



## **“CHOP PD: Charting the Progression of Disability in Parkinson Disease”**

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### **Background**

While there appear to be clinically meaningful benefits of short-term exercise programs on persons with Parkinson disease, claims regarding the long-term effects of exercise on disability are made without research support. The objective of this multicenter prospective study is to examine the 2-year trajectory of disability in a cohort of persons living with the disease. By describing the progression of disability, exercise habits, and physical activity, this investigation will establish an important foundation for future intervention research. Specifically, through the evaluation of the influence of sustained exercise and physical activity, the study is a critical step toward developing a randomized controlled trial of long-term exercise as a means of minimizing disability in persons with Parkinson's.

### **Goals**

The purpose of our study is to follow people with Parkinson's disease for a period of two years to learn how their symptoms, general health, physical activity levels, attitudes towards recreation/exercise, balance, mobility and quality of life change over time. The study is being conducted by physical therapists at Boston University, University of Alabama at Birmingham, University of Utah, and Washington University in St. Louis. Participants visit their local site once every six months over the course of the two year study, for a total of 5 visits during which they will complete a thorough evaluation. We are particularly interested in examining the relationships between the different items we are measuring so that we can determine whether and how different factors influence progression of the disease.

### **Timeline**

This research project started in July 2009. We expect data collection to conclude in July 2012, and data analysis and publications regarding the entire study period to be completed by July 2013.

We are currently conducting the final round of evaluations, which will be completed by July 2012. We are also analyzing data collecting during the first year of the project. At this time, we have analyzed and reported data from the initial testing period. These papers have focused on the overall structure of the ongoing study, the contributors to disability in persons with Parkinson's, the barriers to exercise in these persons, and the ability of specific measures of movement to capture the movement problems faced by persons with Parkinson's. We have just begun analyzing and reporting data from the first year of the project.

### **Relevance**

This research is important to persons with Parkinson's, because it will provide us with valuable information about the factors that contribute to disability and will provide a strong foundation for future studies investigating the effects of exercise regimens on reducing disability in people living with Parkinson's disease.

Through this research we will be able to identify factors that both positively and negatively affect the progression of the disease. Furthermore, we are gathering data on the usefulness of new measures of function



and quality of life as they relate to physical activity and exercise. As a result, we anticipate having information about factors that positively affect mobility and quality of life. As a result, we will be able to make recommendations on measures that clinicians (e.g. physical therapists occupational therapists, neurologists) could use to more sensitively measure function in people with Parkinson's and to provide appropriate interventions and feedback to the person with Parkinson's, based upon these measurements.

### **Future Direction**

We have already begun our next steps, as two of our sites (Boston University and University of Utah) have received follow-up grants to investigate the effects of comprehensive balance exercise programs on fall risk and balance in persons with PD. We anticipate that the findings of the current project, along with these 2 additional investigations, will be provide a strong framework for a larger randomized controlled trial aimed at identifying the key ingredients for a multi-faceted balance program that will significantly reduce falls and risk of falls in persons with PD.