

2022 CARES projects (\$81,000 total awarded)

Improving Access to Care through Transportation and Internet Use for Patients with Atypical Parkinsonism

Johns Hopkins University and Massachusetts General Hospital

6 million people in the United States report transportation barriers that prevent them from their needed medical care. Additionally, recent research has found an increased need for telehealth delivery of specialty care to individuals with Parkinsonian disorders. This project will screen for patients with PSP, CBS & MSA who are challenged to arrange transportation to their neurology appointments, lack reliable internet access/devices for telehealth, or both; the investigators will arrange for transportation or internet-enabled tablets accordingly. This pilot program will test if this increased accessibility improves outcomes of patient access to care, self-reported quality of life and caregiver burden, and if these methods are scalable.

End-of-Life Care Preferences in Diverse Patients with Atypical Parkinsonism

The University of Pennsylvania and the University of California San Diego

PSP, CBD and MSA lead to progressive physical and cognitive impairment and as a result, end of life care is an important concern. No prior study has explored perceptions of goal-concordant end of life care among persons with atypical Parkinsonism. This information is also critical for understanding disparities and developing new approaches to advance care planning in underserved populations and communities. This project seeks to understand the influence of sex, race, ethnicity and other sociodemographic factors on end of life care preferences and behaviors among persons with PSP, CBD or MSA. Knowledge gained from this study can inform interventions to improve access to palliative and hospice care services for people from historically underrepresented and racially diverse communities.

The Greater Chicago Alliance for Support and Education on PSP, CBD and MSA

The University of Chicago, Rush University and Northwestern University

The three medical centers will co-host a virtual 10-week educational series that will cover disease pathology, diagnosis, common motor and non-motor symptoms, treatment strategies from a multidisciplinary perspective, current clinical trials, palliative care and support resources. Each session was recorded and will be available online for on demand viewing (CurePSP YouTube channel or website and each institution's website) and PDF copies of the lectures were also provided to participants. This project aims to unite the local PSP, CBD and MSA community in Chicago and offer an approach to education and support that can be replicated in other centers and regions.

2023 CARES projects (\$110,000 total awarded)

Barriers to Clinical Trial Participation in PSP, CBS and MSA

Oregon Health & Science University and University of Montreal

Clinical trials in atypical Parkinsonism present increased and unique challenges compared to clinical trials in Parkinson's disease. Researchers will conduct a survey addressed to patients and care partners in the United States and Canada to identify barriers to clinical trial participation with atypical Parkinsonism. It will be available in English, French and Spanish and sent out through CurePSP's database/social media and via passive recruitment at across the Centers of Care. Identifying these challenges is an important step for planning trial infrastructure and budgeting as new therapies for PSP, CBS and MSA come down the pipeline.

Atypical Parkinsonism Bootcamp for Advanced Practice Providers

Cleveland Clinic and Cleveland Clinic Lou Ruvo Center for Brain Health

A shortage of fellowship-trained movement disorders neurologists has forced tertiary care centers to rely on advanced practitioners (physician assistants, nurse practitioners) to help meet the unique needs of these patients. As atypical Parkinsonian disorders continue to impact more lives annually, the need for disease-specialized medical professionals could not be greater, as most general neurologists and primary care providers do not feel adequately prepared to care for these patients. To increase confidence in diagnosing and treating these rare diseases among neurology professionals, researchers will host a pilot training course on PSP, CBD, MSA and dementia with Lewy bodies geared towards nurse practitioners and physician assistants. If successful, this program can be replicated and made available to the greater medical community.

Art therapy in PSP: Studying the therapeutic effect on quality of life and caregiver stress

Baylor College of Medicine and Vanderbilt University

In recent years, art therapy has garnered attention as a potentially effective intervention for individuals with neurodegenerative disorders such as Parkinson's disease. Art therapy encompasses a wide array of activities that promote cognitive and motor skills, including shape recognition, motion perception, sensory-motor integration, abstraction and eye-hand coordination. As a result, it holds promise as a therapeutic tool for addressing the intricate challenges faced by PSP people, although this has not been studied to date. This project will explore the feasibility of an 8-week virtual art therapy program for individuals with PSP and begin to investigate the art therapy as an intervention with people with PSP, with a focus on alleviating the symptoms associated with PSP, enhancing the overall quality of life for patients and reducing caregiver stress.