OTHER NON-MOTOR FEATURES OF PD WORKING GROUP

of the PARKINSON STUDY GROUP

Introduction

Non-motor manifestations are among the most common and disabling symptoms in PD, frequently under-reported by patients and under-diagnosed by health care professionals. Many of the non-motor symptoms of PD predate the onset of cardinal motor features of the disease, which positions non-motor symptoms as critical pre-motor markers of synuclein-related neurodegenerative processes. Mechanisms that underlie non-motor symptoms are not well understood, and therapeutic options remain limited. There is therefore a large need to focus clinical care, research and education on non-motor manifestations of PD. The Other Non-Motor Features of PD Working Group (ONMFWG) of the Parkinson Study Group (PSG) aims to bridge this gap through close interactions with the PSG and other working groups.

Goals of ONMFWG

- To increase awareness of non-motor disturbances in PD within PSG, among clinicians, researchers, funding agencies and other professional partners, with an emphasis on autonomic, sleep and sensory disturbances associated with PD;
- To provide a forum for the generation, development, execution, and dissemination of interdisciplinary clinical research studies that will lead to improved understanding of epidemiology and pathophysiology of non-motor manifestations of PD as well as to the development of novel treatment approaches;
- To foster the education of health professionals and the patients' community about non-motor features of PD;
- To counsel appropriate PSG bodies (e.g., Executive Committee, Scientific Review Committee, Mentoring Committee, steering committees of PSG clinical trials) and collaborate with other working groups of PSG on studies that lead to improved understanding and effective treatments of non-motor features of PD.

Potential Scope of WG Activity on Other Non-Motor Features of PD

<u>Project classification:</u>

1. Interventional Trials:
   a. Pharmaceutical
   b. Non-pharmaceutical

2. Non-interventional Studies
    a. Retrospective
        i. Secondary analysis of PSG databases ("data mining")
        ii. Analysis of external databases
    b. Prospective (descriptive or experimental)
        i. Epidemiology
        ii. Clinical features (course, features, associated factors)
        iii. Genetics
        iv. Imaging
        v. Pathology
        vi. Combined approach
    c. Clinical practice parameters
        i. Review/consensus panels for evaluation/development of assessment tools
        ii. Review/consensus panels for treatment strategies

Examples of specific areas of interest for ONMFWG:

- Studies dedicated to autonomic dysregulation in PD with an emphasis on cardiovascular, gastrointestinal and genito-urinary dysfunction in PD;
- Studies dedicated to wide-spectrum disturbances of sleep-wake cycle in PD;
- Studies dedicated to dysfunction of sensory systems in PD, including olfactory and visual systems as well as pain perception;
- Studies dedicated to the development of pre-motor phenotype of PD through research that spans multiple aspects of non-motor manifestations of PD;
- Development of new investigators across multiple disciplines within non-motor spectrum of PD;
- Development of position papers related to many facets of non-motor manifestations of PD.

Procedures for Member Initiated Proposals

The procedures for application for PSG studies and for conduct of the approved studies including Publication Policies are explained in the PSG Policies & Procedures. 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 ONMFWG can act as a facilitator for the discussion and development of the project as a "pre-proposal". OMNFWG 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.

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