



**No one is alone.
Join. Connect. Share.**

Annual Report

October 1, 2023-September 30, 2024



From the President

Pat Gualtieri



We made significant progress in achieving the Goals and Objectives stated in our Constitution and look forward to continued development in 2024-25.

Our mission, intent and focus remains three-fold: Outreach, Support, and Education/Awareness Raising for members, caregivers, the medical and adjunct communities and support groups nationwide. We will continue our efforts to:

- ◆ 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, caregivers and support group leaders

The VA/DC PN Support group continued to meet during 2023-24 via Zoom. Surveys of members supported this format, with the majority expressing little interest in meeting in person at this time. Although we made some effort at organizing a hybrid meeting with a local church, no one elected to attend in person and efforts were abandoned for the time being. With Covid still an issue, and with various access and mobility concerns, it appears that members prefer

maintaining a safe distance and avoiding travel by meeting virtually.

We have continued to support other local PN groups, including those in **Bethesda/Chevy Chase, MD** and **Pittsburgh**, through technical support and meeting participation. The Pittsburgh group has elected to operate with a hybrid format, with the PNSNetwork's technical support. We have also reached out to offer support to a member working to establish a local group in Hartford, CT. We have consulted with her on organizational issues and questions, including her work with local community health directors and the Department of Neurology at a local hospital.

We regularly receive referrals for new members from the Charlotte, 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.

Although there were many negatives to the Covid pandemic, one positive was the ability to meet virtually. 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

"So much valuable sharing! A number of websites, articles, books to peruse. Saved the Chat so I could go back and find."

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.



2024-25 Executive Officers

President

Patricia Gualtieri

*Vice President and
Ambassador/
Moderator*

William Porter

Treasurer

Rebecca Hotop

*Communications
Officer*

Judson Vaughn

IT Analyst, Researcher

Michael Foxworth

For leadership bios:

<https://dcpnsupport.org/>

[about-pn/about-pn-2/](https://dcpnsupport.org/about-pn/about-pn-2/)

[current-leadership/](https://dcpnsupport.org/about-pn/about-pn-2/current-leadership/)

As the PNSNetwork president, and with the support of my Executive Team, we have embarked on a new initiative. In collaboration with members of the **Western Neuropathy Association**, we have held a series of exploratory meetings to determine interest in establishing a **Support Group Leaders (SGL) Consortium**. Nationwide, SGLs, and other PN members, have shown interest in the idea, especially as a means of improved communication. This consortium will enable us to share information, advice, and event planning across groups allowing a more cohesive effort. Several participants have taken on the task of establishing an “InformationHub” and shared Google calendar; work on these continues.

Additionally, **The PNSNetwork** itself 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.

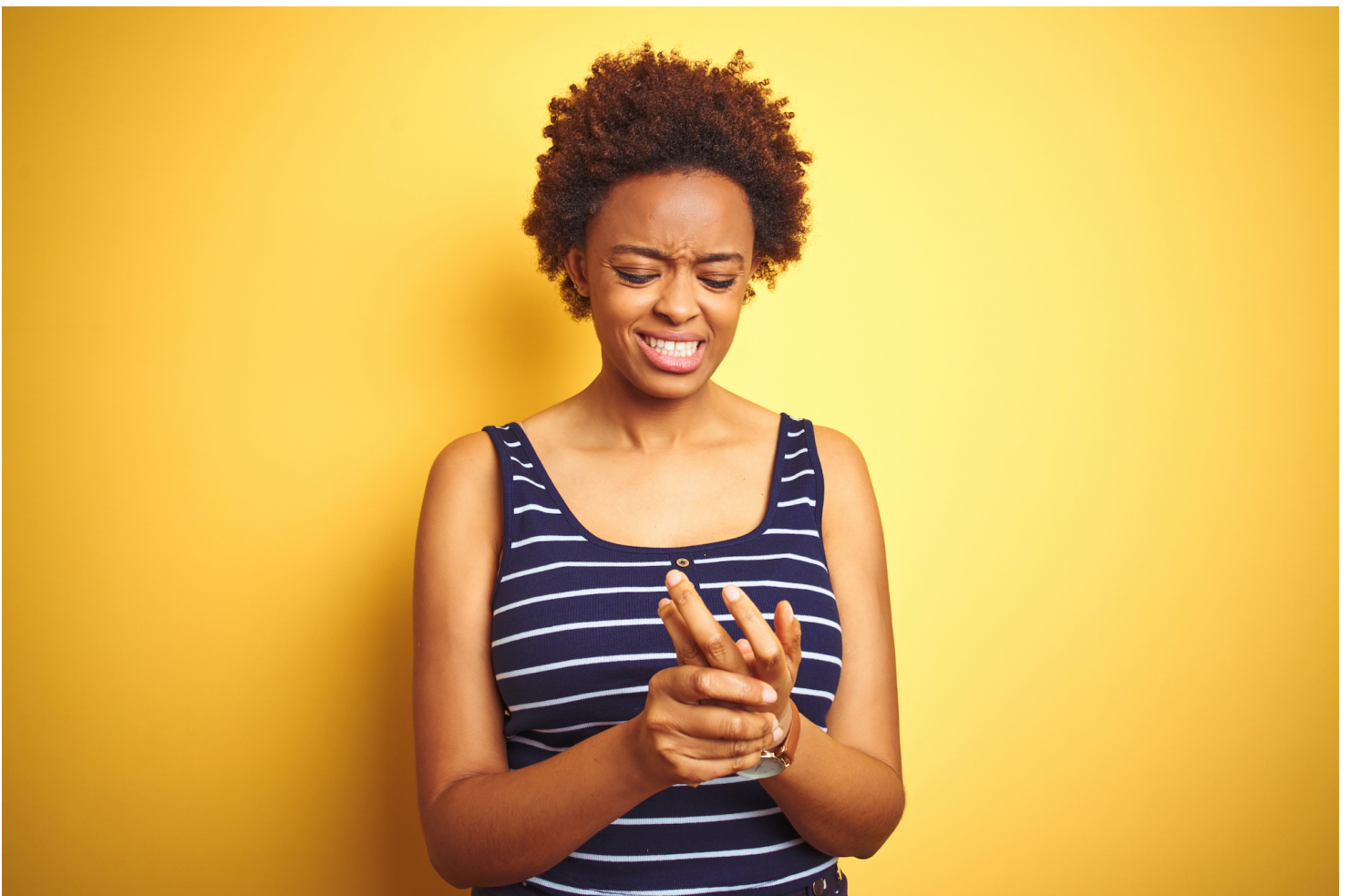
Visit our YouTube channel at <https://www.youtube.com/@peripheralneuropathysupport8948>.

“I found out about tests that my neurologist and pain management physicians SHOULD have requested, IMHO. I learned that there are others with the same symptoms as myself and I don’t feel alone”

“It was informative to hear about the vast number of assistive devices for people with neuropathy.”

Many hours of thought, research and analysis has gone into the maintenance of our website, <https://pnsnetwork.org>. It is a vital source of information for all members of the PN community.

“Great support and so much valuable and inspiring discussion.”



Mission Statement

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

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.

Exit surveys, at the end of monthly meetings, have helped us to identify topics of interest to our members. We are pursuing speakers/presenters on specific topics for the 2025 calendar year. Speaker ideas and contact information are also shared with other local support groups, as we try to meet the needs and interests of our members. We hosted three presentations this past year: 1) a psychologist speaking on emotional and mental health aspects of dealing with PN; 2) an instructor regarding Assistive Technology and Hand Controls; 3) and a pedorthist on Foot Care and Supportive Shoes.



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 joined the **Johns Hopkins University Neurology Department** in January 2024. Dr. Al-Qahtani has indicated his willingness to respond to member questions and plans to address the VA/DC PN Support Group in early 2025.

Financial

Total income for the 2023- 2024 fiscal year (Oct. 1, 2023-Sept. 30, 2024) was \$1190.11. Expenses were \$970.02, mostly for equipment for hybrid meetings and IT subscriptions, including PayPal to avoid using leaderships' personal accounts. Current bank balance is \$5,306.88.



“PN affects us all differently. Having hope is necessary. So keep active mentally and physically as much as possible.”

Most of PNSN's income came from donations from members throughout the fiscal year via checks or online donations through our website <http://pnsnetwork.org/for-members/donations>. Anonymous donors also contributed through two shared resource programs: **Network for Good** and the **PayPal Giving Fund**.

We look forward to continuing the development of the Peripheral Neuropathy Support Network in 2024-25. We anticipate continued progress for our flagship **DC/VA PN Support Group** chapter, and plan to continue our support for the **Bethesda/Chevy Chase, Pittsburgh, and Hartford PN support groups**.

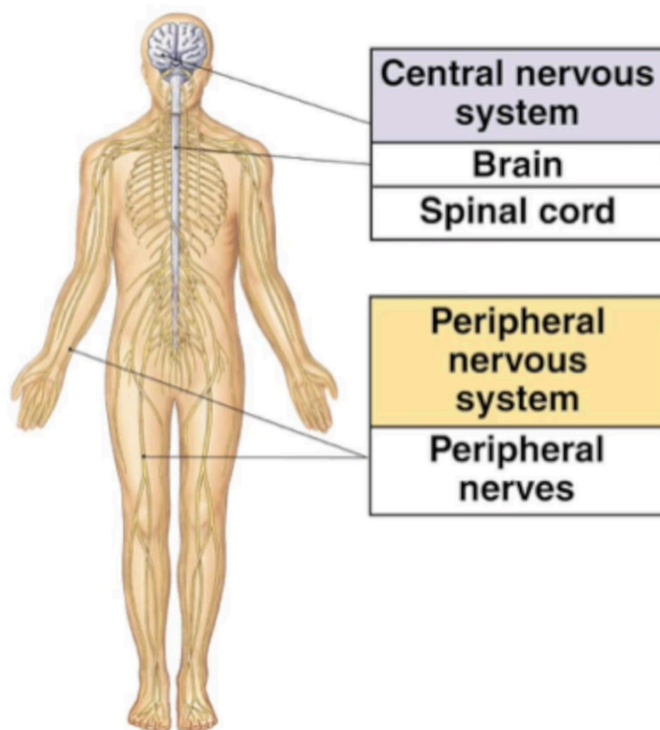
We also plan to continue our collaboration with **The Western Neuropathy Association** and **The Foundation for Peripheral Neuropathy** to further PN support and awareness raising nationwide. Please see our 2024-2025 Objectives for more details.

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.

Patricia Gualtieri
President

Nervous System: Central vs. Peripheral

Neuro = nerve
Pathy = sickness



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Summary of 2023-24 PNSN Accomplishments

Organization Development

- ◆ Confirmed Dr. Abdullah Al Qahtani, **Johns Hopkins School of Medicine**, as Physician Advisor, to PNSN, as well as the Bethesda/ Chevy Chase PN Support Group
- ◆ Filled Program Coordinator duties on Executive Team by assigning other ET members the responsibility for presentations, including soliciting, confirming, and arranging for speakers on topics of interest
- ◆ Identified “Ambassador” position on ET to respond to individual member queries and follow-up when members do not return after initial participation
- ◆ Responded to referrals from other Support Group Leaders from PN sufferers looking to join a virtual support group; provided welcoming letter, introduction to website, and instructions for joining
- ◆ Increased membership of FB Page, ***On Your Feet***, to 408; appointed additional members as Administrators to manage new members/postings and respond to comments and queries
- ◆ Worked on increasing presence, and ensuring consistent messaging, across social media platforms
- ◆ Added recordings of PNSN programs to our **YouTube Channel**
- ◆ Continued publication of informative articles/links on ***Footnotes*** blog, on the PNSN website: <https://pnsnetwork.org>

- ◆ Co-initiated, with the Western Neuropathy Association, an effort to establish a PN Support Group Leaders Consortium for persons of interest across the national PN community. Held three exploratory meetings; initiated an “Information Hub” to improve communication; allowed for the development of a resource clearinghouse and initiated development of a Google Calendar
- ◆ Worked with a member of the Bethesda/Chevy Chase PN support Group to identify online forums to improve response to member questions

Member Growth and PNSN Visibility

- ◆ Maintained average number of member participants at monthly meetings at approximately 30
- ◆ Hosted eleven programs, three with speakers and eight “open discussion” sessions; continued 30-minute “Overtime” feature to allow more social/personal connection
- ◆ Initiated Exit Survey to gauge member response to meeting content and solicit input on various topics
- ◆ Continued participation of ET members in various PN Support Groups across the country, including NC, NY, and TX
- ◆ Offered support to member initiating a group in the Hartford, CT area; consultation, brain storming approaches to invite participation by other health care agencies in the area

- ◆ Continued participation, program coordination and technical support of Bethesda/Chevy Chase, and Pittsburgh PN Support Groups' monthly meetings.
- ◆ Maintained relationship with the Foundation for Peripheral Neuropathy: Advertised availability of PN Support Group meetings, contact information, posting of webinars and recorded offerings, as well as funding initiatives
- ◆ Maintained a strong cash flow, allowing for coverage of all operating expenses

2024-25 PNSN OBJECTIVES

- ◆ Fill vacant slot(s) on Executive team, with primary focus on Program Coordinator position
- ◆ Host eleven monthly meetings, using both speakers and open discussion to meet members' needs; focus on shared information and support
- ◆ Increase membership on mailing list and attendance at meetings
- ◆ Improve personal communication with old and "prospective" new members
- ◆ Maintain PNSN Website, with focus on Calendar and posting of program recordings
- ◆ Streamline member database to improve efficiency

- ◆ Continue providing support to two existing (Bethesda/Chevy Chase and Pittsburgh), and one formative group (Hartford)
- ◆ Maintain strong cash flow
- ◆ Continue collaborative work to establish SGL Consortium



Version History

Version 6.a, October 30, 2024

Version 6.b, October 31, 2024 - some minor financial corrections; date change