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# CURE

Citizens United for Research in

## EPILEPSY

CURE Winter 2013 eUpdate

Dear Friends,

I recently spent two days at a small meeting in Washington, D.C. where CURE invited leading epilepsy researchers to work as a team with the goal of finding a cure for infantile spasms—a syndrome that can be particularly devastating in early childhood. The emphasis on a team approach to science is novel, as the incentives in the field around publishing and sharing of data aren't aligned this way. The researchers who have elected to be part of this approach are excited by a fresh way to collaborate and believe that by working together they can more quickly move science than if they were at it alone. These researchers, who have earned my deep respect, will be working together to set milestones, identify gaps, test ideas, and hopefully find a cure sooner rather than later. Their success might even ignite a new approach to science!



Our International Advisory Panel took a short break from their hard work to pose for a picture: Jong Rho, M.D. – Calgary, Alberta, Canada, CURE's Steve White, PhD and Julie Milder, PhD, Anne Berg, PhD – Chicago, Annamaria Vezzani, PhD – Italy, Howard Goodkin, M.D., PhD – Virginia, Dan Lowenstein, M.D. – San Francisco, Henrik Klitgaard – Brussels, Belgium, CURE Executive Director Bogdan Ewendt.

Throughout the meeting, I was reminded of how critical a team approach is in all that we do at CURE. From the science, to the fundraising to the awareness activities, we are only as strong as the team that we build. I joined CURE's Board of Directors 4 years ago, after losing my son to SUDEP. In a rather short time, I've seen research and awareness around this issue gain dramatic speed. But it hasn't been because of any one person... it's been very much a team effort with families working alongside professionals. Because of this, I believe we will unravel the mysteries of SUDEP so that one day, others will not suffer from the anguish and fear SUDEP causes.

Thanks to all of you for being part of the CURE team. There are always ways to get more involved and I encourage you to reach out, if you haven't already, and join us in this fight.

**Gardiner Lapham**  
CURE Board Member

#### YOUR DOLLARS AT WORK

### CURE Grantee Uncovers A Potential Cause of Childhood Epilepsy

CURE Grantee Peter Crino, MD, PhD, has found important new evidence that the Human papillomavirus (HPV) virus – the most common cause of cervical cancer – may be linked to childhood epilepsy. This breakthrough discovery may lead to a definable cause and treatment for focal cortical dysplasia type IIB (FCDIIB). Dr. Crino's work has significant ramifications for how we think about this type of childhood epilepsy and could lead to new approaches to treatment and prevention.

[\[Read more\]](#)



### Introducing the Infantile Spasms Research Initiative

CURE is proud to announce the launch of its new [Infantile Spasms Research Initiative](#).

Infantile Spasms (IS) is a rare childhood epilepsy syndrome that can have profoundly negative long-term developmental and cognitive consequences. Currently available treatments are not always effective and are often associated with substantial adverse effects.

The initiative is unconventional for the research community; one of the goals is for all funded laboratories to function as part of a collaborative team focused on the common goal of finding a cure for infantile spasms.

The Infantile Spasms Research Initiative has sparked excitement among the epilepsy community - particularly a group of thirty-two investigators CURE has presented with the Advancing Understanding of Infantile Spasms Award. A team of

#### WHAT'S HAPPENING AT CURE



### Joining Forces with Howard Hughes Medical Institute

CURE is pleased to announce an exciting new partnership with the Howard Hughes Medical Institute's Medical Research Fellows Program. CURE will provide financial support for up to three medical students each year to conduct mentored research on epilepsy.

The goal of HHMI's Medical Research Fellows Program is to increase the number of future physician-scientists and medically-trained researchers by immersing medical, dental, and veterinary students in full-time research early in their professional education. This is done before students make plans for their residency or postgraduate training so that they can consider a career as a physician-scientist, dentist- or veterinarian-scientist. The Fellows gain the research training by engaging in basic, translational or applied biomedical research for a full year at academic or nonprofit institutions.

[\[Click here to read the full article\]](#)



### Not Enough Hours In Your Day?

Icelandair has generously donated a 4 day trip for two to Iceland. For the month of February, CURE is auctioning the trip to the highest bidder. Bidding starts at \$2500 and the final amount will fund

key international advisors will lead these investigators and the initiative to accelerate the understanding of IS and advance a new, innovative therapy into the clinic.

The team recently held their kickoff meeting in Washington, D.C. Stay tuned for updates!

### **\$600,000 Awarded to 2013 Grantees**

Citizens United for Research in Epilepsy (CURE) has selected the grant recipients of their 2013 Innovator Awards and Taking Flight Awards.

Innovator Awards are one-year grants up to \$50,000 in support of the exploration of a highly novel concept or untested theory that addresses an important problem relevant to epilepsy. Taking Flight Awards are one-year grants up to \$100,000 in support of young investigators.

CURE's research program addresses the goals of "no seizures, no side effects," with specific focus on the following areas: prevention of epilepsy, including post-traumatic epilepsy; advancement of the search for a cure; elimination of treatment side effects; and elimination of deficits caused by frequent seizures.

After a rigorous grant review process, CURE is proud to announce the following grant recipients from around the country and the world. A total of \$600,000 has been allocated in this first funding cycle for CURE in 2013.

To learn more about the grantees, visit [cureepilepsy.org/research/2013grantees.asp](http://cureepilepsy.org/research/2013grantees.asp)

#### **IN THE NEWS**



### **Low Carbohydrate Diet Effective in Juvenile Myoclonic Epilepsy**

Dietary modification can be an effective adjunct to drugs in people with juvenile myoclonic epilepsy (JME), according to a study reported in *Epilepsy & Behavior*. The study found that children and adults who were able to follow the modified Atkins Diet for at least 1 month experienced a significant reduction in the frequency of seizures.

research in epilepsy; so travelers have the unique opportunity to visit a majestic country, enjoy 24 hours of sunlight atop a glacier, *and* contribute to an important cause. The trip includes two tickets on Icelandair, accommodations, activities, meals and local transportation. It is scheduled for June 19-23. Visit [ [here](#) ] to place your bids!

### **Welcome, Ashleigh and Kacie!**

CURE is excited to introduce two new members of the team: Ashleigh Henrichs as Outreach Coordinator and Kacie Cysewski as Administrative Assistant!

After ten years in the financial publishing field, [Ashleigh](#) moved to the non-profit sector and then joined CURE in 2012. As the Outreach Coordinator, she'll focus on maximizing volunteer and community engagement in CURE's special events and local fundraisers. Ashleigh and her husband have three children, the oldest of whom has epilepsy. She is passionate about finding a cure and is excited to be surrounded by people who share her mission.

[Kacie](#) comes to CURE from the University of Iowa where she earned a degree in communications studies. While attending school, she became involved with multiple philanthropic organizations. Her experience with nonprofits has helped shape the career path she has chosen and Kacie is thrilled to be part of the CURE team, working toward a mission she deeply believes in.

#### **RECAP**



### **Slash the 'Stache, Beginning to End**

If you're feeling nostalgic, or looking for a history lesson in facial hair, check out this clip from CNN – they documented the evolution of one of our biggest campaigns – Slash the 'Stache. Thanks again to our many friends and supporters for helping us raise over \$1 million for research in epilepsy!

[Watch the video](#)

#### **UPCOMING EVENTS**

Check out these great upcoming events across the country!

[\[Read more\]](#)

### Epilepsy, Migraines May Have Family Ties

People with epilepsy have a higher risk for migraines, and now new research offers evidence of a genetic link between the two conditions. The study confirmed that having a strong family history of epilepsy is a strong risk factor for migraine headaches.

[\[Read more\]](#)

### CURE is going quarterly

CURE is implementing a new e-update schedule. We will now be releasing e-updates on a quarterly basis instead of monthly. To stay "in the know," make sure you subscribe to Susan's weekly blog *Chair's Corner*. And follow us on [Facebook](#) and [Twitter!](#)



### Clipper Round the World – Level 2 Training

March 1-11, 2013  
North Sea  
Info: [Event Details](#)



### Hugh-a-thon swim-a-thon

March 2, 2013  
Info: [Event Details](#)



### RE: Epilepsy

March 9, 2013  
Highwood, IL  
Info: [Event Details](#)



### Rhode Island CURE Event

March 22, 2013  
Info: [Event Details](#)



### 50 Candlelight Concerts for Epilepsy Awareness in 50 states

March 22-24, 2013  
Info: [Event Details](#)

[Click here](#) for more information on upcoming events

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