

CCP LEADERS SHARE THEIR EXPERTISE AT NATIONAL CONFERENCE



The American Academy of Cerebral Palsy and Developmental Medicine (AACPD), in conjunction with the International Alliance of Academies of Childhood Disability, held their first combined conference in Anaheim, California in September. AACPD's mission is to provide education for professionals and to promote excellence in research and services benefiting people with childhood-onset disabilities. The Center for Cerebral Palsy at UCLA/OIC (CCP) is a leader in AACPD activities and served as the local host of the conference, which drew more than 1,300 attendees from 72 countries. At the meeting, Dr. William Oppenheim served as AACPD Board Historian. Dr. Rachel Thompson served as Chair of the Awards Committee and taught a hands-on orthopaedic course for professional attendees. Dr. Eileen Fowler organized a parent panel in collaboration with the Tarjan Center at UCLA about the influence of culture on healthcare. Marcia Greenberg served as Chair of the International Committee and spoke in two seminars about her international professional training. Graduate student Andy Vuong, who received a student scholarship to present at the conference, shared the CCP's cerebral palsy brain imaging research.

The Community Forum, an educational event for individuals with CP and their families, was held on the final day, and many CCP patients and families attended. Funding from the CCP, Orthopaedic Institute for Children, the Shapiro Family, and United Cerebral Palsy of Los Angeles, Ventura & Santa Barbara Counties helped to make this a free event. A team of volunteers from the CCP entertained the children with face painting and wheelchair basketball.

INTRODUCING DR. ALLEN S. CHEN



In January 2019, the CCP welcomed Allen S. Chen, M.D., M.P.H., to the team. Dr. Chen serves as Assistant Professor, UCLA Department of Orthopaedic Surgery; Interventional Physiatrist, UCLA Spine Center; Co-Director, Accreditation Council for Graduate Medical Education (ACGME) pain fellowship, UCLA/West Los Angeles Veterans Administration Hospital; and the Director of Adult Cerebral Palsy at the CCP. A double-boarded physiatrist specializing in nonoperative and minimally invasive treatments of the spine, Dr. Chen specializes in treating acute and chronic spine and musculoskeletal conditions without using opiates. In addition, he specializes in the rehabilitation of adults with cerebral palsy. *(continued on next page)*

Dr. Chen graduated cum laude from Harvard University, earned his M.P.H. degree at the UCLA Fielding School of Public Health, and his M.D. degree at New York University School of Medicine. He completed his residency at the University of Washington Medical Center and his pain fellowship at the UCLA/West LA VA Medical Center. Dr. Chen comes to UCLA from Columbia University, where was the chief of Ambulatory Spine at the Ochsner Spine Hospital at New York-Presbyterian and played a central role in building a large multidisciplinary spine hospital. He lectures nationally and internationally, and has published numerous peer-reviewed articles and chapters, including in the prestigious *New England Journal of Medicine*. Dr. Chen is a sought-after expert, who has been interviewed by many media outlets, including the *HuffPost*, *Reuters*, *The New Yorker*, *The Boston Globe*, *Refinery29*, *Readers Digest*, and *WNYC Public Radio*. The CCP team continues to expand to optimize its service to the community. During 2018-19, the Center experienced a 33 percent increase in visits. We are pleased that Dr. Chen will help the Center serve new patients and meet existing clinical needs.

DEPUTY SECRETARY ERIC HARGAN VISITS UCLA



Deputy Secretary Eric Hargan (center) with CCP faculty, staff, and trainees; and Edward Heidig, HHS Regional Director, Region 9 (far right).

their collaborative efforts to grow future leaders in healthcare devoted to working with and advocating for people with disabilities.

The DHHS is a major funder of the Tarjan Center—a university center for excellence in disabilities education, research, and service, and a catalyst for collaboration, innovation, and systems change to advance the self-determination and inclusion of all people with disabilities. As part of its mission, the Tarjan Center helps to build a pipeline of specialists skilled at addressing the needs of people with developmental disabilities, including CP. Trainees gain knowledge and experience that mirror the types of issues they will face in practice, including the application of evidence-based clinical care; interdisciplinary team decision-making; sensitivity to the needs and preferences of individuals with developmental disabilities; and awareness of the impact of cultural differences in practice, policy, and research. They also learn to understand the lives of people with disabilities, the barriers and bias they face, and effective ways to advocate on their behalf.

In the course of his tour, Hargan learned about the interdisciplinary training offered to professionals interested in working with CP patients; medical students, residents, and fellows; physical therapy students; and undergraduates exploring careers in CP care. Currently, trainees are involved in: 1) the clinical programs, including gait analysis for children with CP and clinical trials evaluation; 2) Camp Leg Power, an intensive physical therapy intervention for children with CP that utilizes specifically designed exercises and play activities to promote selective motor control using advanced technologies, such as an ankle robot, knee exercise machine, and gaming technology; and 3) transforming reproductive healthcare for women with disabilities by developing a model OB/GYN clinic for women with CP that will be evaluated and designed for replication beyond UCLA.

The many strengths of the CCP include its proximity to a wide range of UCLA resources, the cross pollination of ideas between different specialties, and collaborations with other programs, such as the Tarjan Center. These resources and partnerships translate into the most advanced care for people with CP and further investment in patients and their caregivers now and in the future.

NEW GIFT TO HONOR CAREER OF DR. WILLIAM OPPENHEIM



William L. Oppenheim, M.D., Director of the UCLA/OIC Center for Cerebral Palsy (CCP) and Margaret Holden Jones Kanaar, M.D. Chair in Cerebral Palsy, and his wife Patricia have recently made a leadership gift toward the establishment of an endowed chair in pediatric orthopedics that will support a faculty member dedicated to treating CP and other neuromuscular disorders.

An internationally recognized expert in this field, Dr. Oppenheim has dedicated his career of more than 40 years to improving patient care and the treatment of CP and other musculoskeletal disorders. Having joined the UCLA Department of Orthopaedic Surgery in 1979, he first founded the Pediatric Orthopaedic Program. As he followed his patients from

childhood into adulthood, he saw the vital need for improved transitional care, particularly because many people with CP lose function and develop musculoskeletal pain as they age. In 1995, he established the CCP at UCLA—a visionary model for interdisciplinary care across the lifespan. It remains one of the first and only such clinics in the country. “Our team quickly recognized the need for such care, made a list of what would be ideal, and then, somewhat naively, embarked on what we felt we could accomplish with our limited resources. Fortunately, we had well motivated colleagues, families, and donors, who shared the vision. And we were soon joined by others who also either had a need or saw the opportunity. Things do not change overnight, but they never change unless you have the courage to embark on the journey.”

Under Dr. Oppenheim’s leadership, the CCP has pioneered advanced treatments for CP, including baclofen pumps, Botox injections, and deep brain stimulation, along with offering traditional orthopaedics and physical therapy. The UCLA SCALE assessment for the evaluation of selective motor control, developed by the CCP, is used all over the world and has been translated into several languages. Dr. Oppenheim advocates for the needs of people with CP through his active engagement with local and global communities.

The establishment of the endowed chair has been boosted by generous support from Peter, Ralph, Shirley, and Alison Shapiro, as well as a group of dedicated patients, colleagues, and friends. Additionally, funding has been awarded from the University of California System’s Presidential Match for Endowed Chairs, a special program that concluded in June 2019 to spur private giving to establish endowed chairs. The William and Patricia Oppenheim Presidential Chair in Pediatric Orthopaedics will enable UCLA physician-scientists to continue improving treatment, advancing basic and translational research, and training the next generation of leaders in orthopaedics who will provide optimal patient care. “Patty and I are most pleased to contribute in this manner in an effort to find new treatments and prevention strategies. We want to attract the brightest and best to improve the quality of life for these patients and families, whom otherwise might be left behind.”

As Dr. Oppenheim approaches his retirement in June 2020, Rachel M. Thompson, M.D., current Associate Director of the CCP, is preparing to carry the torch.

PATIENT PROFILE: A PASSIONATE ADVOCATE FOR PEOPLE WITH DISABILITIES



Deaka McClain is a passionate advocate for people with disabilities. She serves as Chair of the Citizen’s Advisory Commission on Disabilities for the City of Long Beach and strives to be a voice for Americans with disabilities both locally and nationally. People living with disabilities are a significant voting constituency in the United States—according to the CDC, one in four adults in the U.S. (61 million people) live with a disability—yet, few politicians speak to their needs. McClain is committed to changing that.

She did not envision herself in the political arena when she was a child. Instead, McClain dreamed of being a singer or a district attorney, though she was teased and bullied in school because of her cerebral palsy (CP). For a long time she suffered in silence and would not complain, even to her parents. Then, one day in sixth grade, McClain finally challenged



one of her tormentors, standing up to confront her classmate on her own and winning her respect. It was the beginning of her journey as an advocate for the fair treatment of people with disabilities, though she did not think of that at the time.

When McClain was a student at Los Angeles Harbor College (LAHC), one of her classes was held on the second floor of a building with no elevator. McClain raised the issue with the Disabled Student Services Office and the class was relocated to a room on the first floor. Her experience was a catalyst: McClain kept thinking about the bigger picture and took her voice to the student government, where she began drawing attention to the need for other accommodations and resources for students like her on campus and beyond. McClain also started a club to support people with disabilities and made a name for herself through her tireless advocacy work and commitment to engaging others and increasing accessibility for all.

McClain's work caught the attention of faculty, who encouraged her efforts, and before graduating from LAHC, she collaborated with a local newspaper reporter to highlight an issue near campus: an unpaved sidewalk between a bus stop and the school created an impediment to safe access for people

with disabilities. As a result of her outreach, the street was paved.

McClain continued to follow her passion at Cal State Long Beach, where she completed her B.A. degree in Journalism and earned her Master's degree in Public Administration, despite her dyslexia and the limitations imposed by her CP. While in school, McClain advocated to enhance a master plan for accessibility and secured funds for a portable ramp for use at the student union, where both student and community events are held. She also served in student government as Secretary of Disability Affairs, representing 3,500 students. McClain says, "People with disabilities should be part of the conversation. We should not be an afterthought, but a forethought. When decisions are being made, we should be at the table."

She intends to work toward these goals through her political career. Well versed in the policies of the Americans With Disabilities Act, McClain has done her homework, gathering information and keeping up with statistics; she is committed to seeing both sides of a debate in order to achieve meaningful changes and secure equal opportunities for Americans with disabilities. "I'm just doing what I do," she says about her drive to make positive change that has impressed and inspired her professors and peers over the years.

McClain came to the UCLA CCP as an adult patient and has found it to be strikingly superior to other places where she has received treatment. The doctors, she says, have been very honest with her, they respect her wishes, go out of their way to help her, and treat her like a family member. She credits the care she receives at UCLA in supporting her ability to advocate and engage with the community.

As an academic medical center, UCLA is unique in its focus on not only clinical care, but also community outreach. Thanks to clinical coordinator Marcia Greenberg, M.S., P.T., and associate director Rachel M. Thompson, M.D., McClain says she has become even more involved and now sits on the Tarjan Center Advisory Committee at UCLA, where she continues to serve as an effective voice for others.

Philanthropic support transforms the patient experience and accelerates the clinical, research, and educational endeavors of the Center for Cerebral Palsy at UCLA | OIC. For more information, please contact UCLA Health Sciences, Annual Giving at (310) 206-6484 or hsdannualgiving@support.ucla.edu.