

## Care Where It Counts: Understanding the Needs of People with PSP and Related Disorders

**Goals:** People with Progressive Supranuclear Palsy and related disorders like Multiple System Atrophy and Corticobasal Syndrome may have trouble accessing the healthcare that they need, which may affect their quality of life and that of their caregivers. This may be due to many reasons. To ensure our patients receive all the care they need to stay healthy, we are interested in understanding how and why people with Progressive Supranuclear Palsy and related disorders use various health services.

**Benefits:** Your involvement will provide no direct benefit to you, but will contribute to scientific knowledge about Progressive Supranuclear Palsy and related disorders. Your participation will help us identify the unmet needs of people with these disorders, and potentially shape future research into treatments.

**Participants:** People with Progressive supranuclear palsy and related disorders who are 40 years of age or older, speak and read English fluently, live in the United States, have the capacity to use and navigate an online portal to complete a survey, and can provide informed consent.

**Details:** Subjects will participate in an online survey, which will include questions about their medical history, healthcare use, unmet needs, quality of life, and caregiver strain. Subjects will be contacted 12 months following the initial survey to complete a follow-up survey.

To participate, or for more information, please contact Naomi Friede at  
The Marlene and Paolo Fresco Institute for  
Parkinson's and Movement Disorders at NYU Langone Medical Center:

**(646) 501-4871**

**Principal Investigator:** Jori E. Fleisher, MD MSCE

**Contact:** Naomi Friede [naomi.friede@nyumc.org](mailto:naomi.friede@nyumc.org)