improve treatment

discover a cure

the FOUNDATION *for*
PERIPHERAL NEUROPATHY®

DEDICATED *to* REVERSING *the* IRREVERSIBLE

Our mission is to dramatically improve the lives of people living with Peripheral Neuropathy.

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. We will strive to raise awareness of peripheral neuropathy through outreach programs to patients, their families and healthcare professionals.

About the Foundation

The Foundation for Peripheral Neuropathy (FPN) is a 501(c)3 nonprofit organization committed to fostering collaboration among today's most gifted neuroscientists and physicians who are dedicated to neuropathy research and treatment to develop new and effective therapies that can reverse, reduce and one day find a cure for Peripheral Neuropathy. It is our ultimate goal to utilize every means and opportunity to dramatically improve the lives of those living with this painful and debilitating disorder.

Jack Miller is a prominent Chicago area entrepreneur, philanthropist, and is the founder and former President/CEO of Quill Corporation. He is very active supporting a wide variety of community improvement efforts and also serves as Chairman of the Foundation for Peripheral Neuropathy. Mr. Miller was inducted into Philanthropy World magazine's Hall of Fame in January, 2008.

Mr. Miller is one of the 20 million Americans diagnosed with peripheral neuropathy. Having suffered from neuropathic pain since 1995, Mr. Miller understands the challenges of living with neuropathy and has made a commitment to improve the lives of all individuals who suffer with this "hidden disorder." He has dedicated his time and resources to developing programs to educate and raise awareness about the disorder and to help identify potential cures and develop innovative treatments for peripheral neuropathy (PN).

In 1999, Mr. Miller began his foray to support peripheral neuropathy research by creating an endowed professorship, the *Jack Miller Professorship for the Study of Neurological Diseases* at a world renowned University.

To fund further collaborative research and treatment initiatives and to promote educational awareness, the Foundation for Peripheral Neuropathy was established in late 2007. To that end, we have partnered with some of the most accomplished, gifted and dedicated neuroscientists from Johns Hopkins University, Northwestern Medical Faculty Foundation, Beth Israel Deaconess Medical Center-Harvard Medical School and Mount Sinai Medical Center. Each of these important partnerships, while unique in their approach, has a united purpose that is driven by our commitment to advance the diagnosis and treatment of PN.

In the United States and throughout the world, the incidence of peripheral neuropathy continues to rise, and our commitment to make a difference has never been stronger.

Peripheral Neuropathy

The peripheral nerves communicate information between the central nervous system (the brain and spinal cord) and the rest of the body. Sensory nerves are peripheral nerves that transmit sensory information from the body to the central nervous system. Motor nerves are peripheral nerves that transmit information from the central nervous system to the body. Peripheral neuropathy (PN) results when these peripheral nerves are damaged or destroyed and normal communication between the central nervous system and body is disrupted.

Peripheral neuropathy is the manifestation of many different conditions that can damage the peripheral nerves and is considered a neurological disorder rather than one distinct disease. The symptoms and the degree to which they are experienced will depend upon the underlying cause of an individual's neuropathy and on which of the peripheral nerves are involved. For some, symptoms may be barely noticeable, and go on for years without the patient realizing anything is wrong. For others, symptoms are debilitating and constant, often becoming unbearable at night.

These symptoms can begin gradually such as a tingling sensation or numbness that starts in the toes or the balls of the feet and then spreads upward. Eventually, a patient's skin may become so sensitive that the slightest touch is agonizing.

Diagnosing peripheral neuropathy is often difficult because the symptoms are highly variable. Early diagnosis and treatment may offer the best chance for management of symptoms and for prevention of further damage to the peripheral nerves. A thorough neurological examination is required and involves taking an extensive patient history, including: the patient's symptoms, work environment, social habits, exposure to any toxins, history of alcoholism, diabetes, cancer, HIV or other infectious diseases, and family history of neurological diseases. Performing tests that may identify the cause of the neuropathic disorder and to determine the extent and type of nerve damage is also important for proper diagnosis.

The signs and symptoms of peripheral neuropathy may include:

- The sensation of wearing an invisible glove or sock
- Burning, numbness, pain, and/or tingling in the toes, feet, legs, hands, arms and fingers
- Sharp, jabbing or electric-like pain
- Extreme sensitivity to touch, even light touch
- Lack of coordination, weakness or paralysis of the muscles
- Bowel or bladder problems
- Unusual sweating
- Experiencing a sharp fall in blood pressure upon standing, which may cause fainting or light-headedness

Treatment

There are no treatments known today that can cure peripheral neuropathy. If the specific cause of a patient's neuropathy is known, further nerve damage can sometimes be prevented by eliminating the underlying cause, however, the focus of treatment is often on symptom control. Mild pain may sometimes be alleviated by analgesics sold over the counter and more severe pain can sometimes be palliated with prescription drugs or by medical procedures. Other patients find that complementary and alternative therapies combined with other therapies help manage pain caused by peripheral neuropathy. Mechanical aids and physical or occupational therapy can help reduce pain and lessen the impact of physical disability. Although some advances have been made in the diagnosis and treatment of peripheral neuropathies, it is not uncommon for the cause of a patient's neuropathy to remain unidentified, and many patients continue to experience pain and disability despite available therapies.

In general, adopting healthy habits-such as maintaining optimal weight, avoiding exposure to toxins, following a physician-supervised exercise program, eating a balanced diet, correcting vitamin deficiencies, and limiting or avoiding alcohol consumption-can reduce the physical and emotional effects of peripheral neuropathy. Active and passive forms of exercise can reduce cramps, improve muscle strength, and prevent muscle wasting in paralyzed limbs. Timely treatment of injury can help prevent permanent damage.

Testing may include:

- Computed Tomography (CT scan) is a noninvasive, painless process.
- Magnetic Resonance Imaging (MRI) can examine muscle quality and size.
- Electromyography (EMG) involves inserting a fine needle into a muscle to compare the amount of electrical activity.
- Nerve Conduction Velocity (NCV) tests can precisely measure how quickly electrical impulses move along a nerve.
- Nerve Biopsy involves removing and examining a sample of nerve tissue, most often from the lower leg.
- Skin Biopsy is a test in which doctors remove a thin skin sample and examine nerve fiber endings.

To learn more about tests and treatments visit our website at www.foundationforpn.org

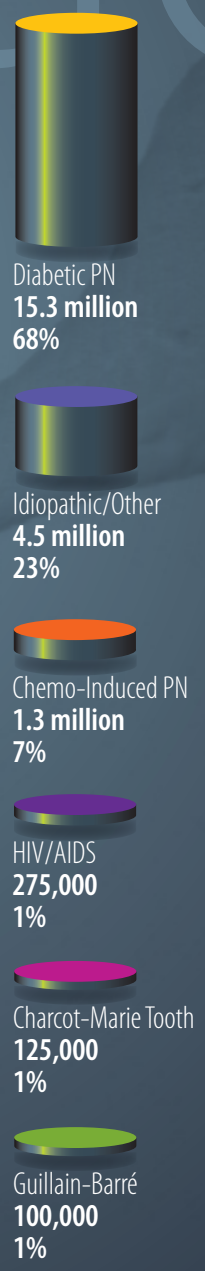
About 20 million Americans suffer from this disorder. Over 100 types of peripheral neuropathy have been identified.

Federal funding for PN research is less than $3.00 for every American with this disorder. 20 million Americans (1 in 15) live with PN—more than 77% are battling other diseases.

statistics

20 million Americans suffer from some form of PN

Diabetes, cancer and HIV alone are expected to increase the prevalence of PN by more than 10% within the next few years. There are 100 identified types of PN. Each unique in its symptoms, patterns of development, and prognoses, with no cures and limited treatment options, the negative impacts of PN on one's quality of life are immeasurable.



Statistical source: *World Health Organization National Institutes of Health National Cancer Institute. Percentages may not add up to 100% due to rounding.*

Most Prevalent Forms of Peripheral Neuropathy

Diabetes
Diabetic peripheral neuropathy (DPN) is the most common type of PN. 23.6 million Americans have diabetes, and 60-70% (over 15 million) of diabetics have DPN. Those with diabetes for more than 25 years and/or are over 40, and have difficulty controlling their blood sugar levels are especially at risk.

Undermanaged DPN is the number one cause of non-traumatic lower limb amputations in the United States.

- Nearly 54,000 diabetics have amputations each year
- Shockingly, 75% of amputations are preventable
- The estimated annual cost to treat diabetes related chronic complications such as DPN is $58 billion

Idiopathic
Idiopathic peripheral neuropathy has no identifiable known cause and therefore is considered the primary disease. If a cause is detected, then the neuropathy is secondary to that and not idiopathic.

Idiopathic peripheral neuropathies occur typically in middle-aged and elderly individuals.

Chemo-Induced
30-40% of all cancer patients have Chemotherapy-induced peripheral neuropathy (CIPN) which is caused by various drugs used in cancer treatments. Chemotherapy is hardest on the nervous system due to the fact the nerve cells are more sensitive than other cells. Sensory nerves are at an increased risk to chemotherapy associated damage compared to motor nerves.

The onsets and resolution of symptoms is variable. Some drugs may cause symptoms during or immediately after the first dose and some have a delayed onset of symptoms, up to several weeks, months, or even years, after the last dose.

Other risk factors for the development of PN

Alcohol abuse
Excessive drinking of alcohol can affect the nervous system, causing numbness of the hands and feet.

Vitamin deficiency
A lack of certain vitamins, especially B-1 (thiamin) and B-12 makes peripheral neuropathy more likely. Pernicious anemia, which occurs when the body cannot absorb B-12 properly, often leads to peripheral neuropathy.

Other health problems
Medical conditions, including certain types of kidney disease and liver disease, or those with family history of genetic diseases that produce peripheral neuropathic pain symptoms and conditions put an individual at risk of developing peripheral nerve damage.

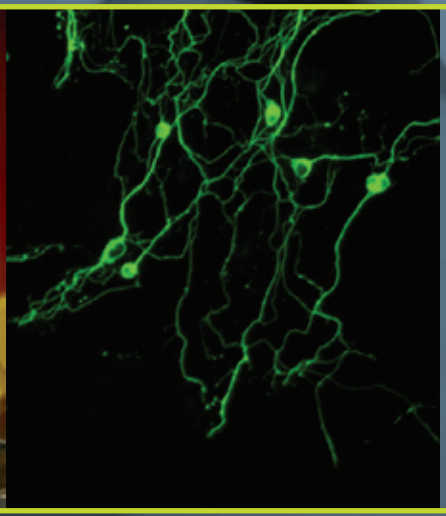
Immune system disorders
Autoimmune diseases, such as celiac disease, Guillian-Barré syndrome, lupus or rheumatoid arthritis, shingles, or an immune system compromised by the human immunodeficiency virus (HIV) or AIDS are often accompanied by the development of peripheral neuropathic conditions. Of all HIV/AIDs patients, 33% have PN.

Repetitive stress
A job or hobby that puts stress on one nerve for long periods of time increases the chances for development of peripheral neuropathy. Playing certain sports or musical instruments and/or using vibrating power tools or even crutches can put pressure on peripheral nerves and cause nerve irritation and damage.

Toxic substances
Exposure to some toxic substances can make one susceptible to peripheral nerve damage. These substances include heavy metals, such as lead, mercury, arsenic and organic solvents; and certain medications, such as those used to treat cancer or AIDS.

together we create hope

Pipetting liquid media to provide nutrient support for neurons



Sensory neurons in a culture dish

Collaboration is the critical link in bringing research to reality.

Foundation leading the charge

No one organization can fund the entire spectrum from basic science through clinical approval and for that reason the Foundation has built its philosophy on building collaborative partnerships with academia, industry and the National Institutes of Health (NIH)—all bring diverse expertise and strength to the table for advancing research that will transform lives. Our value does not lie only in funding, but also in leadership and the ability to bring people from different groups together to examine our overarching research agenda. It is the human return, not the financial return, upon which we must focus.

Collaborative partnerships bridge the gap between research and application. Working together with a common goal is essential to our efforts to bring results from the lab, through development, and to the patient.

We focus our research efforts in three principal areas.

Basic research is the study of how the body works. By understanding normal function, it is possible to recognize the causes and progression of disease, intervene to prevent disease, develop better and more precise diagnostic tools, and discover new treatments and cures. *Translational research* is described as the process of translating basic research into real-world therapeutics in the lives of patients. Sometimes referred to as bench-to-bedside research, basic research scientists provide clinical researchers with new tools for use with patients and clinical researchers can then make new observations about the nature and progression of disease. As a reciprocal and powerful tool that can drive and influence future investigations in the lab, translational research can provide new treatments directly to patients at an accelerated pace.

Along the continuum from basic to translational research are *longitudinal (or clinical) studies*, critical for the translation of research findings to real-world application. These trials help determine if a possible new medication is effective. Without clinical trials, there would be no new drugs. In addition, during clinical trials information can often be obtained which increases our understanding of the disease, why patients respond to a new medicine and give physicians an idea of which medication might work best. During the course of a patient's treatment, they may consider participating in research studies. Another avenue for patients to participate is through databanks, such as the ***Peripheral Neuropathy Research Registry*** (PNRR)***;*** these databanks can lead to spurring new laboratory and clinical studies.

Collaboration must be the norm rather than the exception if we want to accelerate the prevention and the treatments for peripheral neuropathy.

We are serving as a critical link between the researchers, medical providers, and patients. The research methods are there. The talent is there. The support of the medical community is there. And with ongoing public support the Foundation will continue leading the charge for new and effective treatments, prevention and hope for those suffering from PN. This commitment—our commitment—has never been stronger.

leading innovations into the future

Further funding will expand research and accelerate the discoveries of peripheral nerve disease.

Research Partners

Collaborative efforts between our partners and other institutions help us work toward a greater understanding of the cause and progression of PN. The Foundation is proud to provide the financial investments required to lead new medical innovations into the future.

Johns Hopkins University ***Baltimore***

The Peripheral Nerve Center at Johns Hopkins has assembled a group of specialists that provide expertise in most nerve disorders. The goals of the PN Center at Johns Hopkins University are to develop new therapies that will reverse peripheral neuropathies by preventing axonal degeneration and restoring function to patients with sensory neuropathies. Furthermore they engage in developing novel diagnostic strategies, or biomarkers, to more accurately and sensitively diagnose, track and monitor therapy with a special emphasis on identifying underlying etiologies. The center provides a collaborative training environment for neuroscientists committed to neuropathy research.

Northwestern Medical Faculty Foundation ***Chicago***

Northwestern Medical Faculty Foundation (NMFF) Department of Neurology provides treatment and research for a full range of neurological disorders. The department strives to develop and implement educational programs, to conduct basic and clinical research to uncover the causes and cures of central and peripheral neurological disorders, and to advance new therapies. NMFF physicians have areas of subspecialty interest in neurology and many of them are national leaders in their field.

Beth Israel Deaconess Medical Center-Harvard Medical School ***Boston***

The Center for Autonomic and Peripheral Nerve Disorders, Department of Neurology has distinguished research laboratories, clinical and translational research programs, diagnostic laboratories and clinics dedicated to patient care. The research and clinical interests of the Center are those disorders that affect the small nerve fibers, specifically, pain and autonomic dysfunction. The range of research in the Center includes basic science work in the field of diabetic and other neuropathies, novel diagnostic and assessment techniques for painful and autonomic neuropathies, mechanisms of neuropathic disease pathogenesis, and clinical trials of novel therapeutics in neuropathic pain, diabetic neuropathy and autonomic dysfunction.

Mount Sinai Medical Center ***New York City***

The Mount Sinai Peripheral Neuropathy Program was developed in response to the expanding needs of patients with peripheral neuropathy (PN). The Program focuses its efforts on state-of-the-art clinical care, research, outreach, and education in all aspects of diagnosis and treatment of PN. Recognized as a leader in educational activities concerning all aspects of PN and its associated complications, Mount Sinai's PN Program provides structured education and training to physicians, medical students and non-physician healthcare providers.

Data collected, distributed, and shared gives us deeper insight and a broader understanding.

potential is held in our hands

PNRR Peripheral Neuropathy Research Registry

The PNRR consortium was created to foster bold and innovative partnerships that bring together some of the best scientific and clinical talent in a strategic effort to promote collaborative, multi-institutional research.

In 2008, the Foundation for Peripheral Neuropathy initiated the development of the Peripheral Neuropathy Research Registry.

Through the Registry, the Foundation has developed an integrated, interactive application to input, store, and retrieve phenotypic, genotypic and sample information (e.g. DNA). This project is the centerpiece of the Foundation's efforts to facilitate both basic and clinical research studies that will bring improved understandings of the origination and development of peripheral neuropathy. A national and international adoption of the Registry will allow investigators to virtually pool their data and findings and work towards evidence-based diagnostic and treatment methodologies, preventative care, and eventually a cure for peripheral neuropathy.

Unraveling this complex disease requires researchers who are experts in peripheral nerve diseases and talented physicians who see patients regularly. It requires patients who are willing to be active participants in research studies and clinical trials and who, by virtue of their day-to-day experience, can contribute their own observations for new approaches to research.

Raising awareness and education

The Foundation hosts patient seminars and workshops which are educational and community-building. Hosting such events fulfills the Foundation's mission of raising awareness and disseminating knowledge to peripheral neuropathy patients, their family members, and caregivers. These activities promote optimal treatment, coping mechanisms, and care. The seminars and workshops encourage direct interaction and communication between patients, families, and healthcare professionals, with the goal of facilitating discussions that are clearly understandable to a non-scientific audience. All parties involved have the opportunity to share their knowledge and personal experiences of living with painful peripheral neuropathies, and to discuss the current challenges and methods of treatment relating to painful neuropathies. Through our efforts we are raising awareness and providing valuable resources to patients and their loved ones.

Initiating dialogue, increasing collaboration, demonstrating success.

The Foundation's Research Symposiums are designed to examine the status of research in painful peripheral neuropathies with the additional goal of optimizing the development of new therapeutics. The conferences attract experts from basic and clinical science, as well as educational fellows and industry experts. Through the Research Symposiums, the Foundation initiates dialogue, increases collaboration and awareness of complementary strengths for the essential activities and generates funding required to bring new therapies to patients suffering from peripheral neuropathy.

THE MISSION OF THE FOUNDATION FOR PERIPHERAL NEUROPATHY CAN ONLY BE SUSTAINED THROUGH THE GENEROSITY OF PEOPLE WHO SHARE OUR VISION TO ADVANCE RESEARCH AND PROVIDE AN IMPROVED QUALITY OF LIFE FOR THOSE LIVING WITH PERIPHERAL NEUROPATHY. WITH YOUR CONTRIBUTION, YOU BECOME AN IMPORTANT PART OF OUR SUCCESS AND A SPECIAL PART OF OUR FAMILY. WE HOPE THAT YOU WILL SHARE IN OUR COMMITMENT TO DRAMATICALLY IMPROVE THE LIVES OF THOSE LIVING WITH PERIPHERAL NEUROPATHY.

MAKE A difference TODAY

Although scientists have made progress in understanding peripheral neuropathy and its many causes, a cure remains elusive. Only with continued funding will researchers be able to bring about the medical breakthroughs needed to ease the pain and suffering of the millions of Americans with peripheral neuropathy. But the benefits of such research do not end there. As scientists search for new treatments and a possible cure for peripheral neuropathy, they also shed new light on other myelin-related disorders such as multiple sclerosis and spinal cord injuries, which affect hundreds of thousands of individuals worldwide.

We cannot achieve our mission without you.

DONATION OPTIONS

General Giving

- *Donate online by visiting our website at **www.foundationforpn.org**, by phone: 1-847-883-9952, or by mail*

Memorial Gifts

- *A meaningful way to celebrate the memory of a loved one*

Tribute and Honor Gifts

- *A special way to celebrate a birthday, anniversary, wedding, holiday or an occasion of significance*

Favors

- *Consider making a contribution in honor of your guests in lieu of buying traditional party favors*

Take Charge

- *Get creative with fundraising and host your own event! Visit our website at **www.foundationforpn.org** to learn more about creative fundraising ideas*

SPONSORSHIP OPPORTUNITIES

PNRR ■ Young Investigator Awards ■ FPN Research Symposiums ■ Educational Programs

MAJOR GIFTS

Planned Giving ■ Matching Gifts ■ Pledged Gifts ■ Stock Options

The Foundation for Peripheral Neuropathy is a 501(c)3 nonprofit, tax-exempt organization designated by the Internal Revenue Code. Your gift is tax deductible to the full extent allowed by the law.

*For more information about SPONSORSHIP OPPORTUNITIES and MAJOR GIFTS, please call **847-883-9942** or email **info@tffpn.org***

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