

# Stopping Seizures



GOOD  
MEDICINE



*Epilepsy can be a devastating disease, but nowhere more so than in young children. In our first "Good Medicine," a new feature focusing on Bruin health-care heroes, we profile the pioneering UCLA Pediatric Epilepsy Program and its director, Dr. Gary Mathern, who is pushing the boundaries of surgery and saving the lives — literally and figuratively — of dozens of kids every year.*

By Lyndon Stambler

Photos by Mark Berndt



The patients of Dr. Mathern:  
(Facing page, top left) Julia Sanchez;  
(bottom left) Austin Rawnsley;  
(right) Dr. Gary Mathern  
More patients and their parents:  
(This page, clockwise from top left)  
Rachel Waters with son Aiden; Kaitlin  
Tsue; Henry Jones; Hannah Swank

# H

ENRY JONES was born in 2007 with a rare brain deformity called hemimegalencephaly that affected the left side of his brain. He suffered countless seizures. His eyes rolled back in his head. He could not breastfeed. His parents faced the unthinkable. They searched for a pediatric neurosurgeon to remove the left side of Henry's brain.

"Even with four anti-epileptic medications, he was in a constant state of seizure," Monika Jones '89 says about her son's struggle with the disease. "Those seizures would have caused brain damage and then death. We had no choice."

Monika and her husband, Brad, found Dr. Gary Mathern, neurosurgical director of UCLA's Pediatric Epilepsy Surgery Program, who has operated on children as young as 2 months. "My practice is little kids with big, bad brains," says Mathern. "It has to be done early to optimize the cognitive potential for these kids."

Since language develops in the left hemisphere, Monika wanted to know if her son would ever talk. Mathern would not predict the outcome, but said that therapy could help Henry transfer language to the right hemisphere. "He didn't sugarcoat anything," says Monika.

"This is not a risk-free operation," Mathern explains. "Heaven forbid, I have to tell a family that I lost someone on the table. That's a surgeon's worst nightmare."

When Mathern finished the 12-hour surgery, his demeanor softened. The procedure had gone well. "It's terrible to say, but I had handed Gary a zombie before and Gary handed me back a baby," says Monika. "We knew Henry was in there and trusted Dr. Mathern to get him out. Henry looked at me and nursed and smiled. In two months, he was laughing."

Monika and other parents compare Mathern to a chocolate bar with a hard outside and a gooey center, difficult to get to know at first but warm and affable once you do. "I have an emotional tie to every one of these kids I operate on," Mathern says. "After the surgery, they become part of the family. I'm their doctor for life. This is about changing kids' lives. Then the families bond naturally."

That bond is palpable at a July gathering of hemispherectomy alumni at Ackerman Union. Mathern, wearing scrubs after an emergency surgery, greets eight former patients, from 2 to 18 years old. Levon Epstein, 2, smiles in his stroller; Hannah Swank, 4, twirls with her dad; and Aiden Waters, 5, scoots around. Mathern's "kids" also include Kaitlin Tsue, 13, who had her surgery in June; Julia Sanchez, 2; and Jasmine Aispuro, 12.

Austin Rawnsley, 18, the group's elder statesman, underwent his first surgery in 1992 and has had seven surgeries since. Although his right hand hangs limp, he can sink a left-handed three-pointer. He just graduated from Agoura High and will be attending Moorpark College this fall.

"It may take me longer in school, but I can get it done. I'm very intelligent," he says.

## Pioneers and Process

A tiny percentage of the 3 million people in the United States with epilepsy are hemispherectomy candidates. They must have intractable epilepsy that can't be controlled with medication. They also have to have a healthy hemisphere. A multidisciplinary UCLA team assesses risks and benefits. In the worst cases, children who have 100 seizures a day face cognitive impairment or death.

"The seizures can scramble the other side," Mathern says. Without surgery, such children are destined for IQs below 50. "With a hemispherectomy, I'm not creating a normal child," Mathern says. "But if I get a child with an IQ of 70 or greater, that's a huge win."

Former UCLA neurosurgeon Paul Crandall pioneered a surgical epilepsy program for adults beginning in 1961. He encouraged Mathern to understand epilepsy as well as any neurologist. In 1990, Mathern



received a Milken Family Foundation Epilepsy Research Fellowship, followed by an award from NIH.

Doctors Warwick Peacock, W. Donald Shields and D. Alan Shewmon established UCLA's pediatric epilepsy surgery program in 1986. Since its inception, 189 children have undergone hemispherectomies, and approximately 80 percent of the children remain seizure-free. Mathern, who became director in 1997, has performed at least 110 hemispherectomies, 25 percent of them children under the age of 2.

Not surprisingly, this good doctor relates to U.S. Airways Captain Chesley "Sully" Sullenberger, who saved 155 lives when he safely landed his jet in the Hudson River. "When they interviewed him, he said, what's the big deal?" Mathern notes. "I understood what he was talking about. Your mind is not thinking about how things feel. It's what's



**Lives mended:**  
(This page, left) Jasmine Aispuro.  
(Bottom right) Jack Epstein '90  
with son Levon

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the data? How am I going to proceed? It's procedural. There are 50 steps. You can't jump from one to 15. You have to go from one to two, two to three. Your job to make this safe is to focus."

## The Man Behind the Mask

The son of a now-retired Air Force officer, Mathern moved around a lot as a child with his family, including a younger brother who is a noted spine neurosurgeon. Mathern was attending Case-Western Reserve Medical School when a surgeon spotted his skills — and Mathern, who calls neurosurgery "the thinking man's surgery," was stimulated by its puzzle-solving challenges. His interest in pediatric epilepsy arose out of his residency at UCLA, which began in 1986. (He moved to Los Angeles after meeting his wife, film producer Sandra Rabins. They have two grown children.)

The understated Mathern does not come off as a stereotypical brain surgeon. In his cluttered office across from his lab in the Reed Building, conference badges hang from the filing cabinets and stacks of papers and discs pile up on his desk. He keeps a Pez-like doll with a brain that pops up from its head, a toy from a former patient, and a map of the Great Barrier Reef reminds him of his scuba-diving days.

The success stories keep him going. "It certainly ain't the pay," he quips. He recalls a Colorado infant who had a left-sided hemispherectomy several years ago. Her family camped out at UCLA until she

gained enough weight (six kilograms) to safely undergo the surgery. Five years later, he phoned the family and heard the girl's voice on the answering machine. "Hi, this is Emily, please leave a message."

Mathern was so moved by her voice that he had to hang up and call back later.

## Medicine and Miracles

Rachel Waters' son, Aiden, was born with a port-wine stain birthmark on the right side of his face, an indicator of Sturge-Weber Syndrome. She thought that his seizures were controlled by medication, but an EEG last year confirmed that he was having subclinical seizures and ultimately needed to have a hemispherectomy in August 2008. Rachel was reassured by Mathern's vast experience and his strong reputation with other doctors. "It was hard to hear him tell me, so bluntly, what he was going to do to my son. I wanted him to tell me everything would be all right. Instead, he armed me with the facts."

Mathern finished the surgery and announced, "You can hug the surgeon now."

Aiden is seizure-free and is now being weaned off his anticonvulsant medication. He is walking and progressing well. Although he doesn't have language yet, he can hum some tunes. "It was the most difficult decision I've ever had to make, but one I don't regret," says Rachel, the western regional director of the Hemispherectomy Foundation. "The constant worry about seizures has been lifted. We are hopeful that Aiden will be able to talk one day."

Mathern thrives on such hopes. "I've got to do something that's going to hurt these kids," he says. "I'm taking away cortex. I'm doing this now with the prospect of something in the future. Hopefully, if I did this when they were that young, they won't even know who I am." ■

