University of Colorado Achieves Designation of HDSA Center of Excellence for Huntington’s Disease

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In February 2016 the Huntington Society of America (HDSA), the leading patient advocacy organization for Huntington’s disease (HD) in the United States, selected the University of Colorado Movement Disorders Center as one of their Centers of Excellence for research and care of those with Huntington’s disease. Huntington’s disease (HD) is an inherited neurological disorder that may be passed on from generation to generation. Each child of a person with HD has a 50% chance of inheriting the fully penetrant disease gene. If the disease gene is inherited then that person will show signs of the illness in their lifetime. Symptoms of the illness can include involuntary body movements, slurred speech, balance problems, as well as changes in behaviors and thinking. People are typically affected in their 30s and 40s but there is a rare childhood version from a large dose of the gene mutation.

Families of those with HD often have struggles related to the psychiatric problems and patients are sometimes misunderstood by others to have been drinking or doing drugs because of their unusual movements and moods. Many are embarrassed to go out because of the uncontrolled movements of their limbs and faces. Families live with the worry of unpredictable behavior and unknown futures for themselves and their children who may inherit the disease. It is truly a family disease that needs special expertise and care for all members.

The HDSA Center of Excellence designation recognizes the clinical research being done at the University of Colorado as well the high level of care for these families. The goal of the HDSA is to raise standards of comprehensive care for HD by supporting growth and development of programs through its grants. The funding has helped the University of Colorado to form a multidisciplinary clinic care model in HD. Patients and families are seen by a neurologist, nursing, social work and spiritual counselor at present. Future plans are to add psychiatry and genetics with growth of the clinic and to provide telemedicine outreach in rural parts of the state through generous donations from local philanthropists.

Currently, we are conducting two nationwide trials in HD and have been asked to join a global initiative for enrolling families with HD into an international registry. We look forward to increasing awareness in HD and providing expert clinical care and expanding our research efforts in Huntington’s disease.

For more information on HD research at the CU MDC, contact Nicola Haakonsen 303-724-4644
Nicola Haakonsen is the new research recruitment specialist for the Department of Neurology at the University of Colorado School of Medicine. Nicola previously worked as a clinical research coordinator for the MS team within the department and now focuses on clinical research recruitment efforts, strategies and patient education for the entire Department of Neurology. She graduated from Oslo University College, Norway, with a Bachelor in Radiography and a Bachelor of Science in Biology from Metropolitan State University of Denver.

Nicola is excited about her new role within the department and is eager to concentrate her efforts on clinical research recruitment and looks forward to working with the whole Department of Neurology.

Nicola is always happy to speak with patients and healthy volunteers interested in participating in clinical research studies and can be reached at the department's research recruitment line at (303) 724-4644.

The term “dystonia” was first coined in 1911 by the German neurologist Hermann Oppenheim who surmised that the core defect in a group of individuals with an unusual motor disorder was abnormal muscle tone. While the key feature in dystonia is no longer thought to be abnormal muscle tone, how to properly define the disorder remains a subject of debate. In 2013, an international consensus committee sought to revise the definition of dystonia and address limitations of previously proposed definitions. Dystonia is now defined as a “movement disorder characterized by sustained or intermittent muscle contractions causing abnormal, often repetitive, movements, postures, or both.” Dystonic movements are typically patterned, twisting, and may be tremulous. Unique clinical features of dystonia that help distinguish it from other movement disorders were also added to the definition including that dystonia “is often initiated or worsened by voluntary action and associated with overflow muscle activation.” Movement disorder specialists often use the presence of these unique motor features to help diagnose the disorder.

Due to an increasing understanding of its diverse causes or etiologies, as well as a growing appreciation of its varied presentations, a new classification system for dystonia was also recently proposed by an international consensus committee. This new classification system splits dystonia into two parts or axes: 1) clinical characteristics such as age of onset, body parts affected, changes over time, and whether dystonia is isolated or has associated neurological and psychiatric features, and 2) etiology including whether the dystonia is inherited, acquired or sporadic, and whether the dystonia is associated with a degenerative disorder such as Parkinson’s disease. This revised classification system should improve our ability to recognize and diagnose dystonia, and also aid researchers in better identifying the biological mechanisms that cause dystonia so that more effective treatments or a cure can be developed.

On June 4, 2016 the Movement Disorders Center team traveled to Pueblo for the 2nd annual Recent Advances in Parkinson Disease and Essential Tremor conference. With nearly 150 participants, the event was received with overwhelming appreciation. Drs. Olga Klepitskaya, Maureen Leehey, and Benzi Kluger presented novel treatments, the benefits of palliative care for patients and their care partners, and the fundamentals of Parkinson Disease and Essential Tremor. Vincent Nguyen, PT of St. Mary-Corwin Medical Center joined the team to lead interactive physical therapy breaks. Stay tuned for an announcement about the next regional event.

*Left: Dr. Olga Klepitskaya presenting at the Recent Advances in PD and ET event*
Complementary and Alternative Medicine (CAM) refers to health practices that fall outside of standard Western medicine and includes a wide range of therapies including herbal supplements, physical treatments (e.g. massage and chiropractors), diets, and acupuncture. Despite the fact that the majority of people living with Parkinson’s disease (PD) report using one or more forms of CAM there is very little data on the safety and effectiveness of these treatments to guide patients and clinicians.

Fatigue is a common and difficult to treat symptom in PD. As there were some reports of acupuncture helping fatigue in cancer patients and chronic fatigue syndrome, Dr. Kluger and colleagues at the University of Colorado successfully applied to the Michael J. Fox Foundation for a grant to conduct a double-blind placebo controlled trial of acupuncture for PD-related fatigue. Over 90 people with PD-related fatigue in the Front Range participated in this trial. This was also one of the first trials where the University partnered with the Parkinson’s Association of the Rockies (PAR) to meet its recruitment goals.

The results of this trial were reported in the March 2016 edition of the journal Movement Disorders. There were three major findings from this study. First, as has been shown in prior studies, acupuncture was extremely safe with no major side effects noted. Second, over 60% of participants reported a noticeable benefit in their fatigue. Lastly, there was no difference in benefit between participants receiving real or placebo acupuncture treatments. This suggests that acupuncture may work through either placebo effect or other non-specific treatment effects. In other words, the acupuncture procedure (relaxing, focusing on the body, interactions with acupuncturist) may be more important than where the needles are placed. Interestingly, many people in the placebo group went on to get real acupuncture after the study was complete to maintain their benefits.

Given that acupuncture was safe and effective for many patients we continue to recommend this option to interested patients. We are currently analyzing our data to better understand which patients were most likely to respond and to better understand how the placebo effect works in PD.

References:


BEBRF Symposium | August 6, 2016

On August 6, 2016, the CU MDC hosted the annual Benign Essential Blepharospasm Research Foundation’s patient symposium on the University of Colorado Anschutz Medical Campus. Dr. Brian Berman served as program director and spoke about imaging research in blepharospasm. Other presenters at the symposium consisted of an all-star lineup of renowned experts in the field of blepharospasm and Meige syndrome including Dr. Cynthia Comella who gave an overview of neurological eye disorders, Dr. Stanley Fahn who spoke about the epidemiology and genetics of blepharospasm, Dr. Victoria Pelak who spoke on the relationship between blepharospasm and dry eye, Dr. Mark Hallett who spoke on the pathophysiology of dystonia, Dr. Joseph Jankovic who covered the medical treatments for blepharospasm, and Dr. Richard Anderson who talked about the surgical treatments for blepharospasm. This informative and educational event drew over 120 participants, and the reviews have been overwhelmingly positive.
We are looking for the following types of patients interested in research

| Patients with Parkinson’s disease interested in a brain imaging study |
| Patients with cervical dystonia interested in a brain imaging study |
| Patients with any form of dystonia interested in a genetics study |
| Patients and Caregivers with Parkinson’s disease, Multiple Systems Atrophy, Progressive Supranuclear Palsy, Dementia with Lewy Bodies, or Corticobasal Degeneration who are struggling with nonmotor symptoms, social support or emotional issues |
| Patients with Parkinson’s disease and not on medications (or only on monoamine oxidase-B inhibitors) |
| Patients with Huntington disease |
| Patients with blepharospasm and hemifacial spasm |
| Patients with Parkinson’s disease and interested in a study on fatigue and balance |
| Patients with orthostatic hypotension (sudden decrease in blood pressure) |
| Patients with Parkinson’s disease and problems with thinking or memory |
| Patients with drooling from any cause |
| Patients with recently diagnosed, early stage Parkinson’s disease |
| Patients with Parkinson’s disease and have medications wearing off (medication pump study) |

For more information on currently enrolling research studies at the CU MDC, contact:

Nicola Haakonsen
Nicola.Haakonsen@ucdenver.edu
or call our research recruitment line: 303-724-4644

Upcoming MDC Events

3rd Annual Parkinson’s Disease Symposium | October 1, 2016
For more information, visit http://PDeventRSVP.ucdenvermovement.org

The CU Movement Disorders Center (MDC) 
Interdisciplinary Clinic for Parkinson’s Disease (PD)

The Interdisciplinary Clinic at the MDC was specifically designed for patients with PD. This program involves an annual, 2-hour visit, during which patients get a standardized set of evaluations by physical therapists, occupational therapists, speech therapists and a movement disorder neurologist. This program consolidates these into one convenient visit, and allows both providers and patients to more accurately track progression, collect data, and most importantly, provide comprehensive care to our patients.

For more information, contact Jessica Barr, PA 720-848-2080.

GET INVOLVED!
The research being conducted by the MDC team at CU Anschutz Medical Campus is essential to developing tomorrow’s treatments and care. These advances hold promise to vastly improve the lives of patients and families. If you would like to learn more about research at the MDC, or how you can help speed these efforts, contact Carrie Radant Flynn at Carrie.Radant@ucdenver.edu or call 303-724-9146.

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