

On The Move!

The official newsletter for the University of Colorado Movement Disorders Center.

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Meet Stan & Judy Dempsey

Community Partner of 2016 By: Trisha Kendall



Stan is confident, strong, and feeling like himself again.

He also participates in clinical research to help make even more transformative treatments available to those living with Parkinson's disease in the future.

The avid fisherman and lover of the outdoors credits Benzi Kluger, MD, MS; Becky Farley, PhD, MD, PT; Jennifer Anderson, PT, DPT; Stephanie Uszacki, MS, PT, APT, and Noelle Mitchell, SLP for helping him overcome the physical and vocal challenges of Parkinson's disease.

"I'm very happy with my treatment, in particular the LSVT BIG and LOUD programs," he said. "The team there basically saved my life, and I'm more fit now than I was before I had Parkinson's disease."

This world-class care inspired Stan and Judy's giving and advocacy for the center and, Stan notes, that "often small investments yield large returns."

"Giving back is necessary," Stan said. "Philanthropy can be the little stuff sometimes and still be very effective."

Making life-altering care available to more people, regardless of their financial and geographical restraints, is very effective indeed.

The Movement Disorders Center celebrated Stan Dempsey and his wife, Judy, by presenting them with the Center's first annual Community Partner of the Year Award.

For Stan Dempsey and his wife, Judy, giving is all about making a direct and meaningful impact on the lives of others. When it comes to the Movement Disorders Center at the University of Colorado Anschutz Medical Campus, Stan supports the patient assistance program to ensure that people across Colorado have access to the life-changing care that he has received.

"I don't expect to cure Parkinson's disease," he said, "but I do hope to help someone in rural Colorado make it up to their appointment."

He and Judy also supported the launch of the CU Neurology Palliative and Supportive Care Clinic, helping patients and families affected by serious illnesses.

For Stan, the care he receives at the Movement Disorders Center has been truly transformational. Just two years ago, he avoided driving, walked with a cane, was unstable on his feet, and was unclear in his speech.

Today, after lots of hard work and many trips to the Movement Disorders Center,

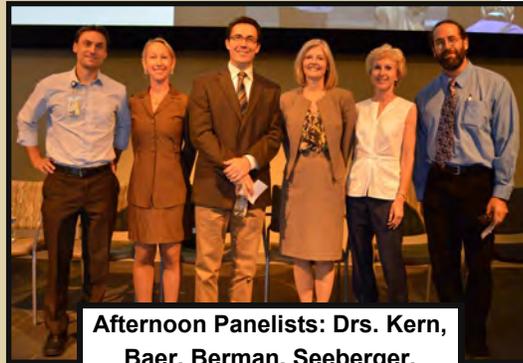
3rd Annual Parkinson Symposium

On Saturday, October 1, 2016, the Movement Disorders Center (MDC) hosted its 3rd Annual Parkinson Disease (PD) Symposium, at the UCHealth Bruce Schreffel Conference Center. Hundreds of patients, family, and caregivers attended the day-long function. Drs. Maureen Leehey, Drew Kern, Olga Klepitskaya, Benzi Kluger, Margaret Schenkman, Brian Berman, Victoria Pelak, Lauren Seeberger, and Heather Baer presented workshops on various topics in PD including cannabis, advanced treatment options, deep brain stimulation surgery, non-motor symptoms, exercise & activity, research advancements, vision, gastrointestinal symptoms, and pain in PD.

MDC Patient Advisor Karen Talcott also spoke on coping with a PD diagnosis. The event program included several audience-engaging group activities including LSVT Global BIG&

LOUD therapies, PWR! Moves exercise, and Rehabilitative Rhythms music therapy. Art as Action presented a dance routine and PD poetry performed by patients. Event videos and presentations can be viewed on the MDC website, ucdenvermovement.org, under the "Resources" tab.

Our 2017 Symposium will be held on September 30.



Afternoon Panelists: Drs. Kern, Baer, Berman, Seeberger, Leehey, and Kluger



Meet the MDC Team: *Whitney Tice, CRNP*

I was born in Chicago, IL and grew up in Mequon, WI. To avoid the frigid WI winters, I travelled out east to earn my BSN in Nursing from Georgetown University in Washington, DC and began my career as an ICU RN.

Five years later, I returned to the east to attend Simmons College and obtain my Masters in Nursing and have begun my second career as a Family Nurse Practitioner at the School of Medicine in the Neurology Department's Movement Disorders Clinic.

Movement is an area in neurology I find most intriguing and I particularly have an interest in Deep Brain Stimulation therapy for people with Parkinson.

I strive to deliver healthcare that is holistic in nature and empower patients to manage their diseases through education and self-awareness.

I am excited to join a group of wonderful providers at the world class University of Colorado.

MDC Pilot Grant Winners

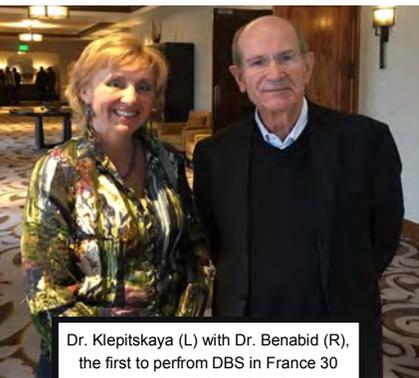
The Movement Disorders Center is excited to support the following Pilot Grant Projects. Congratulations to our winners!

Christopher Groth, MD/Brian Berman, MD, MS Researchers at UCD have identified specific areas of the brain where there is reduced binding of the inhibitory brain chemical, GABA, to its receptors. With funding from the CU MDC, Drs. Groth and Berman will investigate the amount of GABA in these brain areas using a specialized magnetic resonance imaging technique to increase understanding of how reduced inhibition causes dystonia. This knowledge could help design better treatments for dystonia, including dystonia that affects patients with Parkinson disease.

Trevor Hawkins, MD/Lauren Seeberger, MD The aim of the project is to build a database of patients with Spinocerebellar ataxia (SCA). SCA 1,2,3, and 6 are the most common autosomal dominantly inherited cerebellar degenerative diseases and produce imbalance, poor coordination, speech difficulties, and ultimately a wheelchair bound state. Our increased understanding of underlying genetic defects and advances in molecular genetic research have brought us to the threshold of treatment trials. We hope to further clarify the common presentations and genetic markers of the disease to foster further clinical research for these as of yet incurable diseases.

Isabelle Buard/Benzi Kluger, MD, MS In a series of breakthrough studies, Michael Thaut and his colleagues developed Neurologic Music Therapy (NMT) and found it can address many gross motor impairments and improve gait and balance. The idea is that rhythm is the essential component relating music to motor behavior. The mechanism of action is called "rhythmic entrainment" which means one system's motion or signal frequency alters the frequency of another system. The effect of NMT has not been investigated yet. Based on literature and preliminary studies, Ms. Baud and Dr. Kluger will test the efficacy of NMT in comparison to Occupational Therapy as standards of care in adults.

Advances in DBS by Olga Klepitskaya, MD



Dr. Klepitskaya (L) with Dr. Benabid (R), the first to perform DBS in France 30 years ago & recipient of the Lasker-DeBaker award in biomedical science.

Deep Brain Stimulation (DBS) is a surgical treatment during which very thin electrodes are implanted into deep structures of the brain to apply constant, high frequency electrical stimulation that normalizes function of these structures and, thus, improves symptoms of the disease. DBS is a proven effective treatment for carefully selected patients with Parkinson disease (PD), Essential tremor, and Dystonia. DBS has been used for almost 30 years and there are about 150,000 patients around the world who live with implanted DBS. Recently, there have been some exciting developments in this area.

First is the change in the recommended timing of DBS surgery during the course of PD. DBS is indicated for advanced PD when medications no longer provide sustained reliable improvement. In the past, DBS was reserved for very advanced cases, but recent studies demonstrated the benefits of earlier DBS. Currently, DBS surgery is recommended to be considered as early as four years from the onset of PD and/or within one year from the time response to medication becomes inconsistent. Studies of even earlier DBS are currently underway and preliminary data are promising.

Second, while DBS electrode implantation is typically done while patients are awake, a new "asleep" technique recently became available for selected patients under general anesthesia. In the Rocky Mountain Region, *the University of Colorado is the only center where MRI-guided "asleep" surgery is performed.*

Next, in the past, patients with implanted DBS were not able to receive MRI scans. Now, MRI scans can be done for patients with a Medtronic DBS system that must satisfy strict criteria. Anybody with implanted DBS who needs an MRI scan must consult a DBS clinician to check if the system is compatible with MRI.

Finally, a new DBS system designed by St Jude Medical became available last year. This system provides additional opportunities, including the ability to direct or "steer" electricity within the target in the brain to maximize benefits and minimize the effects of stimulation.

- * We will expand on all of these and other DBS developments in our future newsletter issues.
- * If you are interested in knowing more, we invite you to attend our upcoming patient education events, sign up for our bi-monthly classes in the treatments of advanced PD, or schedule an appointment with one of our DBS experts - Drs. Klepitskaya, Seeberger, or Kern.

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
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303-724-9146
giving.cu.edu/parkinsons



New DBS equipment from St. Jude Medical.
Courtesy of www.sjm.com

Questions & Answers

Questions submitted by patients at the 3rd Annual Parkinson Disease Symposium and answered by our Movement Disorders specialists.

- Q. Is the MDC moving toward becoming a Parkinson Center of Excellence (COE)?**
A. Yes! The MDC has worked hard to meet and maintain the standards of a Parkinson disease COE. We are currently on a waiting list to apply for COE status.
- Q. How does someone with PD become a patient of the Movement Disorders Center?**
A. Please call 720-848-2080 to schedule an appointment. Then have your current provider fax a referral and any recent notes and

- results to 720-848-0117.
- Q. Do most ophthalmologists know about and are able to prescribe prism lenses for reading glasses?**
A. Yes, most ophthalmologists are able to prescribe prism lenses, but it's always a good idea to call the ophthalmologist's office and ask before scheduling an appointment.
- Q. A person with PD repeatedly places an object more than half off of a flat surface and is oblivious to the spills and broken dishes that result. Is this PD Vision related?**
A. In addition to causing slowed movements, Parkinson disease (PD) can cause reductions in the magnitude of movements or hypometria. Patients with PD often have hypometria of handwriting,

- which we refer to as micrographia (small writing). Hypometria is not thought to be related to vision changes in PD, but rather may stem from changes in a patient's ability to generate and maintain the force and/or speed needed to perform the movement accurately.
- Q. How do I deal with stress that comes with a new PD Diagnosis?**
A. The CU Movement Disorders Center offers a special small group session to help newly diagnosed people with Parkinson adjust to their diagnosis and learn more about it. (See the back of this newsletter for more information.) The Parkinson Association of the Rockies is also a great resource to help locate nearby support groups.

Parkinson Disease Small Group Educational Session

The Movement Disorders Center at University of Colorado Denver is excited to offer two small group education forums for people living with Parkinson disease (PD). The **Newly Diagnosed Group** is facilitated by a PD clinician and a person living well with PD. The **Advanced PD Group** focuses on current, available treatment strategies for advanced PD, including pharmacological, surgical, and research.

Both educational sessions include a brief presentation from a specialist in PD, an open discussion in a small group setting in order to address your specific questions and concerns, and handouts for support and resources in your local community.

When:

Second Thursday of the month from 1 pm – 4 pm, alternating months

Where:

University of Colorado Hospital, Anschutz Outpatient Pavilion, Department of Neurosciences
4th floor conference room

To register:

Visit <https://neurologyevent.ucdenver.edu/mdc> or Contact Alan Hall at 720-848-8761.

Fee:

\$20 covers person with PD and support partner, light snacks, and resource materials.

Additional information:

This event is open to the community. You do not have to be a patient at UCH to join. *Sessions may be canceled if fewer than 3 participants sign up for a particular date.*

**We're always looking for patients interested in research.
We're currently looking for the following patients.**

- Patients with Parkinson disease who have problems with thinking or memory
- Patients experiencing excessive drooling
- Patients who have recently diagnosed, early stage Parkinson disease
- Patients with Parkinson disease and a wearing off of medication or dyskinesias
- Patients with Parkinson disease and an interest in a brain imaging study
- Patients with Parkinson disease and needs for supportive care or challenging symptoms
- Patients with dystonia or blephospasm diagnosis
- Patients who have cervical dystonia and an interest in a brain imaging study
- Patients with Huntington's disease
- Patients with Essential Tremor, Progressive Supranuclear Palsy, Corticobasal Degeneration, or Multiple Systems Atrophy
- Patients with a diagnosis of ataxia
- Patients who have Parkinson disease with tremor and an interest in medical marijuana
- Patients who have dementia and an interest in music therapy

For more information or to get involved with our research, please contact our Research Recruitment Specialist.

303-724-4644

Stay Informed

- Join our mailing list and receive updates on events, research, and more. Visit ucdenvermovement.org, click on "Resources" and then "Subscribe."
- For upcoming events, classes, and other resources, visit ucdenvermovement.org and click on the

Mark Your Calendars!

Our 4th Annual Parkinson Symposium will be held on Sat., Sept. 30, 2017
Please check our website for more details in the coming months.