

Outlook

Patient Voice Newsletter

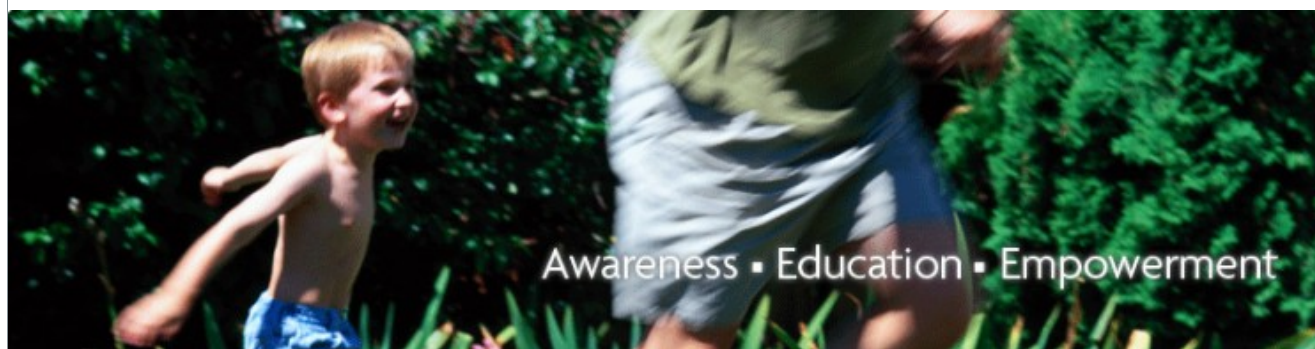
From Neuropathy Action Foundation <patientvoice@naf.ccsend.com>

Date Mon 7/13/2026 6:34 PM

To c_olney@hotmail.com <c_olney@hotmail.com>

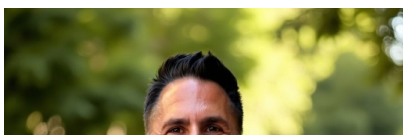


Patient Voice - July 2026 Issue -----Visit our Website



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20 Years of Hope, Advocacy, and Impact



Dear Scott,

Several years ago, before AI and toll booth automation I was crossing a San Francisco toll bridge when I heard what sounded like a party coming from an upcoming booth. As I pulled up to it, I looked inside and saw a man dancing and singing. "What are you doing?" I asked. "I'm having a party," the tollbooth man replied. "What about everyone else?" I

asked, feeling kind of embarrassed as I pointed to the workers in the other booths. "What about them?" the man said. "Each day I watch as they climb into their vertical booths...for eight hours a day, their brain is on hold, and they are dead on the job until the end of the day when they re-emerge and go home."

Fascinated, I asked "what's different for you? You look like you are having so much fun." The man laughed and said, "I do not understand why anybody would think my job is boring...I have a corner office with windows on all sides. I can see the Golden Gate Bridge, San Francisco, and the Berkeley Hills. Half of the Western world vacations here...and I get to stroll in and admire the view while I practice dancing every day!"

Looking back on this conversation made me think about the neuropathy community and how over the past 20 years since I founded the NAF I have learned from so many of you about the power of attitude. I have learned that our lives are not determined by what happens to us, but by how we react to what happens; not by what life brings to us, but by the attitude we bring to life. So, here's hoping that whatever may come your way during this historic 20 Year Anniversary year for the NAF that you maintain a positive attitude which in turn causes a chain reaction of positive thoughts, events, and outcomes.

As we celebrate our **20 – Year Anniversary** we are asking for your support. Please join us in celebrating our history by securing our future. A donation of any amount can be made at **[NAF Contribution Form](#)**.

Warmest Regards,
Dominick Spatafora
Founder and President

Multifocal Motor Neuropathy (MMN) Patients Wanted for Focus Group

MMN is one of the most underrepresented conditions in clinical research, and the daily reality of managing it rarely shows up in the data.

Researchers are launching a study to understand the patient experience with current treatment options - what's working, what's not, and what the real day-to-day reality is for patients with MMN. Before the study begins, we're running a focus group with MMN patients to make sure the study is designed with the patient needs in mind and reflects your real experiences.

To participate, you can sign up for Novellia, a free app and platform that brings all your medical records together in one place, at **[Novellia.com](#)**. Once you're in, let us know you're interested in the focus group and we'll be in touch.

[https://novellia.com/?](https://novellia.com/?utm_source=affiliate&utm_medium=referral&utm_campaign=affiliate_program&utm_content)

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Medicare's Six Protected Classes Must Be Protected for Seniors

The NAF joined The Partnership for Part D Access and over 100 other organizations urging congressional leadership to oppose CMS's proposed GUARD Model and protect Medicare's six protected classes policy. The group letter urged congressional leadership to oppose the CMS Guarding U.S. Medicare Against Rising Drug Costs (GUARD) Model and defend Medicare's six protected classes policy.

Congress established the six protected classes to ensure that seniors and people with disabilities can access the full range of medications for serious conditions, including cancer, HIV, neurological disorders, mental illness, and organ transplant rejection. The treatment for these conditions are often not interchangeable. Patients may spend years working with their clinicians to find the right medication regimen. Once stabilized, uninterrupted access is essential.

The GUARD Model threatens that stability. CMS's own analysis estimates that the model would increase beneficiary cost sharing by \$3.6 billion. Rebates would not reduce costs at the pharmacy counter. Many Medicare beneficiaries live on fixed incomes. Higher out-of-pocket costs will force difficult choices and may lead some patients to delay or forgo treatment.

We support efforts to improve affordability in Medicare Part D. However, reforms must strengthen access, not weaken it. The six protected classes policy has longstanding bipartisan support and remains a critical safeguard for vulnerable patients.

The letter sent on May 29, 2026 can be viewed here:

[6pc_coalition_sign-on_letter_\[final\]-1.pdf](#)



Finding My Voice Through Cancer and Neuropathy

By: Margaret Wesseling

In 2024, I underwent chemotherapy for cancer. As the months went on, I found myself struggling not only with the physical effects of treatment, but also with feelings of boredom, helplessness, and isolation. I couldn't work. I didn't have the energy to do most of the things I normally do. Treatment seemed endless and I felt trapped in circumstances I couldn't change. I found myself focusing more on what I had lost.

What helped me climb out of that was writing.

At first, writing simply gave my mind something positive to focus on. It offered a way to pay attention to the world again instead of endlessly replaying fears and frustrations. As I continued, it became something more. Writing helped me discover new perspectives, connect with other people, and regain a sense of growth and possibility. In a very real way, it reconnected me with my life.

After chemotherapy ended, I developed peripheral neuropathy in my hands and feet. At its worst, my feet were completely numb. I struggled with balance and walking, experienced stabbing pains, and a constant sensation of cold in my feet. Although the neuropathy has gradually improved, it remains part of my daily life. Once again, writing has been an important source of support.

One of the things I value most about writing is that it connects us to ourselves in a positive way. Rather than sinking into whatever is wrong (illness, pain, fear, frustration ...) it invites us into an active process: finding the right words to describe a thought, an observation, a memory, or an experience. And it can be done in many ways. Words can be written with a pen, typed on a computer, spoken aloud, or recorded using a phone. For people whose neuropathy makes writing or typing difficult, today's technology offers many ways to express ourselves.

There is something surprisingly powerful about finding the right words. It creates a sense of purpose and accomplishment. It reminds us that we are still creative, thoughtful, and engaged with the world around us. It also helps build community. When we share our words with others, we discover that we are not alone. When others respond to our writing, and when we respond to theirs, connections form.

Importantly, writing does not have to focus only on illness. We are more than our diagnoses. We can write about our memories, our dreams, the beauty we notice around us, the people we love, or the questions that matter to us. At the same time, writing can help us work through challenges and uncover unexpected possibilities. Sometimes solutions emerge. Sometimes we simply gain a little more clarity and peace.

That is why I created Find Your Own Voice, an online writing course for beginning writers living with chronic illness. The course offers gentle writing prompts, supportive discussion, and a welcoming community for people who want to explore self-expression and connection through writing.

If you would like to learn more, please visit: m2write.com/find-your-own-voice-course

Margaret Wesseling is a writer and writing teacher who developed Find Your Own Voice to help people living with chronic illness.

Multifocal Motor Neuropathy (MMN) Patients Needed for Paid Research Study

IQVIA, a company that conducts market research for authorities, organizations, or pharmaceutical companies is currently conducting a market research study among people with Multifocal Motor Neuropathy (MMN) and their caregivers (someone who supports people with MMN and will be taking part in this research alongside the person they provide support for) on behalf of an international pharmaceutical company.

The aim of this study is to understand the entire journey of people living with MMN, from symptom onset to long-term management. We would like to understand your experiences living with MMN, the challenges you face, the steps involved within your healthcare journey, and work together to identify areas of change within healthcare systems to improve care and the experience of people with this condition.

The paid study involves a **60-minute** virtual interview. Following your interview, a 30-minute virtual interview may be conducted with a caregiver (if you have one and if they feel comfortable sharing feedback about their experience supporting you). The discussion will take place online (via a computer with microphone and webcam).

In addition to the interview, patients will be asked to complete some questions via smartphone over a period of four weeks. This will help us better understand your experience living with MMN. These activities will include, but are not limited to, taking videos and/or audio recordings and pictures of daily tasks, sharing text-based answers, and completing short tasks relevant to the research. These activities will take a total of 60 minutes across the four weeks. We will provide full support on how to complete these tasks. You will need a smartphone with internet access, camera, and video capability.

As a thank you for your participation, patients will receive a total **honorarium of \$250** as described below:

- \$125 for completing the 60-minute virtual interview
- \$125 for completing all four weeks of smartphone activities

If applicable, caregivers who participate in the separate 30-minute caregiver interview will receive \$75. If you are interested, please complete the following eligibility survey to confirm your participation: <https://survey.zohopublic.eu/zs/rABxbV>. Please email Britney Jiron at Jiron@exafield.com should you have any questions.

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Do You Suffer from Chemotherapy Induced Neuropathy?

Chemotherapy-induced peripheral neuropathy (CIPN) is a condition that may occur following chemotherapy treatment. It can present as numbness and tingling in the hands and feet and pain and weakness in the extremities. Dr. Jian Kong and his research team at Massachusetts General Hospital are conducting a clinical study investigating the feasibility and symptom-reducing effects of guided acupuncture imagery treatment for CIPN.

This study consists of 16 guided imagery sessions over 8 weeks and 3 online clinical assessments. All sessions will be conducted via Zoom (no onsite visits required). To be eligible to participate in this study, you must be over 18 years of age, have a current or past diagnosis of stage I-III breast cancer, and experience symptoms of neuropathy.

Additionally, the individuals who would be eligible for this study are those who reside in Massachusetts and surrounding states.

Please email kmgh3@mgh.harvard.edu or call 617-726-5004 if you are interested or have questions.

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