



WESTERN NEUROPATHY ASSOCIATION

Hope through caring, support, research, education, and empowerment

From Being Heard to Being at the Table - Government-Level Advocacy: What I've Learned by Showing Up

Samantha Fields, WNA member, September 2026

When I was asked to talk about government advocacy, my first thought was, *I'm not sure I'm an expert at this.*

I'm not a lobbyist. I'm not a policy analyst. And I certainly didn't start out knowing how government works.

I'm a Medicaid member who started showing up.

I've been involved in Medicaid advocacy since 2019, and over time that has taken me from telling my own story to sitting at tables with state agencies, health plans, policymakers, and other people who actually have the ability to change systems.

And probably the biggest lesson I've learned is this:

You don't have to be an expert to be an effective advocate. You have to be willing to show up, tell the truth about what is happening to real people, and keep showing up.

Start with your story — but connect it to the bigger picture.

Personal stories are incredibly important.

My own experiences with neuropathy and disability have given me plenty of stories to tell. But I've learned that if I only tell my story, people may hear it as an individual problem.

So I try to take the next step.

Instead of just saying:

"This happened to me."

I ask:

Why did this happen?

Is this happening to other people?

And then:

What could we change so it doesn't keep happening?

That's the difference between personal advocacy and systems advocacy.

For example, transportation isn't just a problem because I personally need transportation.

I can talk about what happens when a person with a disability can't get to an appointment, a meeting, a grocery store, or an opportunity to participate in their community.

Now we're talking about access, independence, and participation.

That's a policy issue.

Learn who can actually change the thing you're trying to change.

This has probably been one of my biggest lessons.

When something isn't working, it's really easy to think, *I need to talk to my legislator*.

Sometimes you do.

But sometimes your legislator isn't the person who can fix the problem.

It might be a state agency.

It might be Medicaid.

It might be a regulatory agency.

It might be a contractor.

It might be someone sitting in a workgroup writing the policy or designing the program.

So one of the first questions I ask is:

"Who actually has the authority to change this?"

That question can save you an enormous amount of time.

What can we actually do at the grassroots level?

This is where I think WNA has a huge opportunity.

You don't need to have a Washington, D.C. office to have a federal advocacy program.

You need people willing to take small, coordinated actions.

And I would focus on a few things.

1. Know your members of Congress.

Every person should know their two U.S. Senators and their U.S. House member.

You can find your House member by ZIP code through the official House website, and the Senate provides contact information for every senator.

For those of us in Colorado, our two senators are:

- Senator Michael Bennet
- Senator John Hickenlooper

Both offices specifically invite constituents to contact them about federal issues, and both offer ways to request meetings.

And don't overlook the district offices.

You don't have to fly to Washington.

You can request a meeting with congressional staff in your own community.

Senator Bennet, for example, has a Pikes Peak office in Colorado Springs.

2. Stop sending generic emails.

This is really important.

I don't think "Please support neuropathy" is particularly powerful.

Instead:

"I'm your constituent. I live with peripheral neuropathy. Here's what it has done to my life. Here's what I want you to do."

Then make one specific request.

One email.

One issue.

One ask.

That's much easier for a congressional office to understand and act on.

3. Make phone calls.

A phone call to a congressional office can be incredibly simple.

You don't need a speech.

You can say:

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

That's it.

You don't have to argue with anybody.

You don't have to be a policy expert.

You're making your position known.

The Senate itself says constituents can contact senators by web form, mail, telephone, or in person. The Capitol switchboard is 202-224-3121.

But here's where I think we can get much more strategic.

Don't just ask Congress to "fund neuropathy research."

Ask for something specific.

And we actually have an excellent example.

Peripheral neuropathy has already been made eligible for research through the Department of Defense's Peer Reviewed Medical Research Program, or PRMRP.

That happened because of national neuropathy advocacy.

But here's the catch:

Congress has to keep neuropathy on the eligibility list.

It isn't automatic.

The Foundation for Peripheral Neuropathy identifies maintaining peripheral neuropathy's eligibility in the PRMRP as a current federal advocacy priority.

That gives us a very concrete ask:

"Please support continued eligibility for peripheral neuropathy in the Department of Defense Peer Reviewed Medical Research Program."

That's much stronger than:

"Please do something about neuropathy."

We're telling Congress exactly what we want.

And there's a reason this matters beyond one research program.

Federal research funding can lead to better understanding of the causes of neuropathy, better diagnostics, new treatments, and potentially disease-modifying therapies.

The NIH's National Institute of Neurological Disorders and Stroke specifically supports peripheral nerve research, including research into causes, treatments, prevention, biomarkers, and neurological health disparities.

In fact, NIH currently has a highlighted research topic specifically focused on acquired neuropathy, noting the limitations of current treatments and the need for disease-modifying approaches.

So this isn't asking government to fund some vague idea.

There is already a federal research infrastructure to build on.

4. Ask for a meeting with congressional staff.

This is something I really want people to understand.

You don't necessarily need to get a meeting with the Senator or Representative.

Meeting with their health policy or legislative staff can be incredibly valuable.

And you can ask for it.

WNA could request a meeting and say:

"We're a national neuropathy organization representing people living with peripheral neuropathy. We'd like to brief your health policy staff on the impact of neuropathy and discuss federal research priorities."

Then bring three things:

A few patient stories.

A few compelling facts.

Three specific requests.

Not 25 requests.

Three.

5. Build a "Neuropathy Constituent Team."

This is something I think WNA could really do.

Imagine if every WNA member was encouraged to identify:

Who are my two senators?

Who is my representative?

Who is their health policy staffer?

Then imagine 50 WNA members contacting their offices around the same issue.

Then 100.

Then 500.

That's grassroots advocacy.

And it doesn't require everyone to do the same thing every week.

It means that when there is an important federal action, WNA can say:

"This week, here's the issue. Here's why it matters. Here's exactly what to ask for."

And then members actually do it.

6. Tell the story where policymakers aren't expecting to hear it.

One of the biggest problems with neuropathy is that it is often invisible.

So we need to make it visible.

Not just with statistics.

With stories.

What does it mean when you can't feel your feet?

What happens when you fall?

What happens when you lose the ability to use your hands?

What happens when you can't work anymore?

What happens when you need a wheelchair?

What happens when you're afraid to walk across a parking lot?

What happens when you can't drive?

What happens when you spend years looking for an answer?

Those are policy stories.

And we should be collecting them.

What would REALLY work at the federal level?

I think there are **four things**.

First: A very specific ask.

Don't go to Congress and say, "Help people with neuropathy."

Say:

"Keep peripheral neuropathy eligible for PRMRP research funding."

Or:

"Increase federal research investment in peripheral neuropathy."

Or:

"We want Congress to recognize neuropathy as a significant neurological public health issue."

Specific beats broad.

Second: Bipartisan support.

Neuropathy isn't a Republican issue.

It isn't a Democratic issue.

It's a health issue.

People across the political spectrum have neuropathy.

Veterans have neuropathy.

Older adults have neuropathy.

People with diabetes have neuropathy.

Cancer survivors have chemotherapy-induced neuropathy.

People have hereditary neuropathies.

And people have neuropathy where we still don't know the cause.

That gives us an opportunity to make this something members of Congress can support regardless of party.

Third: Numbers + stories.

We need both.

A policymaker needs to be able to say:

"This affects a significant number of people."

But they also need to remember the person who sat across from them and said:

"I can't feel my feet anymore."

The numbers establish importance.

The stories establish urgency.

Fourth: Persistence.

This is probably the most important one.

One email isn't advocacy.

One meeting isn't advocacy.

One social media post isn't advocacy.

Advocacy is:

showing up, building relationships, making a specific ask, following up, and coming back.

Eventually, you want congressional staff to recognize WNA.

You want them to know who you are.

You want them to know that when neuropathy comes up, WNA is the organization they should call.

That's when you've moved from being a constituent who has a problem to becoming a resource.

And that's really the goal.

I don't think the goal should simply be:

"How do we get politicians to care about neuropathy?"

I think the goal is:

"How do we make neuropathy impossible for policymakers to overlook?"

We do that by being organized.

By being specific.

By bringing people with lived experience to the table.

By collecting the stories.

By collecting the data.

By building relationships.

By working across political lines.

And by giving policymakers something they can actually do.

You don't have to be a lobbyist.

You don't have to know how Washington works.

You don't have to fly to D.C.

Start with your own congressional offices.

Make a phone call.

Send a personal message.

Ask for a meeting.

Tell your story.

Make one specific request.

And then do it again.

Because sometimes the most powerful advocate isn't the person with the biggest organization or the loudest voice.

It's the person who keeps showing up.

And if WNA can organize hundreds of people living with neuropathy to keep showing up together, I think we can make neuropathy a much harder issue for Washington to ignore.