

Western Neuropathy Association



ADVOCACY

Your Voice Can Make A Difference

Samantha Fields, WNA member

.pptx created by Katherine Stenzel, WNA Director



How To Be An Advocate

Being an Advocate is
NOT being a Policy
Expert

Being an Advocate is
simply being a
constituent

Federal
policymakers
need to hear
directly from the
people living with
peripheral
neuropathy

- They need to hear about YOUR neuropathy.
- They need to hear that it is not only about pain.
- They need to hear that neuropathy affects our balance, mobility, employment, independence, the ability to use our hands and our quality of life.



Where to start?

1 - Know who represents YOU

You have **three federal representatives:**

- **2 U.S. Senators**

Your state's two senators represent you

- **1 U.S. Representative**

Your House member represents your specific congressional district

You do not need to live in Washington D.C to have influence in the federal government.

Search the websites below...

- **2 U.S. Senators**

www.senate.com

- **1 U.S. Representative**

www.house.com

...to find your Senators and Representative



2 - Make ONE specific request

A specific request is
more effect than simply
saying:

*“Please do something
about neuropathy.”*



The **Department of Defense Peer Reviewed Medical Research Program (PRMRP)** supports federal research in different diseases.

Request:

*Please support continued eligibility for **peripheral neuropathy** in the Department of Defense Peer Reviewed Medical Research Program and support increased federal research investment in PN.*

3 – Tell Them YOUR Story

Keep your story short and concise. Here's an example.

- *I'm your constituent and I **live with peripheral neuropathy**.*
- *My neuropathy **affects** ... (add about you)*
- *One thing I wish policy makers **understood** is ... (add about you)*
- *I'm asking you to **support** continued federal research funding for peripheral neuropathy, including maintaining peripheral neuropathy eligibility in the Department of Defense Peer Reviewed Medical Research Program.*
- *Please **share** my message with your health policy staff and let me know how you plan to support this issue.*



Your story
+
a specific ask
=
advocacy





4 – CALL your congressional office



Capital Switchboard 202-224-3121

You don't need a speech. Say:

"I'm a constituent and I live with peripheral neuropathy. I'm calling to ask the Senator/Representative to support continued federal research funding for peripheral neuropathy, including PRMRP eligibility. Could you please make sure the health policy staff receives my message?"

That's it – you made your voice heard.



A blurred background image showing a group of people in a meeting or workshop. Many of their hands are raised, suggesting an interactive session or a vote-taking exercise. The image is overlaid with a semi-transparent dark blue filter.

5 – ASK for a meeting

You don't have to meet with the Senator or Representative personally.

Ask for the staff member who handles health policy.

You can request a meeting in your local congressional district office or virtually.

WNA members could meet as a group:

Ask for the staff member who handles health policy.

“Would your health policy staff be willing to meet with a small group of people living with peripheral neuropathy?”

WNA members could meet as a group:

Bring:

2-3 people living with neuropathy
a few powerful stories
a few key facts
one or two specific requests

6 – What actually gets ATTENTION?

Less Effective

“Neuropathy is terrible. Please help us.”

More Effective

“I’m your constituent. I live with peripheral neuropathy. It has caused me to lose I’m asking you to support continued federal research funding for peripheral neuropathy and maintain its eligibility for the PRMRP.”

The Formula

I am your constituent.



This is what neuropathy has done to my life.



This is why it matters beyond me.



This is exactly what I want you to do.

7 – WNA's grassroots goal

Imagine if 100 WMA members did this

- 100 members identify their members of Congress
- 100 members tell their stories
- 100 members make the same specific request
- 100 members ask for meetings

And WNA keeps track of the responses

- That's no longer one person advocating
- That's a constituency!

8 – YOUR Action Plan

Action Plan

- Find my U.S. Representative
- Find my two U.S. Senators
- Send my personal story
- Make a phone call
- Make the PRMRP/research funding request
- Ask for a meeting with health policy staff
- Tell WNA what response I receive



Remember...

**You do not have to be an expert
You do not have to know how Washington works
You do not have to be LOUD**

**You just have to show up, tell your story, make a specific
request...
...and keep on showing up**

***Your neuropathy experience is not just your story –
It is evidence of what needs to change.***

Sample Letter

Subject: Please Support Federal Research and Advocacy for Peripheral Neuropathy

Dear Senator/Representative [NAME],

I am your constituent, and I live with peripheral neuropathy. I am writing to ask you to support increased federal attention and research funding for peripheral neuropathy, including continued eligibility for peripheral neuropathy research through the Department of Defense Peer Reviewed Medical Research Program (PRMRP).

For me, neuropathy is much more than pain or numbness. I have lost significant sensation in my hands, feet, and lower legs. It affects my mobility, balance, ability to use my hands, and independence. Things that most people don't think twice about—walking safely, holding objects, opening containers, using my hands, or simply knowing where my feet are—can become difficult or impossible. And I'm not an isolated case.

Peripheral neuropathy affects millions of Americans and can result from many different causes, including diabetes, chemotherapy, autoimmune conditions, hereditary disorders, and other neurological diseases. For many people, however, we still don't know why it happens or how to stop its progression.

Current treatments often focus on managing symptoms rather than addressing the underlying nerve damage. People living with neuropathy need better answers: better diagnostics, better treatments, and ultimately treatments that can prevent or reverse nerve damage. That is why federal research funding matters.

I am specifically asking you to:

- 1. Support continued eligibility for peripheral neuropathy in the Department of Defense Peer Reviewed Medical Research Program (PRMRP).**
- 2. Support increased federal research funding for peripheral neuropathy and peripheral nerve disorders.**
- 3. Recognize neuropathy as a significant neurological and public health issue—not simply a symptom of another condition.**

I also hope you will hear directly from people living with neuropathy when considering federal health and research priorities. We are not just statistics. We are people trying to remain independent, work, participate in our communities, and live our lives despite conditions that can fundamentally change how we function.

I would appreciate knowing your position on federal research funding for peripheral neuropathy and whether you would support maintaining peripheral neuropathy eligibility for the PRMRP.

I would also welcome the opportunity to speak with your health policy staff about the lived experience of people with neuropathy and what we need from our federal government.

Thank you for your time and for representing me in Congress.

Sincerely,

[Name]

[City, State]



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