PROGRESSIVE SUPRANUCLEAR PALSY (PSP)

PSP is a life-limiting, adult-onset neurodegenerative disease. PSP is often known as an "atypical Parkinsonism" because of overlapping symptoms with Parkinson's. It is caused by an abnormal build-up tau protein in brain cells, like what happens in Alzheimer's disease.



PREVALENCE

With 6-10 people in 100,000 living with PSP, it has a similar prevalence to amyotrophic lateral sclerosis (ALS). These are likely underestimates because many people with PSP are misdiagnosed with another condition.



PROFOUND IMPACTS OF PSP

The average life expectancy of PSP is 7-8 years, half that of Parkinson's. Seeking a diagnosis consumes a third of this time The emotional, physical and financial tolls of the disease on families are immense and require heavy utilization of healthcare resources.

SYMPTOMS AND DIAGNOSIS

A clinical diagnosis is made through a neurological exam, medical history, brain imaging and ruling out other conditions. Confirmation of PSP can only be made through a post-mortem study of brain tissue.



ISSUES WITH WALKING, BALANCE, POSTURE AND COORDINATION



CHANGES IN PERSONALITY AND COGNITIVE FUNCTIONING



WEAKNESS OF EYE MOVEMENT AND POOR



SWALLOWING, LEADING TO RISK OF CHOKING AND LUNC



SPEECH AND DIFFICULTY EXPRESSING WORDS



PROBLEMS CONTROLLING
THE BLADDER, LEADING
TO HIGH RISK OF URINARY
TRACT INFECTIONS

The list of symptoms above is not exhaustive and the presentation/progression of PSP is very individual.

RESEARCH: KNOWLEDGE GAPS AND OPPORTUNITIES

The cause of PSP is unknown and there are no FDAapproved treatments for PSP at this time. There is an urgent need and opportunity to work together to:

Raise awareness of PSP to cut down time to diagnosis and getting the right care

Find reliable diagnostic markers of PSP (e.g., wearable devices, blood test, brain imaging)

Determine environmental and genetic risk factors for PSF

Develop effective treatments and, ultimately, a cure!



TREATMENT AND CARE

Currently, there is no known cure and there are no treatments to prevent PSP or slow the progression. Levodopa therapy, developed for Parkinson's, is often used but may offer limited benefit. Medications, exercise and therapies are focused on safety and management of symptoms.



CurePSP is the leading nonprofit organization dedicated to the awareness, care and cure of progressive supranuclear palsy, corticobasal degeneration and multiple system atrophy. Science, community and hope are at the heart of CurePSP's mission and all of our services. For more information, please visit www.curepsp.org or contact Jessica Shurer, MSW, LCSW, Director of Clinical Affairs and Advocacy, at shurer@curepsp.org