

## **CAMP LEG POWER MAKES PHYSICAL THERAPY FUN FOR KIDS**



This Summer, the Center for Cerebral Palsy (CCP) once again held a unique camp experience for children with cerebral palsy. Campers exercised in the play yard with therapists and in the lab using a specialized knee exercise machine and an ankle robotic system with gaming technology for motivation. Meanwhile, researchers studied how the brain changes in response to this motor control therapy. Physician-scientists from the CCP, UCLA Brain Mapping Center, Department of Pediatrics, and the Tarjan Center at UCLA—a University Center for Excellence in Disabilities Education, Research and Service—worked together to evaluate each child’s unique needs. They used brain MRIs to

identify the damage responsible for movement limitations and design physical therapy based on these assessments. UCLA undergraduate students served as camp counselors and worked during the school year to assist with data analysis—an experience intended to inspire the next generation of clinicians and researchers.

When children are born prematurely, the area of the brain that controls leg movements can be damaged, resulting in spastic diplegic cerebral palsy (CP), the most common type of CP. Most children with spastic diplegic CP may walk, but skilled movement of hip, knee, and ankle joints is limited. The therapeutic and research benefits of Camp Leg Power are complimented by the social component. “Having a summer program that lets campers participate in creative therapeutic activities with their peers builds skills and confidence. And we make sure it really is fun,” says Eileen Fowler, Ph.D., P.T., Director of the Kameron Gait and Motion Analysis Laboratory and the Peter William Shapiro Chair for the Center for Cerebral Palsy. This summer’s six participants, ages 7 to 14, attended 15 sessions of intensive therapy focused on improving their leg motor control, strength, and walking ability. Parents reported that the kids walked and performed activities with more confidence and endurance as a result. They also loved the social aspect of the camp and enjoyed the exercises and games.

Camp Leg Power relies on donations to offer these comprehensive services at no cost to children and their families. The CCP launched a crowdfunding campaign earlier this year and, thanks to the generosity of nearly 60 donors, was able to support the operational, research, and social aspects of the camp. The discoveries made at camp will help guide interventions for future patients.



## FAMILY FORUM BRINGS TOGETHER PATIENTS, FAMILY MEMBERS, AND MEDICAL EXPERTS



*Center for Cerebral Palsy faculty and staff*

The Family Forum, organized by the CCP and held on March 17, 2018, brought together patients, family members, and medical experts to exchange ideas on such CP-related topics as orthopedic and spasticity management, socialization and school, advocacy, women's health, targeted therapies, and access to computer games. The day began with William L. Oppenheim, M.D., Director of the Center for Cerebral Palsy and Margaret Holden Jones Kanaar Chair in Cerebral Palsy, reviewing current developments in CP. Rachel M. Thompson, M.D., Associate Director of the CCP, discussed current trends in orthopedic management and spasticity control. Eileen Fowler, Ph.D., P.T., Director of Research and Education for the CCP, reviewed the research projects that have been completed in the past year and those still in progress. The "Movement and Games" session featured Debbie Fragner of Children's CP Movement, who presented Ability Ballet, a dance-based therapy program for children with CP. The CCP members discussed a new collaboration with Microsoft to design computer games accessible to children and adults with CP. Another session, "The Science of Making Friends at School," presented by Elizabeth Laugeson, Psy.D., from the Tarjan Center, explored how socially successful children interact with their peers, with a focus on



*OIC Las Niñas Volunteer with a family forum attendee*

how children and their parents can help support social skills development to enhance school experiences. The "Women's Health" session discussed challenges women with CP face in accessing quality services. Katharine Hayward from the Tarjan Center and Angela Chen, M.D., from the UCLA Department of OB/GYN presented a project aimed at removing physical and attitudinal barriers to quality care at UCLA and at collaborating institutions across the United States. The next family forum will be held in conjunction with the annual conference of the American Academy for Cerebral Palsy and Developmental Medicine, which will take place in Anaheim, California in September 2019.





## OPPENHEIM RECEIVES DISTINGUISHED SERVICE AWARD

**William L. Oppenheim, M.D.**, Margaret Holden Jones Kanaar Chair and Director of the Center for Cerebral Palsy, was recently honored with the American Academy of Pediatrics (AAP) Distinguished Service Award. The highest honor of the AAP Section on Orthopaedics, this award recognized Dr. Oppenheim's dedication to excellence in patient care, research, and teaching spanning his 40-year career.

## DONOR SPOTLIGHT: PETER SHAPIRO



*Ralph, Shirley, and Peter Shapiro*

Peter Shapiro is passionate about helping people with disabilities. Having grown up with a sister with CP, he thinks deeply and multilaterally about the needs of people with physical and intellectual challenges. He believes that families need help navigating and utilizing the resources available for their loved ones. Early detection of cerebral palsy and timely therapeutic interventions can make an enormous difference: children with damaged hearing, for example, can learn to speak if diagnosed and treated early; if that window is missed, a person might never gain speech. Dentistry—a normal part of a healthy life—is a challenge for people with disabilities: few dentists are trained to work with these patients; it is common for

dental insurance for people with disabilities to cover exams only once every three years; without regular exams, serious infections and problems can develop, causing suffering and necessitating more complex treatments. Safe and effective pain management is another vital need in Peter Shapiro's view, and is an area where the CCP has made great strides: many people with disabilities live with a great deal of pain. Oral medications can create addiction and make the body used to a given drug. Pain management treatments offered at the CCP, including injections and implanted pumps, deliver medication to the pain site with no harmful side effects and minimal chances of an accidental overdose. Peter is emphatic that educating families and the wider public on seemingly small steps in medical management can make a huge difference in the lives of individuals with disability.

Through philanthropy and advocacy, the Shapiro family—Ralph and Shirley, Peter, and his sister Alison—have touched many programs at UCLA that support services for the disabled community, including the CCP. Peter is impressed with how the staff at the CCP treats patients with dignity, care, and love; working with them across their life-span; offering a spectrum of therapies from physical therapy to surgery; organizing family forums; and training specialists in other countries to care for patients with CP. The Shapiros have been unstinting supporters of the CCP. In 2008, they established the Peter William Shapiro Chair for the Center for Cerebral Palsy, which Dr. Eileen Fowler currently holds. In 2015, they made a significant donation to support the Transforming Healthcare for Women with Disabilities Program. Committed to empowering families and caregivers, the Shapiros helped support this year's Family Forum. "Society has a responsibility to care for the most vulnerable individuals and families. Our partnership with UCLA empowers faculty and students with the knowledge to meet that need," says Peter. Being able to help others makes him happy.

## FAMILY SPOTLIGHT: THE DIFRONZO FAMILY



*The DiFronzo family*

Eleanor DiFronzo's passion for helping children with disabilities is rooted in her childhood. Her brother was struck by a car when he was 15 years old and his injuries were so severe that doctors had given up on him. But Eleanor's mother refused to accept hopelessness; she worked intensely for a year, bringing her son from being totally dependent on others for his care to full health—he went on to have a successful professional life. After that, she began providing foster care for other children with medical and behavioral disabilities. Eleanor continued in her mother's footsteps. Together with her husband Vince, she has raised dozens of children with moderate to severe disabilities. Given how much of their time is spent with doctors, Eleanor is emphatic about the importance of compassion and understanding toward children and their families on the part of medical professionals—qualities that are rare in her experience because of the severity of her children's conditions; many doctors, in her view, are not willing to invest time and money in treating kids who will not have full and productive lives.

Eleanor found her ideal doctors at the CCP: "that's why parents drive from all over California to see them," she says with enthusiasm. Eleanor felt that Dr. William Oppenheim has treated her, Vince, and their children like family: listening to

them with compassion, understanding their concerns, respecting the kids, approaching parents like partners in decision-making, and learning with them how to help their boys. He performed a hip surgery on Ramon DiFronzo and even from vacation remained in close contact with the family, helping them manage the difficult post-operative recovery. Ricky DiFronzo had a terrible leg problem; Dr. Oppenheim "made it perfect," in Eleanor's words. Dr. Rachel Thompson, the CCP's Associate Director, performed surgery on Ricky's arm, enabling him to extend, rotate, and use it more functionally. The treatments Ricky received at the CCP put him on a path toward a full and productive life. Dr. Thompson also performed extensive pelvis and hip surgery on Aaron DiFronzo that "created a new boy from hips down." Dr. Thompson is "kid-oriented," according to Eleanor, the kids are happy to see her, and her caring and optimism motivated Aaron to improve and thrive after surgery. "Dr. Oppenheim set the high standard of care," Eleanor says, "and made sure that the next doctor filling his shoes will approach patients with equal care, compassion, and knowledge. He found his successor in Dr. Thompson. She is off the charts: a great listener, caring, compassionate... she is down to earth, one of us, but with all this wonderful knowledge and ability to do what she does. I hope she can be with us 30-40 more years, changing lives and giving hope to the kids and families." Marcia Greenberg, too, has been "a huge instrument in keeping everything together and coordinating all aspects of children's care. They need to clone her. She is one in a million."

**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, Senior Director of Development, UCLA Health Sciences at (310) 206-2435 or [jbrown@support.ucla.edu](mailto:jbrown@support.ucla.edu).**