FALL 2021 • VOLUME 1

Penn
University of Pennsylvania

Penn U19 Center on Alpha-Synuclein Strains in Alzheimer's Disease and Related Dementias

THE CORE REPORT

KEEPING THE CLINICAL CORE IN THE KNOW

Over the past year and a half we have had the pleasure of talking to many of you during phone calls or research visits. It is always great to connect with our research participants and hear how you are doing and what might be new in your lives. We consider ourselves very lucky to work with such a great group of people, who graciously participate in many of the research endeavors we have here at Penn.

Many of you have asked what is new with our research and how else you can be involved. In an effort to stay in communication with you and for us all, the Clinical Core, to be "in the know", our team decided to create a newsletter to keep us all connected.

What You Can Expect

The idea for our newsletter is to be comprehensive and enjoyable to read. Some items you can expect to find in *The Core Report* are: research updates, publications that highlight our research, recruitment news, events, staffing updates, interviews, and feature pieces on some of our participants.

Your Voice

What would you like to see in future newsletters? If you would like to share your thoughts or suggestions, please reach out to us so that we can consider featuring your ideas in a future newsletter. Feel free to write in and just say hello. We always enjoy hearing from you. We hope that you enjoy the first edition of *The Core Report* and, as always, thank you for your participation.

Yours Truly,
The Clinical Core Team
Contact: sarah.shaw@pennmedicine.upenn.edu

A WALK TO STAMP OUT PARKINSON'S

October 16, 2021
8:30-10:00am
Philadelphia Zoo
$45 Fee (Covers the walk, a t-shirt, and admission to the zoo for the day!

To register for **TEAM PENN**, visit: https://bit.ly/PDWalkTeamPenn

Also, RSVP to the event on the Parkinson's Disease and Movement Disorders Center (PDMDC) Facebook Group!

FROM UDALL TO NIA U19

Many of you and your loved ones are long-term research participants and will always know and refer to this study by its former name, the "Udall Center". During the past two years we have received many questions asking what the difference is between the Udall Center and the "NIA U19" study. The simple answer is that the main difference is funding. Research studies need funding to support the various aims of the research. The study that you participate in is now funded by the National Institute on Aging (NIA) through a U19 grant award. The U19 award is a tremendous honor as it allows a team of investigators working with a NIH project scientist to target their joint efforts around specific research objectives. To better explain our previous and existing objectives, we asked Dr. John Trojanowski, Director of the Penn NIA U19 Center to weigh-in.

"The overall goals of the University of Pennsylvania U19 "Center On Alpha-synuclein Strains in Alzheimer Disease & Related Dementias" are to clarify the mechanisms of pathological alpha-synuclein (aSyn) mediated progressive neurodegeneration in Alzheimer's disease (AD) and related dementias (ADRD) linked to diverse strains of pathological aSyn. We hypothesize that accumulations of pathological aSyn lead to neuron dysfunction and death due to misfolding and transmission of different strains of pathological aSyn to form Lewy bodies (LBs) and neurites (LNs), and that aSyn and AD pathology interact to modify the distribution of each other and contribute to behavioral impairments. To accomplish the Center goals, we pursue the following Specific Aims:

- Projects I and II seek to elucidate aSyn strains underlying diverse synucleinopathies using in vitro (I) and in vivo (II) models.
- Project III analyzes regional neuropathology in ADRD synucleinopathies and correlates these findings with diverse cognitive difficulties and structural imaging.
- Project IV uses state-of-the-art technologies, including measures of cognition, blood and cerebrospinal (CSF) biomarkers, and genetics, to better understand, diagnose and manage diverse ADRD synucleinopathies.

This Penn U19 Center addresses these key issues with support by four Cores: Administrative Core A, Clinical Core B, Neuropathology, Biomarker & Genetics Core C and Data Management, Biostatistics & Bioinformatics Core D. The work of this Penn U19 Center, which grew out of an eleven-year Penn Udall Center, will open up new drug discovery targets and biomarkers."

THE UPENN NIA U19 CLINICAL CORE

The UPenn Clinical Core of the NIA U19 (formerly the Udall Center) has four primary aims, all in the service of U19 Projects and other Cores:

- To recruit, assess and retain Parkinson's disease (PD) research participants.
- To obtain biomarkers, biofluids and tissue from PD participants.
- To help educate the medical community and general public on PD disorders and train the next generation of PD researchers.
- To contribute high-quality clinical and biomarker data to the Penn Integrated Neurodegenerative Disease Database (INDD).

Currently there are 165 active participants in the Clinical Core, nearly all of them are diagnosed with Parkinson's disease (PD). Over the past 15 years, 425 participants have been enrolled, making the Clinical Core one of the largest, longest-running, active clinical PD cohorts in the world. Clinical data, biological data, and biospecimens collected from Clinical Core participants have been used internally, but also shared (in a de-identified fashion) with researchers around the country and the world, helping to improve our understanding of Parkinson's disease through many landmark publications.

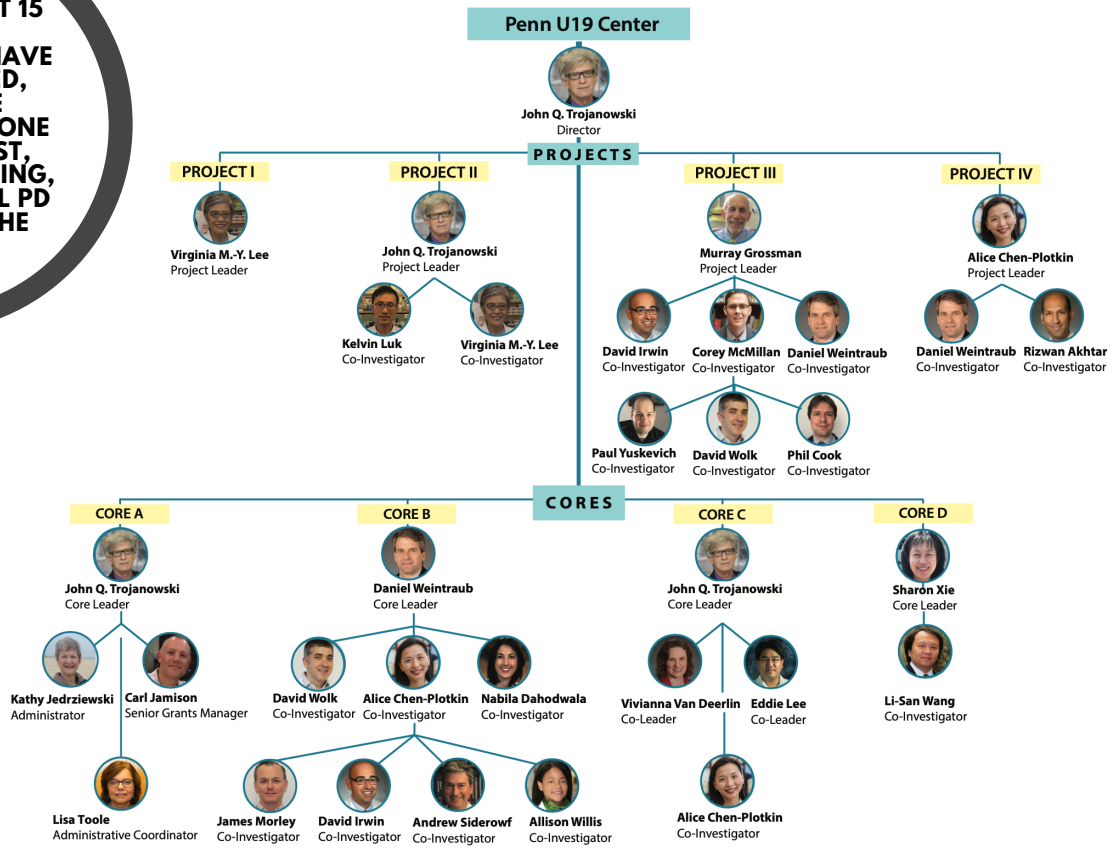
The Clinical Core includes the following personnel, all dedicated to making sure that the UPenn NIA U19 continues to conduct groundbreaking research and serve as a resource for the PD research community worldwide: Dr. Daniel Weintraub (Core Lead); Sarah Shaw (Project Manager); Eugenia Mamikonyan and Julia Gallagher (Research Co-ordinators); and Drs. Andrew Siderowf, Nabila Dahodwala, Allison Willis, Alice Chen- Plotkin and David Wolk (Co-Investigators).

In addition to continuing to follow as many existing participants possible, the Clinical Core is actively recruiting new participants, with a focus on traditionally under-represented populations in PD research, including women, Black, Hispanic, and Asian individuals.

Newly enrolled participants will have annual in-person or virtual assessments. We request that all participants have a one time blood draw at study entry, 1-2 brain MRIs over time, and consider a lumbar puncture and brain autopsy in the future. For more information on study participation, please contact the Clinical Core Project Manager, Sarah Shaw.

- Daniel Weintraub, MD
Clinical Core Lead

"OVER THE PAST 15 YEARS, 425 PARTICIPANTS HAVE BEEN ENROLLED, MAKING THE CLINICAL CORE ONE OF THE LARGEST, LONGEST- RUNNING, ACTIVE CLINICAL PD COHORTS IN THE WORLD."



MEET YOUR U19 RESEARCH TEAM

Daniel Weintraub, MD

Dr. Weintraub is Professor of Psychiatry and Neurology at the Perelman School of Medicine, and Psychiatrist at the Parkinson's Disease Research, Education and Clinical Center (PADRECC) at the Philadelphia Veterans Affairs Medical Center. A board-certified geriatric psychiatrist, he conducts clinical research in the psychiatric and cognitive complications of Parkinson's disease. He serves on multiple task forces and working groups of the International Parkinson and Movement Disorder Society (IPMDS), co-chairs the Cognitive-Behavioral Workgroup of the Fox Foundation-funded Parkinson's Progression Markers Initiative, is an Advisor to the Critical Path for Parkinson's Consortium (CPP), and is Associate Editor of Movement Disorders Journal.

Julia Gallagher

Julia Gallagher is a clinical research coordinator for the NIA U19 research study. She is from North Carolina and graduated from UNC-Chapel Hill in 2019 with a degree in Psychology. Shortly after graduation, she moved to Philadelphia to work at Penn and has now been here for two years. Her specific research interests include neurodegeneration and traumatic brain injury. While not at work, she enjoys reading in the park, watching new TV shows, and going to concerts and shows. She has loved getting to meet many of you over the past two years and is looking forward to continuing her work with U19!

Eugenia (Gina) Mamikonyan

Gina Mamikonyan has been working for the University of Pennsylvania since 2004. Gina intended to become an elementary school teacher and initially majored in education at Temple University. After some very interesting neuropsychology classes and careful consideration, she changed her major to Psychology and completed a Masters Degree program at Drexel University. Gina interviewed with Dr. Daniel Weintraub in the fall of 2006 and joined his team of coordinators shortly thereafter. Fifteen year later, she still loves being a research coordinator, her co-workers, and working for Dr. Weintraub. Gina has worked on many clinical and observation trials concerning Parkinson's disease and Alzheimer's Disease. When Gina is not seeing research participants and chasing trains to and from University City, she enjoys spending time with her family, including her husband Ernie and two daughters, Sophia (12) and Olivia (8), and knitting.

Sarah Shaw

Sarah Shaw is originally from Baltimore, Maryland but began calling Philadelphia her home in 2016. Sarah has worked in clinical research since 2006. Since landing at the University of Pennsylvania in 2018, she has been working in clinical research project management, most recently as the project manager for the NIA U19 study. Outside of office hours, Sarah enjoys being outdoors, reading, writing, taking classes at Penn, and spending time with her husband Mark, cat Winston, and dog Alma.

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Thank you for reading!

~ THE CLINICAL CORE