

EASING ANXIETY: THE SURGICAL PREPAREDNESS PROGRAM AT UCLA HEALTH

The following is an excerpt from an article originally featured on UCLA Health Connect. To view the story in its entirety, visit: uclahs.fyi/CCP-Surgical-Preparedness.

Ten-year-old Scarlett Ferguson is an actress who enjoys playing make-believe, swimming, and hanging out with her friends. Her doctor, Rachel Thompson, M.D., describes her as sweet, punky, and intelligent. “She embodies what you would want if you had a daughter — she is kind and independent,” says Dr. Thompson, Director of the CCP.

When Dr. Thompson first met Ferguson, she primarily used a wheelchair for mobility, and her hips were coming out of their sockets — something for which children with cerebral palsy (CP) are at risk. Dr. Thompson discussed the condition with Ferguson’s family and agreed on surgery to put her hips back into socket, lengthen her hamstrings and straighten out her knees, which were becoming more flexed, limiting her ability to stand independently.

“After her first surgery, she had a lot of anxiety and a lot of fear moving her legs afterward. I think a lot of it had to do with the fact that she just didn’t know what to expect,” Dr. Thompson says. “Part of her having so much anxiety got me thinking about how we can help patients — before going into the operating room all the way to recovery — go through surgery without that anxiety and without that fear. She really inspired us to think about how we can do that better.”



Scarlett Ferguson with her mom, Keri

Preoperative Anxiety

The anxiety of facing one surgery, let alone multiple operations — a common situation for patients with CP — can have a very real impact, says Dr. Thompson. Studies have shown that children with greater preoperative anxiety experience more pain and are more likely to consume more pain medications postoperatively. They exhibit high rates of postoperative anxiety, sleep disturbance and delirium. If anxiety goes unaddressed, data show, it can manifest in interactions with medical professionals and impact recovery.

In an effort to improve outcomes and the experience for children and their families, Dr. Thompson and her colleagues conducted a study to determine if managing pre-surgery expectations through more education and improved pre-operative communication could improve post-surgery satisfaction and decrease post-operative pain. “We found that higher anxiety immediately before surgery is directly correlated to postoperative pain and use of narcotics,” she says. “That tells us that if we actually intervened in that pre-surgery anxiety, we might be able to improve outcomes.”

These findings were the motivation for Dr. Thompson to create the Surgical Preparedness Program, which provides children and their families with preoperative education in the form of a video and handouts. By normalizing surgery and providing thorough education, Dr. Thompson aims to decrease anxiety, decrease postoperative pain and allow children to have confidence in their medical providers and in themselves.



No Surprises



Scarlett Ferguson with Rachel Thompson, M.D.

Ferguson says one of the things she loves about Dr. Thompson is that she takes her time with her. “She doesn’t talk about me, she talks to me,” Ferguson says of Dr. Thompson. “She talks to me like a person. She explains how the surgeries will work so that I don’t feel as uncomfortable when I go into the operation room. She also takes good care of me.” Dr. Thompson says she and her team aim to talk to the child and their family about each detail of the surgical process — from where they will go when they arrive, to whom they will meet, if they’ll get an IV and what to expect postoperatively.

“We try to give them a timeline of when we think they’re going to be 50 percent better, 90 percent better and 110 percent better, so that families leave our clinic preoperatively without the panic that they came in with,” Dr. Thompson says. “We want them to come to the day of surgery feeling like they’re ready and know exactly what’s going to happen. There’s not going to be any surprises.”

Since meeting Dr. Thompson, Ferguson has had three surgeries: one to reconstruct her hips, pelvis, and knees, one to rotate her femurs, and one to fix a broken plate in her leg. The last surgery was an emergent one due to her right femur bone being osteoporotic, the density of the bone brittle and weak. “Dr. Thompson did her best to work with the bone but the femur bone was very soft and didn’t accept the hardware,” says Keri Ferguson. “Six days after that surgery, her bone rejected the hardware, sort of spit it out, and her leg broke in half. We went in for emergency surgery the next day.”

Scarlett had been working for Disney and was scheduled to film two weeks after the initial surgery. She already had the wardrobe and was very excited, her mother told us.

Dr. Thompson knew Ferguson was filming some princess scenes and wanted her cast to match her outfit, thinking her favorite colors, pink or purple, might work. She called her mom from the operating room, asking which color she preferred. “I was like, ‘Oh my gosh, I am so glad you called me! Pink and purple do not work. Please don’t put pink and purple on her,’” Keri Ferguson recalls. One of the major costumes Scarlett was going to film with was a Cinderella gown, which was blue. “Dr. Thompson not only had put this really sweet blue cast on that matched her gown perfectly, but she also took white pieces and cut out hearts and put hearts on her cast. She even put one at the bottom of her foot because her foot was going to be showing on camera,” Keri Ferguson says. “It really was very sweet that she had that extra care and compassion and took the time to consider Scarlett, her needs and her work as an actor. It just made it really special, personal and fun.”

For every surgery, steps have been taken to reduce anxiety as much as possible — a level of attention and care unmatched by other health systems, says Keri Ferguson. With the Surgical Preparedness Program, Dr. Thompson’s hope is that other children and families will feel as prepared and confident as the Fergusons, and that by sharing Scarlett’s experience, other children will feel at ease. Dr. Thompson is “really hoping that this is a first step to try to treat the whole child, even in surgical specialties.”

GIFT FROM THE SHAPIRO FAMILY INTEGRATES SOCIAL WORK INTO CEREBRAL PALSY CARE

Over the summer, Peter Shapiro and the Shapiro family made a significant contribution to establish a social work fellowship in special patient care settings, including the CCP.

This gift to the UCLA Department of Social Welfare funds a part-time contract staff supervisor position and two second-year social work graduate students each year for three years. The Shapiros are unwavering champions of the CCP, and this meaningful act of philanthropy underscores their decades of commitment to excellence in special patient care.

“As a society, we have a duty to meet the needs of the most vulnerable members of our community,” said Peter Shapiro. “By funding this particular fellowship at UCLA, we hope to accomplish two things: integrate social work into the care team to provide greater support to cerebral palsy patients as well as their families, and teach aspiring social workers the best practices to help this population.”

The fellow spends three days a week at the CCP with Dr. Rachel Thompson and nurse practitioner Dana Connolly, supporting adults and children with CP, as well as their families. The program is supervised by Michael O’Hara, M.S.W. ‘14. Passionate about improving quality of life, increasing health equity, and addressing the social determinants of health, Michael is thrilled to return to her alma mater to take on this role.

She sees social work as a vital part of the care team, offering individuals and their families essential services such as mental health support, patient advocacy, and assistance in navigating health care systems.

In collaboration with Dr. Thompson, Dana, and Michael, fellows in the program evaluate patients and identify needs related to day-to-day living, mental health, accessibility, surgical care, finances, and more. Because individual abilities and symptoms associated with CP vary widely, there are many factors — medical and non-medical — to consider when treating this population.

When students conduct patient assessments, Michael emphasizes the importance of looking at individuals and their caregivers in the context of their larger environments, taking into account factors like school and work, family dynamics, and cultural practices. While social workers are equipped to independently handle many of the issues that arise in these initial consultations, some solutions must be outsourced. In these instances, social workers in the CCP continue to assist patients.

For example, most of the children treated at the CCP qualify for California's Children's Services (CCS), a state program that provides diagnostic and treatment services, case management, and physical and occupational therapy to those under 21 with certain health conditions, including CP. While CCS is an invaluable resource for eligible children, it is a complicated system that can be difficult to utilize, especially for a busy caregiver. Michael and the fellows guide families through CCS enrollment, helping to ensure that patients receive the life-changing services to which they are legally entitled. In the process of partnering with families to make the most of CCS, fellows not only learn about the variety of resources available to support those with CP, but also how to operate within the health care system as a patient advocate.

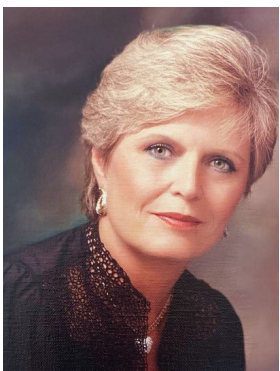
While this fellowship program is designed to help patients, it also offers a lot of relief to the care team as a whole. It is no secret that health care providers at the CCP are deeply dedicated to the success and well-being of their patients in all aspects of their lives. However, since physicians and other experts have a limited amount of time in each appointment, they usually have to concentrate on treating the patient's complex health condition, as opposed to tackling that patient's equally important concerns that, while perhaps not directly related to CP, affect their wellness. Michael has found that adding a social worker to the team enables medical personnel to focus on treatment, knowing there is a specialist in place to resolve non-clinical issues.

Through their generosity, the Shapiros have created a special opportunity to expand whole-person and family-centered care on campus. The graduate students in this program are showing a great deal of promise, and the fellowship has the potential to shape professional collaboration and patient care in general at UCLA. The Shapiros are encouraged by the exceptional performance of the students so far, and they are optimistic about the long-term impact of this fellowship. "We are confident that, as a result of this collaborative program, patients will receive enhanced care for cerebral palsy — now and into the future."



Program supervisor Michael O'Hara (left) and fellow Lou Marie Reyes

REMEMBERING LENA LONGO



Lena Longo, a loyal, longtime friend of the CCP, passed away on July 26, 2021. A devoted mother, lifelong learner, and distinguished philanthropist, Lena was a powerful force for good. Her dedication to special patient care and advocacy was formed when one of her daughters was diagnosed with severe CP, and she began supporting the CCP in 2004. She was committed to advancing research in this field, establishing the Lena Longo Endowment for Cerebral Palsy Research to help accelerate discovery at the center.

In our 2016 newsletter, we asked Lena about why she gives back to the community. Her answer inspired us all: "Once you meet someone with cerebral palsy, they automatically have your heart. It's not something you can just walk away from." While Lena is deeply missed by everyone at the CCP, her legacy of compassion and generosity will endure for years to come. She is survived by four of her children, 10 grandchildren, and many nieces and nephews.

THE INTERNATIONAL CHILDREN'S PROGRAM: MEET LIZANIA!



For more than 60 years, the International Children's Program (ICP) — a collaboration between UCLA Health and the Orthopaedic Institute for Children (OIC) — has been helping pediatric patients outside of the United States receive preeminent orthopaedic care at no cost for conditions such as CP, scoliosis, clubfoot, and others. The ICP provides comprehensive support for patients, including medical care, assistance with immigration and international travel, lodging, transportation, and more.

A main component of the program involves ICP physicians crossing the border into Mexico to evaluate patients. If doctors determine that a patient is in need of more advanced care, the process to get that child to Los Angeles for treatment is initiated. Over the course of six decades, this unique program has transformed the lives of more than 150,000 children and their families.

One of these patients is Lizania, a 10-year old girl from Mexico, who has spastic cerebral palsy. We learned about Lizania from Claudia Ortiz, manager of the ICP. Before entering the program, Lizania was being treated only with physical therapy, unable to walk or support her trunk. She was completely dependent on her mother and grandmother. While her mother worked, Lizania's grandmother attended school with her each day, assisting her with basic activities of daily living.

Once in the program, Dr. Rachel Thompson devised a two-step surgical strategy to help Lizania gain independence; she had the second of those surgeries in 2018. Almost two months after that procedure, she was standing with leg braces, and four months later, she was walking — an outcome far greater than the care team was anticipating. Lizania is now able to manage her basic physical needs on her own, which has increased her confidence and decreased strain on her grandmother.

When Lizania first entered the program, she was understandably in low spirits; however, as her health began to improve, so did her state of mind. Claudia describes Lizania as a bubbly preteen, who loves all things girly. She has taken full advantage of her newfound mobility, enjoying days at school and playing outside. Lizania's growth is monitored by ICP doctors, and she may require additional surgery to further enhance her physical abilities. But for the time being, Lizania's care team is excited by the gains she is making and ready to help her reach her full potential.

Claudia shared that Lizania's mother is especially pleased with her daughter's progress, telling us that she said she is "so happy, so grateful" and that she "has so many expectations for the future because Lizania is such a smart girl."

Deeply inspired by the care that her daughter continues to receive, Lizania's mother has returned to school to become a physical therapist, so that she will one day be able to support other children with CP. One of the most special aspects of the ICP is the community's willingness to pay forward the kindness they have received. In fact, it was a former patient who led efforts to establish the clinics in Mexico that changed the trajectory of Lizania's life.

The International Children's Program is funded entirely through philanthropy. To learn more about how you can sustain this work, please visit: www.ortho-institute.org/ways-to-give/donate-online/

MARCIA GREENBERG'S NEXT CHAPTER

After more than two decades, Marcia Greenberg, P.T., is retiring from her position as clinical coordinator of the CCP. In many ways, Marcia has been the glue of the CCP, facilitating treatment plans and helping patients reach their goals.

Marcia began her career at Rancho Los Amigos National Rehabilitation Hospital, first providing physical therapy to adult patients with traumatic brain injuries, then eventually supervising the care given to those with spinal cord injuries. She also spent a period of time training other physical therapists and students in the best techniques in gait analysis.

Ironically, Marcia never anticipated that she would go into pediatric care; however, after years of teaching, she was ready to directly support patients again. At a conference, Marcia met Dr. Eileen Fowler, Director of Research and Education for the CCP and Director of the Kameron Gait and Motion Analysis Laboratory. Dr. Fowler strongly encouraged her to join the CCP team, and the rest is history.

A truly rewarding aspect of Marcia's long career at the CCP has been watching her patients evolve from children and teenagers into successful young adults. Because CP requires continued care, a real connection forms between patients and providers. "20 years — I've seen kids grow up. I've seen people get married. I've seen them have kids, graduate college. It's a relationship," she remarked.

One of Marcia's most meaningful moments on the job came in the form of a text message. She was working with a teenage boy, whom she's known since he was three years old, and asked him what he wanted to achieve at this stage in his treatment. There was a lot he hoped to accomplish, but he especially wanted to go to college. He kept making significant progress medically, and shortly after Marcia announced her retirement, she got the text that meant so much: her patient had just been accepted to the University of California, Berkeley.



While stepping down as clinical coordinator is bittersweet, Marcia knows the CCP will remain a life-changing resource in the community. She is especially heartened by the growing focus on family-centered care. "We're not just dealing with muscles and bones," she says, "not only is there a person, but that person is connected to a family."

Outside of CCP, Marcia consults for Momentum Wheels for Humanity, a non-profit that strives to globally promote greater inclusion for people with disabilities. Through this organization, she has been contributing to a USAID-grant project in Ukraine, educating physical therapists and developing a clinical placement program. Now that COVID-19 restrictions are lifting, Marcia hopes to travel to Ukraine in the spring to further advance these efforts.

Because she does not yet want to entirely step away from patient care, Marcia will remain in her position in the Kameron Gait and Motion Analysis Laboratory. Next time you see Marcia in the lab, be sure to congratulate her on an extraordinary career and well-deserved retirement!

FAMILY FORUM

This unique program provides education to patients with CP, their families, and caretakers. This year's forum will focus on spasticity control, muscle disease, and remaining active and strong with CP.

Keynote Speaker:

Matthew J. McLaughlin, M.D., M.S.

Pediatric Rehabilitation Medicine, Children's Mercy Hospital Kansas City

Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Clinical Assistant Professor of Rehabilitation Medicine, University of Kansas School of Medicine

Saturday, April 2, 2022

Orthopaedic Institute for Children

403 W. Adams Blvd., Los Angeles, CA 90007

Registration: 12:30 – 1:30 p.m.

Program: 1:30 – 4:45 p.m.

Reception: 4:45 – 6:00 p.m.

For general information and inquiries, please contact the OIC administration office:

Melissa Strodbeck

mstrodbeck@mednet.ucla.edu

213-742-1102

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 310-824-3096 or JenniferVBrown@mednet.ucla.edu