Progressive Supranuclear Palsy Clinical Data Elements

Principal Investigator Responsible for Accuracy of Data (Name): **Subject ID Number:**

Is this data Longitudinal (Follow-Up) Data? Yes ☐ No ☐

Subject: ZIP Code (1st 3 digits): _____ Country of Residence _____

Family Member Samples in Repository? Yes ☐ No ☐ Unknown (subject adopted) ☐ If Yes, list subject ID/s: _____

Year of Birth _____ **Gender**: Male ☐ Female ☐

Ethnic Category (as reported by subject) Check one: Hispanic or Latino ☐ Not Hispanic or Latino ☐

Racial Categories (as reported by subject) Check One:

American Indian/Alaska Native ☐ Asian ☐ Native Hawaiian/ Other Pacific Islander ☐

Black/African American ☐ White/Caucasian ☐ More than One Race ☐ Other ☐ Unknown ☐

Additional Racial and Ethnicity Information: _____

Diagnosed By: Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Pediatrician ☐
Primary Care Physician ☐ Psychiatrist ☐ Psychologist ☐ Does Not Apply (Population or Family-Based Control) ☐

Data Collected By: Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Primary Care Physician ☐ Pediatrician ☐ Psychiatrist ☐ Psychologist ☐ Research Coordinator ☐ Registered Nurse ☐ Research Coordinator/ RN ☐

Family History of Progressive Supranuclear Palsy **Present** ☐ **Absent** ☐

If Present, List All Affected Family Members:_____

Best Clinical Diagnosis (check one):	**Present**	**Absent**		**Present**	**Absent**
Progressive Supranuclear Palsy	☒	☐	Alzheimer's disease	☐	☐
Diffuse Lewy Body Disease	☐	☐	Corticobasal Ganglionic Degeneration	☐	☐
Multiple system atrophy	☐	☐	Dementia	☐	☐
Other (specify)_____	☐	☐			

Age at symptom onset _____

DO NOT USE THIS CDE to COLLECT PARKINSON'S DISEASE SUBJECTS - USE PARKINSONISM CDE
PSP MUST USE BOTH THE PARKINSONISM AND THE PSP CDE

Signs Suggestive of PSP Diagnosis:	**Present**	**Absent**		**Present**	**Absent**
Vertical Gaze Palsy	☐	☐	Symptom Onset Not Due To: visual, vestibular, cerebellar, sensory dysfunction	☐	☐
Slowing of Vertical Saccades	☐	☐			
Intact Oculocephalic Reflexes	☐	☐			
Bradykinesia	☐	☐	Frontal Lobe Dysfunction (bradyphrenia, forced grasping, perseveration, utilization behavior)	☐	☐
Rigidity (axial>limb)	☐	☐			
Parkinsonism with Asymmetrical Onset	☐	☐			
Emotional Incontinence	☐	☐			

Features Suggestive of Another Diagnosis:

	Present	**Absent**		**Present**	**Absent**
Response to Levodopa	☐	☐	Focal Sensory Deficit	☐	☐
Tremor	☐	☐	Early Severe Autonomic Involvement	☐	☐
Cerebellar Signs	☐	☐	History of Hypoxia/Anoxia	☐	☐
Oculogyric Crisis	☐	☐	History of Alien Limb Syndrome	☐	☐
Neuroleptic treatment onset	☐	☐	History of Repeated Stokes	☐	☐
Hydrocephalus	☐	☐	History of Encephalitis	☐	☐
Delusions	☐	☐	Unilateral Babinski Sign	☐	☐
Early Severe Dementia	☐	☐	Brain Tumor	☐	☐
Whipple's Disease	☐	☐	Prior History of Repeated Head Injury	☐	☐

Optional Data: **PSP Rating Scale Total Score _____**