

VA

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Veterans Health Administration
Parkinson's Disease Research,
Education & Clinical Centers**NATIONAL VA PARKINSON'S DISEASE****C O N S O R T I U M***Education · Collaboration · Advocacy*

THE TRANSMITTER

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Article Reviews

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Skin Biopsy Detection of Phosphorylated α -Synuclein in Patients With Synucleinopathies.

Finding a reliable diagnostic biomarker for synucleinopathies, which include Parkinson's disease (PD), Multiple System Atrophy (MSA), Dementia with Lewy Bodies (DLB), and Pure Autonomic Failure (PAF) is an urgent unmet need. Gibbons and colleagues tested a skin biopsy to detect phosphorylated α -synuclein in a blinded, 30-site, cross-sectional study of academic and community-based neurology practices. They compared the detection rates of cutaneous α -synuclein in PD, MSA, DLB, PAF, and healthy controls. After refining the diagnosis of these conditions with a centralized expert panel, 223 met the consensus criteria for synucleinopathy, and 120 met the criteria as controls. The proportions of individuals with cutaneous phosphorylated α -synuclein detected by skin biopsy were 92.7% (89 of 96) with PD, 98.2% (54 of 55) with MSA, 96.0% (48 of 50) with DLB, and 100% (22 of 22) with PAF; 3.3% (4 of 120) of controls had cutaneous phosphorylated α -synuclein detected. The authors conclude that a high proportion of consensus-diagnosed synucleinopathy patients had phosphorylated α -synuclein detected by skin biopsy, including PD. External validation in unselected clinical populations is needed to evaluate the performance of this biomarker in routine clinical care.

Gibbons CH, Levine T, Adler C, et al. Skin Biopsy Detection of Phosphorylated α -Synuclein in Patients With Synucleinopathies. *JAMA*. 2024 Apr 16;331(15):1298-1306. URL:

<https://pubmed.ncbi.nlm.nih.gov/38506839/>

Outcomes of Focused Ultrasound Thalamotomy in Tremor Syndromes

The non-invasive approach of magnetic resonance image-guided focused ultrasound (MRgFUS) thalamotomy has become a popular treatment for medication-refractory essential tremor (ET). More recently, MRgFUS thalamotomy has been applied to other tremor types including Parkinson's disease tremor (PDT) and dystonic tremor (DT). Research investigating optimal targets for and efficacy of MRgFUS in these tremor disorders is limited.

This study investigates the long-term outcomes of unilateral MRgFUS thalamotomy in treating different tremor syndromes at St Vincent's Hospital in Sydney, Australia between November 2018 and May 2020. It involved 66 patients who underwent the procedure for essential tremor (ET) (n=32), dystonic tremor (DT) (n=25), and Parkinson's disease tremor (PDT)(n=9), with post-treatment follow-ups up to 36 months. The ventral intermedialis nucleus (VIM) was targeted in all patients and the posterior subthalamic area (PSA) and/or ventralis oralis anterior (VOA) were also targeted in some participants. Results showed that ET and DT patients experienced significant improvements in hand tremor scores (HTS) and Quality of Life (QUEST) scores, with about 61% improvement in HTS and 50% in QUEST for ET, and similar results for DT. However, PDT patients saw initial improvements that decreased over time, with benefits lasting only up to 12 months. The study also highlights a possible decay in quality-of-life gains over time among DT patients in contrast to retention of these benefits in ET patients. The study suggests that while MRgFUS thalamotomy is effective for ET and DT, PDT patients may face a higher risk of treatment failure within months following intervention. Additional research into MRgFUS target optimization, particularly for PDT, is needed.

Peters, J., Maamary, J., Kyle, K., Olsen, N., Jones, L., Bolitho, S., Barnett, Y., Jonker, B. and Tisch, S. (2024), Outcomes of Focused Ultrasound Thalamotomy in Tremor Syndromes. *Mov Disord*, 39: 173-182. <https://doi.org/10.1002/mds.29658>

Barriers and facilitators for healthcare providers to implement family-centered care in Parkinson's disease: a scoping review

Parkinson's disease presents many challenges not only for patients who suffer from it but also for caregivers. Relationship-based or family-centered care has been used for many years as a partnership between health care providers and families to promote health in patients. This approach has proven to be effective in supporting the patient and caregiver while improving outcomes. A research study was done to identify and synthesize the barriers and facilitators to the implementation of family-centered care in Parkinson's disease (PD) and to provide a reference for evidence-based Parkinson's disease nursing practice. In this systematic review that followed PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) model, researchers sought to explore barriers and facilitators to implementing family-centered care in PD. A scoping review of 35 studies was done and focused on family-centered care in PD and roles of healthcare providers. The studies were conducted in the US ($n = 15$), Canada ($n = 2$), Australia ($n = 5$), Netherlands ($n = 4$), England ($n = 3$), Africa ($n = 1$), China ($n = 1$), Brazil ($n = 1$) and Sweden ($n = 1$). Two multicenter studies were also done and carried out between seven European countries, the US and Canada. The studies were performed in home settings ($n=18$), non-institutionalized communities ($n=8$) and outpatient settings ($n = 9$). Results from this systematic review suggest that barriers and facilitators to implementing family centered care are multifactorial including physiological, environmental, education, group experiences, culturally based conflicts and individual and family consultations. Further clarification of family-centered care in PD and the

importance of the role of healthcare providers in delivering ongoing care is needed however implementing family-centered care in PD is vitally important to improve outcomes for PD patients, caregivers and families.

Sun, W. J., Peng, Y. J., & Liang, Y. (2023). Barriers and facilitators for healthcare providers to implement family-centered care in Parkinson's disease: a scoping review. *Frontiers in neurology, 14*, 1231654. <https://doi.org/10.3389/fneur.2023.1231654>

Committee Activities

Clinical Care Committee

- **Rotation of Committee Chair:** Leadership for the clinical care committee rotates amongst the PADRECCs. The Philadelphia PADRECC leads the committee for May/June. The committee meets via conference call the first Tuesday of the month at 12pm (EST)
- **Standardize and Optimize Clinical Care:** The committee continues to discuss treatment strategies, new medications and other procedures, and other clinical issues to improve patient care and outcomes across the national PADRECCs service area. It also serves to provide clinical support to the PADRECC Associated Sites by focusing on procedures and measures to standardize clinical care across the PADRECC network.
- **Recent agenda items have included:**
 1. Future planning to enhance clinical service provision at PADRECCs : Suggestions and Strategies
 2. Discussion of PADRECCs collaboration with their facility VA Home Based Primary Care Teams
 3. Exploring the integration of VA Mind Brain Program for treatment of functional movement disorders into PADRECC clinical services-exploring PADRECC staff interest in becoming trained to offer this therapy
 4. Discussion of new therapies in the pipeline and possible use in the VA in the future

Education Committee

- **PADRECC/EES Movement Disorder Series-Webinars:** knowledge-based webinars to provide VHA healthcare professionals with current practice standards and emerging trends in the treatment of Parkinson's disease and other movement disorders. CEs are typically provided for the live webinars. Check out the following link for a list of past webinars and if you are interested in receiving a recording of a past webinar please email Gretchen.glenn@va.gov and list the date/topic of interest: https://www.parkinsons.va.gov/Consortium/Presentations/Audio_Conference/MDS.asp
 - **MDS VI: Planning underway for Fall 2024: Potential topic: Other Movement Disorders**

- **National VA PD Newsletter: 2024 VA Parkinson Report-** Currently accepting PADRECC and PADRECC Associated Sites (formally Consortium Center) highlights/updates from the last year.

Submission guidelines

- Highlight clinical, research or education accomplishments in the last year
 - Limit submission to **300 words** (*submissions will be shortened at the discretion of the editors if over the 300 word limit*)
 - Feel free to provide pictures to go along with submission. Be sure to have signed consents on file for any pictures including patients/care partners
 - Deadline: June 7th Email to Gretchen.glenn@va.gov
- **PD Hospital Safety Training Presentation:** exploring the development of a short grab and go presentation for VA CLC, CNH and Veteran State Home staff to improve the care of Veterans with PD who reside there.
 - **The Parkinson's Foundation/VHA Partnership:** several updates of PF/PADRECC materials are in process and will be shared in the next few months. In addition, planning for the **2024 Veteran Webinar Series** is underway with 4 webinars slated this fall, more information coming soon!
 - **Parkinson's Disease Rehab-Community of Practice on Microsoft Teams-** collaboration with rehabilitation subject matter experts across the VA with interest in PD to develop this COP to address and enhance rehabilitation care for Veterans with PD and similar conditions. The goal of the platform is to share evidence-based knowledge to inform PD-specific rehabilitation practices, provide access to up-to-date resources, program success and opportunities for improvement. All are welcome to join:
https://teams.microsoft.com/l/channel/19%3a_NAJNcVxoyd5XB0M_UnwK4Ym7vi8C971TC0xqerdfst1%40thread.tacv2/General?groupId=bf9f6fc8-06da-401e-99c5-6dd0b47494ee&tenantId=e95f1b23-abaf-45ee-821d-b7ab251ab3bf
 - **National Website Maintenance:** The committee performs periodic maintenance checks of the National Website to ensure information is current and up-to-date.
 - **PADRECC Transmitter:** This committee continues to assemble and distribute this e-newsletter every other month.