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## Dear Friend,

The Neuropathy Action Foundation (NAF) is partnering with a research company to find participants for a nation-wide, paid usability research study (not a clinical trial) for a new medical device related to CIDP and MMN therapies. The following individuals are eligible to be screened for participation:

- Individuals with CIDP or MMN and who are on IG therapy (Please note that experience administering subcutaneous IG therapy is **NOT** required).

AND/OR

- Caregivers/family members who help administer their friend or family member's IG therapy

Participants will each be paid \$180 for taking part in the two-hour usability study interview as an honorarium. Interviews will be scheduled in areas and at times that are convenient for interested participants. Transportation to and from the study interview location may also be arranged and provided if needed. In some regions, remote interviews may be conducted.

The usability study interview will involve:

- Watching a short video on how to use the new device
- Trying it out on your own (using a foam pad, **NOT** your body – **NO** medication or actual infusions are involved)
- Giving your feedback and opinions about what you like or don't like about it

The interviews are one-on-one (not a group). Extensive precautions have been put in place to minimize the risk of spreading COVID-19. [CLICK HERE](#) to provide your contact information if you are interested in participating or learning more about the study. You may also contact Yuki Sun directly at [ysun@evolutionengineering.us](mailto:ysun@evolutionengineering.us) or (814) 777-1965.

Thank you for your consideration of this research opportunity on behalf of CIDP and MMN patients.

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## New Interactive Book on Pain Relief

Wisconsin Neurologist Dr. Neal Pollack's much awaited book "Pain Relief is Only One Call Away" just rolled off the press. It is the first ever interactive book which affords direct contact with a pain specialist. Just a few of the many topics covered in the book include:

- You Are What You Eat
- Breathing, It's Essential
- The Conscious and Unconscious State
- Exercise to Prevent Pain

## Pain Relief Procedures

Dr. Pollack attempts to provide his readers with a better understanding of what is producing your pain, new ways to make it disappear, and at the same time pick up a phone and connect to a doctor specifically help guide you becoming pain free. Dr. Pollack will provide a portion of book sales to the NAF. Please visit [painreliefcallaway.com](http://painreliefcallaway.com) should you wish to order a book.



## Tell the NAF Your Patient Story

Now, more than ever before the NAF needs patient stories from the neuropathy community regardless of what type of neuropathy you or your loved one has. We need stories of courage and compassion, love and loss, triumph and tragedy, hope and resilience; stories of agonising uncertainty and the delightfully unexpected. The NAF wants to share your story in an upcoming "Patient Voice" newsletter, on our website or with elected officials when we are advocating for the neuropathy community. People living with neuropathy and those who love them have the inherent ability to be passionate and persuasive storytellers and advocates. This is because their words come from the heart and from first-hand experience. Please send us your written story along with a photo of yourself or contact us for more information at [info@neuropathyaction.org](mailto:info@neuropathyaction.org).

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## Your Legislators Are On Social Media. Are You?

The number of individuals using social networking sites such as Facebook, Twitter, LinkedIn, and YouTube is growing at an astounding rate. Facebook has 2.89 billion active monthly users and Twitter sees approximately 500 million tweets per day – that's 6,000 tweets every second.

Given the numbers, social media mobilization has become an integral part of any successful advocacy effort. It's an effective way to engage and coalesce the neuropathy community and opinion leaders from across the U.S. around a single subject. Social media offers opportunities for rapid knowledge exchange, dissemination and response among many people. It can direct communication at a particular user, and it can turn up the volume on a particular topic by sheer numbers of engagement.

Tweets, retweets, posts, likes, and shares have added another layer of communication and influence to public policy debates.

At the NAF, we've been working hard to harness the potential of social media with our community during critical debates. We believe our social advocacy - and especially yours - during last year's legislative sessions made a big difference.

Moving forward we see it as a valuable communication and influencer tool and hope to see more of our community engage. Targeting legislators and opinion leaders with a consistent message from the neuropathy community can make a big difference in the outcome of a vote or position statement.

The NAF team is thankful for our community, that has created a growing presence for neuropathy patients across social media with 1,575 followers on Twitter and 3,581 likes on Facebook. The NAF thanks you for your due diligence and engagement with social media on behalf of the neuropathy community. This will be an increasingly important advocacy tool and we appreciate your time and willingness to engage and share pertinent information with your networks.

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## Small Fiber Neuropathy Rising in the US, But Why Is a Mystery

Megan Brooks

November 03, 2021

Over the past two decades, there has been a significant increase in the number of adults in the United States with small fiber neuropathy (SFN), but in many cases, no cause can be determined. The exact reason for the increase in isolated SFN "remains unclear," Christopher J. Klein, MD, of the Mayo Clinic in Rochester, Minnesota, told *Medscape Medical News*. However, "we noted during the study period the population has had increased BMI, which appears to be a risk factor for this disorder, with many (50%) developing either glucose impairment or frank diabetes during the study period even if not present at first small fiber neuropathy presentation, also with associated higher triglyceride levels," he explained. The study was [published online](#) October 27 in *Neurology*.

### Significant Upward Trend

Investigators reviewed the records of all 94 adults diagnosed with pure SFN (no large fiber involvement) between 1998 and 2017 in Olmsted and adjacent counties in Minnesota — and compared them with 282 adults of similar age and gender who did not have neuropathy. The incidence of SFN over the entire study period was 1.3 per 100,000 per year and the prevalence was 13.3 per 100,000. There was a "significant upward trend" in SFN incidence over the study period that could not be attributed to the availability of intraepidermal nerve fiber density testing, the authors report. The median age of onset of

SFN was 54 years and two thirds were women (67%). Diabetes, obesity, and [hypertriglyceridemia](#) were significantly more common in patients with SFN compared with matched controls. These metabolic risk factors are also associated with peripheral neuropathy regardless of fiber type.

Autonomic symptoms were common and generally mild, affecting 85% of patients with SFN, and included male [erectile dysfunction](#), [constipation](#), light-headedness and palpitations, urinary symptoms, [diarrhea](#), dry eyes and mouth, sweat abnormalities, and gastroparesis. [Insomnia](#) and use of opioid pain medication were more common in those with SFN than matched controls. More than one third (36%) of patients with SFN developed large fiber neuropathy an average of 5.3 years after developing SFN. During an average follow-up of 6.1 years, adults with SFN were significantly more likely to suffer [myocardial infarction](#), [congestive heart failure](#), [peripheral vascular disease](#), stroke, diabetes and rheumatologic disease.

For 70% of patients, no cause for SFN could be determined. Diabetes (15%) was the most common cause identified. Other less common causes included Sjögren syndrome, lupus, [amyloidosis](#), and [Fabry disease](#). "It is important to quantitatively diagnose patients with SFN as many non-neurological musculoskeletal causes can mimic the disorder," said Klein. "If rates of progression are rapid, sinister causes such as out-of-control diabetes, hereditary [transthyretin] TTR amyloidosis, and Fabry disease can be responsible. For other patients, rates of progression are slow and generally do not lead to significant neurologic impairments," he added. "However," he said, "internal medicine follow-up is important for all as this disorder associates with development with higher risk of cardiovascular disease, including commonly heart attacks." Of note, although mean age at death was not significantly different in patients with SFN than controls (70 vs 73 years), there was a significantly higher number of deaths in patients with SFN than in matched controls from the time of symptom onset, the researchers report.

#### Important Research

This "important" study sheds light on the comorbidities and longitudinal consequences of SFN, write Brian Callaghan, MD, with the University of Michigan, Ann Arbor, and J. Robinson Singleton, MD, with the University of Utah, Salt Lake City, in an [accompanying editorial](#) in *Neurology*. The study demonstrates clearly that SFN has "metabolic risk factors similar to those seen for sensory predominant peripheral neuropathies affecting a broader range of fiber types. As a result, therapies that address metabolic risk factors are likely to help prevent or treat both conditions," they write. Callaghan and Singleton add that a key strength of the study is the detailed follow-up that examines SFN progression over time. "The authors found that patients with SFN do not report high disability and that progression tends to be slow. Therefore, patients with SFN can be counseled that progression and disability are likely to be modest in most cases. However, when patients do progress quickly, uncommon etiologies should be sought," the editorialists write.

### Invitation to Interview Patients Using Dynamic Orthotic Devices

Clarion Healthcare, a life sciences consultancy, is seeking peripheral neuropathy patients who currently use a dynamic orthotic upper limb orthotic device (for example Myopro, Regrasp, Bioness, Neomoano, etc.) due to their condition for a one hour discussion regarding their experiences with such devices. Qualified patients will be compensated with an honorarium of \$100 for their time and insights. If you are a qualified patient interested in participating in this study, please email Remy Peace at [rpeace@clarionhealthcare.com](mailto:rpeace@clarionhealthcare.com) to schedule your interview

at a mutually convenient time during weekdays between 8am and 6pm EST, between January 25<sup>th</sup> and February 4<sup>th</sup>.

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