



Parkinson Association of Northern California

®Building Community For The Journey®

How PANC Began

A small support group in the Arden Arcade garage of Clarence Youngren became incorporated in 1996 and has become one of the leading independent networks of local support, education, and awareness for Parkinson's disease in the country.

What We Are

PANC is a 501(c)(3) nonprofit organization with a goal to provide services that improve the quality of life for those facing Parkinson's Disease throughout Northern California.

Many PD organizations exist. However, we are hands-on and boots-on-the-ground organization that directly serves the residents of Northern California.

Our Mission

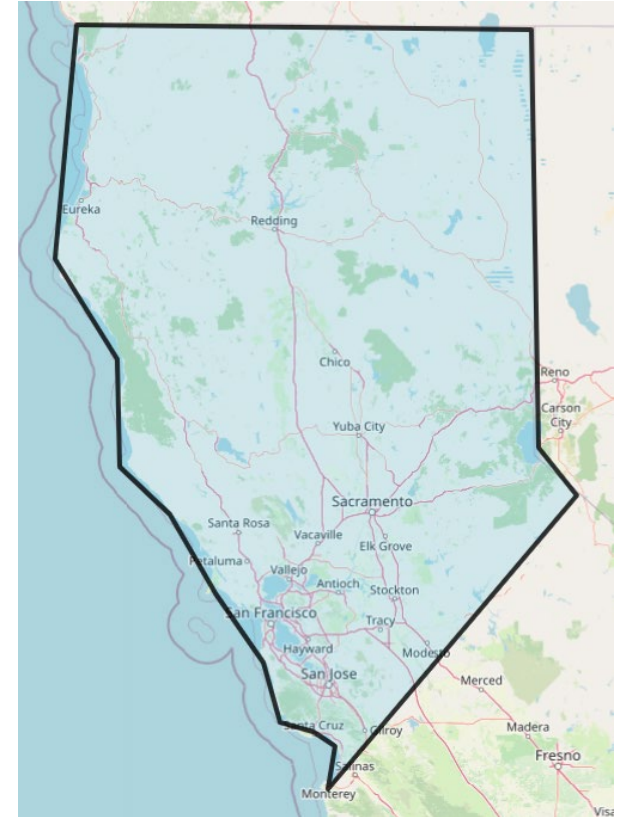
We are dedicated to enhancing the lives of people with Parkinson's, their families and care partners throughout our region. Our motto is, "Building Community for the Journey."

Operations

- Budget: Just over \$415,000 annually with \$350,000 in reserves
- Region: Most of Northern California
- Office: Folsom
- Staff: 2 (Extremely active Board, medical panel and volunteers)
Adding a third staff person in July, 2024

Programs & Services

- ✓ Support Groups
- ✓ Care Partner Respite Grants
- ✓ Resource for information on PD
- ✓ ParkinsonWise® and other trainings
- ✓ Newsletters
- ✓ Annual Education Conference
- ✓ Advocacy Efforts
- ✓ Collaboration and sharing of knowledge with affiliated organizations
- ✓ Fundraising efforts and more!



How Do We Fund PANC?

- Donations (general, in memory, donor-advised charitable funds, employee matching, etc.)
- Sponsorships (conference, COP Walk, et.)
- Grants (for program development – current are rural development and ParkinsonWISE II)
- Fundraising (TopGolf, auction, 3rd Party, Facebook, Big Day of Giving, Annual Appeal, etc.)
- 3rd Party fundraising events (Lion's COP Walk, Archival Museum, Comedy Night, etc.)
- Speaking opportunities

What are the expenses?

- Keeping the “lights” -- Rent, utilities, operations, staff, CPA, attorney, technology
- Respite grants – \$30,000 year
- Conference – Right around \$115,000 (\$145 pp)
- Other – Insurance, travel, newsletter, marketing, postage, processing fees, etc.

Major Parkinson's Non-profits

Michael J Fox Foundation (National) – Research & advocacy

Parkinson's Foundation (National) – Hospital kit & Q&A hotline

Davis Phinney Foundation (National) – “Every Victory Counts” books

PMD Alliance (Regional) – Webinars, online exercise, support groups

Community Foundations

Sacramento Regional Community Foundation

Placer Community Foundation

PANC's Medical Community Network & Journal Club

A unique entity in the PD medical community, our Medical Advisory Panel (MAP) and Journal Club bring together a multi-disciplinary group of medical professionals from NorCal's four major healthcare systems and the Veteran's Administration

Sutter Medical Group

Erica Byrd, MD

Nicklesh Thakur, DO

Fred Weiland, MD, FACNM

Lin Ramatowski RN, FNP

Kaiser Permanente

Suketu M. Khandhar, MD

Meghan Anderson, NP

Jeanine Perry, NP (Retired)

Kaiser Rehabilitation Svcs

Erin Vestal, PT, DPT, NCS

Christine Shade, PT, DPT, NCS

Jennifer Lieu, PT, DPT, NCS

UC Davis Health

Norika Malhado-Chang, MD

Jonathan Snider, M.D.

Lin Zhang, MD

Laura Sperry, FNP

Dignity Health

Ehsan Hadi, MD

Veteran's Administration

Mai Vuong, MD

Parkinson's disease and Care Partner Support Groups

PANC currently facilitates a network 48 area support groups (and growing). **Each group is unique** and determines the pace, topics, and direction of their group.

PANC provides the following services to its affiliated groups:

- Liability insurance coverage for meeting locations
- Funds management (for specific groups for specific purposes)
- Listing of potential speakers
- Annual Support Group facilitators' workshop – May of each year
- Meeting information listed on PANC's website, newsletters, etc.
- Customized promotional brochures and business cards
- Ongoing committee and staff support

Recently formed groups:

- Salinas PD Support Group
- Ukiah PD Support Group
- Chico PD Support Group
- Humbolt Support Group

PANC's Respite Care Grant Program

100% funded by PANC's fundraising efforts, this program supports individuals who serve as care partners to people with Parkinson's disease who need time for self care. Subsidized grants for the cost of respite care provided by Del Oro, Passages and Redwood Caregiver Resource Centers (CRC).

Program Guidance

- Grantees can be awarded \$600 grant for use at an affiliated CRC (Redwoods for Benicia)
- May apply once per 12-month period
- Must provide proof of Parkinson's disease diagnosis
- Care partner must be able to meet, interview, and support planning through CRC
- Must reside in one of the counties served by CRC

Annual Education Conference

Saturday, September 28, 2024 @the Grounds in Roseville

8:00 am to 3:00 pm -- Cost \$40 (in-person)

Keynote speaker, professional speakers, panel discussions,
question and answer session, lunch, commraderie, & exhibit fair

2023

In-person attendance: 644 Virtual attendance: 104

Preliminary 2024 Program Highlights

Keynote speaker -- Sharon Krischer (aka “Twitchy Woman”)

GI & GU Issues

Cognition Issues

Orthostatic hypotension

Research updates

PANC Publications

The Parkinson Path (Quarterly) -- Mailed or emailed

Pertinent information/updates on events, support groups, services, new technologies, and articles provided by local Parkinson's disease experts and MAP members.

Update (Monthly) – Emailed

Uplifting articles, resources, and links on all things PD.

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THE PARKINSON PATH



The Parkinson Association of Northern California is an organization dedicated to enhancing the lives of people with Parkinson's, their families and care partners.



Get *The Parkinson Path* delivered straight to your email inbox by contacting Sharon@panctoday.org

Evolving Deep Brain Stimulation

by Erica Byrd, MD, Linda Ramatowski, NP and Nick Thakur, DO of Sutter Medical Group

Deep Brain Stimulation (DBS) for Parkinson's disease has been a valuable treatment option since its approval by the FDA in 2002. DBS treats the motor symptoms of Parkinson's disease including tremor, stiffness (rigidity) and slowness (bradykinesia). DBS is considered an "advanced therapy" for persons with Parkinson's disease that meet certain criteria including a diagnosis of idiopathic Parkinson's disease for at least 4 years with motor fluctuations (i.e. "on/off" symptoms, troublesome dyskinesia) or refractory tremor. DBS is contraindicated for patients having a diagnosis of atypical parkinsonism, dementia or significant psychiatric disease. Additionally, a comprehensive evaluation is required that involves MRI brain imaging, neurosurgical and neuropsychological evaluations and testing of medication responsiveness.

The main components of a DBS system are the leads placed in the brain and a programmable pacemaker-like device under the skin in the chest. The implantation of the leads is done via brain surgery performed by a specialized neurosurgeon. This is followed by the programming phase, in which the device's settings are adjusted by the movement disorders neurological team, typically in more frequent appointments starting several weeks after the surgery until optimal settings are found. Programming takes several months after surgery to reach the target settings.

In the last decade the DBS field has grown tremendously. Recent advances and innovations have delivered multiple options to patients and clinicians and have made this an exciting time for DBS. There are now three manufacturers of DBS devices: Medtronic, Abbott and Boston Scientific. The newest innovations are lead types that are "directional" meaning some of the energy can be focused in one part of the lead, limiting side effects and battery use. All three manufacturers have this lead



ParkinsonWISE®



In partnership with Kaiser Permanente Neuroscience, ParkinsonWise® was created as class for non-medical fitness and wellness experts to learn how to work successfully with PWP.

Attendees include personal trainers, massage therapists, yoga, Pilates, tai chi, dance instructors, Rock Steady Boxing coaches, swim coaches, etc.

Why ParkinsonWise€ ?

- Teaches wellness strategies for and understanding of unique needs of people with Parkinson's
- Increases exercise and movement services in the PD community
- Trained professionals are listed on the www.panctoday.org website and can be easily located for those looking for providers

**ParkinsonWISE II for Assisted Living and In-Home Care Staff
And ParkinsonWISE III for Care partners coming in 2025!**

National Plan to End Parkinson's Act

Drafted by the Michael J Fox Foundation, The National Plan to End Parkinson's Act was reintroduced by bipartisan legislators in Congress last Spring and passed through the Senate in May 2024. It's currently sitting on the President's desk for signature.

First of its kind of legislation aimed at preventing, treating, and curing Parkinson's disease and unites the federal government and private enterprise to create an advisory panel to look at:

- Increasing federal research funding
- **Developing more effective pathways for treatments and cures;**
- Improving early diagnosis;
- **Sparking new and improved models for patient care;**
- Creating standards and measures to prevent Parkinson's disease;
- Enhancing public awareness of the disease.

2024 PANC Initiatives

- Promotion of **Mental Health CEU course** developed with the San Diego Parkinson's Association related to the specifics of Parkinson's disease for Mental Health professionals
- Development of a live course related to the specifics of **caring for Parkinson's disease patients for and care partners assisted living facility and in-home care staff** (ParkinsonWISE II) (ParkinsonWISE III)
- Refresh PANC's internal **policies and procedures** to comply with 501 c3 law
- **Rural outreach and PANC/SG's marketing** project
- Advocacy work on behalf of **Parkinson's disease**
- **Review/upgrade Support Group MOU and benefits**
- Review of **Respite Grant** process and procedures

What We Need to Clean/Improve

- Marketing, social media
- Branding (logos, mission/vision, guide/fonts, etc.)
- Website
- Policies and procedures
- Committee/Task Force structures
- Communication
- Filing/record keeping

Misc.

- **PANC Technology?**

 - QuickBooks (financials) (CPA)

 - Bloomerang (constituency database)

 - Wix (website) www.panctoday.org

 - Zoom (virtual meetings)

- **How identify self as Board member?**

 - PANC badge

 - Director, Parkinson Association of Northern California

 - Shirts?

- **Advice?**

 - Be curious

 - Be proud

 - Build relationships with fellow Board Members, staff, the community, and constituents

 - Have fun!

Questions?



Parkinson Association
of Northern California