

UCSF Pediatric Epilepsy Center of Excellence

Pioneering Care for Patients and Families



UCSF Benioff Children's Hospital
San Francisco

“ If we were able to fully support our young patients and their families through this unpredictable diagnosis, attending to their educational and psychosocial needs and alleviating their physiologic stressors, through PECE, we will empower them to truly live the lives they are capable of. ”

– Joseph Sullivan, MD, future director, PECE



How Long Can You Wait?

You know how it feels to wait. Time slows to a glacial pace. Your stress level rises, your heart pounds. And when the wait is finally over, you feel a rush of relief.

What if the wait never ended?

Every parent or caregiver of a child with recurrent, spontaneous seizures knows that interminable wait all too well. Nothing compares to that all-encompassing fear of the next seizure. Relief from that fear does not exist. How can you provide all the necessary care and treatment for your child, manage the needs of your family, and focus on your work when all you can think about is your child's next seizure?

With your support, the UCSF Pediatric Epilepsy Center of Excellence (PECE) will expand its exceptional, state-of-the-art treatment to a comprehensive program that fully and compassionately supports families.

Understanding Epilepsy

Inside the brain, electrical signals pass messages between brain cells. Your body relies on your brain's ability to interpret those messages. If those signals are disrupted, a seizure can affect any process your brain coordinates. Some people are overcome with a sense of panic before a seizure, others with dizziness or nausea, but for many there is a profound sense of having exited their body, leaving it to fend for itself.

Imagine not trusting your brain to take care of your own body. Now imagine how that must feel to a child.

In the United States, epilepsy affects more than 300,000 children under the age of 14. Existing on a spectrum with many different types of seizures of widely ranging severity, epilepsy also has biological, cognitive, psychological, and social consequences. In roughly 70 percent of epilepsy cases, the cause is unknown.

Epilepsy is complex, making diagnosis and treatment difficult. Ensuring the best outcome for children with epilepsy requires early diagnosis, active treatment by qualified specialists, and ongoing management in a supportive environment.

Comprehensive Support for Patients and Families

This is about your child and your family. Nothing is more important.

PECE brings together many specialists to address symptoms and treat the whole patient while holding the entire family in its care.

We understand what it is like to wait...because we wait with you.

PECE builds upon the existing program to fully support patients and their families in new ways. It empowers our physician-scientists to discover new approaches to treatment and provides an environment that is ripe for uncovering the basis for a cure.

Monica's Story

Monica Martinez loved to run, jump and play. So at age 5, when she would hop up in the middle of the night and run around, her mother thought it was a behavioral issue. "She would get up several times and start jumping from one bed to the other like a monkey," says Estreya Lund, Monica's mother. When it became unmanageable, Estreya took Monica to the emergency room, where she was told: "There's nothing wrong. Take her home, it's just a spell."

Over the next month, Monica's condition worsened. Despite the local doctors telling her not to worry, Estreya knew something was wrong. She decided to take Monica to a different hospital. There she finally learned that Monica's energetic behavior and screaming fits actually were seizure activity. "It was so bad that every few seconds, Monica would clench her entire body and urinate," Estreya recalls. After months of medication failed to stabilize Monica's condition, Estreya and Monica were referred to UCSF, where finally, a medication was identified and Monica's condition stabilized.

But even stable meant one or two severe seizures every few weeks.

"Her seizures were so severe that she would stop breathing and turn blue," Estreya says, her voice wavering with the memory. "They happened around the clock, so all I could do was wait. I wasn't getting any sleep. I had to watch her 24/7." This strained the entire household. Burdened by the stress and the financial implications, Estreya and her husband, Christopher, eventually divorced.

“ You will be sleepless in a way far more profound than the darkest hours of your child's newborn days. There is no sleep, because you're always worried you'll miss a seizure. Even when you do sleep, you only half-sleep. ”

– Jennifer Parker, parent of a young patient



“I couldn’t focus on anything but Monica,” she says. “I tried to keep a job, but I just missed too much work. I even became a lunch lady at Monica’s school just so I could be there. I would have given anything to have counseling and educational help, but we could barely afford Monica’s care on one income.”

Getting educational support for Monica was another headache. “It took three years to get an individualized education plan (IEP),” says Christopher Lund, Monica’s stepfather. “We had to battle constantly, moving from one group to the next, repeatedly proving our case.”

Despite many interventions, including participation in drug trials, Monica’s seizures continued. She needed surgery. After a week of mapping, Joseph Sullivan, MD, associate professor of neurology and pediatrics, discovered that Monica’s seizures started in the area of her brain controlling speech. Surgery was far too risky. Instead, Dr. Sullivan recommended that Monica have a vagus nerve stimulator (VNS) implanted to regulate her seizures and provide some much-needed relief.

Now 17, Monica continues to have seizures, and while the VNS regulates her symptoms, she is self-conscious of how it changes her voice when it is activated. She has a supportive group of friends but dreads bringing new people into her circle.

“Every new person in my life gets the seizure talk from my mom and dad,” she says, her voice dampened and gravelly from the VNS. “I have to know my friends won’t freeze if I have a seizure. But I want to be like other teenagers and go out with my friends. I just want to be normal.”

Give PECE a Chance

PECE wants children like Monica to realize their potential and be all they can be. To better serve the community, PECE will expand to provide supportive, wrap-around services – embracing patients with multidisciplinary care, educational assistance, social work, mindfulness, and counseling services. With beautiful new facilities in the UCSF Ron Conway Family Gateway Medical Building at Mission Bay, PECE can direct funding toward treatment and support services.

Funding Opportunities

With your help, PECE will expand the existing treatment program to provide new services and surround families with a compassionate, facilitative care community:

Clinical trial coordinator: Provides patients with improved access to new therapies and clinical trials. The coordinator educates and informs about available trials and navigates and streamlines the application process.

Educational liaison: Assists families searching for safe and developmentally appropriate educational placement. The liaison also informs and helps parents with individualized education plans and other instructional tools.

Family wellness specialist: Offers a range of developmentally appropriate activities including yoga, mindfulness, meditation, and stress management. Studies have shown these activities improve quality of life and reduce seizure frequency. Also counsels families and provides patient activities to allow parents privacy to discuss next steps or meet with doctors and specialists.

Pediatric psychiatrist: Monitors and follows a family's personal journey while providing individualized treatment and support. Many children with epilepsy have mental, emotional, and reasoning issues, and some antiepileptic drugs, though beneficial, can trigger psychiatric symptoms. Responding to the whole person by diagnosing, treating, and preventing psychological disorders is part of PECE's mission.

Marriage and family therapist: Specializes in helping families living with epilepsy and provides support for patients and family members dealing with the impact of the condition.

Genetic counselor: Focuses exclusively on pediatric epilepsy to find potential genetic abnormalities that may help explain a child's diagnosis. Technology has given us the ability to detect the findings



but not the understanding to act upon them. A part-time genetic counselor will unlock the potential of this valuable data.

Patient concierge:

Concentrates on the patient experience and plans patient visits to make the most of each clinical experience. Also assists families with scheduling follow-up appointments and specialist services.

Social worker: Navigates public and private insurance to access equipment, find rehabilitative and respite care, and identify assistance programs while helping families connect with community, government, and private resources.

Pediatric epilepsy translational research fellow: Researches patient-centered advances in pediatric epilepsy care and coordinates clinical trials. Possible research projects include developing technology to provide virtual doctor consults; exploring wearable devices for quick, accurate, and worry-free monitoring; identifying new antiepileptic drugs and exploring zebrafish models to develop more precise, personalized treatments.

Faculty support and leadership (professorships): Provides a permanent endowment to support leaders of PECE into the future and fuels the passionate work and leadership of Joseph Sullivan, MD, right now. Signifying belief in the contributions of a leading faculty member, an endowed professorship also aids in the retention and recruitment of top talent yet to come.

PECE Begins with You

We invite you to join us in founding the UCSF Pediatric Epilepsy Center of Excellence – bringing about the future of epilepsy care at UCSF.

You can help a patient like Monica reach full potential and provide families with comprehensive support.

To make your gift or for more information about how you can help PECE change lives and support families, please contact:

Chris Anderson, senior director of development for children's health at (415) 502-7365 or Chris.Anderson@ucsf.edu.

