

Atypical Parkinsonian Disorders Working Group

of the Parkinson Study Group

The PSG is uniquely suited to carrying out research in the atypical Parkinsonian disorders-- progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA)-- due to its extensive network of movement disorders specialists who specialize in these rare disorders. The mission of this working group is to conduct clinical interventional and observational research in the Parkinson-plus disorders (PSP, CBD and MSA) and to serve as a multi-institutional academic resource for investigators.

The initial goals of the Atypical Parkinsonian Disorders working group are to:

- 1) To develop and validate outcomes measures for monitoring disease progression
- 2) To develop surrogate markers for disease progression in PSP, CBD and MSA
- 3) To identify predictors of disease progression within each disease, by analyzing completed clinical trials.
- 4) To collaborate on and develop investigator-initiated clinical trials in PSP, CBD and MSA.

Potential scope of WG projects:

1. Interventional Trials
 - a. Pharmacologic (pharmaceutical drugs in development, extending indications of approved medications)
 - b. Non-pharmacologic (e.g. exercise, nutrition, other therapies)
2. Non-interventional Studies
 - a. Retrospective
 - b. Secondary analysis of clinical trial databases (“data mining”)
 - c. Prospective (descriptive or experimental)
 - i. Epidemiology
 - ii. Genetic studies
 - iii. Clinical features (course, features, associated factors, validation studies)
 - iv. Imaging studies
 - v. Pathology studies
 - d. Clinical practice parameters
 - e. Review/consensus panels for evaluation/development of diagnostic or risk assessment tools
 - f. Review/consensus panels for treatment strategies

Initial proposed projects of the working group include:

- 1) Validation study of the research criteria for probable CBD (Armstrong, Litvan et al. 2013) using autopsy-confirmed cases at the institutions of working group members.
- 2) Validation of a PSP disability rating scale under development.
- 3) Combining trial data from completed PSP clinical trials to examine predictors of disease progression.

Procedures for Member Initiated Proposals

The procedures for application for PSG studies and for conduct of the approved studies are explained in the [PSG Constitution & Bylaws](#), Article X. All PSG proposals have to be reviewed by the Scientific Review Committee, and then a decision will be made by the

Executive Committee, based on the recommendation of the Scientific Review Committee. However, before this formal stage is reached, the CBWG can act as a facilitator for the discussion and development of the project as a “pre-proposal”. CBWG leadership will periodically announce request for pre-proposals that can be submitted using a special form and be discussed with the interested WG members by e-mail, conference calls, and eventually during WG meeting during the annual PSG meeting. Article XII of the [PSG Constitution & Bylaws](#) explains the Publication Policies that result from PSG projects.

The working group is chaired by:

Anne-Marie A. Wills, M.D. M.P.H
Co-Chair

Irene Litvan, M.D., FAAN, FANA
Co-Chair