

RE Children's Project

## RE Children's Project Appoints Scientific Advisory Board

### Scientific Advisory Board Helps Direct Research Funds and Direction for Study of Rare Childhood Disease Rasmussen Encephalitis



The RE Children's Project Scientific Advisory Board

The RE Children's Project, a non-profit dedicated to supporting scientific research directed towards the treatment and cure of the rare childhood disease Rasmussen Encephalitis, is pleased to announce the formation of a Scientific Advisory Board that will oversee research initiatives funded by the non-profit.

Appointed to the RE Children's Project Scientific Advisory Board are: Gary Mathern, M.D., professor of Pediatric Neurosurgery and director of the UCLA Pediatric Epilepsy Program at Mattel Children's Hospital and Ronald Reagan UCLA Medical Center, Los Angeles; Frances Jensen, M.D., professor of Neurology, director of Epilepsy Research, Boston's Children's Hospital; Carlos Pardo, M.D.,

associate professor of Neurology and Pathology, The Johns Hopkins Hospital, Baltimore, Md., Helen Cross, Ph.D., Prince of Wales chair of Childhood Epilepsy, Great Ormond Street Hospital for Children, United Kingdom; and Christian Bien, Ph.D., chief physician, Mara Hospital, Germany.

"The RE Children's Project is approaching its second anniversary and it is the appropriate time to form a board of scientific advisors," noted Seth Wohlberg, founder of the RE Children's Project. "Previously, we avoided forming a scientific advisory board to maintain our flexibility and to ensure that we attracted the widest participation in our deliberative meetings and research symposiums. But now, as we are looking at year two of the RE Children's Project and all that we've accomplished, it is a very exciting and logical step to have a Scientific Advisory Board as we attract additional funds for allocating to research into RE."

UCLA, Children's Hospital Boston, Johns Hopkins Hospital, Great Ormond Street Hospital and Mara Hospital, along with their respective physicians on the RE Scientific Advisory Board, as well as The Children's National Medical Center and the NYU Comprehensive Epilepsy Center, under the leadership of Dr. William Galliard and Dr. Orrin Devinsky, respectively, are also part of the unique RE Children's Research Consortium whose goal is to make clinical information as well as brain tissues and biological samples more available for research purposes directed towards RE.

RE typically affects previously normal children between the ages of two and fifteen

years old; it rarely affects adults. The disease process characteristically runs its course over a one to two year period during which time one half of the body function 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. The only known "cure" is a cerebral hemispherectomy — the removal or disconnection of the affected side of the brain. This radical surgery has been the standard form of treatment for more than 50 years. Recent progress in understanding of the disease, and the emergence of therapies that slow disease progression and help control symptoms, has led some researchers to believe that more targeted and effective medical treatments are potentially within reach.

Seth Wohlberg and his family founded the RE Children's Project after their daughter Grace, who in 2008 and only ten years old, started to experience epileptic seizures. After months of testing, her parents learned that she had the extremely rare neurological disorder of RE. Grace underwent an initial hemispherectomy surgery in February 2009. However, her seizures recurred so her parents then brought Grace to UCLA for additional surgery, which was performed by Mathern in March 2010. Today, Grace is back in school adjusting to her new life with the assistance of a full-time aid. While the surgery has stopped the seizures, Grace faces lifelong disabilities that resulted from the surgery including partial blindness, cognitive issues and learning how to walk again. Since then, the foundation has sponsored cross-disciplinary research conferences and funded leading edge research around the globe focused on finding the cause and an eventual cure for RE. The organization also supports research dedicated toward the recovery process following hemispherectomy surgery.

To learn more about the RE Children's Project and support its research, visit <http://www.REChildrens.org>.

Rasmussen's encephalitis (RE) is a rare neurological disease that causes intractable epileptic seizures, cognitive deficits and paralysis of 1/2 of the body. The disease process typically runs its course over a 1 to 2 year period during which time one half of the body is rendered useless — hemiplegia — and epileptic seizures continue unabated.

RE typically affects previously normal children aged between two and ten years. An unusual feature of the disease that sets it apart from other inflammatory diseases of the central nervous system, is that it is usually confined to one hemisphere of the brain. RE is resistant to standard anti-seizure medicines thus making possible the only known "cure" for the condition — a surgical hemispherectomy — the removal or disconnection of the affected side of the brain. Recent progress in understanding of the disease, and the emergence of therapies that slow disease progression and help control symptoms, has led some researchers to believe that more targeted and effective medical treatments are potentially within reach.

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