuals who are 70 ½ or above are required to take a minimum distribution from their IRA account. For those individuals who either do not need this distribution or do not want to pay the taxes or feel the tax effect on this distribution, the IRS allows up to \$100,000 to be donated to a charity without penalty or tax implication.

### **4 Structured Planned Giving Vehicles.**

Many common planned giving structures such as charitable gift

annuities, charitable remainder trusts, charitable lead annuity trusts, among others, can be even more beneficial for the donor because of the current tax environment and 100% AGI limit for cash contributions.

### **5 Charitable Bequests.**

Many of our kind donors have taken the initiative to ensure that we can continue to fund educational and research programming and research initiatives by including a bequest to *the Foundation for Peripheral Neuropathy* in their will. Through their legacy, we are able to help more patients and perhaps one day find a cure. Please consider taking this important step as well. We are happy to provide you with all the information you need to present to your financial advisor or lawyer. Please contact Nancy at [nancy@tffpn.org](mailto:nancy@tffpn.org) for more information.

*We recommend contacting your financial advisor or lawyer about any of the structures or giving plans mentioned in this article. We are also happy to provide information or refer you to one of our advisors for any additional information.*

# Common Causes of B VITAMIN DEPLETION

By LivOn Labs

The eight vitamins of the B family are critical to maintaining healthy nerves. They're some of the most commonly supplemented, some of the most readily available in the drugstore vitamin aisle, but some of the most difficult to absorb—from both food and supplements. And when it comes to getting what you need out of vitamins, absorption is what matters.

Various substances and conditions interfere with your ability to absorb B vitamins from food and supplements.

**MEDICATIONS** | Sometimes the area of your body that is malfunctioning is also responsible for absorbing B vitamins. When you take drugs to treat the condition, they may inadvertently deplete B vitamins.

Take acid blockers. The most commonly prescribed drugs block the production of stomach acid to treat acid reflux and heartburn. Unfortunately, you need stomach acid to extract B12 from food. Antibiotics kill the harmful bacteria causing an infection. They also kill the friendly bacteria in your gut that are required for healthy digestion, thus may deplete thiamine, B2, niacin, B6, biotin, folate, and B12. Blood pressure medications are often diuretics, causing increased excretion of unabsorbed B vitamins in urine.

Oral contraceptives and hormone replacement therapy drugs are also associated with lower levels of B2, B3, B6, B12, and folate. Researchers don't know why. Same goes for some hypoglycemic drugs that are consistently associated with low folate and B12 levels.

**DIGESTIVE CONDITIONS** | B vitamins are absorbed in the small intestine. Compromised digestive function interferes with that process, leading to vitamin depletion.

Atrophic gastritis damages the stomach lining, which is where a protein responsible for B12 absorption is made, and can lead to B12 deficiency. Celiac disease damages the small intestine, making absorption of folate difficult. B12 deficiency is also higher in people with celiac than the general population.

Crohn's disease and chronic diarrhea increase excretion of thiamine and interfere with absorption of B12. Irritable bowel disease can prevent folate absorption.

Older adults are also prone to B12 and folate deficiency due to lower stomach acid (as its production declines with age). A shortage of healthy gut bacteria can deplete biotin.

**BARIATRIC SURGERY** | Altering the digestive tract impedes nutrient absorption, which is why the bariatric supplement industry exists. Forty-nine percent of post-bariatric patients are deficient in the essential nerve nutrient thiamine (B1). B12 and folate depletion are also common.

**DIET** | Here's where it gets a little weird. Polyphenols, beneficial substances in coffee and tea, can decrease thiamine. Folate from some sources can be significantly decreased by cooking. Boiling broccoli and spinach cuts the folate content in half, while the nutrient remains in cooked beef and potatoes. A diet low in zinc can also cause low folate. Alcohol and smoking are also known to deplete B vitamins.

Sometimes nutrient levels are about more than what you eat. It's good to be aware of the common causes of B vitamin depletion to include targeted supplements in your diet.



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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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