



On The Move!

The official newsletter for the University of Colorado Movement Disorders Center

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Contact Us

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

For appointments
 Anschutz: 720-848-2080
 Boulder: 303-544-3900
 Lone Tree: 720-848-2200
 VA: 720-723-6204
 Denver Health: 303-436-4949

To participate in clinical research
 303-724-4644
 neuroresearch@cuanschutz.edu

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

Neuro-Palliative Care: What is it?

Antonia Pusso, MD, *Movement Disorders Fellow*

What is Palliative Care?

Palliative care is specialized medical care that focuses on providing relief from symptoms and stress of a serious illness with the goal of improving quality of life for both patients and families. Palliative care is provided by a team of doctors, nurses, social workers, and chaplains. Neuro-palliative care is the palliative care approach with the focus on patients with neurologic disease, specifically serious chronic illnesses such as Parkinson’s disease, atypical parkinsonism, and Huntington’s disease in addition to many other neurologic diseases. The focus is on symptoms, coping, and future planning. Symptoms can include pain, fatigue, constipation, nausea, loss of appetite, sleep, depression and any psychological or spiritual sources of suffering, with the goal of helping people live as well as possible for as long as possible. In addition, palliative care providers have specialized training in communication and aid in conversations to align goals of care with next steps.

Palliative Care for Parkinson’s Disease

Over the past few years there has been increased focus and attention on the importance of Neuro-palliative care in many chronic neurologic illnesses,



including Parkinson’s Disease (PD). Though much work is being done to find a cure or medication to slow down progression, PD remains a progressive neurodegenerative illness. The palliative care approach focuses on the “whole-person” that includes not just physical symptoms, but social, spiritual, and psychological aspects of each person’s lived experience with their

disease. PD affects much more than a person’s movements and each person’s experience with their disease is different. In 2020 there was a large clinical trial comparing outpatient palliative care with standard care in patients with PD and related disorders and found that the patients receiving palliative care had better quality of life in addition to better symptom control (1).

Recognizing the importance of this approach to care for quality of life and wellbeing of patients and families the Parkinson’s Foundation launched an initiative to make Neuro-palliative care a standard practice at all PD Centers of Excellence in the United States.

Is Neuro-palliative Care right for me or my loved one?

This approach to care is applicable to patients and families at any stage of a

(Continued on page 2)

serious illness including at time of diagnosis, at life transitions, and end-of-life care. This approach can evolve and shift to fit the patients' and families' needs as disease progresses. Palliative care can be provided at several different tiers. Primary palliative care, the first tier, can be incorporated into the practice of your primary neurologist. This is a focus of the Parkinsons Foundation Neuro-palliative care initiative to improve communication around care preferences, non-motor symptom management, and family/caregiver support. Some patients may require more intensive symptom management and additional support where specialty Neuro-palliative care may be particularly useful.

If you are interested in seeing our Neuro-palliative care specialists, ask your primary neurologist for a referral and for more information please visit: www.neuropalliative.org

References

1. Kluger BM, Miyasaki J, Katz M, Galifianakis N, Hall K, Pantilat S, Khan R, Friedman C, Cernik W, Goto Y, Long J, Fairclough D, Sillau S, Kutner JS. Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders: A Randomized Clinical Trial. *JAMA Neurol.* 2020 May 1;77(5):551-560.

Are you considering giving this holiday season?

We are thankful for the generosity of our donors this past year to elevate our work and progress in the field of Movement Disorders. With the help of our donors, we have:

- Funded Movement Disorders Center's Pilot Grant Program for early-career clinician and bench researchers
- Expanded outreach of Deep Brain Stimulation to surrounding states
- Provided additional training to staff in specialized care
- Trained neurologists to become next generation leaders in Movement Disorders research and clinical care through funded Fellowships
- Increased support for patients in Huntington's Disease clinic
- Advanced complex research projects

If you are interested in supporting the University of Colorado Movement Disorders Center during the holiday season, you can contact our CU Advancement colleague, Marti Laule at marti.laule@cuanschutz.edu or by phone at 720-202-7845 to learn more about how your gift can make an impact. You can visit our website

Stay in the Know About Upcoming Events!



This year the Movement Disorders Center hosted its annual education events for Parkinson's disease and Huntington's Disease. We chose to host these events virtually and look forward to hosting them in person again soon when it is safe to do so. The center also hosted "New Medications for Parkinson's Disease" in April for Parkinson's Disease Awareness Month and "The Genetics of Huntington's Disease" in May for Huntington's Disease Awareness Month. The providers gave 67 talks throughout the year to support groups, care partners, providers, and medical trainees virtually and in person. Recordings of all of many of our talks can be found on our website (www.cumovement.org) under Community, then Educational Resources.

Providing education to our Movement community is truly a privilege. The faculty and staff of the Movement Disorders Center firmly believe in giving patients, care partners, and families the resources they need to advocate for the best healthcare possible.

We encourage you to sign up for our monthly e-newsletter so that you will be the first to know about our upcoming educational events. You'll stay in the know about our center, current research, and what's going on in the Movement Disorders Community. We will never share your sell your personal information and you can expect about one email per month.

To join our mailing list, visit our website (www.cumovement.org) or scan the code to the right with your smart phone.



Updates from the Parkinson's Foundation Center of Excellence

Interim Director | Michelle Fullard, MD, MSCE

With the departure of Dr. Maureen Leehey (see page 6), Dr. Michelle Fullard will be serving as Interim Director of the University of Colorado Movement Disorders Center Parkinson's Foundation Center of Excellence. We feel that Dr. Fullard's research expertise will be an incredible asset to this role.

The Parkinson's Foundation launched a Palliative Care initiative over the summer for all of the Centers of Excellence across the nation. The University of Colorado Movement Disorders Center has jumped in with both feet! This initiative focuses on five pillars including annual advanced care planning, management of non-motor symptoms, support for psychosocial issues, care partner support, and timely referrals to palliative care. While our center addresses all of these pillars, we are looking forward to improving processes and making these pillars stronger within our center. Through this initiative, we will get to work with and learn from other centers around the United States.

Our faculty and staff continue to train in these areas and we have been providing additional education to patients, care partners, families, and medical providers and trainees around Palliative Care. We encourage you to learn more about Neuro-Palliative Care through our own Neuro-palliative Care Clinic at <https://medschool.cuanschutz.edu/palliativecare>.



CENTER OF EXCELLENCE

Are you interested in participating in research? We have many ongoing clinical trials and investigator-initiated studies. Our research recruitment team is ready to help you find a study that fits you. Resources are available in English and Spanish via phone and email. Contact us today at 303-724-4644 or neuroresearch@cuanschutz.edu.

Researcher Spotlight | Michelle Fullard, MS, MSCE



Dr. Fullard's research focuses on improving care for patients with Parkinson's disease, as well as developing interventions to reduce and eliminate disparities in Parkinson's disease care.

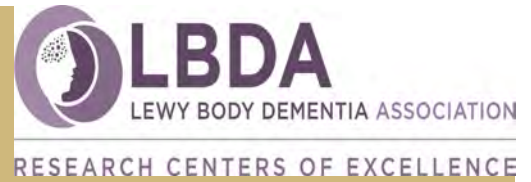
In one study, Dr. Fullard and her team developed a best practice alert for the electronic medical record system in the hospital that alerts

providers if they order a medication that a patient with Parkinson's disease should not receive. Since patients with Parkinson's disease already have low levels of dopamine in the areas of the brain that facilitate movement, they should not receive medications that block or further reduce dopamine. These include commonly used anti-nausea and antipsychotic medications, which, if given, can lead to complications and longer hospital stays. Since the best practice alert was initiated, the use of these medications for hospitalized patients with Parkinson's disease has been reduced by almost 50%. The team is now looking at whether the reduction in use has also led to a reduction in complications and length of hospital stay.

A second study is focused on improving patient-centered care and shared decision making around advanced therapies for Parkinson's disease. She is working with Dr. Dan Matlock from the Colorado Program in Patient Centered Decisions to develop a decision support tool. This tool will provide patients with an individualized output regarding the risks and benefits of Deep Brain Stimulation (DBS) surgery based on their age, gender and symptoms. The decision support tool will help patients consider their values and preferences when making a decision about DBS to ensure they make the best possible decision for themselves. She is also creating an Ambassador Program for DBS surgery that will match volunteers who have undergone DBS surgery with those who are considering DBS surgery. This program will allow DBS candidates to hear the patient perspective of DBS surgery, which may help inform their decision.

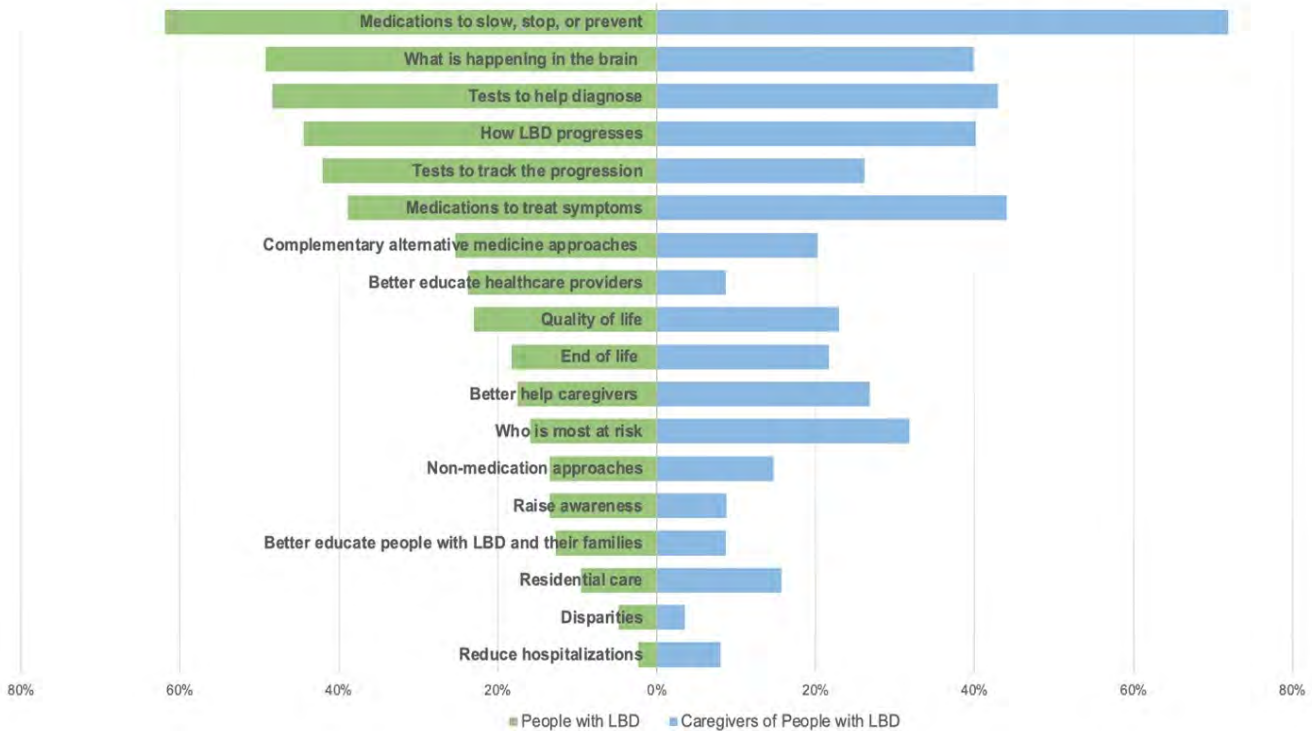
Updates from the Lewy Body Dementia Research Center of Excellence

Co-directors | Samantha Holden, MD, MS & Victoria Pelak, MD



Partnering with the community personally affected by LBD is a priority for the LBDA RCOE network. Dr. Samantha Holden and Dr. Melissa Armstrong (University of Florida LBDA RCOE) lead the Community Engagement working group for the LBDA. Dr. Holden and Dr. Armstrong recently performed an online survey of 131 people living with LBD and 832 caregivers of people with LBD, asking about their priorities for future research studies (see figure). This is the largest survey of people personally affected by LBDA on their care needs and research priorities and a scientific paper is in preparation. Three clinical trials investigating new treatments for Lewy body dementia are in planning stages and CU is planning on serving as a study site. Enrollment of participants with LBD would likely begin in the spring of 2022. The 7th International Lewy Body Dementia Conference will take place in June 2022 in Newcastle upon Tyne, UK. This will be the first in person meeting of the RCOE investigators since June 2019.

What areas of LBD research are most important to you?



Updates from the Huntington's Disease Center of Excellence

Director | Emily Forbes, DO, MS

The HDSA Center of Excellence at the University of Colorado Movement Disorders Center has a new director, Dr. Emily Forbes. Dr. Forbes is an Assistant Professor of Neurology with a strong background in genetics.



Over the past year, Dr. Forbes has reinstated a spiritual counselor into the monthly HD Clinic. The clinic is also excited to welcome back Meghan Smith, LCSW to the HD Clinic. Additionally, the HD Clinic now offers a genetic counselor during the HD Clinic. Kaitlin Smith, CGC has fellowship training in Adult Neurology. Dr. Forbes is working on initiatives to add more services to our monthly clinic day in 2022.

Sleep Disturbances in Parkinson's Disease

By: Heather Heiser, MD, *Movement Disorders Fellow*

As many with the disease know, Parkinson's disease (PD) affects much more than a person's movement. One of the most common other symptoms is a disruption or change in sleep. Over 60% of patients with PD report experiencing at least one sleep disorder following their diagnosis. This is nothing new to the world of understanding Parkinson's disease; in fact, Dr. James Parkinson, the physician who first described the disease in 1817, mentioned the disruption in normal sleep patterns in the first published paper describing PD. Much more recent studies note that patients with PD have various changes to their sleep architecture – that is, how long they stay or how stable their various different stages of sleep are, such as “Slow wave sleep” (deep sleep) or REM sleep. Just as Parkinson's disease is different for every patient, there are many different ways that a patient may have disruption of normal sleep and not every patient with PD may experience what is described below; but better understanding of what may be occurring can help lead to changes, treatment, and overall better sleep.

The most common sleep disorder seen in PD is insomnia: an inability to initiate or maintain sleep. This may mean laying down but taking hours to fall asleep, or being able to fall asleep fine but then waking up once, twice, three times and then having difficulty falling back asleep. Often, but not always, this is tied to excessive daytime sleepiness. This becomes more common with disease progression, advanced motor symptoms and, for unclear reasons, in males. Some medications can be activating – making it difficult to fall asleep when you want to – or cause somnolence – making it too easy to fall asleep during the day. Therefore it is important to discuss with your physician if the timing of your medications need to be changed to combat these side effects or perhaps have them work in your favor in promoting sleep at night and wakefulness during the day. Another possible treatment is melatonin. Melatonin is a natural chemical secreted by the brain at higher levels beginning around dusk and then drops secretion around dawn. There are some studies that suggest melatonin secretion is lower or has a disruption in the natural timing in patients with PD. Discuss with your physician if melatonin is a good treatment option and to guide dosage.

A common question PD specialists ask their patients about is something the patient might not even be aware is happening, called REM-behavior disorder (RBD). This may also be called dream enactment. Usually, when in the REM sleep stage, the body is



“atonic”, meaning it is paralyzed except for breathing muscles. In those that have RBD, this paralysis is lost and so when they are experiencing running or fighting in a dream, they will often act it out in the bed. Partners often describe swinging arms or kicking legs or yelling out. A sleep study (polysomnogram) can be done to clarify the diagnosis. RBD can occur many years before any other symptom of Parkinson's disease. In a study of patients with isolated RBD (no other symptoms or diagnosis) who were followed for 14 years after the diagnosis, 82% were eventually diagnosed with a neurodegenerative syndrome, mostly PD or Lewy Body dementia. Therefore it is considered a “prodromal” finding (an early symptom) in PD and as such is an important focus in research into disease-modifying and neuroprotective clinical trials. It is still important to know about even if a patient has already been diagnosed with PD because of safety concerns. Some movements can be so violent that patients fall out of bed or accidentally hurt their bed partner, so alterations in bed type or

arrangement may need to occur to promote safety for both people.

Two other common sleep disorders are obstructive sleep apnea and restless leg syndrome. While research is conflicting on whether these disorders are more common in PD than the general population, they are overall common enough to be an issue for many patients with PD. Obstructive sleep apnea (OSA) is not just snoring but involves apneic events – cessation of breathing with a slight arousal that the patient may or may not be aware of. It is important to treat OSA because to reduce cardiovascular risks and it may also significantly help daytime somnolence. OSA is diagnosed with a sleep study and is often treated by sleep specialists with various interventions, including a CPAP machine.

Restless leg syndrome is an uncontrollable urge to move the legs, usually accompanied by an unpleasant sensation in the legs. It is partially relieved by moving the legs. Many medications used in PD are also used for treating RLS. For some, a dysregulation of iron metabolism may play a role, so your doctor may ask for a blood sample to assess your iron stores and treat accordingly.

No matter what underlying diagnosis is disrupting sleep, it is always good to try and practice good “sleep hygiene.” Here are some tips for sleep hygiene that can help promote good sleep:

- Avoid caffeine later in the day
- Exercise regularly
- Keep a regular bedtime
- Learn ways to better manage stress- a therapist may help in creating coping skills
- Reduce bedroom noise
- Avoid long daytime naps, though short ones are likely not to affect sleep
- Avoid screen time in bed or shortly before bedtime including phones and tablets

If you cannot fall asleep don't stay in bed, get up and read or do a small activity and then come back and try again.

Congratulations to Dr. Maureen Leehey!

After 29 years of dedicated service to Movement Disorders at the University of Colorado School of Medicine, Dr. Maureen Leehey will be retiring in March of 2022. Dr. Leehey will continue to have an impact in the world of Movement Disorders. Throughout the years, she has trained 38 clinicians, researchers, and students, has published over 130 scholarly journal articles, and have given over 125 talks locally, regionally, nationally and internationally throughout her tenure. She will continue to be a part of the Movement Disorders Center as Professor of Neurology *Emerita*.”



Dr. Leehey is looking forward to spending more time with her family, traveling, and getting involved in projects to help save the environment.

Dr. Leehey has thoughtfully considered which providers each of her patients will work best with and will give a warm, in depth hand off to another Movement Disorders neurologist in our section.

With Dr. Leehey's departure, the Movement Disorders Center is working on hiring a new Head of Movement Disorders. Drew Kern, MD, MS is serving as Interim Head until a new head of the section is hired.

“Thank you,” simply is not enough for all that Dr. Leehey has contributed to the Movement Disorders community. She will be missed in our clinics and day-to-day operations, but we wish her the best in her upcoming endeavors and look forward to hearing about her adventures.

Movement Disorders Center Launches Large Telehealth Initiative to Serve Rural and Underserved Populations

The University of Colorado Movement Disorders Center recently launched a program to serve patients in rural and underserved communities. Underserved populations are those who have too few providers or do not have good access to medical care. For these communities, medical care—especially specialty care—is geographically or financially not available. Movement Disorders is a specialty within Neurology that focuses on treating neurological conditions that either cause too much movement and too few or slowing of movements. This disorders include Parkinson’s disease and Huntington’s Disease.

Funding from this project is awarded by Colorado’s Medicaid program, Health First Colorado and is granted for three years.

The first part of the project was a series of advertisements letting people know that shaking hands might be more than just normal aging. “Many patients with movement disorders don’t know they have a disease that can be treated,” says Dr. Maureen Leehey. “They think their symptoms are just a natural part of the aging process, but they are not.”

Through this program, patients who have Medicaid will be able to meet with a movement disorders neurologist. If the patient is diagnosed with a movement disorder, the specialists would work to manage the patient with their established primary care provider and through telehealth visits between the movement disorders specialists and patient. Patients who are seen by neurologists have significantly better health outcomes than those who are not seen by specialists.

A second part of the project will provide education to primary care physicians about movement disorders—especially Parkinson’s disease and Huntington’s Disease through the nonprofit organization ECHO Colorado. This is a series of presentations that will focus on diagnosing and managing movement disorders as well as when it’s time to refer patients to a movement disorders

neurologist for additional care. These educational sessions use case series to help providers learn about diagnosing movement disorders.

A final piece of the project will be to provide consulting services to primary care providers. If providers in rural areas or those who provide care for underserved populations have a difficult case, they will be able to reach out directly to a movement disorders neurologist. The neurologists will provide recommendations to the physicians.

The faculty of University of Colorado Movement Disorders Center believe that all patients deserve equal access to care and support they need without the burden of traveling long distances or worrying about finances.

In addition to faculty who are dedicated to serving these populations, the Movement Disorders Center has also hired a project manager and designated scheduler for this project.

If you are a patient with Medicaid and Parkinson’s disease or Huntington’s Disease, please call 303-720-0443.

If you are a provider interested in attending our education, please visit <https://echocolorado.org/echo/identifying-and-treating-tremor-parkinsons-and-chorea/>. This education series is for medical providers only; this series is not for patients.



University of Colorado Movement Disorders Center Faculty

Drew Kern, MD, MS

Associate Professor of Neurology & Neurosurgery
Interim Head, Movement Disorders Center
Co-director, Advanced Therapies for Movement Disorders

Jeanne Feuerstein, MD

Assistant Professor of Neurology

Emily Forbes, DO, MS

Assistant Professor of Neurology
Director, Huntington's Disease Society of America Center of Excellence

Michelle Fullard, MD, MSCE

Assistant Professor of Neurology
Interim Director, Parkinson's Foundation Center of Excellence
Co-Director, Movement Disorders Research Program

Trevor Hawkins, MD

Assistant Professor of Neurology
Director, Movement Disorders Fellowship Program

Teresa Lee, MD

Instructor of Neurology

Jessica Barr, PA-C

Senior Instructor of Neurology

Dorothy Mathiesen, NP

Instructor of Neurology

Meghan Smith, LCSW

Instructor of Neurology

Isabelle Buard, PhD

Assistant Professor of Neurology
Co-Director, Movement Disorders Research Program

Heather Baer, MD

Associate Professor of Physical Medicine & Rehab

Samantha Holden, MD, MS

Assistant Professor of Neurology, *Neurobehavior*

Christina Vaughan, MD, MHS

Associate Professor of Neurology, *Neuro-palliative*

University of Colorado Movement Disorders Center 2021 Year in Review

67 Educational Talks

- 25 Patient, Care partner, and Families
- 30 Providers
- 12 Medical Learners

19 Publications

4 Fellows Trained

- 2 First-year fellows graduated to their second year
- 2 Second-year fellows who graduated from our fellowship program

51 Clinical Research Trials

- 31 Parkinson's Disease
- 5 Huntington's Disease
- 5 Ataxia
- 5 Dystonia
- 5 Others

Thank you to all of the patients, care partners, families, providers, and community who attended our educational events, participated in research, and trusted us with their clinical care.

We look forward to continuing to serve the Movement Disorders Community in 2022.

We hope you have a safe and wonderful holiday season and start to 2022.

