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Purpose and Vision of Rochester Parkinson Network

Rochester Parkinson Network is dedicated to empowering people in the Greater Rochester region affected by Parkinson disease (PD) by providing knowledge and fostering relationships that enhance quality of life. We aim to cultivate a supportive community and bridge information gaps. Our vision is that every person affected by PD is connected to the information, resources and allies they need to thrive.

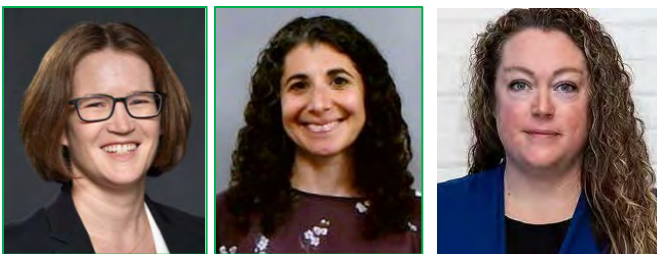
How We Came to Be

Recognizing the locally unmet need, a group of five passionate volunteers founded RPN in of the spring of 2022. Those co-founders are deeply embedded in the local PD community, as people with PD, as care partners, and as providers of medical care to the local PD community. Each of them is supremely dedicated to bringing RPN's vision to life. They constituted RPN's first Board of Directors and supplied the original infusion of time, talent and treasure that made RPN a reality. That initial cash infusion was supplemented by an agreement with the Parkinson's Foundation that made it possible for RPN to take a lead role in supplying local PD support services and building the local community that has become RPN.



Our first Board of Directors (L to R): Kevin Hylton (President), Dave Henning (Treasurer), Dr. Michelle Burack (Secretary), Yvonne Hylton, Dan Kinel, Ron Knight, and Dennis Whitney

RPN Board of Directors



New Board members (L to R): Dr. Ruth Schneider, Jessie Preston and Lindsay Perez

After only two years, RPN still considers itself in the formative stages and has recognized the need on its Board for additional talent and skills. To that end, the Board pictured above has recently grown with the addition of Ruth Schneider, MD (University of Rochester), Jessie Preston, MA, CCC-SLP (Nazareth University), and Lindsay Perez, MSPT. Each brings valuable insights and talents, community and university connections, medical and scientific knowledge and a deep understanding of the

impacts of PD on individuals and the community. The RPN Board remains laser focused on the development and delivery of highly valued services and fiscally responsible decision-making. With the support of talented volunteers and the local community, RPN intends remain a vital and sustainable entity serving the people in the Greater Rochester area affected by PD for years to come.

Closing the Gap on Unmet Needs

When assessing the needs of the local PD community, several issues are often raised. Among them is the dearth of in-person services on the west side of Rochester; lack of transportation options for those without other means; support and information for the newly diagnosed; help with understanding medication and surgical therapies; low-cost aide services and/or respite care grants; the lack of racial diversity in programming; and more. RPN has begun to tackle these needs. We're coordinating a few volunteers who have stepped up to provide transportation to RPN events and support groups. We developed a prototype informational



package for newly diagnosed people so they can leave the neurologist's office with the basic knowledge that provides a path forward after receiving the life-changing news of a PD diagnosis. A generous local donor has provided funding and leadership to address several of these needs. Two medical professional

volunteers are developing a *Newly Diagnosed Boot Camp* to help affected people navigate the uncertainties that come with a PD diagnosis. So although we're making some progress, as an all-volunteer organization, RPN can do only so much when the need is so great. We plan to continue to develop new programming to address these needs. However, in order to make real progress, growing our volunteer base is a necessity.

Volunteers



What gets done at RPN happens because passionate volunteers dedicate their time and expertise to make things better. We all benefit from the help of 32 active volunteers, but more are needed to help with running programs, advertising and communications, and spearheading new initiatives. PD can make it difficult to volunteer but if you have the ability and desire or have a family member or friend with time and a passion to help, please contact us. We need your help.

By the Numbers (April '22 to June '24)

- Produced and hosted 16 monthly education and social programs
- Over 800 people engaged through in-person education programs
- More than 40 active donors impacting the lives of thousands in our community
- Received a total of \$17,252 in individual and corporate donations
- Received 5 governmental proclamations for World Parkinson's Day thus improving awareness among local elected officials
- Engaged 32 active volunteers who provided hundreds of hours of their valuable time and skills to make available RPN a reality
- Nearly 400 email subscribers and growing
- Networked with 11 local, national and international PD organizations to bring the most relevant, timely and useful information to the local PD community
- Made the Davis Phinney "Every Victory Counts" manual available in 31 local libraries
- Conducted 19 Needs Assessment Q&A meetings to determine most pressing needs within the local PD community
- Nearly 300 unique visitors to our website who are able to access over 30 PD resources in one place
- Recorded education events and created a YouTube channel and offered digital versions of handouts for those unable to attend in person

Accomplishments and Impact

From humble beginnings in 2022, RPN has become a highly valued and respected member of the local PD community. We understand that knowledge, while vitally important to living your best life with PD, is not enough. Our understanding of the importance of community is reflected in these accomplishments:

- Became a 501(c)(3) non-profit able to receive tax-deductible donations
- Built partnerships and networked with local, national and international organizations and support groups to bring information, services and advocacy opportunities regarding public policy changes and greater funding to support people with PD and their care partners
- Periodically assessed information and service needs within the local PD community and matched programming to those needs
- Ran, collaborated on or joined in dozens of monthly education, support and social events throughout the Greater Rochester area where people affected by PD can interact, laugh, cry and learn in a safe and supportive environment
- Initiated a live, bi-annual PD forum with MJ Fox Foundation attended by more than 175 people, combined with research recruitment to bring attention to locally conducted studies and participation opportunities that will lead to better treatments and eventually, a cure
- Created a Speakers Bureau for use by local support groups to extend the knowledge base
- Developed a timely, interactive website with PD news, events, support, and local, regional, national and international services together with a list of local clinical social workers and mental health professionals with PD experience
- Established a phone line staffed by people with PD, care partners and a medical professional to help with resource and information needs
- Published quarterly newsletters to keep the community informed about RPN and how it can help make life with PD more manageable
- Grown our reach into our target audience from a few dozen in 2022 to about 500 in 2024 with the ultimate goal of reaching all of the local PD community, including the underserved
- Supported local businesses by collaborating on recreation and social events
- Attracted volunteers who have dedicated their time and skills to help develop and deliver valuable local services unavailable elsewhere

Appreciation for contributors

RPN has been fortunate to have the generous financial support of more than 40 active donors. Those donations make possible the programs and services described throughout this report. Without that support, RPN would cease to exist. But In addition to the financial contributions made to RPN, the contributions of skills, time and energy are what make RPN an effective, community-focused organization. From graphic design to website management; from running education events to managing finances; from delivering enlightening content to social and community engagement; our volunteers are **priceless!**

