

2024 PN Summer education Series

WEBINARS | JULY 9 | JULY 12 | JULY 17 | JULY 25 | JULY 31 | AUG 1

Thank you for joining us! *We will begin shortly.*

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Empower Your Voice: ***Advocating for*** Peripheral Neuropathy

Thank you for joining us!



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Before We Begin



This presentation is being recorded. The recording link will be emailed to you and posted on the FPN website in the coming days.



Submit your questions anytime via the Questions Box. We will try to answer as many as we can.



Audio issues? You can dial in by phone (check your email for dial-in instructions).



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Lindsay Colbert
Executive Director
the Foundation for Peripheral Neuropathy



Mark Vieth
Lobbyist for FPN
CRD Associates, Washington, D.C.



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Let's Level Set!

*When our advocacy program started
&
FPN's accomplishments with the DOD & the NIH*



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Our Advocacy Program: *The What and the Why*

- **For over five years**, FPN has been advocating for public policies that support research and treatment advancements for peripheral neuropathy.
- Working with **federal and state legislators** and regulatory bodies to ensure patients have access to high-quality, affordable care.
- Efforts have led to **significant funding increases for research**, including securing eligibility for peripheral neuropathy studies in the Department of Defense's Peer Reviewed Medical Research Program for the last four years, resulting in millions of dollars in research grants.
- Strengthening our relationship with the National Institutes of Health (NIH), the largest biomedical research funding agency.



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The Department of Defense's Peer Reviewed Medical Research Program

- In 2020, FPN's advocacy efforts achieved inclusion of "peripheral neuropathy" in the DoD's PRMRP for FY 2021.
- Secured **over \$8 million in funding for peripheral neuropathy research in 2021**; 41 applications focused on this condition from a total of over 1,000 applications.
- The FY21 PRMRP had a budget of \$370 million for 42 conditions, resulting in 10 awards (2 shared).



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FY21 Awards in PN

Institution	Project Title	Award Amount
TEXAS, UNIVERSITY OF, HEALTH SCIENCE CENTER AT SAN ANTONIO	Simultaneous Voltage and Calcium Imaging from Primary Sensory Neurons in Live Mice	\$310,000.00
COLUMBIA UNIVERSITY MEDICAL CENTER	Discovery of Neuroprotective Small Molecules Against Chemotherapy-Induced Peripheral Neuropathy	\$322,958.00
ST. JOSEPH'S HOSPITAL AND MEDICAL CENTER	MRI Biomarkers of Traumatic Peripheral Nerve Injury and Repair: Validation and Multisite Application	\$1,628,512.00
VANDERBILT UNIVERSITY MEDICAL CENTER	MRI Biomarkers of Traumatic Peripheral Nerve Injury and Repair: Validation and Multisite Application	\$1,730,000.00
OHIO STATE UNIVERSITY, THE	Nonviral Gene and Reprogramming-Based Cell Therapies for Peripheral Nerve Injury	\$2,359,841.00
OHIO STATE UNIVERSITY, THE	Nonviral Gene and Reprogramming-Based Cell Therapies for Peripheral Nerve Injury	\$790,159.00
TEXAS MEDICAL BRANCH, UNIVERSITY OF, GALVESTON	Specialized Lipogenic Macrophages in Diabetic Peripheral Neuropathy	\$316,000.00
NORTHWESTERN UNIVERSITY, CHICAGO, ILLINOIS	A New Humanized Mouse Model for the Study of Peripheral Neuropathies	\$291,332.00
JOHNS HOPKINS UNIVERSITY	Tesamorelin Therapy to Enhance Axonal Regeneration, Minimize Muscle Atrophy, and Improve Functional Outcomes Following Peripheral Nerve Injury and Repair	\$362,700.00
CALIFORNIA, UNIVERSITY OF, SAN DIEGO	Multiplexed In Vivo Epigenome Engineering for Therapeutic Targeting of Chronic Pain	\$2,528,000.00



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The Department of Defense's Peer Reviewed Medical Research Program

- **In 2022**, three out of 28 applications for peripheral neuropathy research were awarded funding, totaling more than **\$4.6 million**, from a \$370 million appropriation covering 42 topics.



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FY22 Awards in PN

Institution	Project Title	Award Amount
MAYO CLINIC	Immunoprofiling of Diabetic and Nondiabetic Lumbosacral Radiculoplexus Neuropathy	\$318,000.00
GEORGE MASON UNIVERSITY	DNA-Based Hydrogels for Peripheral Nerve Repair	\$317,780.00
DTx PHARMA	Development of an RNA Therapeutic for the Treatment of Charcot Marie Tooth 1A	\$3,878,453.00



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The Department of Defense's Peer Reviewed Medical Research Program

- **In 2023**, three applications for peripheral neuropathy research were awarded funding (2 shared), totaling **over \$3.5 million**, from a \$370 million budget covering 50 topic areas.
- Peripheral neuropathy was renewed as an eligible condition for the FY24 PRMRP, with a \$370 million fund covering 42 topic areas.



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FY23 Awards in PN

Institution	Project Title	Award Amount
HENRY M. JACKSON FOUNDATION	A Novel miR-155 Therapy for the Treatment of Peripheral Neuropathy	\$319,151.00
MD ANDERSON CANCER CENTER, UNIVERSITY OF TEXAS	Targeting Local B Cells to Prevent Chronification of Neuropathic Pain	\$3,064,079.00
RICE UNIVERSITY	Targeting Local B Cells to Prevent Chronification of Neuropathic Pain	\$165,704.00



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The Department of Defense's Peer Reviewed Medical Research Program

- Peripheral neuropathy was **renewed** as an eligible condition for the FY24 PRMRP, with a \$370 million fund covering 42 topic areas.
- Applications recently closed and more information about the awards will be announced in early 2025.
- Interested in **becoming a peer reviewer** in the future?



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The National Institutes of Health (NIH)

- Two years ago, Committee on Appropriations acknowledged the importance of peripheral neuropathy research – this is due to FPN's advocacy efforts.
- On July 27, 2023, the Committee approved the fiscal year 2024 Labor-Health and Human Services-Education Appropriations Act.
- The Committee's report included a call for NIH to develop a **coordinated approach to peripheral neuropathy research**.



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The National Institutes of Health (NIH)

- Recommended **NIH research focus areas**:
 - Developing a natural history database
 - Collecting serial blood biomarkers
 - Creating a tissue bank
 - Identifying genetic risk factors
 - Facilitating diagnosis and treatment
- The Committee **also urged NIH to support research on idiopathic peripheral neuropathy**, which affects 10 million Americans.



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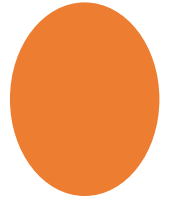


The Power of Advocacy

*The Foundation for
Peripheral
Neuropathy*

Goals for Today!

- Help You Better Understand our Requests
- Harness Your Passion – Focus Your Energy
- Educate You on the “How Things Work” on Capitol Hill
- Update you on the Current Environment
- Make You Feel Comfortable as an Advocate





Agenda

- Who are our “Advocates”?
- The Climate
- Our Requests
- How to communicate with your elected officials
- How to Have a Good Meeting
- Q & A

Who Are Our Advocates?

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



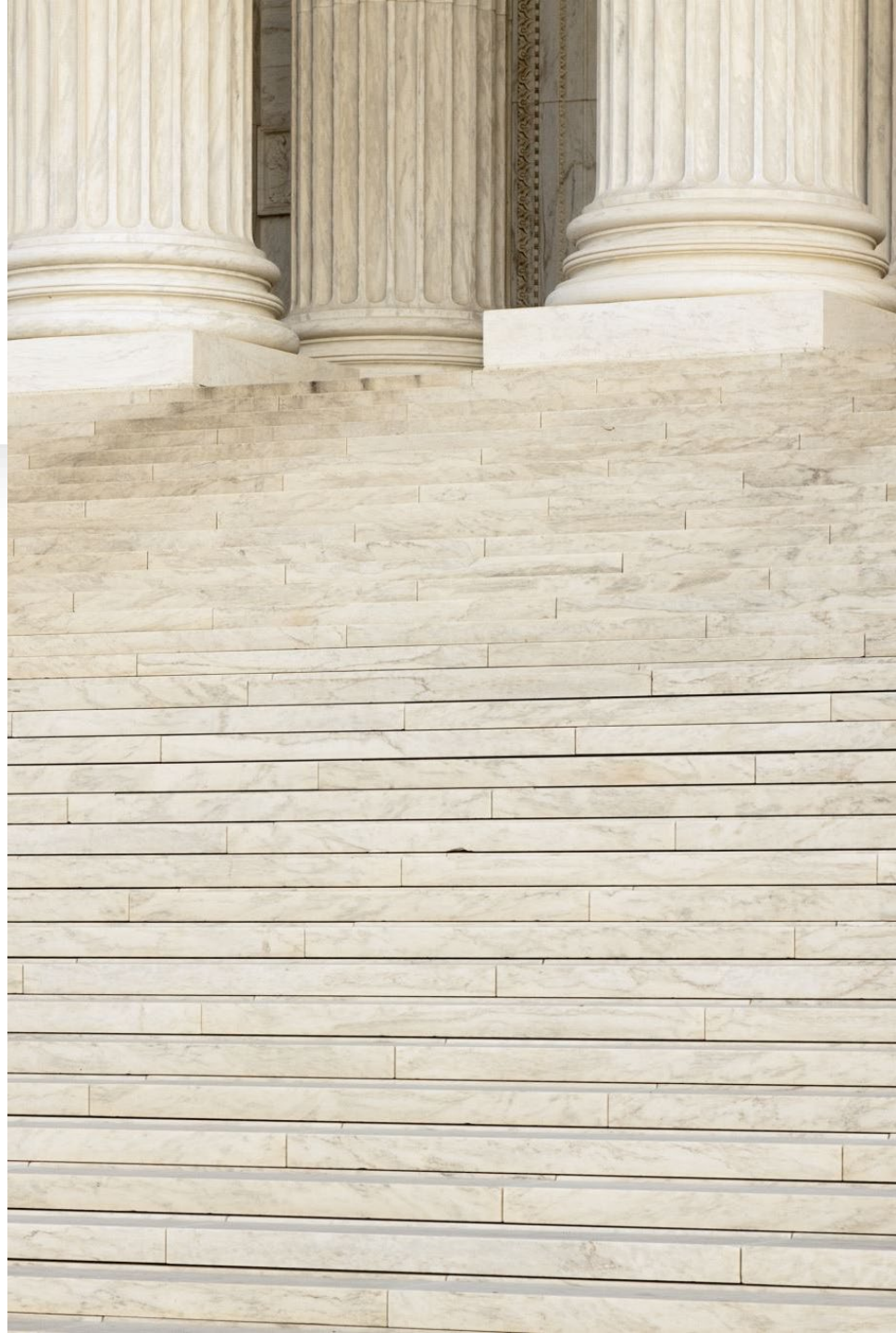
The Climate...



- Election Year-Presidential and Congress
- Ukraine, Israel, Border
- Budget Stalemate
- 50 members of Congress—7 Senators and 43 Representatives— not seeking re-election in 2024

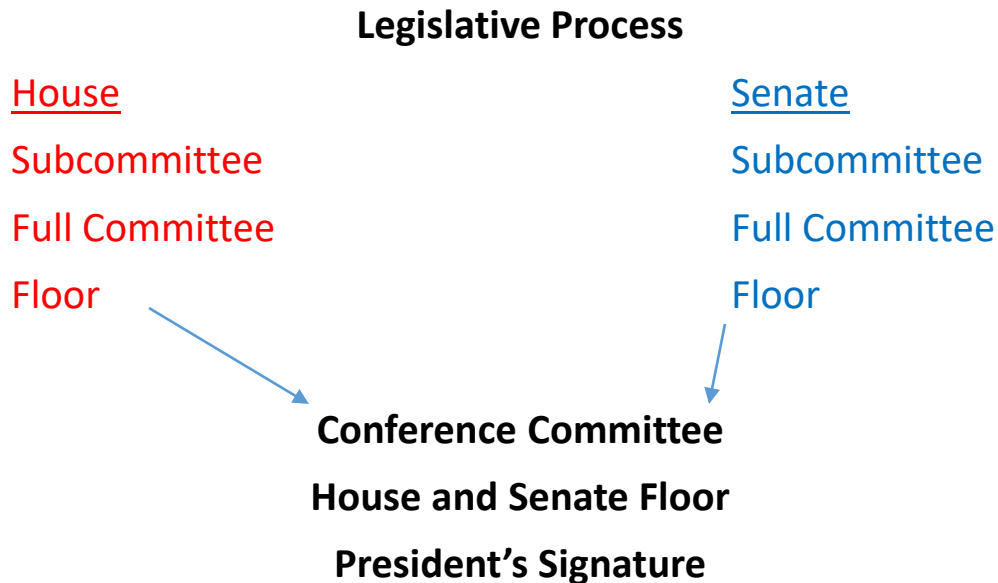
Our Requests

- Renew designation of “Peripheral Neuropathy” in the Peer Reviewed Medical Research Program at the Department of Defense
- FY25 Defense Appropriations Act (Senate Only)
- Increase funding for PN at the National Institutes of Health (NIH)



Appropriations Process

- **Which Appropriations Bills Fund Medical Research?**
 - 1) Labor-Health and Human Services-Education (NIH)
 - 2) Defense (DOD-CDMRP)



Communicating With Members of Congress

- In Person-Washington, DC
- In Person-State Offices
- Zoom/Virtual
- Email Letters
- Attending Public Events back home



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



Potential “Diversions”

- 2024 Presidential Election
- Drug Pricing
- Immigration
- International Affairs (Ukraine, Middle East)
- Taylor Swift



SUNIL AGARWAL & IAN BAKER..

Don't...

- Be Hostile or Threatening
- Give Gifts (including meals)
- Suggest Cutting Other Disease Research
- Engage in Political Arguments
- Mention Political Contributions



Questions?



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Thank you for joining us!

Please consider a \$25 donation to fund this series and future programming.



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**WATCH THE
RECORDINGS:**



Did you like this webinar? Please take our survey at the end of this webinar. A recording will be uploaded on our website at FoundationForPN.org shortly.

Support FPN! If you have not already, please consider making a \$25 gift to help fulfill our mission of improving the lives of those with peripheral neuropathy. Give securely using the QR code:

Anything else? 847-883-9942 info@tffpn.org
485 E. Half Day Road, Suite 350, Buffalo Grove, Illinois 60089.



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