

# Momentum builds in quest to find cure for childhood brain disease

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How do you find a cure for a devastating pediatric brain disease so rare that it can take decades to build a meaningful research base?

In 2010, the parents of a patient created the Rasmussen Encephalitis (RE) Children's Project to help solve this problem. In a short amount of time, the foundation has raised funds to establish a consortium of top researchers, build a collection of samples of the disease from around the world and support projects to study the disease tissue and search for [genetic links](#). The goal is to find a cure.

Researchers at the David Geffen School of Medicine at UCLA have played a vital role in the ongoing research, and the foundation recently provided a second round of funding to continue their work. The gift of \$125,000 builds on the organization's donation of \$111,000 made in 2011.

"We are still in the early stages of research, but our momentum is building," said Seth H. Wohlberg, founder of the RE Children's Project, and father of Grace, 15, who was stricken by the disease when she was 10 years old. "One of our key accomplishments has been to create an international system so that we can coordinate and transfer RE [brain tissue](#) and DNA material from the patients and parents. Collecting these samples is vital to advancing the research."

With the additional funding, UCLA researchers will apply cutting-edge DNA sequencing technology to determine whether a virus, or some other

infectious agent, causes RE. They also plan to develop an animal model of the disease using cells obtained from the RE samples.

The researchers include Dr. Gary Mathern, professor of [pediatric neurosurgery](#) and director of the UCLA Pediatric Epilepsy Program at Mattel Children's Hospital; Carol Kruse, professor of neurosurgery; and Geoffrey Owens, visiting assistant researcher in neurosurgery.

"I am grateful to collaborate with a devoted father who has taken on the enormous task of advancing research for RE," said Mathern. "Thanks to his leadership, we now have the network to collect the tissue and DNA needed to study the brain, immunologic cells and genetics to unlock what causes this disease and develop new treatments or a cure. The RE Children's Project has truly helped accelerate our research, bringing new information and resources that could have taken 10 more years to develop to the forefront today."

Rasmussen Encephalitis is a neurological disease that causes intractable seizures, cognitive deficits and paralysis of half of the body. It is very rare and only a few hundred cases have been reported worldwide. RE typically affects previously normal children between the ages of two and ten years old. The disease process can run its course over a one to two year period during which time one half of the body is rendered useless and epileptic seizures continue unabated.

An unusual feature of the disease is that it is usually confined to one hemisphere of the brain and is resistant to standard anti-seizure medicines. Currently the only known "cure" is radical—the surgical removal or disconnection of the affected side of the brain known as a hemispherectomy.

In the summer of 2008, the Wohlberg's 10-year-old daughter Grace started to experience epileptic seizures. After months of testing, her

parents learned that she had the extremely rare neurological disorder. Grace underwent an initial hemispherectomy surgery in February 2009. However, her seizures recurred so her parents then brought Grace to UCLA to complete the hemispherectomy which was performed by Mathern in March 2010.

Today, Grace attends high school with the assistance of a full-time aide. While the surgery has stopped the seizures, Grace faces lifelong disabilities including partial blindness, cognitive issues and learning how to walk again. She is also active in helping her father promote the RE Children's Project.

"It's really supportive to let people know our story," said Grace. "Every year, my dad does a fundraiser and a lot of people come out to support it. It's fun to be there and see all the people who care and want to help."

Provided by University of California, Los Angeles

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