

Resources for People with Parkinson's Disease (PD)

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There are many resources available for people with Parkinson's disease (PD) and their families. Here's an overview of some key resources you may find useful:

The Parkinson's Foundation offers a bilingual helpline (1-800-4PD-INFO) to answer questions and provide local referrals.

Patients are encouraged to see a movement disorder specialist for specialized PD care.

When possible, patients are encouraged to be evaluated by a movement disorder specialist for specialized care. Often movement disorder centers offer comprehensive care and patient resources.

We encourage people with PD, family members, and caregivers to check out additional resources listed below to access the support and information they need to navigate life with Parkinson's disease.

General PD Education

- Parkinson's Disease Overview:
 - o https://pdnexus.org/individuals/
- Parkinson's 360:
 - o https://www.michaeljfox.org/parkinsons-360
- Understanding Parkinson's by the Parkinson's Foundation:
 - o https://www.parkinson.org/understanding-parkinsons
- Michael J. Fox Foundation's monthly educational webinars on various topics:
 - o https://www.michaeljfox.org/webinars

Genetic Counseling

- American College of Medical Genetics clinic finder:
 - o https://clinics.acmg.net/
- National Society of Genetic Counselors directory:
 - https://findageneticcounselor.nsgc.org/
- Remote commercial genetic counseling services:
 - o https://informeddna.com/
 - o https://www.genomemedical.com/individuals/#schedule







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Community Resources

- PMD Alliance support group information:
 - o https://www.pmdalliance.org/
- The PD Movers Living and Thriving with Parkinson's Disease in our Black and African American Communities:
 - o https://heyzine.com/flip-book/a5d24ed7a2.html#page/l

Spanish Resources

- EP Salud en Casa (Webinars to live well with Parkinson's):
 - o https://www.parkinson.org/espanol/recursos-y-apoyo/ep-salud-en-casa
- Library of all Spanish Resources by the Parkinson's Foundation:
 - o https://www.parkinson.org/espanol/recursos-y-apoyo
- Spanish Podcast: Substantial Matters
 - o https://www.parkinson.org/espanol/recursos-y-apoyo/podcast
- Guía Parkinson 360:
 - o https://www.michaelifox.org/conociendo-la-enfermedad-de-parkinson

Specific Studies

- Parkinson's Progression Markers Initiative (PPMI) (Fox Foundation):
 - o https://mysmelltest.org/
- PD GENEration study (Parkinson's Foundation):
 - o https://www.parkinson.org/advancing-research/our-research/pdgeneration

Other Research Information and Studies

- Michael J. Fox Foundation's guide on navigating clinical trials:
 - https://www.michaeljfox.org/sites/default/files/media/document/011519_PDEC_PATIENT_ GUIDE_CAN_WEB_linked.pdf
- Fox Trial Finder:
 - o https://www.michaelifox.org/trial-finder
- U.S. website and database of research studies:
 - o https://clinicaltrials.gov/

Disclaimer: Our IU team does not necessarily endorse the resources provided. First discuss any questions or concerns related to these resources with your doctor.

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