



On The Move!

The official newsletter for the University of Colorado Movement Disorders Center

Faculty

Maureen Leehey, MD, FAAN
Division Chief

Lauren Seeberger, MD, FAAN
Movement Disorders Center Director

Brian Berman, MD, MS, FAAN
Michelle Fullard, MD, MSCE
Trevor Hawkins, MD
Drew Kern, MD, MS

Heather Baer, MD
Abigail Collins, MD
Samantha Holden, MD, MS
Christina Vaughan, MD, MHS, MS
Jessica Barr, PA-C

Contact Us

Movement Disorders Center
303-724-8984
movement@ucdenver.edu

For appointments
720-848-2080

To participate in clinical research
303-724-4644

To donate to our center
303-724-9146
giving.cu.edu

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MDC Honors Exemplary Community Leader

Nicole Leith, MS

The Movement Disorders Center hosted its 6th Annual Parkinson Disease Symposium on Saturday, October 26, 2019. During the symposium, the Movement Disorders Center was honored to present Diane Cook with our award for Exemplary Community Leader.

The MDC is grateful to have Diane serve on its advisory board considering all she has done for the Parkinson's Community. She is a former management consultant with expertise in designing leadership and training programs, as well as a past International Conference Director for Deepak Chopra. She put those skills to use when designing her self-efficacy course for newly diagnosed PD patients, PD SELF (Parkinson Disease Self Efficacy Learning Forum), an eight-month program that meets once a month, and is focused on using the scientifically-based principles of self-efficacy to help both patients and caregivers improve the quality of their lives while coping with PD. Classes are led by co-facilitators: one person with Parkinson disease and one PD professional. To her knowledge, this is the only Parkinson's-focused self-efficacy program in the world.



PD SELF started as a successful small clinical trial and has now expanded to 16 sites across the United States. Both immediate and long-term assessments show statistically significant improvement in quality of life for PD patients, despite, for many, declining physical health. Similar

assessments also show quality of life improvement for caregivers. At the present, there are three such programs in Colorado.

As a result of her PD SELF work, she is a frequent speaker and has presented abstracts at, among other events, the Sydney and Berlin Parkinson's and Movement Disorders Congress, the Montreal and Portland World Parkinson's Congress, and the New York Academy of Sciences. She also started what has become the annual Clinical Research Conference.

Diane has participated in 15 clinical trials to date and serves as a patient consultant on several studies.

Nationally, Diane has served on the People with Parkinson's Advisory Council, the Steering Committee of the Clinical Trails Transformation Initiative, and Parkinson's Action Network (PAN) Colorado State Director. In addition to her service on our advisory board, she also currently serves as a Patient Representative to the FDA and a Patient Advisor at the Movement Disorders Foundation of Denver.

Movement Disorders Center Fellows

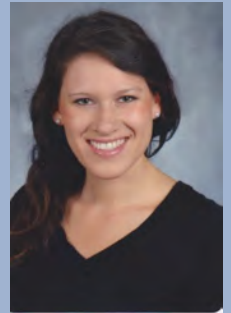
This summer, the Movement Disorders Fellowship Program graduated Kirstin Mitrovich, MD and Kristin King, MD. Dr. Mitrovich is now practicing in Utah and Dr. King is practicing in Oklahoma. We wish them all the best and look forward to continued collaborations.

Please join us in welcoming two new fellows to the Movement Disorders Fellowship Program.



Caroline Goldin, MD

Dr. Caroline Goldin is from Atlanta, GA. She majored in neuroscience at Vanderbilt University in Nashville, TN, then attended medical school at Emory University in Atlanta, GA. She completed her internal medicine internship and neurology residency at the University of Colorado Hospital and stayed for movement disorders fellowship. Caroline lives with her husband, Will; one-year-old daughter, Nora; and their three rescue dogs. She enjoys running and has competed a full and multiple half marathons. She also enjoys playing guitar, drawing and painting, and baking.



Teresa Lee, MD

Dr. Teresa Lee was born and raised in Chicago, Illinois. She completed her undergraduate studies in psychology at the University of Notre Dame. She then went to medical school at Georgetown University School of Medicine in Washington DC, where she fell in love with neurology and movement disorders. She returned to Chicago for her neurology residency at Rush University Medical Center. Dr. Lee enjoys hiking, running, and yoga and is excited to be living out West.

University of Colorado LBDA Research Center of Excellence Symposium

By Samantha Holden, MD, MS

On Saturday, December 14, 2019, the University of Colorado Lewy Body Dementia Association (LBDA) Research Center of Excellence held its inaugural community education symposium, furthering the center’s mission to increase awareness, improve clinical care, and provide education and support for Lewy body dementia. Partnering with the Department of Psychiatry, through the generous support of the Michael K. Cooper Professorship of Neurocognitive Disease, this educational conference focused on Lewy body dementia, the second most common cause of dementia after Alzheimer’s disease. Lewy body dementia is an umbrella term that encompasses both dementia with Lewy bodies (in which cognitive difficulty occurs first) and Parkinson’s disease dementia (in which motor symptoms, like tremor, occur first). Over 100 people, including a mix of people personally affected by Lewy Body Dementia and interested health care professionals, registered for the half-day event, which took place at the Hyatt Regency Aurora. The keynote speaker for the event was Melissa Armstrong, MD, MSc, the director of the University of Florida Dorothy Mangurian Clinical-Research Headquarters for Lewy Body Dementia. Dr. Armstrong is a nationally-recognized leader in patient- and caregiver-centered clinical research and presented her keynote address on “Partnering with Your Medical Team in Lewy Body Dementia” at the symposium. Other invited guest speakers included Angela Taylor, the Senior Director of Research and Advocacy for the LBDA, Deb Wells, the Director of Operations for the Alzheimer’s Association Colorado Chapter and former Lewy body dementia care partner, Jill Lorentz, of Summit Resilience Training, and Larry Hendershot, who is living with Lewy body dementia himself. Faculty from the Behavioral Neurology section of the Department of Neurology at the University of Colorado, including Dr. Samantha Holden, Dr. Victoria Pelak, Dr. Brianne Bettcher, Dr. Brice McConnell, and Dr. Peter Pressman, presented lectures on clinical features and management options for Lewy body dementia. 94% of attendees reported that the symposium fully met or exceeded their expectations and 83% felt their understanding of Lewy body dementia was greatly improved by attending. Drs. Holden and Pelak, the co-directors of the LBDA Research Center of Excellence at CU, look forward to continuing similar outreach events in the future.

The Role of Genetics in Parkinson Disease

By: Lisa Deuel, MD

Genetics 101

In order to see how genetics can cause PD, it is important to understand the basics. First of all, everyone has two sets of 23 chromosomes in every cell in their body, so 46 chromosomes total – one set comes from your mother and one from your father. These chromosomes contain all of your genetic material, called *DNA*. Think of this as a blueprint for making proteins, which determine how your body is put together and how it works. Proteins must be built in a very specific way in order to work the way they are meant to. If the genetic code is changed during protein building, problems can occur. Permanent changes in the genetic code are called *mutations*. When mutations happen in certain cells in the body, they can be passed to children.

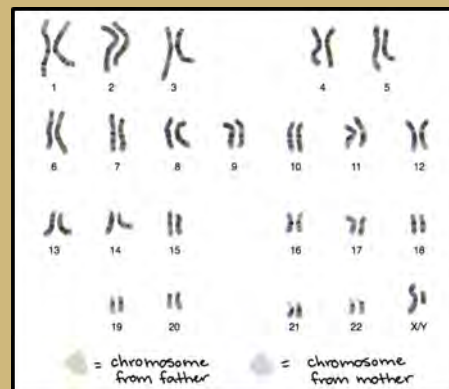


Image courtesy of Khan Academy

Genetics in Parkinson disease

PD was first described by James Parkinson in 1817 after he observed a group of people with the same symptoms: slow movement (*bradykinesia*), stiffness (*rigidity*), tremor, and walking issues. There was no other test to make the diagnosis, just his examination. As far as they knew, PD just happened out of the blue. It wasn't until 1990 that some neurologists reported PD in many members of an Italian family and thought it could be passed from generation to generation through DNA. Then in 1997, scientists found a mutation in some people with PD in the gene for a protein called *alpha-synuclein*. When this gene is mutated, alpha-synuclein is built wrong and clumps up in cells as *Lewy bodies*. Now, there are dozens of genetic mutations that we think increase the risk of PD. If you have one, it doesn't mean you will definitely get PD in your lifetime. We think that other things play a role too, like other genes and the environment.

People often ask if they should have genetic testing, and we recommend it if you have a family history of PD, have symptoms starting early (< 50 years old), or are of an ethnicity/nationality where PD is more common (Ashkenazi Jewish, North African Arab-Berber). If you are in one of these groups, still only about 3 out of 10 people have a gene mutation. If you are not, then it is much less likely (1 out of 20 people). We do not recommend testing for children of people with PD, because even if they have a genetic mutation, it does not tell us if and when that person will get symptoms. If you have any questions about this, you should always ask your doctor rather than testing through a commercial program. Genetic testing is cheaper now than it was in the past, so it is much more available to people.

Research opportunities

Many groups want to study patients with genetic mutations, because these genes can be a target for drugs that stop, slow, or treat PD:

- At the University of Colorado, researchers are testing drugs that block the LRRK2 gene in patients with LRRK2 mutations, so that less of the bad protein is made.
- The Michael J. Fox Foundation is recruiting people with PD across the country to join the Fox Insight study – involving online questionnaires and genetic testing [<https://foxinsight.michaeljfox.org>]
- The Parkinson's Foundation has a study called PD GENERation, which has free genetic testing and genetic counseling for people with PD at select sites [<https://www.parkinson.org/PDGENERation>]



First Meeting of the Brain-Gut Axis and Implications Group

In October, the University of Colorado Movement Disorders Center hosted it's first Brain-Gut Axis meeting. The group met to talk about the potential impact gut health has on the brain. In attendance were neurochemists, pulmonologists, epidemiologists, movement disorders neurologists, neurosurgeons, and bench scientists.

During this meeting, members of each discipline explained the relevance of the gut and brain in their area of research. As a result, many collaborative projects have begun.

We look forward to the updates to come from these ventures.

6th Symposium Recap



Congratulations to Nicole Leith, MS who won the University of Colorado Department of Neurology's Employee of the Quarter . This award is given to employees within the department who have accomplished extraordinary achievement within the organization.

Nicole Leith currently serves as the Movement Disorders Center Coordinator and Outreach Specialist. She started with the department in February 2015 and "has taken a pivotal role in the UC MDC providing program management for the MDC PF COE and MCD HDSA COE. As such, she develops and implements symposia, raises the funds for them and manages reservations, puts out [the] newsletter and updates our website."

Nicole received multiple nominations for this award as a result of her dedication and commitment to the department, its employees, and providers, and the community they serve. One of her nominees said " I just wanted to let you know that Nicole is doing an amazing job. She goes well beyond her responsibilities...I am sure that I speak for the other [s] when I say that I really couldn't do what I do without her."

The MDC hosted its 6th Annual Parkinson Disease Symposium on Saturday, October 26 at the Bruce Schroffel Conference Center. The conference was co-hosted by the Parkinson's Foundation and was the first since MDC achieved the Center of Excellence designation.

MDC welcomed 290 patients, care partners, and family members and 43 volunteers and representatives from partnering community organizations, including Davis Phinney Foundation, Parkinson Association of the Rockies, Rehabilitative Rhythms, Reconnect with your Body, LSVT Global, Parkinson's Pointe, and PD SELF.

The conference included talks about Etiology and Medications (Teresa Lee, MD), Genetics (Lisa Deuel, MD), Hospital Stays and Surgery Following a PD Diagnosis (Michelle Fullard, MD, MSCE and Jessica Barr, PA-C), Eye and Vision Problems (Erin Van Dok,

O.D.), Research (Maureen Leehey, MD, FAAN), Sex and Intimacy (Susan Coates, *Susan Coates Coaching*), and Sleep (Brian Berman, MD, MS, FAAN). The day was emceed by Lauren Seeberger, MD, FAAN.

In review of the presentation, attendees commented "Best symposium attended in a long time. Presentation length just right to cover topics and maintain attention. Enjoyed the variety of topics. Speakers presented well and able to relate to PD individuals and interject a bit of humor." Another attendee said, "We are new to PD and are thrilled to find out there are awesome resources available such as this conference."

The symposium will be moving to the CU South Denver campus for 2020. While this may be farther away for some of our attendees, the new location's amenities promise to be a great match for the needs of attendees and the conference.

The 2019 symposium presentations and slides are available on the Movement Disorders Website (www.ucdenvermovement.org).

Save the Dates!

3rd Annual Huntington's Disease Patient and Family

Saturday, June 13, 2020

Event details will follow at a later date

7th Annual Parkinson Disease Symposium

Saturday, October 3, 2020

Cu South Denver, Lone Tree, CO

Sign up for our newsletter to be the first to know about our events

Interested in Participating in Research?

We're always looking for patients interested in research. For more information or to get involved with our research, please contact our Research Recruitment Specialist, 303-724-4644.

To view a list of our studies, please visit www.ucdenvermovement.org. Click on the "Research" tab and then follow the link to view a list of our current research studies.

Get Involved!

Our world-class team of physicians and researchers are dedicated to providing the highest quality of care for patients today while developing cures and novel treatments for tomorrow.

Private support is essential to pushing the boundaries of science and bringing life-changing research and care to the patients who need it most. With your support, we will continue providing the region's most comprehensive patient care and conducting innovative research that will transform healthcare around the country.

Learn how you can help:

Carrie Radant Flynn

Carrie.Radant@ucdenver.edu

303-724-9146

giving.cu.edu/parkinsons