



CURE

**CITIZENS UNITED FOR
RESEARCH IN EPILEPSY**

Research on Epilepsy Toward Patient Impact

Laura Lubbers, PhD
Chief Scientific Officer

Our Mission

- **CURE**'s mission is to find a **cure for epilepsy**, by promoting and funding patient-focused research.



CURE's new CEO, Beth Dean



EDUCATION

UNIVERSITY OF CHICAGO, GRADUATE SCHOOL OF BUSINESS, MBA

INDIANA UNIVERSITY, SCHOOL OF PUBLIC & ENVIRONMENTAL AFFAIRS, MPA

CORNELL COLLEGE, BA

PROFESSIONAL EXPERIENCE

ELI LILLY & COMPANY

Marketing Professional, Insulin Brand Team

ABBOTT LABORATORIES

Senior Product Manager, Neuroscience Marketing

LUNDBECK (Formerly OVATION PHARMACEUTICALS)

Vice President, Early Commercialization, New Product Planning & Life Cycle Management

Vice President, Onfi Business Leader

Vice President, Epilepsy Marketing

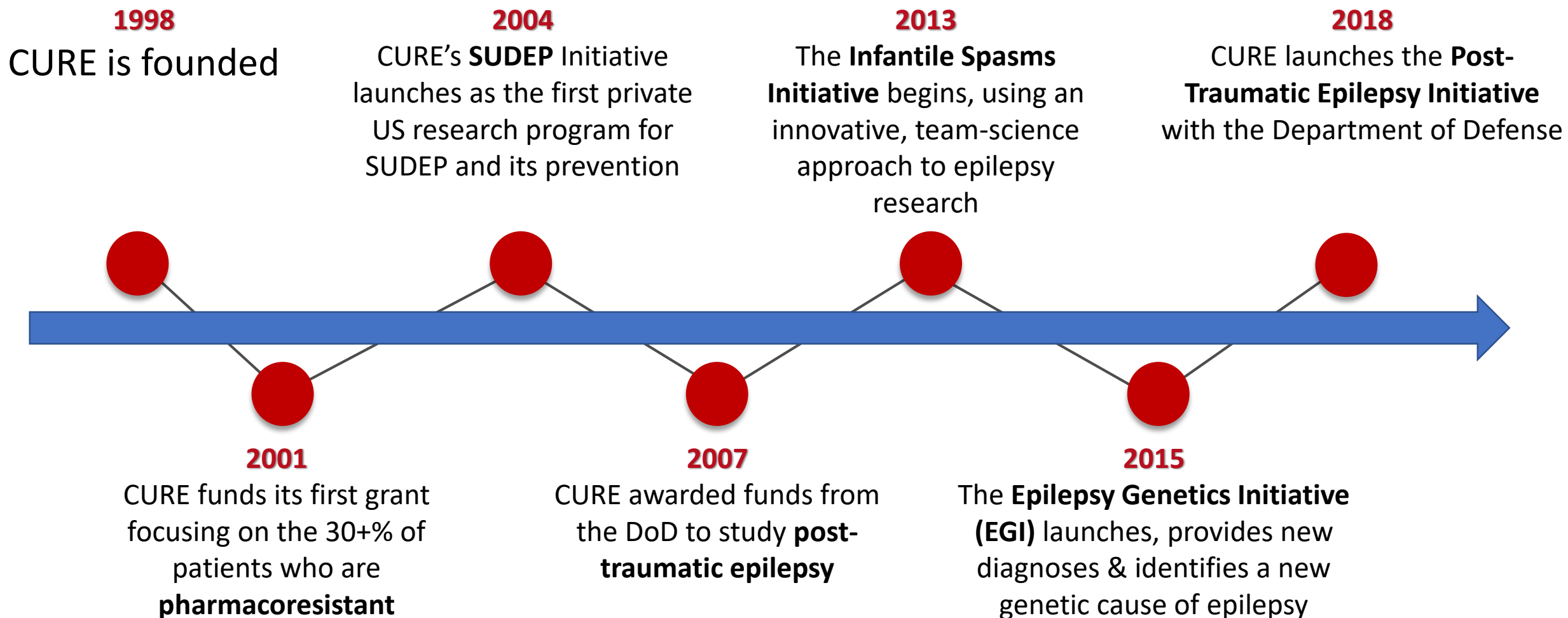
AQUESTIVE THERAPEUTICS

Vice President and General Manager, CNS Products



CURE Has Funded More Than **230** Scientific Projects
in **15** Countries

CURE Research highlights, by the years



CURE Research

Investigator-Initiated Grant Programs



**Acquired
Pediatric
Pharmacoresistant
Sleep
SUDEP**

❑ **CURE Epilepsy Award** reflects CURE's focus on scientific advances that have the potential to truly transform the lives of those affected by epilepsy, with prevention and disease modification as critical goals

❑ Up to \$250,000 over 2 years

❑ **Taking Flight Award** seeks to promote the careers of young investigators to allow them to develop an independent research focus.

❑ Up to \$100k over 1 year

**Call for Letters of Intent for both awards in
November 2019**

CURE Research

Precision Medicine Epilepsy Genetics Initiative



❑ Enrollment

- ❑ 415 people with epilepsy
- ❑ 1039 total enrollments

❑ Diagnoses

- ❑ 13 new diagnoses based on existing whole exome sequences
- ❑ Increases diagnostic yield by ~6.5%

❑ Publications

- ❑ De novo variants in the alternative exon 5 of SCN8A cause epileptic encephalopathy, *Genetics in Medicine*, 2017
- ❑ De novo mutations in PPP3CA cause severe neurodevelopmental disease with seizures, *Am. J. Human Genetics*, 2017
- ❑ The Epilepsy Genetics Initiative: Systematic reanalysis of diagnostic exomes increases yield, *Epilepsia*, 2019

❑ Data released to research community

- ❑ The EGI Data Browser (Columbia University, NY)
- ❑ NIH Database of Genotypes and Phenotypes (dbGaP)

❑ Next Analysis: Summer 2019

CURE Research

Post-Traumatic Epilepsy Initiative



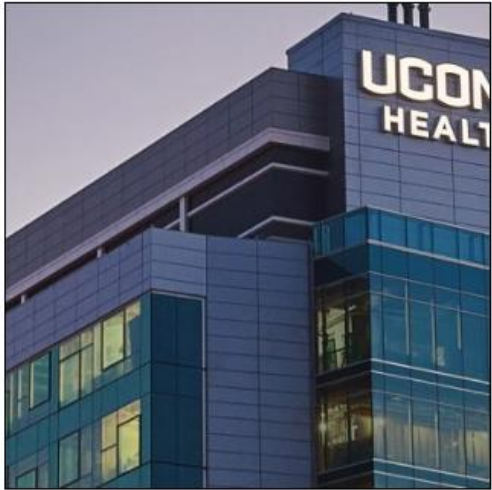
In collaboration with the U.S. Department of Defense, CURE created a research program focused on post-traumatic epilepsy (PTE) as a result of traumatic brain injury

❑ The Team:

- **Victoria Johnson, University of Pennsylvania**
Neuropathological mechanisms of epileptogenesis in post-traumatic epilepsy
- **Jeffrey Loeb, University of Illinois, Chicago**
Targeting epileptogenic effects of subarachnoid blood in TBI
- **Harald Sontheimer, Virginia Polytechnic Institute & State University**
Vascular injury, gliosis & neurogenesis as drivers for post-traumatic epilepsy
- **Kevin Staley, Harvard University**
The role of extracellular matrix injury in post-traumatic epilepsy
- **Kevin Wang, University of Florida**
Identifying proteomic, metabolomic and microRNA signatures for spontaneous seizures in a rat model of brain injury
- Other participants
 - Art Toga, Laboratory of NeuroImaging, University of Southern California: Data repository & case report form development
 - AES/ILEA Translational Task Force: Common Data Elements

CURE Research Support

CURE Frontiers in Research Seminar Series



Epilepsy and Drug Discovery in Larval Zebrafish

Tuesday, April 23, 2019

University of Connecticut School of Medicine,
Academic Way Farmington

Speaker: Scott Baraban, PhD (University of California San Francisco)

Host: Eric Levine, PhD

LEARN MORE



Seminars at:

- University of Utah School of Medicine
- University of Connecticut Health Center
- University of Washington
- Dartmouth-Hitchcock-Medical Center
- University of Cape Town
- Baylor College of Medicine
- Boston University
- Expesicor, Inc & The University of Montana

Call for applications for 2020 seminar series to be released in May 2019

CURE Research Support



You are invited to participate in the Basic Mechanisms of the Epilepsies (BME) Workshops in Yosemite National Park,

For the past 5 decades, the Basic Mechanisms of the Epilepsies (BME) Workshops has provided a unique opportunity for basic research scientists in epilepsy to

2019 Conferences:

▪ 4 Basic & Translational Research Conferences

- Jasper's Basic Mechanisms of the Epilepsies, Yosemite, CA
- Gordon Research Conference on Inhibition in the CNS, Newry, ME
- Epilepsy Precision Medicine, Half Moon Bay, CA
- Park City Epilepsy Meeting: Cutting Edge Approaches to Transform Therapy Development, Park City, UT

▪ 3 Family Advocacy Research Conferences

- STXBP1 Investigators and Family Meeting, Philadelphia, PA
- 2019 CFERV Conference on GRIN, Atlanta, GA
- 4th International Symposium on Hypothalamic Hamartomas, Washington DC

▪ 2 Clinical Conferences

- Residential International Course on Drug Resistant Epilepsies, Tagliacozzo (AQ), Italy
- 8th Eilat International Educational Course: Pharmacological Treatment of Epilepsy, Jerusalem

Research Resources



Leaders in Epilepsy Research Webinar Series

2019
Epilepsy & Pregnancy
Transition of Care
Dietary Options for Epilepsy
Epilepsy Surgery
...more topics to come



Discovery News



Day of Science Gatherings

Houston, March
Boston, May

**Other cities & dates to be
announced**

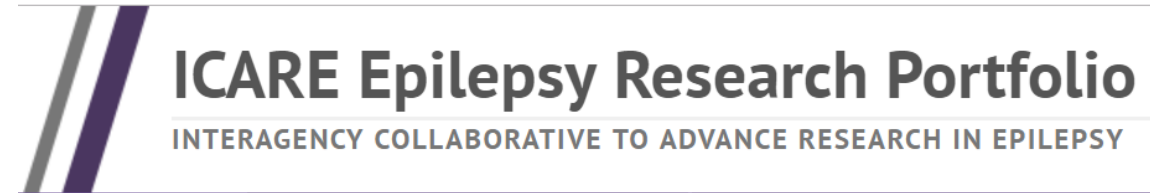
Research Advocacy

2000



Curing the Epilepsies

2010



2012

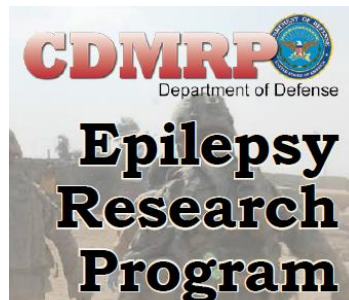
EPILEPSY
across the SPECTRUM
PROMOTING HEALTH AND UNDERSTANDING

2014

Monday, December 8, 2014

NIH initiates "Centers Without Walls" to study sudden unexpected death in epilepsy

2015



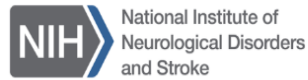
2018



Epilepsy Leadership Council Policy Agenda

Revising the NINDS Benchmarks for Epilepsy Research

Incorporating the patient perspective



Curing the Epilepsies



AMERICAN
EPILEPSY
SOCIETY



Dec 2018

Benchmark Chairs, Leads & ELC liaisons meet at AES to discuss progress & next steps for epilepsy research

June 2019

ELC members contribute vignettes of experiences to accompany scientific reviews for publication

**Spring 2020
Conference**



Curing the Epilepsies

April 2019

ELC provides feedback on future research opportunities & 2020 conference agenda to Benchmark Chairs

September 2019

ELC drafts editorials to accompany scientific reviews

Thank you from the CURE Research Staff



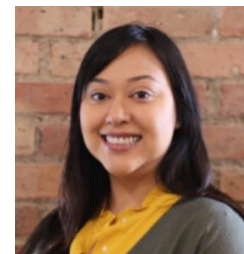
Laura S. Lubbers, PhD
Chief Scientific Officer



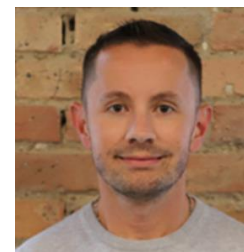
Priya Balasubramanian, PhD
Associate Director, Research



Lauren Harte-Hargrove, PhD
Associate Director, Research



Alexandria Granados
Manager, Research Administration



Brandon McLaughlin
EGI Project Manager