

Parkinson Association of Northern California

"Community For The Journey"

panctoday.org

About Parkinson's disease (PD)

- Parkinson's disease (PD) **is the fastest growing neurodegenerative disorder of today.** Difficult to diagnose and get a diagnosis.
- Over 1 million people in the U.S. (16.5% of the worldwide cases) have been diagnosed, and more than 6 million people in the world. The U.S. has just over 4% of the world's population. Does not include the undiagnosed.
- **Lifelong and progressive.** Currently no cure.
- **Unique to each person.** Various types of PD.
- As the progression varies from person to person, symptoms can not be predicted.
- Men statistically have more cases than women; that is changing.
- People don't die from PD, but often from a symptom of it.

About Parkinson's disease (PD)

- In 2024, the cost of PD to individuals, families and the U.S. government **was \$82.2 billion.**
- \$58.4 billion of that is direct medical costs & the rest in non-medical costs (Early forced retirement, family caregiver wages, disability expenses, home modifications, etc.)
- The federal government spends nearly \$25 billion annually for disability, Medicaid, and Medicare costs.
- An estimated 90% of people diagnosed with PD receive Medicare benefits.

The cause of Parkinson's Disease is likely a combination of genetic and environmental factors. Exposure to environmental chemicals or toxins such as rural living, well water manganese, and pesticides.

- 20- 30% of PD risk is explained by genetics.
- The rest attributed to head injury (i.e. football, wrestling) & heavy drug use, but **mostly exposure to the pesticide paraquat (and like derivatives), the cleaning solvent trichlorethylene (TCE) and Agent Orange.**
- 10 to 40 years from environment exposure to diagnosis. Legislation pending on **paraquat and TCE as they are legal in the U.S. and very few other countries.** (Paraquat is illegal on golf courses in the U.S.)
- Due to an aging population and the increase in environmental toxins, **researchers project the number of people with PD will double by 2040 – a pandemic.**

What is Parkinson's Disease?



Progressive, neuro-degenerative disease affecting the basal ganglia

Presents with a deficiency of dopamine (neuro-transmitter)

Characterized by four primary motor symptoms

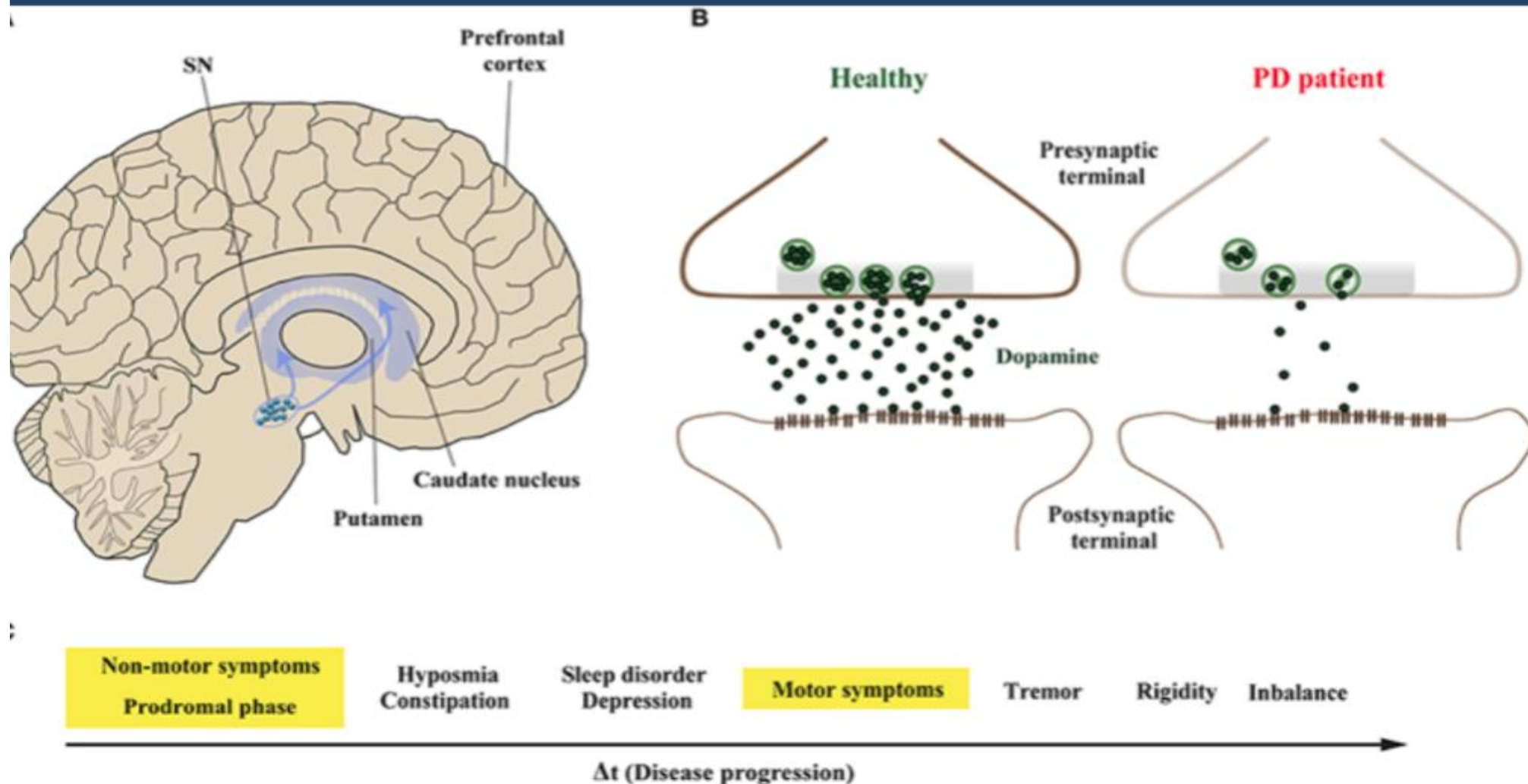
Bradykinesia
(slow movement)

Postural Instability
(imbalance)

Rigidity
(stiffness in all
muscles)

Tremor
(at rest, often in
the hands)

Region of the brain affected: Basal Ganglia controls movement, cognition, learning and emotional processing.



PRIMARY MOTOR SYMPTOMS

- ❖ Bradykinesia: slowness of movement
- ❖ Rigidity: stiffness, limited flexibility
- ❖ Tremor: resting
- ❖ Postural instability: off balance when standing

NON-MOTOR SYMPTOMS

- ❖ Freezing: "my feet are glued to the floor"
- ❖ Micrographia: small handwriting
- ❖ Mask-like expressions: lack of facial expressions
- ❖ Unwanted acceleration
- ❖ Stooped posture/leaning forward
- ❖ Decreased arm swing while walking (can affect balance)
- ❖ Speech problems: drooling, quiet voice, choking, difficulty swallowing
- ❖ Cramping: any muscle group
- ❖ Many more autonomic nervous system dysfunctions, including anxiety, apathy, and depression

THE PARKINSON'S ICEBERG

WHAT PEOPLE SEE

Tremor
Rigidity

Bradykinesia
Postural Disturbance

WHAT PEOPLE DON'T SEE

Sleep Issues
Mood Issues
Thinking / Memory Issues
Gastrointestinal Issues
Feeling Lightheaded or
Dizzy Upon Standing
Pain

Sexual Issues
Fatigue / Daytime Sleepiness
Hallucinations
Visual Disturbances
Impulse Control / Related Disorders
Urinary Issues

GOOD OPTIONS FOR EXERCISE

- ❖ Boxing (Rock Steady specific for Parkinson's)
- ❖ Table Tennis
- ❖ Swimming
- ❖ Dance for PD
- ❖ Yoga and Chair Yoga
- ❖ Tai Chi
- ❖ Bicycling
- ❖ Walking

ONLINE & IN-PERSON EXERCISE OPPORTUNITIES

- ❖ Davis Phinney Foundation
- ❖ Parkinson's Foundation
- ❖ Brian Grant Foundation
- ❖ Dance for PD
- ❖ LSVT Foundation
- ❖ North State Therapy Choir
- ❖ PD Active
- ❖ Rock Steady Boxing

Medication Management

Gold Standard Medication

Sinemet (Carbidopa/Levodopa combination) taken the same time each day, usually taken 3 times a day. Take with water or sparkling water for absorption at least 30 minutes before or after consuming protein. As with most drugs, there are side effects. Sinemet can decrease the signs of Parkinson's Disease. Sinemet often takes 45-60 minutes to really kick in.

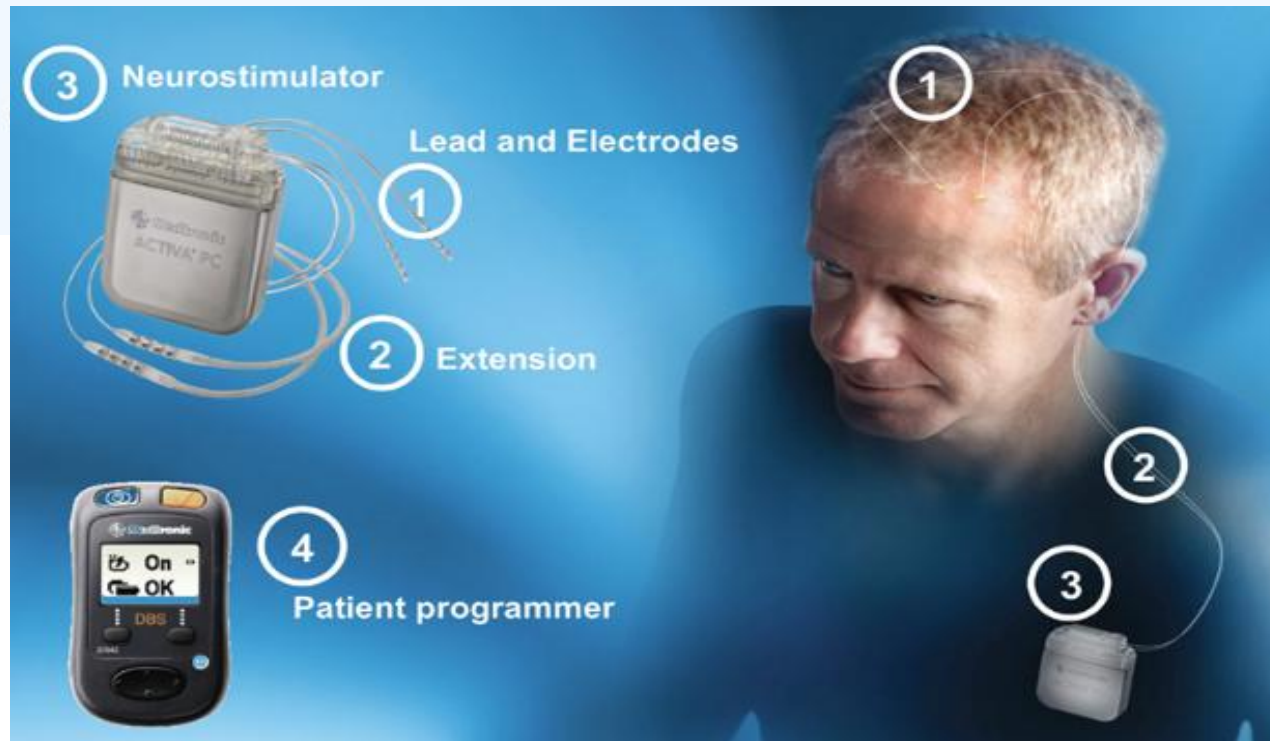
Other Medications

- Anticholinergics
- MAO-B inhibitors
- COMT inhibitors
- Amantadine

▶ All medications have side effects, interactions with other medications and vitamins should be discussed with the prescribing doctor.

DBS (Deep Brain Stimulator)

- Surgical procedure that a neurosurgeon implants a small wire (lead) into the brain and connects to a pulse generator implanted under the skin. The DBS is most effective for treating movement symptoms like dyskinesia, rigidity and tremors.



Developing a Management Team



»»» **Neurologist** Manage medications and additional care needs

»»» **Physical Therapist** Assist with walking, transfers, balance, posture, equipment, fall risk, and exercise routine

»»» **Speech Therapist** Assist with swallowing/choking, speaking difficulties, cognitive assessment and drooling issues

»»» **Occupational Therapist** Assist with management of everyday needs (dressing, eating, bathing, toileting and writing), visual change strategies, and driving related skill assessment

»»» **Psychiatry / Mental Health** Cognitive assessment, strategies to manage depression, anxiety, apathy, hallucinations and memory problems

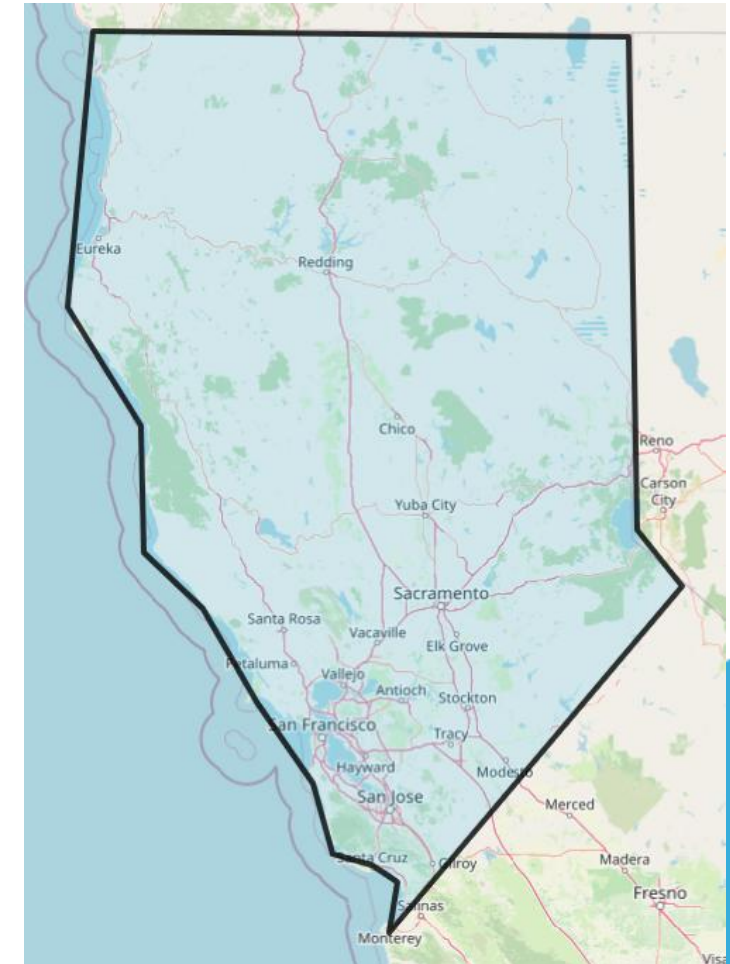
»»» **Dietician** Help manage nutritional issues related to Parkinson's, create customized meal plan with proper protein intake, adjusting for balance of hydration and management of swallowing challenges and constipation



About the Parkinson's Association of Northern California

- Founded 1996
- Funded by the generosity of community donations, sponsorships, grants, and fundraising activities
- Independent Parkinson's network
- Just about \$500,000 budget annually
- 51 Support Groups (and growing) throughout most of Northern CA
- 2.5 staff, contract employee, and active and working Board of Directors

Other PD organizations exist; however, we are hands-on and boots-on-the-ground to serve local needs.



PANC Finances

Income

- Donations (general, in memory, in honor of, etc.)
- Annual Giving campaigns (late November and Big Day of Giving in May)
- Event Sponsorships
- Grants (Rural alliance, ParkinsonWISE, thus far)
- Fundraising (Third party events i.e. COP Walk, Comedy Nights, speaking opportunities, Sailing4Parkinsons, etc.)

Expenses

- Rent, operations, staff, contract staff (CPA, attorney, technology team, etc.)
- Respite grants (budgeted as \$12K annually)
- Conference (right around \$110k – about \$130 pp)
- Technology platforms, insurance, travel, marketing, postage, processing fees,

Partner Organizations

- Michael J Fox Foundation – *Research and Advocacy*
- Parkinson's Foundation – *Hospital Guide*
- Davis Phinney Foundation – *Every Victory Counts*
- Independent Parkinson's Network– *Groups in U.S.*
- Movement Disorders Policy Coalition
- California Caregiver Resource Centers
- Sacramento Regional Community Foundation
- United Parkinson's Advocacy Coalition (UPAC)
- University of the Pacific

PANC's Medical Community Network

A unique entity in the medical realm, our Medical Advisory Panel (MAP) and Journal Club bring together a multi-disciplinary group of medical professionals from NorCal's 4 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

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

Our Parkinson's disease and Care Partner Support Groups

We facilitate a network 51 area support groups, all facilitated by volunteers (social workers in some markets). Some veterans, singles, care partner, Spanish, etc. groups.

Why do people participate in support groups?

- Psychosocial support
- Share similar experiences
- Hear from experts on health and wellness solutions
- Learn strategies to lift depression, loneliness, or anxiety
- Build personal empowerment and sense of meaning
- Get educated on all things Parkinson's

What do we provide for support groups?

- Liability insurance, speakers list, brochures and business cards, annual training, listing on website, etc.

Care Partner Respite Care Program

PANC promotes the support of individuals who serve as care partners to people with Parkinson's disease by subsidizing the cost of respite care provided by regional Caregiver Resource Centers (CRC).

Program Guidance

- Grantees can be awarded \$800 grant for use at an affiliated CRC
- May apply once per 6-month period
- Must provide proof of Parkinson's disease diagnosis
- Must reside in one of the counties served by CRC
- Provided 48 grants in 2024

Annual Education Conference



October 24 at Cal Expo, Sacramento

9:00 am to 3:00 pm

One of largest PD conferences in the country
2025 featured actor/PD activist Ryan Reynolds

Keynote speakers, panel discussions,
question and answer session with experts, lunch, exhibit fair

In-person or Zoom – Recording provided

2025 Stats

In-person and virtual attendance: 1,008

Exhibitors/Sponsors: 62



Other Services

ParkinsonWISE® -- Seminars to educate about Parkinson's disease and best practices on working with this constituency

- Caregivers
- Exercise Instructors
- Senior living center and in-home care services staff

Monthly e-newsletter -- Resources, uplifting articles, links to classes/exercise, and advocacy alerts

Rural Parkinson's Alliance – Educate agricultural workers about Parkinson's disease and bilingual services plus inform general medical community in rural areas about the condition

2026 PANC Initiatives & Wish List

- Monthly webinars (pending)
- Free exercise opportunities for each support group
- Hire social workers to lead groups and respond to medical inquiries
- Update website, logo, bylaws, policies (pending)
- Advance the work of the Rural Parkinson's Alliance and potential mobile clinics in the Central Valley ("Parkinson's Alley")
- Advocacy work on behalf of eradicating harmful chemicals and PD
- Prepare for audit – federal/state grant opportunities
- Increase staff – development team

Misc.

PANC Technology

- Financials – QuickBooks and CPA
- Bloomerang – Constituency database
- Wix – websites
- 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, and PD community
- Have fun!

BOARD CALENDAR

Monthly Board Meetings (Zoom) – 3rd Wednesday of month 5:30 – 7 pm

August 27 -- Vacaville Comedy Fundraiser

October 23 -- PANC Conference VIP Reception TBD (5:30 to 7)

October 24 – PANC Conference at Cal Expo (all day)

January 9 or 16 – Annual Strategic Planning TBD

April 4 – Cancel Out Parkinsons Walk in Roseville

April 11 and 12, 2027 – Sailing4Parkinsons Regatta in Tiburon

Community events and committee's/task forces as needed