

## *A Letter from the President*

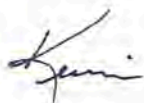
Dear friends of Rochester Parkinson Network,

There are many ways to think about the health of a community but nearly impossible to imagine any definition that doesn't take into account the well-being of those with chronic illness. Those so burdened can thrive only with access to the right combination of medical and allied care, support services, and community-based organizations focused on ensuring that people are connected to the right information, resources and allies.

Rochester Parkinson Network is such an organization. We are laser focused on providing actionable information through our monthly education events; delivering curated resources of the highest quality from local, national and international sources through our website; and connecting people affected by PD with allies both within and outside the Greater Rochester area through social engagement opportunities and collaborations with organizations such as Lifespan, University of Rochester, Nazareth University, Rochester Accessible Adventures and others. The list grows as the value that RPN brings is more widely recognized and appreciated. As impressive as these accomplishments have been for an organization that is less than three years old, we have a long way to go to reach the entire Greater Rochester PD community.

A 2022 study by the Fox Foundation and others found that annually in the US, about 90,000 people are diagnosed with PD, about 50% more than previously estimated, and that number is growing. Moreover, by the year 2030, there will be 1.2 million people diagnosed with PD in the US, alone. There are roughly 4,000 to 5,000 people in the Greater Rochester area that have already been diagnosed with PD. For each one of them, imagine roughly four additional people - spouses, care partners, parents, children, and colleagues thus affected. That translates to a local population of around twenty to thirty thousand people affected by PD. So, even though our volunteers have donated more than 2,300 hours in the past year and our donors have provided financial gifts that allow our all-volunteer organization to meet our modest needs, our job will continue to get bigger into the foreseeable future. RPN now reaches about 500 people per month. We need your help to reach further into the community. If you know of someone who has PD or meet someone facing the challenges that PD brings, please direct them to RPN so together, we can make this a healthier community for those living with the chronic illness that is Parkinson disease. Thank you for your continued support.

Sincerely,



Kevin Hylton

## INSIDE...

- Our volunteers are **AWESOME!**
- New Board members add new talents & connections
- RPN's 2024 accomplishments were **HUGE**
- Upcoming Education events
- PD Resource Expo coming in April
- Rochester Community Health Foundation provides matching donation to RPN



## Our Volunteers...Just Wow!

Volunteers are the lifeblood of an organization like RPN. Without paid staff, nothing would happen without them. We asked our 23 active volunteers to estimate the number of hours they donated to RPN over the past year and the tally was 2,328! They set up tables and chairs for events, recruited presenters, developed new programming, managed the phone line, created relationships with fantastic collaborators, connected with municipal, county and state elected officials, appeared on various radio and TV programs advocating for people with PD, ran support groups, counseled those newly diagnosed with PD, curated our website, developed marketing materials, and the list goes on. They are tireless, innovative, and committed to making positive change in our community so that people affected by PD can thrive.

Thank you, Volunteers, for making Rochester a better place for people affected by PD.



Volunteers (L to R)  
Cindy Sokolowski,  
Mary Sanderson,  
Rick Briggs  
and Joe Sokolowski

## New Board Members Add Talents & Connections

RPN welcomed four new Board members in 2024. Lindsay Perez, Jessie Preston, Pauline Rutberg and Dr. Ruth Schneider bring their considerable skills and connections in the community to RPN and add depth to our Board. Check out their bios on our website. When you see them, please extend a warm welcome.

## RPN's 2024 Accomplishments Were Huge!

Extending RPN's reach into the local PD community is of paramount importance if we are to become a powerful force to inspire change. That work involves adding collaborations and expanding partnerships to make PD resources more easily accessible. RPN did the following and more in 2024...

- drew nearly 700 people to 16 events, more than doubling 2023 attendance
- created an RPN YouTube channel for our recorded events
- added programming at the Ogden library on the west side of Rochester and at the Highlands of Pittsford on the east side
- placed Davis Phinney's "Every Victory Counts" manual in Monroe County libraries
- collaborated with Lifespan, URMC, Nazareth University, Rochester Accessible Adventures, University at Buffalo, independent support groups and others to help grow awareness of PD in the community
- advocates secured multiple proclamations from local and state governments recognizing World Parkinson Day and RPN's value in the local community
- responded to numerous calls on RPN's dedicated phone line (585-770-1570)
- began a mental health counseling program for people newly diagnosed with PD
- held a research forum attended by nearly 200 people with guest presenters from the Michael J Fox Foundation and four regional Parkinson disease research institutions
- expanded the RPN website to include curated, actionable PD news from around the world
- added to the RPN website a listing of local, state-licensed counselors serving clients with chronic illness or medical issues that cause emotional difficulties
- became a United Way agency authorizing donations to RPN through direct payroll deduction

**You are the NETWORK. Please send your ideas, suggestions, and feedback through our website, by email at [RocParkNet@gmail.com](mailto:RocParkNet@gmail.com), by phone at (585) 770-1570 or by US post at PO Box 18606, Rochester NY 14618.**



## Upcoming Education Events

New events are always being planned at RPN. We have several currently in the works for the first half of the year. Remember that all of our Education Events are free. For dates, times, locations, presenters, additional details and how to register, tune in to [RocParkNet.org/events](http://RocParkNet.org/events). Here is a partial list:

- **Name That Scam** - Join us and Dan Lyon from Lifespan's Fraud, Scam and Identity Theft Protection office for this outrageously fun, musical way to learn about how to recognize and protect yourself from telephone and online fraud.
- **Memory and Cognition** - Dr. Mia Weber from URM's Memory Care program will address cognitive declines in PD and help you to develop strategies to manage them and optimize brain health. She will be joined by Jessie Preston of Nazareth University's Speech and Language Pathology Department who will assist Matt Taylor, Trivia Master, in a trivia contest to exercise both your brain and your voice.
- **Navigating Transitions to Higher Levels of Care** - Many of us will contemplate how we will manage our lives depending on the progression of our PD. Amy Chesire of URM's Movement Disorders Clinic will discuss stages of PD as a roadmap to identify care needs and understand community options while reducing stress and maximizing support.
- **Managing Legal Issues with PD** - Are you still working but contemplating when and how to leave the workforce due to PD? Steve Modica, Esq. will help you understand the intricacies of Social Security and private short- and long-term disability, state retirement systems, and more. Don't lose benefits to which you're entitled because of avoidable mistakes.

## Parkinson's Awareness Month

April is Parkinson's Awareness Month. RPN has arranged for many of the buildings and natural features in Rochester (think High Falls) with architectural lighting capability to be illuminated in vivid blue for the week of April 7-11. RPN will join with PD Avengers ([PDAvengers.com](http://PDAvengers.com)) to illuminate 11.8 million blue lights in cities across the globe representing the 11.8 million people worldwide diagnosed with PD. You can join the movement by illuminating your house, office, a doorway and even your walker in blue light and sharing your pictures here.

## PD Expo Planned for April 26th, 2025

RPN's Research Forum in April of 2024 was so well received that we've decided to run another event that coincides with the start of spring: a PD Resource Expo. We will host, in one place, a resource fair featuring useful tools and services for people with PD and their care partners such as assistive technologies, mobility aids, wearable devices, accessible recreation and leisure providers, pharmaceutical companies, home safety devices and modification contractors, speech and communication tools and providers, home health aid providers, and much more. The format will be similar to a business trade show where tables will be staffed by reps from each organization. In addition, in an adjoining room, there will be short presentations by several pharma companies describing their latest PD treatments and those presentations will be repeated on a schedule throughout the day. The event will run from 10:00 AM until 4:00 PM on Saturday, April 26 at the JCC on Edgewood Avenue in Rochester. Registration is encouraged. Stay tuned to the RPN website for more information including presentation schedules, participating organizations, etc. If you represent such an organization and are interested in participating, please contact us at 585-770-1570.

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## Rochester Community Health Foundation Awards Matching Grant to RPN

The mission of the Greater Rochester Health Foundation (GRHF) is "to pursue and invest in solutions that build a healthier region where all people can thrive". RPN's vision statement (Every person affected by PD is connected to the information, resources and allies they need to thrive) is perfectly aligned with GRHF's mission.

Tom Bartlett is a co-founding partner at Cobblestone Capital Advisors in Rochester and his wife, Julie, manages the Newly Diagnosed Counseling Program for RPN and is a member of RPN's Programming committee. In addition to being strong supporters of RPN, Tom is also on the Board of GRHF.

GRHF has a very generous program by which it matches up to 5x any donations that members of their Board of Directors make. RPN is grateful to be in the top tier of Tom's philanthropic priorities, grateful that he and his wife are so invested in Rochester and grateful that GRHF believes in and supports RPN's work.

### Key Financial Contributions to RPN in 2024

Jo Zimmerman's multiple donations have supported existing RPN programs and enabled development of signature programs that support needs in the Greater Rochester PD community. Without her unwavering support, we could not have come as far in so little time nor could we dream as big. Thank you, Jo!

Our hearts are full of gratitude for our wonderful supporters. They choose any of a number of ways to donate their treasure: some by check; some through our website; some through workplace payroll deduction (RPN is now a United Way agency able to receive donations through payroll deduction offered by many local employers); and still others give during United Way's Roc The Day program. We thank you all.

## 2024 Contributions (Contd.)

No matter the method used by our donors, all contributions support our vision: That every person affected by PD in the Greater Rochester region is connected to the information, resources and allies they need to thrive. We want to thank the many individuals and organizations whose generosity has been critical to supporting and sustaining RPN's work. We thank all of the following for putting your trust in Rochester Parkinson Network and for your extremely generous contributions throughout 2024.

### RPN Champions (\$5,000 and greater):

- ★ Greater Rochester Health Foundation
- ★ Jo Zimmerman

### RPN Boosters (\$1,000 - \$4,999):

- ★ Tom Bartlett
- ★ Kathy and Andy Holt
- ★ Patrice Ryan
- ★ Joe and Cindy Sokolowski

### RPN Benefactors (\$500 - \$999):

- ★ James Brady
- ★ Jane and Everett Charette
- ★ Richard Goldstein
- ★ Mary Lou Kernahan
- ★ Sherry Phillips and Richard Margolis
- ★ John and Judy Messenger

### RPN Patrons (\$250 - \$499):

- ★ Robert Bergin
- ★ Julie Blum
- ★ Candace Hylton
- ★ Dr. Ruth Schneider
- ★ Mac and Betsy Warner
- ★ Karen and Jack Westra

### RPN Friends (up to \$250):

- ★ See Pg. 5

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## Contributors (Contd.)

### RPN Friends (up to \$249):

- ★ Linda Albrecht
- ★ Lori Anschuetz
- ★ Mary Antak
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- ★ Raymond Bracalenti
- ★ Patricia Bradford
- ★ Carolyn Cass
- ★ Helen Cherniak
- ★ Carolyn Corretore
- ★ Jean Dailey
- ★ Mary Ellen Dangler
- ★ Mary Jo Deichmiller
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- ★ Suzanne Ernst
- ★ Deborah and Andrew Essa
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- ★ Jennifer Lesinski
- ★ Bobbi Lesser
- ★ Whitey and Sandy Link
- ★ Debra Littleton
- ★ Julie Lombart
- ★ Judy and John Malone
- ★ Dr. MaryJo Marro-Tobin
- ★ Marilyn McNaughton
- ★ Valerie McPherson
- ★ Rebecca Menendez
- ★ Karen Miltner
- ★ Stacy Mohr
- ★ Karen Morris
- ★ Donna and Sam Muto
- ★ Douglas and Denise Nolan
- ★ Gary Odell
- ★ Maha Atma Kaur Oesterly
- ★ Rodrick Palma
- ★ David Patric
- ★ Paypal Giving Fund
- ★ Monica Piraino
- ★ Michael Power
- ★ Beverly Rees
- ★ Daniel Robertson
- ★ Claudia Segura
- ★ John and Pamela Severin
- ★ Julie Smith
- ★ Mary Solomon
- ★ Aric Spitulnik
- ★ Gail Spitulnik
- ★ Linda Starsmore
- ★ Tagliente
- ★ Susan B Turner
- ★ Celene Fryba-Uczen
- ★ Debra Vater
- ★ Mary Pat Vogel
- ★ Marie Warda
- ★ Terrie L. Willoth
- ★ Karen Woch
- ★ Marshall and Karen Wren and Kathryn Young



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