

Peripheral Neuropathy Support Network

No one is alone.
Join. Connect. Share.

Annual Report

October 1, 2022-September 30, 2023

A word cloud graphic where the word "HOPE" is the largest and most prominent. Other words are arranged around it in various sizes and orientations, including "knowledge", "education", "awareness", "information", "manage", "hybrid", "support", "in-person", "influencer", "service", "positivity", "compassion", "action", "listening", "resource", "socialize", "peer-to-peer", "community", and "exercise".

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From the President

2022-23 has proven to be another successful growth and development year for the Peripheral Neuropathy Support Network (PNSN). We have focused on our mission to have a positive impact on the PN community at large through patient education, awareness raising, and outreach. Our aims continue to be three-fold:

- Build our own local support group into a vital, helpful resource for our members.
- Help create and maintain local support groups across the country.
- Provide a collection of verified resources for PN patients and caregivers.



Patricia Gualtieri, President

While continuing our safety precautions during Covid through Zoom meetings, we have also begun developing an opportunity for in-person meetings at a local church. This hybrid setup will allow members a choice as we again offer the opportunity to meet and socialize. We have secured access to a room with WIFI capabilities, enlisted the help of church staff, and purchased needed equipment. Alternatively, members may still maintain a safe distance by meeting virtually.

We have continued to support other local PN groups, including Bethesda/Chevy Chase, MD and Pittsburgh, through technical support and meeting participation. We have also reached out to encourage a member

who is considering starting a group in Hartford, CT. We regularly receive referrals for new members from the Asheville, North Carolina PN Support Group; prospective members are contacted and invited to join either the DC/VA group or the B/CC group in Maryland.

There are no geographical limits, due to Zoom capabilities, allowing participants to join from across the country and even from points international. We regularly receive messages from PNSN meeting participants who confirm the value of our meetings, as well as email and other communications we send responding to their requests for information and help in dealing with their Peripheral Neuropathy.

I have represented the Peripheral Neuropathy Support Network at quarterly support group leader meetings called by the Foundation for Peripheral Neuropathy. We are in further discussion with the Western Neuropathy Association and other local groups to move

2022-23 Executive Officers

President

Patricia Gualtieri

Vice President and Ambassador/Moderator

William Porter

Treasurer

Rebecca Hotop

Communications Officer

W. Judson Vaughn

IT Analyst, Researcher

Michael Foxworth

Program Coordinator

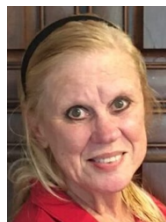
Joanne Jessen

For leadership bios:

<https://dcpnsupport.org/about-pn/about-pn-2/current-leadership/>



*William Porter, VP
& Ambassador/
Moderator*



*Rebecca Hotop,
Treasurer*



*Judson Vaughn,
Communications
Officer*



*Michael Foxworth,
IT Analyst,
Researcher*



*Joanne Jessen,
Program
Coordinator*

forward on initiating our own summit and subsequent regular meetings. This will enable us to share information, advice, and event planning across groups allowing a more cohesive effort.

The PNSN has continued to develop resources, including videos on our YouTube channel, that other groups may use in lieu of speakers as a focus for their meetings. This saves time and effort on the part of leaders, while still meeting member needs for information and answers. Visit our YouTube channel at <https://www.youtube.com/@peripheralneuropathysupport8948>.

“Being part of this group has ... enabled me to encourage others who face these challenges The road ahead is uncertain, but we do not travel it alone.”

Consultancies

PNSN was instrumental in providing early support for Dr. Gregory Maassen’s transcontinental eBike tour to raise awareness and funding for Peripheral Neuropathy. Dr. Maassen joined the Board of the Foundation for Peripheral Neuropathy in January, 2023. On his return from the eBike



Dr. Gregory Maassen

tour, two members, myself and Judson Vaughn, met with Dr. Maassen on a consultancy basis. Gregory is a multimedia, digital marketing strategist and videographer. *Gratis*, he advised us on ways to improve our support for local groups with enhanced use of specific technologies, including AI, CHAT GPT, and other

Vision Statement

Using technology tools and platforms, provide the support, education, and content volunteers need to start and sustain a growing number of community groups for PN patients and their caregivers.

Mission Statement

To help PN patients and their caregivers, by providing tools, support, and content to a network of local support groups.

software. A dozen articles are in process offering vetted information to members on a variety of topics. These will be posted on our website for easy access.

Additional information and responses to questions and comments are regularly posted on our FaceBook page, *On Your Feet*. We also publish a monthly blog called *Footnotes*, which features alerts on events, webinars, research, articles, and news from around the country.

PNSN is pleased to announce that Dr. Abdullah Al-Qahtani has agreed to serve as the Physician Adviser to both the DC/VA and Bethesda/Chevy Chase PN Support Groups. Dr. Al-Qahtani will be joining the Johns Hopkins University Neurology Department in January 2024.

Financial

Total income for the 2022-2023 fiscal year (Oct. 1, 2022-Sept. 30, 2023) was \$4,406. Expenses were \$1,848, mostly for equipment for hybrid meetings and IT subscriptions, including PayPal to avoid using leaderships' personal accounts. Current bank balance is \$5,928.



Most of PNSN's income came from donations from members throughout the fiscal year via checks or online donations through our website <https://pnsnetwork.org/for-members/donations/>. Anonymous donors also contributed through a program called *Network for Good*.

With the generous support of one of our members, the Peripheral Neuropathy Support Network held a matching fundraising campaign in the Fall of 2022 to solicit member donations. It was very successful, raising more than \$2,500 for ongoing operating expenses and equipment purchases.

The Future

We look forward to continuing the development of the Peripheral Neuropathy Support Network in 2023-24. We anticipate continued progress for our flagship DC/VA PN Support Group chapter.

We also anticipate further development of the Bethesda/Chevy Chase chapter and the local group in Pittsburgh. We are providing continued outreach to two potential new groups, one in Herndon, VA and the other in Hartford, CT. The establishment of the Herndon group at Floris United Methodist Church will represent our first effort to re-initiate in-person meetings, allowing for more socialization and less isolation.

We will be reaching out to the Foundation for Peripheral Neuropathy, the Western Neuropathy Association, and other local groups to coordinate and enhance our efforts in reaching those suffering from Peripheral Neuropathy.



“I had never heard of peripheral neuropathy before I was diagnosed ... I've learned more from this group than from any medical practitioner or publication.”

As President, I gratefully acknowledge the support and contributions of our Executive Team, volunteers, donors, and advisors who have enabled us to continue our work on behalf of patients with Peripheral Neuropathy and their caregivers.

I look forward to continuing our important work in the coming year. The efforts of the Board, coupled with input from our members and other PN groups, will enable the sharing and hope promised in our Mission Statement.

Patricia Gualtieri
President



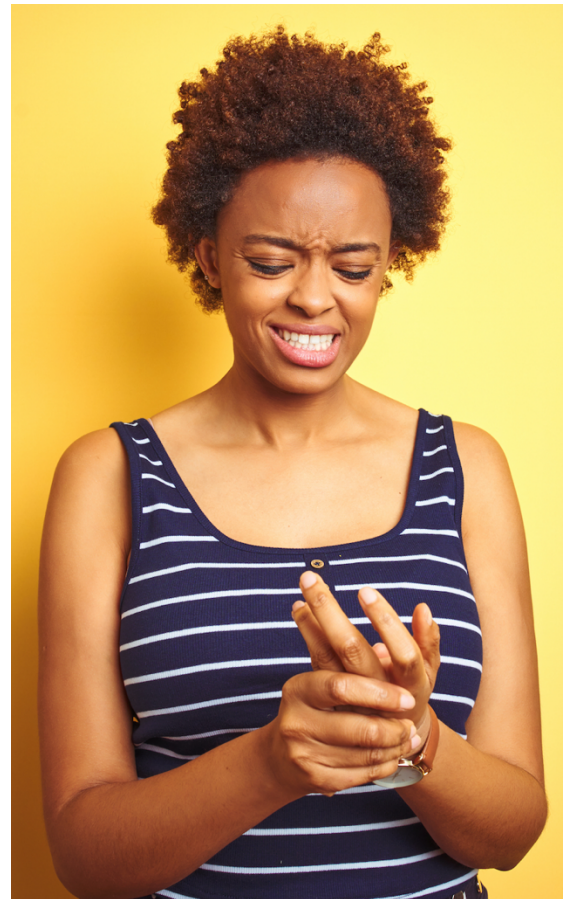
Summary of 2022-23 PNSN Speakers & Events: DC/VA Support Group

October 1, 2022	Dr. Kristy Townsend - Presentation on Evaluating Medical Claims
November 5, 2022	Open discussion of topics of interest
December 3, 2022	Dr. Maryam Dadkhah Impact of lifestyle choices on PN, including diet and nutrition
January 2023	Positivity Strategies to Help Manage PN
February 4, 2023	Dr. Mary Eicher Difficulties in Diagnosing Neuropathy
March 4, 2023	Tour of Mobility City with Q and A with Bennett Helfgott
April 1, 2023	Open discussion of topics of interest
May 6, 2023	NaborForce and Seniors Helping Seniors - Support for Aging in Place
June 3, 2023	Open discussion of topics of interest
July 2023	Summer break; no meeting
August 5, 2023	Open discussion of topics of interest
Sept 9, 2023	Improving Balance and the Dangers of Falling - Videos, plus open discussion

Summary of 2022-23 PNSN Speakers & Events: Bethesda/Chevy Chase, MD Support Group

October 2022	Dr. Brett McCray, JHM Neurologist & PNBCC Advisor
November 2022	Open discussion
December 2022	Open discussion
January 2023	Foot Care with Dr. Adam Isaac
February 2023	Open discussion
March 2023	Open discussion
April 2023	Nabor Force and Seniors Helping Seniors
May 2023	Open discussion
June 2023	Open discussion
July 2023	Open discussion
August 2023	No Meeting
September 2023 -	Open discussion

"This community is special because it uses our differences to highlight our commonalities to improve the shared condition of us all: peripheral neuropathy."



Proposed 2023-24 Objectives

PNSN plans to continue improving our structure and organization, enhancing our presence online and growing our membership in 2023-24. Goals include:

The Organization Development

- Fill vacant slots on the Executive Team.
- Increase Executive Team and member contributions to website, Facebook, YouTube and other Social Media efforts.
- Improve personal communication with members, including responses to emails and FB comments; reach out to prospective and new members to encourage further participation.
- Investigate PR and fundraising/grant writing options.
- Explore convening a summit with other PN groups/networks; once established as a “Leaders’ Group”, initiate regular meetings.
- Ensure brand/consistent message across social media platforms; develop and/or enhance presence.
- Create an Advisory Board for PNSN, separate from the Board of Directors, to tap external resources; meet on a regular basis and/or use as resource to answer questions raised.
- Hold Annual Meeting of Board of Directors to meet 501(c)(3) requirements and get consensus on future direction.

“I wandered alone for over ten years with chronic, severe pain from PN until one day a friend asked why I wasn't in a support group. Joining this group has taught me that I am not alone; that other people have tried solutions I have not; that others understand how I feel. It's all in the name ‘Support Group’.”

Member Growth and Visibility

- Increase membership by 10%.
- Explore instituting a tiered paid membership system.
- Finalize small group starter kit to encourage formation of additional groups.
- Upgrade IT and video features to enhance content, usefulness.
- Connect Bill Porter, Ambassador, with specific member from Stafford, VA to explore formation of a Southern Virginia Chapter.
- Create more of a PNSN “presence” in the tri-state area by pursuing contacts in NY, NJ, and CT; potential for development of additional local chapters.



"The PN Support Group ... brings us all together to have a safe space to educate one another, share our experiences, and to encourage all of us to live our best lives."