



# ***Welcome!***

*FPN Webinar:*

## **FPN Advocacy Program:**

*Updates from the Hill*

Tuesday, February 4, 2025

***We will begin our presentation shortly.***



*the* FOUNDATION *for*  
PERIPHERAL NEUROPATHY®

***Today's moderator:***



**Lindsay Colbert**  
*Executive Director*  
*the Foundation for Peripheral Neuropathy*

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## Before We Begin



This presentation is being recorded. The recording link will be emailed to you so you can view it again later.



Submit your questions anytime via the Questions Box. We will try to answer them during this webinar.



We are now pleased to offer closed captioning. Check your dashboard to activate the tool.

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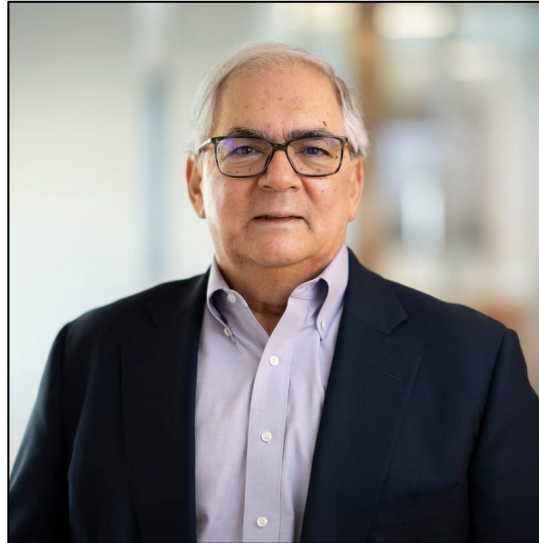


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## ***Today's Experts:***



**Mark Vieth**  
*Lobbyist*  
CRD Associates



**Lou Mazawey**  
*Attorney*  
Groom Law Group  
*FPN Past Board President*



**Ron Lissak**  
*Executive Vice President*  
Positrigo, Inc.  
*FPN Board President*

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Advocacy in 2025



# Agenda

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- Introduction: Lou Mazawey, Board Member, *the* Foundation *for* Peripheral Neuropathy (FPN)
- Peripheral Neuropathy in the PRMRP
- How Advocacy Works
- Role of NIH
- Status of FY25 Appropriations
- Example of Individual Advocacy (Ron Lissak, FPN Board President)
- FY26 Request
- Q & A



# Introduction

## Lou Mazawey

Past Board  
President, Board of  
Directors

*the* Foundation for  
Peripheral  
Neuropathy



# What is the PRMRP?

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- Peer Reviewed Medical Research Program, part of the “Congressionally Directed Medical Research Program”
- Funded at \$370 million in FY24
- Includes dozens of “eligible topics” determined by statute (Defense Appropriations Act)
- “Peripheral Neuropathy” has been an eligible topic since FY21
- Conditions and funding added by the Senate only (House plays no role)
- PN would not have been added without advocacy!





# CDMRP FY23 Appropriations



Research Program	FY23 \$M	Research Program	FY23 \$M
Alcohol and Substance Use Disorders	\$4.0	Orthotics and Prosthetics Outcomes	\$15.0
Amyotrophic Lateral Sclerosis	\$40.0	Ovarian Cancer	\$45.0
Autism	\$15.0	Pancreatic Cancer	\$15.0
Bone Marrow Failure	\$7.5	Parkinson's	\$16.0
Breast Cancer	\$150.0	Peer Reviewed Alzheimer's	\$15.0
Chronic Pain Management	\$15.0	Peer Reviewed Cancer (20 Topics)	\$130.0
Combat Readiness Medical	\$5.0	Peer Reviewed Medical (50 Topics)	\$370.0
Duchenne Muscular Dystrophy	\$10.0	Peer Reviewed Orthopaedic	\$30.0
Epilepsy	\$12.0	Prostate Cancer	\$110.0
Hearing Restoration	\$5.0	Rare Cancers	\$17.5
Joint Warfighter Medical	\$25.0	Reconstructive Transplant	\$12.0
Kidney Cancer	\$50.0	Spinal Cord Injury	\$40.0
Lung Cancer	\$25.0	Tick-Borne Disease	\$7.0
Lupus	\$10.0	Toxic Exposures	\$30.0
Melanoma	\$40.0	Traumatic Brain Injury and Psychological Health	\$175.0
Military Burn	\$10.0	Tuberous Sclerosis Complex	\$8.0
Multiple Sclerosis	\$20.0	Vision	\$20.0
Neurofibromatosis	\$25.0	<b>TOTAL = \$1.52B</b>	

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- Eating Disorders
  - Maternal Mental Health
  - Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome
  - Neuroactive Steroids
  - Neuroinflammatory Responses to Emerging  
Viral Diseases
  - Non-Opioid Therapy for Pain Management
  - **Peripheral Neuropathy**
  - Proteomics
  - Sleep Disorders and Restriction
  - Suicide Prevention
  - Trauma

**Neuroscience**

# What is the Role of Advocacy?

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- **What is Advocacy?**

“Any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others”

- **First Amendment to the U.S. Constitution**

“Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and **to petition the Government for a redress of grievances.**”



# Who Are Our Advocates?

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- Patients and Family Members
- Researchers
- FPN Staff and Board Members



# Types of Advocacy

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- Write to your Members of Congress (email)  
(patients and researchers)
- Meet with your Members  
(DC in-person, back in the district, or virtual)
- Attend public meetings back in district
- Targeted Meetings by FPN Staff and Consultants

## **What works best?**

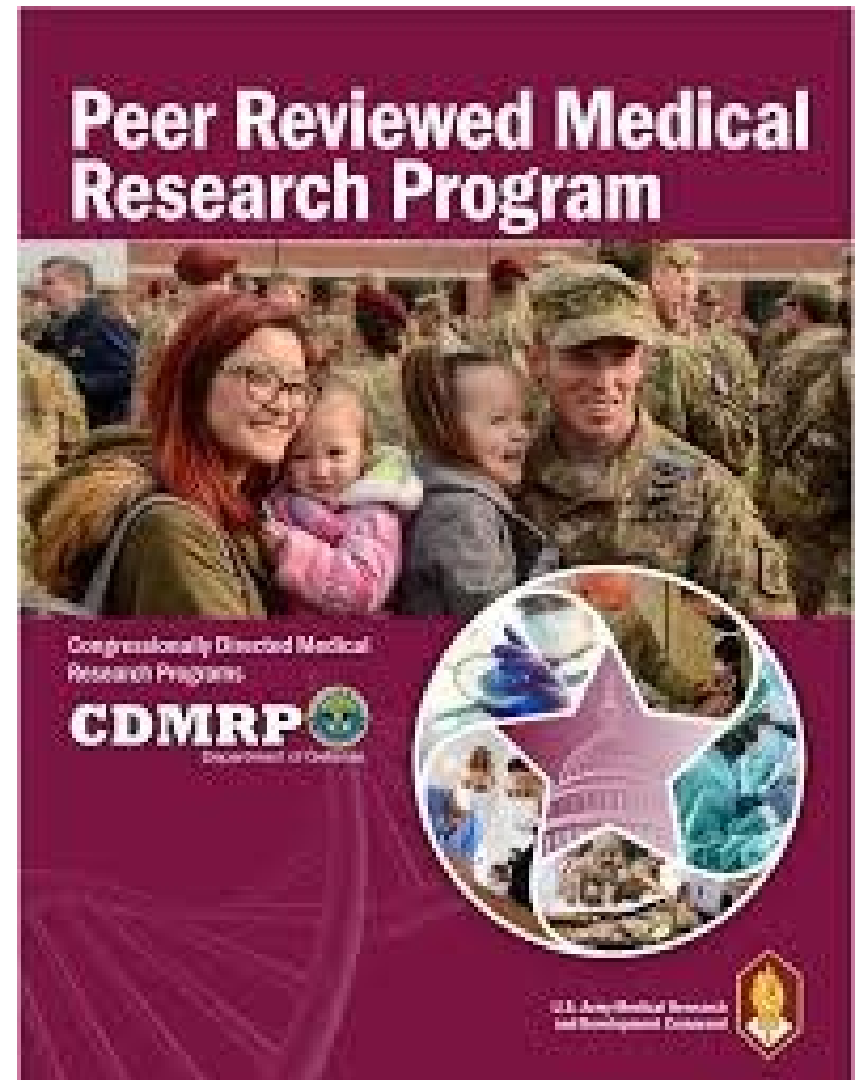
- Telling your personal story
- Research funds back in home state
- Connection to military/veterans



# Consumer Reviewer for the PRMRP

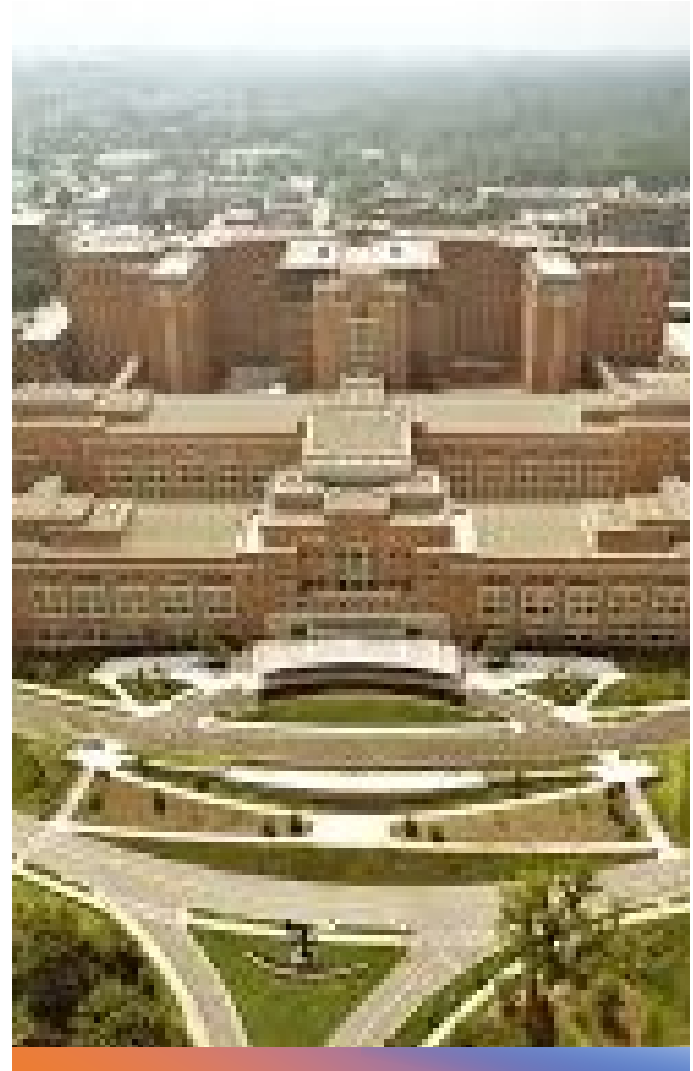
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- **Two Step Review Process for PRMRP Grants**
  - Scientific Review
  - Consumer Review
- **Who are Consumer Reviewers?**
  - Patients
  - Family Members
  - Foundation/Association employees
  - **Could be you!**



# Role of the National Institutes of Health (NIH)

- Most PN research funded through National Institute of Neurological Disorders and Stroke (NINDS)
- NIH overall funding \$47 BILLION
- Congress does not appropriate NIH funding by disease!
- PN estimated \$236 million overall in FY25 (\$143 million in FY18)
- FPN Strategy-language in NIH funding bill and meet directly with agency.



# Status of FY25 Funding

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- Senate Appropriations Committee passes FY25 Defense Appropriations Act (8-1-24)
- PN included as eligible condition in PRMRP
- No floor action
- Full House approved its version on 6-28-24
- Continuing Resolution through March 14, 2025

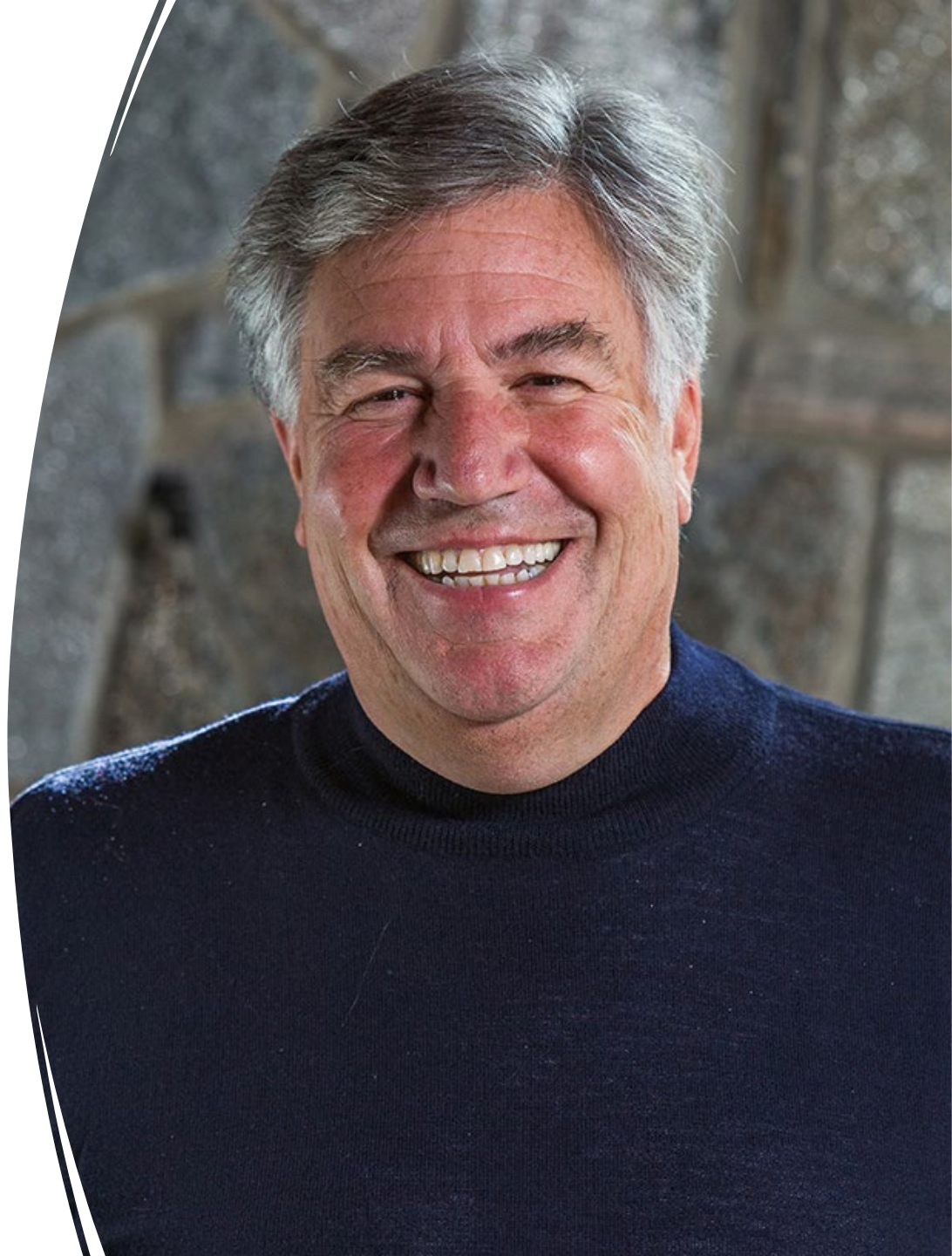




# Example of Individual Advocacy

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- Ron Lissak, President of the FPN Board of Directors



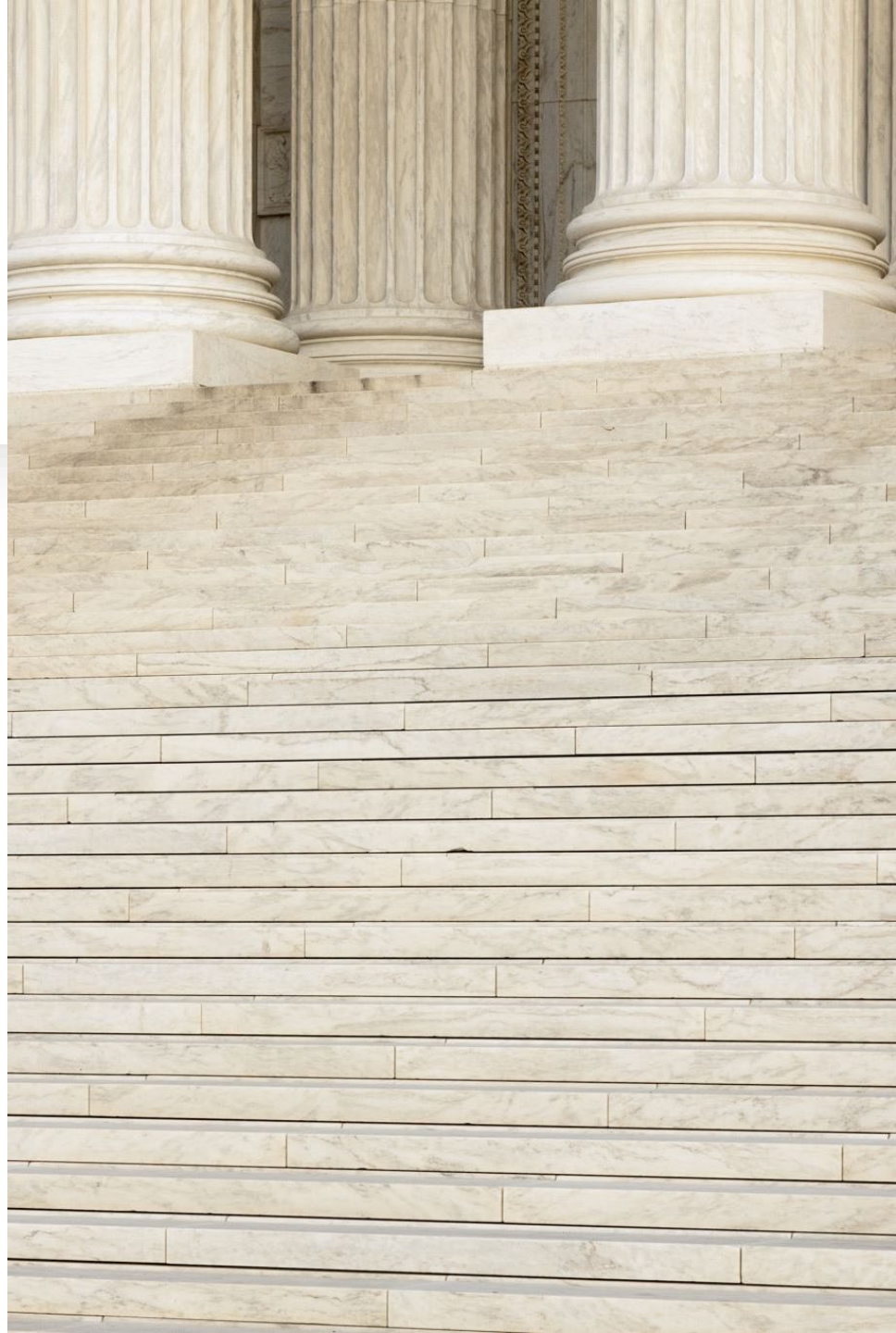
# The Climate...



- New Administration and Congress
- Budget Stalemate
- Emphasis on Spending Cuts

# Our Requests

- Renew designation of “Peripheral Neuropathy” in the Peer Reviewed Medical Research Program at the Department of Defense
- Protect and Grow the PRMRP (\$370 million)
- Increase overall funding for the National Institutes of Health (NIH) and specific funding for PN research.



# Key Senators

- **Susan Collins (R-ME)**

*Chair, Senate Appropriations Committee*

- **Patty Murray (D-WA)**

*Ranking Member, Senate Appropriations Committee*

- **Mitch McConnell (R-KY)**

*Chair, Appropriations Subcommittee on Defense*

- **Chris Coons (D-DE)**

*Ranking Members, Appropriations Subcommittee on Defense*

# Defense Appropriations Subcommittee

- Sen. Lisa Murkowski (R-AK)
- Sen. Lindsey Graham (R-SC)
- Sen. Jerry Moran (R-KS)
- Sen. John Hoeven (R-ND)
- Sen. John Boozman (R-AR)
- Sen. Shelley Moore Capito (R-WV)
- Sen. John Kennedy (R-LA)
- Sen. Dick Durbin (D-IL)
- Sen. Jack Reed (D-RI)
- Sen. Brian Schatz (D-HI)
- Sen. Tammy Baldwin (D-WI)
- Sen. Jeanne Shaheen (D-NH)
- Sen. Chris Murphy (D-CT)

# The Meetings...

- Tell your personal story: How does PN affect you!
- Educate about PN and federal support for PN research
- Use Visuals (pictures, etc.)
- Don't Get Sidetracked
- Get to the Ask!
- Explain in Simple Terms
- Don't try to answer a question you can't answer.
- Get follow up information (business card, when you can follow up)
- Take Photo and Share with Foundation





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# Questions?

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## Thank You for Watching!

**Did you like this webinar?** Please take our survey at the end of this webinar. A recording will be uploaded on our website at [www.foundationforpn.org](http://www.foundationforpn.org) shortly. Stay tuned.

**Do you like us?** Please consider supporting us so that we can continue to fulfill our mission of improving the lives of people living with Peripheral Neuropathy. You can give securely online, via mail or via phone. Every dollar matters!

**Can we help with anything else?** Call 847-883-9942 or email [info@tffpn.org](mailto:info@tffpn.org). You may also mail inquiries and donations to *the* Foundation *for* Peripheral Neuropathy at 2700 Patriot Blvd, Suite 250, Glenview, Illinois 60026.

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