Summer 2025 Issue

We Move U

Movement Disorders Newsletter

Editor's Corner

There's a lot to catch up on from our division. In this issue, we are proud to highlight Perla Thulin, MD, the longest-standing member of our movement disorders team. We also feature the latest advancements in deep brain stimulation (DBS) therapies, which are expanding and revolutionizing the programming options available to our patients. Next, we share an exciting discovery made by our scientists at the Pulst and Scoles research lab.

In our Education Corner, we focus on the important topic of nutrition in Parkinson's disease (PD). Managing nutrition in PD is complex—not only due to the need to support optimal brain health through lifestyle, but also because of challenges related to medication interactions and common gastrointestinal issues in PD.

We then introduce two multidisciplinary clinics: the Movement Disorders Supportive Care Clinic, which focuses on palliative care needs, and the Atypical Parkinsonian Disorder Multidisciplinary Clinic, which employs a "one-day clinic" model. We are also honored to share our designation as a Mission MSA Center of Excellence, which reflects our commitment to high-quality care for patients with multiple system atrophy.

With these changes, we hope to broaden our support for the movement disorders community at large.

Jumana Alshaikh, MD

Assistant Professor
Movement Disorders Division
Department of Neurology

Our Partners

Parkinson's Foundation CENTER OF EXCELLENCE

curePSP UNLOCKING THE SECRETS OF BRAIN DISEASE

MSA CENTERS OF EXCELLENCE

Huntington's Disease Society of America

NAF National Ataxia Foundation ATAXIA Centers of EXCELLENCE Experts in Care & Collaboration

DYSTONIA COALITION

Meet the Movement Disorders Team

Neurologists

- Jumana Alshaikh, MD
- Panagiotis Kassavetis, MD, PhD (adjunct)
- Guillaume Lamotte, MD, MSc
- Paolo Moretti, MD (division chief)
- Laura Pesántez-Pacheco, MD
- Stefan Pulst, MD, Dr med (department chair)
- John Steffens, MD
- Paola Testini, MD
- Perla Thulin, MD

HEALTH UNIVERSITY OF UTAH

Get to Know Our Team Members

Perla Thulin, MD

Perla Thulin, MD, is a board-certified neurologist, movement disorders expert, and Associate Professor of Neurology. She obtained her BA in human biology and MD at Stanford University, then after an internal medicine internship at the Jewish Hospital in St. Louis, Missouri, she completed her neurology residency in the Harvard-Longwood neurology residency program. Her fellowship training in movement disorders and geriatric neurology was conducted at Oregon Health Sciences University, after which she began her career at the University of Utah. She hails from Napa, California, and has many relatives in northern California. Her own family resides in Utah.

We asked Dr. Thulin a few questions to learn more about her!

What are your hobbies?

I love learning, especially about history, and my hobbies include painting, listening to Audible books, listening to music, hiking, cross country skiing, and traveling.

What excites you the most about your job?

I most enjoy the feeling of helping a patient improve their quality of life, the detective work in diagnosing a medical problem, and learning from engaging in discussions with my colleagues.

What is a new skill that you want to learn?

I am striving to learn to play the guitar and would like to improve my Italian!

What's New in Movement Disorders?

Deep Brain Stimulation (DBS) Devices Are Getting Smarter

We're fortunate to live in a time when medical technology is rapidly evolving—and many of these advancements are helping us care for patients in more personalized and effective ways. In the world of deep brain stimulation (DBS), several exciting updates are now available across different device manufacturers.

Medtronic: Smarter Sensing for Personalized Treatment

Medtronic DBS systems now offer two new features that build on their existing ability to sense abnormal brain activity:

Advanced Practice Clinicians

- Meghan Zorn, PA-C

Neurosurgeons

- Shervin Rahimpour, MD
- Ben Shofty, MD, PhD

Ancillary Team Members

- James Ballard, PT, DPT, GCS, WCS (physical therapist)
- Lindsay Embree, PhD (neuropsychologist)
- Sidney Heil (health educator specialist)
- Emily Spoth, LGC, MS (genetic counselor)
- Rebecca Stark (health educator)

Nurses

- Desiree Dunn, RN
- Shannon Mulder, RN
- Sharon Poulter, RN

Clinical Research Coordinators

- Kendra Fowler
- Annalee Hovinga

Fellow

- Conor Flavin, MD

- **Electrode Identifier:** This tool helps your provider determine which electrode might be the most effective for your programming by identifying where the strongest abnormal brain waves are coming from.
- **Adaptive DBS (aDBS):** This feature allows your device to adjust stimulation current levels automatically, based on real-time changes in brain activity. For example, if the device detects an increase in abnormal brain wave patterns associated with your symptoms, it can increase stimulation. When fewer abnormal waves are detected, it can reduce stimulation—all within a range set by your provider.

Boston Scientific: Image-Based Programming & Longer Brain Leads

Boston Scientific has also introduced impressive updates to their DBS platform:

- **Illumina Algorithm:** This tool uses MRI and CT images of your brain with the exact location of your DBS leads, to suggest personalized programming settings. It's like having an algorithm that generates a program based on a map of your brain in a way that aligns with your unique brain structure and how your DBS leads are uniquely placed.
- **16-Contact Leads:** In addition to standard leads that have eight stimulation contacts, Boston Scientific now offers longer leads with 16 contacts. This allows for a larger area of the brain to be targeted, which can be especially helpful for patients with more complex symptoms that may benefit from stimulation in multiple brain regions.

Abbott: Leading the Way in Remote Access

Abbott continues to be the only DBS system that offers remote programming through telemedicine. This means that, when appropriate, your provider can adjust your settings with a video visit from the comfort of your home without the need for an in-person visit to the office. Additionally, their patient programmer can be integrated with your personal smartphone, allowing you to manage your settings directly through a convenient app—no need to carry a separate device.

As these technologies evolve, so does our ability to tailor DBS therapy to better suit each individual. If you have questions about how these features may apply to your care, please talk to your neurologist—we're here to help you make the most out of these exciting tools.

Jumana Alshaikh, MD

Utah Researchers Solve the Mystery of a Rare Balance Disorder

In 1996, neurologists at the University of Utah described a new neurodegenerative disease that affected the cerebellum and sensory nerve cells, leading to gait instability (ataxia) and other neurologic symptoms. The disease, now called SCA4, was found in a Utah family; the neurologists studying it found that it passed on from a parent to 50% of their offspring. They then mapped the disease to chromosome 16, but the identification of the causative gene and mutation remained unknown—despite the use of advanced genetic methods.

Almost 30 years later, the Pulst laboratory and collaborators were finally successful in pinpointing the mutation: An expanded DNA repeat in the ZFHX3 gene. They employed a novel technique called *single strand long-read whole genome sequencing*. Both by ancestry research and by examining the precise make-up of the DNA adjacent to the repeat mutation, the Pulst group was able to show that all currently known families with SCA4 in the US and Europe trace back to southern Sweden, and that this mutation may have only happened once in human history. SCA4 came to Utah with one of the early pioneers born at the beginning of the 19th century. Knowledge of the precise nature of the SCA4 mutation now allows the development of therapeutics targeting the mutation.

Stefan Pulst, MD, Dr med

Professor and Chair of Neurology
Movement Disorders Division
Department of Neurology

Education Corner

Graduate Students Create Educational Video Series on Nutrition and Parkinson's Disease

Graduate students from the Department of Nutrition and Integrative Physiology at the University of Utah have spent the past two years researching the role of nutrition in managing Parkinson's disease (PD). In collaboration with Paolo Moretti, MD, and Guillaume Lamotte, MD, MSc, and grounded in evidence-based literature, the team developed a comprehensive eight-part video series designed to support individuals living with PD in optimizing their nutrition and overall wellness.

To ensure the content addressed the most relevant concerns, the students surveyed patients from the Movement Disorders Clinic at the University of Utah. Survey responses guided the selection of topics, allowing the series to reflect the community's most pressing needs and interests.

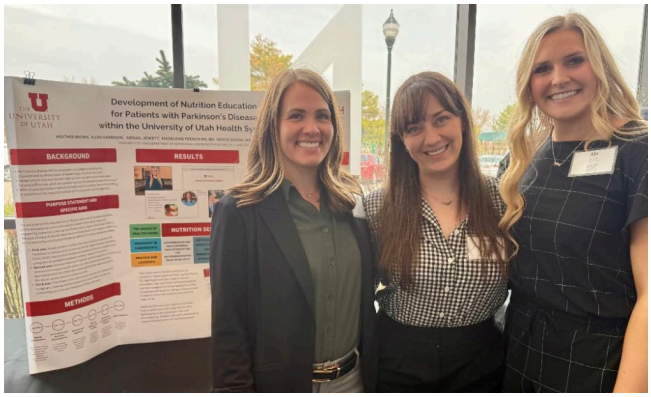
The video series includes the following topics:

1. The Basics of Healthy Aging
2. Movement for Those with Parkinson's Disease
3. Protein and Levodopa
4. Mediterranean and MIND Diets
5. Gastrointestinal Symptom Management Through Nutrition
6. Navigating the Kitchen with Parkinson's Disease
7. Food Texture Modification Demonstration
8. Orthostatic Hypotension and Management Strategies

Watch YouTube Series

This series aims to empower the Parkinson's community through practical, research-backed strategies that can be implemented in daily life.

To explore the full video series, please visit the "Nutrition in Parkinson's Disease" video series on YouTube.



Heather Brown, MS

Nutrition Specialist / Certified Intuitive Eating
Osher Peak Health & Fitness

Resource Center

The University of Utah MSA Center of Excellence

Multiple System Atrophy (MSA) is a progressive neurological disorder that can cause a multitude of symptoms in any combination, including slow movements, impairments in balance, poor coordination, bladder dysfunction, sleep disturbances, constipation, and poor blood pressure control.

Earlier this year, the University of Utah was designated as an MSA Center of Excellence.

As the only academic medical center in a large catchment area, our team is highly sought out for the diagnosis and long-term care of patients with MSA. Our team benefits from dedicated specialists in movement disorders and autonomic disorders, social workers and coordinators, an embedded clinical pharmacist, specialized nurses, physical therapy, occupational therapy, speech services, and a strong partnership with specialties such as urology, palliative care medicine, and gastroenterology. The University of Utah is also nationally recognized as a research site for clinical trials. In collaboration with other Centers of Excellence worldwide, the University of Utah will establish the standard of care, enabling patients with MSA, their care partners, and their families to access

necessary specialized care while also contributing to the advancement of MSA research and education.

Creation of an Atypical Parkinsonian Disorder Multidisciplinary Clinic

The movement disorders team is pleased to announce the creation of a multidisciplinary clinic for people living with atypical parkinsonian syndromes. Atypical parkinsonian syndromes are conditions that share symptoms with Parkinson's disease (PD) like slowness of movement and rigidity; however, the causes and progression of these diseases are different from that of "classic" PD. Such syndromes include progressive supranuclear palsy, multiple system atrophy, and corticobasal syndrome. In a multidisciplinary clinic, patients can visit multiple providers in one day. Studies show that multidisciplinary clinics lead to better outcomes for many conditions. This "one-day clinic" model has the potential to improve care for people living with an atypical parkinsonian syndrome.

After a preliminary intake meeting, families arrive for their appointment. In some cases, tests may be done on-site. Patients then meet with providers, one at a time. Patients meet with a movement disorders specialist, a movement disorders specialized nurse, and a social worker. The providers compare notes and consult with each other before agreeing on the path forward, and then they discuss the plan with the family. Fast referrals are placed to other medical specialties and rehabilitation services. In some cases, consultations in these multidisciplinary clinics may be done virtually.

The clinic is currently offered once a month. We hope to expand it in the future.

Guillaume Lamotte, MD, MSc

Assistant Professor
Movement Disorders Division
Department of Neurology

Movement Disorders Supportive Care Clinic

What Is Supportive Care?

Supportive care for movement disorders is a holistic approach that focuses on improving a person's quality of life by addressing their physical symptoms, emotional health, social needs, and overall well-being—not just treating the disease itself. The goal is to treat the whole person, respecting their values and preferences, and to support them and their families through every stage of their condition. This care can start at diagnosis and can continue alongside visits with your other providers.

What Is the Movement Disorders Supportive Care Clinic?

It is a visit or a series of visits for established patients at the University of Utah with Meghan Zorn PA-C, an experienced Movement Disorders provider with additional training and interest in Palliative and Supportive Care.

What Should I Expect During Visits?

Visits will be tailored to your individual needs and goals, respecting your values and preferences and can include the following:

- Comprehensive conversations about your diagnosis and prognosis. Patients and their families often have questions about their current condition and what to expect in the future—topics they may not have had the opportunity to discuss during routine appointments.
- Management of complex symptoms, with close follow-up to address bothersome issues. Some symptoms require more frequent check-ins to adjust medications or to discuss non-pharmacological strategies.
- Discussion of emotional, social, and spiritual well-being. We are whole people, and it is important to acknowledge that health and disease are interconnected and influenced by a multitude of factors beyond just the physical symptoms of a disease.
- Support for care partners. When caregivers have access to sufficient support, they often

experience enhanced mental well-being, decreased stress levels, and a heightened sense of satisfaction. These improvements not only benefit the caregivers themselves but also contribute to more positive outcomes for the individuals under their care.

- Advanced care planning. By documenting your healthcare preferences, you provide clear guidance to your family and medical team, ensuring that your wishes are respected even if you're unable to voice them yourself.
- Referrals to additional supportive services, such as speech therapy, physical therapy, occupational therapy, social work, nutritionists and other specialists.
- Partnering with Palliative Care to share care for complex patients and timely referral to hospice if appropriate

If this is something you're considering, please reach out to your Movement Disorders provider.

Meghan Zorn, PA-C

Movement Disorders Division
Department of Neurology

Research & Clinical Trials

The Movement Disorders Division is currently recruiting patients for the following research studies:

Parkinson's Disease Studies

Utah Parkinson Disease Registry: This state-wide registry is run by the Utah Department of Health in collaboration with the Department of Neurology at University of Utah to collect information about Parkinson's disease (PD) that will help improve our knowledge about its causes and treatment. You can sign up at www.updr.org.

SPARX3 Phase 3 Clinical Trial: The purpose of this study is to learn more about the effects of aerobic exercise on people with Parkinson's disease who have been diagnosed in the last three years and have not started taking medications for their PD symptoms. For more information about the study, visit https://www.sparx3pd.com. To be screened for enrollment please call 801-587-3181, or email G.Olivier@utah.edu.

Hemodynamic Responses to Exercise in Individuals with Parkinson's Disease with and without Orthostatic Hypotension and on and off Levodopa: This study investigates the autonomic response to exercise in people with PD with and without orthostatic hypotension. If interested, contact guillaume.lamotte@hsc.utah.edu.

ROSSINI: This global, real-world evidence study examines the long-term effectiveness of continuous subcutaneous levodopa infusion in patients with advanced PD during routine clinical practice. This is an observational study. To learn more, contact clinical research coordinator Kendra Fowler at 801-581-7828 or kendra.fowler@utah.edu.

Multiple System Atrophy Studies

CYPRESS: This is a phase 3, multicenter, randomized withdrawal and long-term extension study of ampreloxetine. It examines the treatment of symptomatic neurogenic orthostatic hypotension in participants with multiple system atrophy. To learn more, contact clinical research coordinator Kendra Fowler at kendra.fowler@utah.edu or 801-581-7828.

Essential Tremor Studies

ADROIT (Abbott DBS Registry of Outcomes for Indications Over Time): This international, prospective, long-term study examines the safety and effectiveness of Abbott DBS devices. Our site is actively enrolling essential tremor patients. To learn more, contact clinical research coordinator Kendra Fowler at kendra.fowler@utah.edu or 801-581-7828.

Physiologic Correlates of Vocal Tremor Affecting Those with Essential Tremor: Essential tremor is one of the most common movement disorders in the world. Approximately 30% of these individuals exhibit a vocal tremor, with the majority being female. This study evaluates mechanisms of vocal tremor and their effects on communication, with the goal of advancing current and future treatments. Contact clinical research coordinator

Derrik Legler at derrik.legler@hsc.utah.edu if interested.

Huntington's Disease Studies

Enroll-HD: This is a worldwide, longitudinal research study of Huntington's disease (HD). Clinical information and biological samples are collected at annual visits to try and find new treatments for the disease. Our site is actively enrolling participants with HD as well as their families. To learn more, contact clinical research coordinator Kendra Fowler at kendra.fowler@utah.edu or 801-581-7828.

Dystonia Studies

Next-Generation Clinical Phenotyping and Pathophysiology of Laryngeal Dystonia and Voice Tremor: The University of Utah is a participating research site on this P50 grant awarded by the National Institutes of Health (NIH)/National Institute on Deafness and Other Communication Disorders (NIDCD). The study creates specialized centers and cross-disciplinary research focused on understanding the clinical and pathophysiologic features of laryngeal dystonia (i.e., spasmodic dysphonia) and voice tremor. For more information, please contact jessica.ku@hsc.utah.edu.

Deep Brain Stimulation in Laryngeal Dystonia and Voice Tremor: This study is part of the P50 grant awarded by the NIH to further understand laryngeal dystonia and tremor. Any patient with essential tremor and dystonia that has or is going to undergo deep brain stimulation (DBS) is eligible. This study is trying to understand if and how the voice is affected by DBS surgery. Please contact jessica.ku@hsc.utah.edu for more information.

Mild Cognitive Impairment Studies

Syn-D Study: This study investigates the utility of skin biopsy testing for diagnosing mild cognitive impairment secondary to dementia with Lewy bodies (DLB) or Alzheimer's disease. If interested, contact guillaume.lamotte@hsc.utah.edu.

MCI/AD Motor Function and Brain Connectivity Studies: We are recruiting research participants for two studies involving patients with mild cognitive impairment and Alzheimer's disease, as well as healthy older adult volunteers. These studies focus on learning about changes in motor function, cognition, and brain connectivity on MRI, as well as looking at the effects of lecanemab and donanemab infusion therapies on changes in motor function and brain connectivity. If interested, please contact Vincent Koppelmans at vincent.koppelmans@utah.edu.

Postural Orthostatic Tachycardia Syndrome (POTS) Studies

Regeneron: This phase 2, double-blind, placebo-controlled, single-dose study examines pharmacodynamics, pharmacokinetics, safety, and monoclonal antibodies in patients with postural orthostatic tachycardia syndrome (POTS). To learn more, contact clinical research coordinator Kendra Fowler at 801-581-7828 or kendra.fowler@utah.edu. □

Upcoming Events

Events

The University of Utah Idaho Falls Parkinson's Disease (PD) Symposium is on 20 September 2025 at the Snake River Event Center. Registration and the agenda will be sent out via listserv closer to the event. For questions, contact 801-585-2354 or sidney.heil@hsc.utah.edu.

The University of Utah St. George Parkinson's Disease (PD) Symposium on is 01 November 2025 at the St. George Courtyard Marriott Center. Registration and the agenda will be sent out via listserv closer to the event. For questions, contact 801-585-2354 or sidney.heil@hsc.utah.edu.

Recurring Events

An SLC Parkinson's disease (PD) monthly support group takes place on the third Thursday of every month at 6 pm at the Imaging and Neurosciences Center's large conference room located at 729 Arapeen Dr.

A University of Utah support group for progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA), and care partners takes place on the second Thursday of every month from 5 to 6 pm, meeting virtually. To receive the link, contact

sidney.heil@hsc.utah.edu.

A PD caregiver support group takes place on the second Wednesday of every month at 12:00 pm on Zoom. Please email rebecca.starks@hsc.utah.edu to receive the link.

A Huntington's disease (HD) caregiver support group takes place on the second Monday of every month at 4 pm, meeting virtually. For additional information, call 435-216-3250.

An HD gene positive & at-risk support group takes place on the second Monday of the month at 6:30 pm, meeting virtually. Contact 435-216-3250 for more information.

PD 101 for newly diagnosed patients will take place on 19 September 2025 from noon to 1 pm. It will feature Guillaume Lamotte, MD. It will be hosted on Zoom. Please RSVP to Sidney Heil at sidney.heil@hsc.utah.edu to receive the link. We host this event every six months; the following date will be announced in the next newsletter.

Singing to Strengthen Voices: Choir for Those with PD meets every Monday from noon to 12:30 pm on Zoom. Patients with other movement disorders such as HD are also welcome to join. The meeting ID is 956 0421 6953; the passcode is CHOIR.

If you are interested in receiving emails about events, research studies, and updates relevant to our Parkinson's Disease Center of Excellence, you can subscribe to our Parkinson's Community Information listserv by sending an email to rebecca.starks@hsc.utah.edu.

Read Issue Online

Support Our Mission

The mission of the Department of Neurology Advancement Team is to foster philanthropic opportunities within the division that support education, research, patient care, and community outreach. Our division is responsible for some of the best research, education, and medical services in the United States. The Advancement Team helps raise money to support these endeavors. We work with individual donors, foundations, corporations, faculty, and staff. If you have any questions about how you can become involved, please visit our website.

Make a Difference