

## HERE TO SERVE YOU DURING COVID-19 AND BEYOND

The Center for Cerebral Palsy at UCLA | OIC (CCP) remains open and ready to serve you during the COVID-19 pandemic and beyond. At UCLA Health, our leadership is engaged in addressing the demands of COVID-19, while sustaining safe operations for our entire community of patients. In accordance with systemwide guidelines, the CCP is following all UCLA protocols to ensure a safe environment, such as screening policies, universal masking, and social distancing. We are proud to continue offering in-person care as well as telemedicine options for orthopaedics and physical therapy at UCLA and OIC.

For the most up-to-date resources and details on UCLA's ongoing response to the novel coronavirus, visit the [COVID-19 web page](#).

For any questions about appointments and care at the CCP, please contact us directly at (310) 825-5858 or visit our webpage at [www.uclahealth.org/ccp](http://www.uclahealth.org/ccp). It is our privilege to partner with you, especially during this year.

## THE CCP WELCOMES DR. KRISTEN STEARNS-REIDER



In July 2020, the CCP welcomed Kristen Stearns-Reider, Ph.D., P.T., to the team. Dr. Stearns-Reider serves as adjunct assistant professor in the Department of Orthopaedic Surgery at the David Geffen School of Medicine at UCLA. She received her M.S. in physical therapy from the University of California, San Francisco, where she focused on improving the quality of life of individuals with neuromuscular and musculoskeletal disorders. Dr. Stearns-Reider received her Ph.D. in biokinesiology from the University of Southern California. As part of her doctoral training, she designed and implemented a training program aimed at improving hip muscle performance and discovered that this program improved movement patterns consistent with a decreased risk of anterior cruciate ligament (ACL) injury. Following her Ph.D., she completed a two-year postdoctoral fellowship at the University of Pittsburgh investigating how age-related changes in the extracellular matrix (ECM)—the non-contractile portion of muscle—contribute to impaired skeletal muscle regeneration. She then completed a second postdoctoral fellowship at UCLA studying the mechanisms underlying failed muscle regeneration in Duchenne muscular dystrophy with a focus on the effects of excess ECM deposition, or fibrosis, on muscle stem cell function.

In this next phase of her career, in collaboration with CCP Director Rachel Thompson, M.D., Dr. Stearns-Reider will build on her prior research experience to investigate muscle pathology and patient function in cerebral palsy (CP). Her long-term goal is to combine the basic science experience gained during her postdoctoral fellowships with her clinical training and expertise in biomechanics to conduct translational research investigating the mechanisms underlying muscle dysfunction and fibrosis in CP. Findings from her research will support the development of improved therapeutic strategies to address muscle contractures and patient function in CP and other musculoskeletal disorders. This work advances the Center's vision for discovery and excellence.

## RESEARCH HIGHLIGHT: UCLA STUDY OF INFANT AND TODDLER LEG MOVEMENT



Eileen Fowler, Ph.D., P.T., director of the Kameron Gait and Motion Analysis Laboratory and Peter William Shapiro Chair for the Center for Cerebral Palsy, and Loretta Staudt, M.S., P.T., research physical therapist, are conducting a study of infant and toddler leg movement to develop an observational assessment of motor control for infants and toddlers. Infants at risk for having cerebral palsy (CP) can now be identified as early as 3 months of age providing opportunity for very early intervention. Leg movement of babies who are typically developing will be compared to those who have CP or are at risk for CP. Funded by the Cerebral Palsy Foundation, this study will help to design effective therapies targeted toward a crucial time when motor systems are undergoing rapid development.

Participation in this research study is voluntary. Participation or non-participation does not affect enrollment or benefits that you or your child/ward receive at UCLA. The study is currently open to infants and toddlers ages 3 months up to 4 years, including typically developing infants and toddlers, infants at risk for motor delay, and infants and toddlers with a diagnosis of cerebral palsy with the ability to tolerate positioning and play in various positions. Parent and child participation in a video recorded play session via teleconference is involved. For more information about joining the study, please [click here](#).

## REFLECTIONS FROM DIRECTOR EMERITUS DR. WILLIAM OPPENHEIM



William L. Oppenheim, M.D., Margaret Holden Jones Kanaar, M.D. Chair in Cerebral Palsy, Distinguished Research Professor, Cerebral Palsy and Orthopedic Surgery, and Director Emeritus of the Center for Cerebral Palsy at UCLA | OIC (CCP), transitioned to emeritus status in June 2020, following more than 40 years of work dedicated to improving patient care and the treatment of CP and other musculoskeletal disorders. We sat down with him to gather his reflections on his tenured career.

### Looking back at your long career and your establishment of the CCP in 1995, are there any aspects of your work as director that make you especially proud?

I am proud of the team that we assembled, and the family-friendly and close working relationships that were created. We allowed our group the freedom to work four days a week so that they could have more time with their young families. As a result, all of the employees became long-term employees over nearly two decades, limiting turnover and sustaining expertise as we all grew together. They were exceptionally productive, all of them achieving national and international prominence in their own

fields, positively impacting our working relationships with others, and impressing our partners who stepped up to support our mission. We became family before family-friendly workplaces came into vogue, leading the way for many others.

I am particularly proud of our team's performance during fiscal challenges. Our members have helped with fundraising and made selfless contributions. Both the Department of Orthopedics and the Orthopedic Institute for Children, as well as our development team, deserve credit for their continuing support along with all of our donors. It has been a team story in every sense and at every level. After begging and borrowing for many years to get basic resources for providing multidisciplinary care, we now have the ability to do long-term and strategic planning, in order to take our program to the next level. One example is our new program in muscle physiology headed by Kristin Stearns-Reider, Ph.D., and Rachel Thompson, M.D.

### What advice would you give to people working to advocate for people with CP?

CP affects nearly half a percent of the population. Remind people that if you do not know of someone in your immediate family or a neighbor's family that is affected, that is unusual. CP can emerge in any generation. It is really everyone's issue. Advocating for the needs of children and adults with CP to legislators and decision-makers is critical. This can be achieved by joining with like-minded individuals and organizations that address similar issues. There is strength in numbers. Look to the work of United Cerebral Palsy of Los Angeles, Ventura and Santa Barbara Counties ([www.ucpla.org/about-us](http://www.ucpla.org/about-us)) and the Cerebral Palsy Foundation ([www.yourcpf.org](http://www.yourcpf.org)) as models.

### Looking ahead, what are you excited about for the future of UCLA's CCP?

We have expanded our professional roster to include physical medicine and rehabilitation, so we can maintain our ability to see patients throughout the lifespan. We were the first clinic in California to offer a lifespan clinic. Dr. Rachel Thompson, who is taking my place, is just terrific. She has added to the number of patients seen and performed new approaches and skills. Her work with Dr. Stearns-Reider developed a UCLA-based basic science program investigating the associated muscle physiology and altered ultrastructure present in CP, an area largely neglected in this population. This will have very important long- and short-term impacts as we move the field forward and expand the available treatments.

### What about CP research and treatment? Are there areas in which you anticipate new advances in years to come?

There are continuing advances in prevention, monitoring, and treatment. Registries utilizing sophisticated computer algorithms combine patients into state, national, and international registries to better track clinical issues in large populations of people with CP. A recent study found that 14% of cerebral palsy cases are linked to a person's genes, and these cases are becoming more amenable to both pre- and post-natal recognition and treatment. Medical and surgical treatments are continually being refined and made safer and more readily available. Society at large is more inclusive of people with disabilities. Many home building codes now take disability into account allowing for future wheelchair mobility, for example. As we have often said, there are two types of individuals, those who are presently disabled, and those who will be disabled. Keeping the big picture in mind will help our aging populations cope with disability issues they thought applied only to childhood disability. We have made a lot of progress, but we can and will do even better in the future.

## What have been some highlights of your retirement?

I have had exceptional cooperation from my department and my group in smoothing my way into retirement. First, after looking for someone well versed in CP, disability, neuromuscular diseases, and instrumented gait analysis, we were very fortunate to locate and recruit Dr. Rachel Thompson. This allowed me to gradually reduce my patient care responsibilities over the past year. My use of Zoom has increased, and my committee work and attendance at academic teaching conferences has continued. I am officially on part-time recall, so I can keep in touch, and continue with teaching conferences, hopefully without getting in the way. Very few people have such an opportunity. Finally, in cooperation with the UC Office of the President, we established the William and Patricia Oppenheim Presidential Chair in Pediatric Orthopaedics. This recognizes not just my contribution, but also recognizes our entire program and team efforts to advance the field and further CP and disability issues research and teaching at UCLA.

## COMMUNITY CORNER: SCOOPS OF INCLUSION



The CCP team is proud to know 9-year-old twins Scarlett and Henry, two stars of Scoops of Inclusion by Infinite Flow Dance, a short film and online learning platform celebrating diversity and empowering kids to take an active role in making the world a more inclusive place. Scarlett, who has CP, is a patient of Dr. Rachel Thompson.

In the film, the twins take a tour of their new school, the School of Us, a radically inclusive school. They visit classrooms and meet their new teachers, and an adventure ensues. Made for kids, schools, and families, Scoops of Inclusion is led by multi-racial dancers with and without disabilities, is available at no cost, and comes with lesson plans and worksheets suitable for school curricula or family activities. Scoops of Inclusion aims to entertain while sharing valuable lessons on disability inclusion, accessibility, diversity, identity, allyship, and empathy.

CCP partner Keri Ferguson, mom to Henry and Scarlett, said of the project, “we are extremely proud of the kids’ involvement and performance in Scoops of Inclusion. This story was loosely inspired by some of their real-life experiences and it speaks to the value of ALL people. Scoops of Inclusion is purposeful, informative and fun!” Scoops of Inclusion premiered in October 2020 and includes open captioning, ASL interpretation and audio description. To view the short film, please visit [www.scoopsofinclusion.org](http://www.scoopsofinclusion.org).

## SPOTLIGHT ON ADVOCACY: JUNE ISAACSON KAILES



A leader and pioneer, June Isaacson Kailes has been at the forefront of progress for decades, advocating for people with disabilities and driving systemic change. Inspired during college by antiwar protests, the women’s movement, and civil rights movement, Kailes sought to pursue barrier removal and advance equal rights for people with disabilities and has been involved in advocacy work ever since.

“Seeing so many inequities ignites a fire in the belly that translates into the fuel to stick with something,” says Kailes. “Systemic change is incremental.” With a master’s degree in social work and long-serving as a disability policy consultant, Kailes continues to drive change, moving the needle in emergency planning, response and recovery, as well as healthcare policy and access at the local, national and international levels. She has worked with FEMA, the Centers for Disease Control and the United States Departments of Homeland Security and Health and Human Services, among others.

Kailes is the author of two after action reports, “Southern California Wildfires After Action Report” and “Getting It Wrong: An Indictment with a Blueprint for Getting it Right, Disability Rights, Obligations and Responsibilities Before, During and After Disasters,” that paved the way for substantial changes in emergency management. Her work provided roadmaps that were widely adopted to guide the integration and inclusion of disability and functional needs issues in emergency preparedness.





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Kailes also has guided the emergency management arena away from the vague term “special needs” toward thinking about how operational plans and implementation can be made more specific and robust in acknowledging the wide range of people with functional needs and including such considerations in emergency planning. From communication needs and physical access, to equipment, transportation, and the application of policies, procedures and services that support all people’s safety, her work has transformed the field.

“There was some magical thinking that went into the idea of putting everyone with a disability on a registry to help them in an emergency,” cites Kailes as an example. Through her commitment and deep expertise, she has helped operationalize such flawed approaches to ensure that good intentions become practical solutions that can be achieved in a meaningful way.

Similarly, in the health care sphere, Kailes has worked to shift paradigms and spur institutional change. Starting in California, she worked with the state for more than a decade to integrate elements of physical access into public health plans. When people choose a healthcare provider, they need to know: is there an accessible route from parking and public transportation to the facility, are there accessible parking spaces, is assistance available getting on and off of a preferably height-adjustable exam table? Following her dedicated advocacy work in CA, the plans she outlined, such as her “Disability-Competent Care Self-Assessment Tool” and “Competency Planning Checklist for Providing Healthcare to People with Disabilities,” have been adopted by a national Medicare provider as well as multiple states across the country. These tools encourage compliance with the Americans with Disabilities Act and assist organizations and institutions in more successful inclusivity planning and service practices.

Despite all of the advancements that Kailes has helped generate over the years, she continues to see how much work remains to be done. “We need to insist on a lot more progress in government enforcing the civil rights of people with disabilities and putting in place the kinds of services that allow people to live independently and productively in the community.” She sees this all the more starkly against the backdrop of the COVID-19 pandemic, especially considering the pandemic’s effect on people living in nursing homes. “These are battles we’ve been fighting for a long time,” says Kailes, who cofounded one of the first independent living centers in California, after witnessing the lack of options for people to make their homes accessible or get the assistance they needed. To address some of the inequities brought to light during the pandemic, Kailes has written “Tips for Planning a Rapid Emergency COVID-19 Response,” which she provides online to all as a resource for distribution.

Kailes encourages other people to get involved in addressing disability issues and advancing equal rights. “Pick out people whom you admire or someone who could be a mentor, ask a lot of questions to a lot of people, surround yourself with those who are interested in pursuing the same kind of change you are, and acknowledge that it takes a long time,” she says. “Always speak up! It’s not about being liked; it’s about being respected. You have to be a raging incrementalist. There’s a lot of training out there on making change. Take advantage of that and join other people with disabilities pursuing progress.”

A longtime colleague of Dr. Eileen Fowler, Kailes partners with the CCP, and the team is honored to call her an innovator and a friend. To learn more about June Kailes and access some of her many resources and publications, visit her website at [www.jik.com](http://www.jik.com).

**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 Jennifer Brown, UCLA Health Sciences Development at [JenniferVBrown@mednet.ucla.edu](mailto:JenniferVBrown@mednet.ucla.edu) or (310) 824-3096.**