

Epilepsy Foundation Research

“Making a Difference”

Foundation Research Program

▶ *EF receives 200+ proposals/year; funds ~50*

- Training Grants: seed grants for young investigators
- Research Fellowships
- Targeted Research Grants
- Translational Research Grants
- Research Infrastructure Grants

▶ *Clinical Trials web page at EF site*

▶ *Partnerships with sister organizations*

▶ *Research newsletter*

Key Goals

- ▶ Coordinating research agendas w/sister orgs
- ▶ Maximizing research dollars
- ▶ Furthering NINDS Epilepsy Benchmarks:
 - ‘Prevent epilepsy and its progression...’
 - ‘Develop new therapeutic strategies...’
 - Prevent, limit, and reverse co-morbidities
- ▶ Incorporating IOM report recommendations:
 - Studies to Improve Surveillance and Prevention
 - ...to Improve Health Care and QOL
 - ...to Raise Awareness

Research Fellowships

- ▶ Post-Doctoral Research Fellowship
- ▶ Research and Training Fellowships for Clinicians
- ▶ Pre-Doctoral Research Training Fellowship
- ▶ Behavioral Sciences Student Fellowships
- ▶ Behavioral Sciences Post-Doctoral Fellowships
- ▶ Health Sciences Student Fellowships
- ▶ *Fall 2011: 150 proposals submitted; 35 awarded*

Targeted Research Initiatives

- ▶ Cognitive and Psychiatric Aspects of Epilepsy
- ▶ Health Outcomes
- ▶ Morbidity and Mortality
- ▶ Pediatric/Youth
- ▶ Severe Symptomatic Epilepsies
- ▶ Women with Epilepsy
- ▶ *Spring 2012: 36 proposals submitted; currently finalizing*

EF Grants for Co-Morbidities

- ▶ Since 2005, EF has funded 20+ researchers to study co-morbidities of epilepsy
- ▶ EF grants for research in co-morbidities total at least \$1m
- ▶ Funding for these aspects of epilepsy have had few other sources: mood disorders, cognitive functioning, psychiatric aspects, and mortality

EF Grants for MM (20): 2005 – Present

► **Depression/Anxiety:**

- In children: Learned hopelessness model—developing interventions
- Causes: Hormonal dysregulation due to seizures? Inflammation of certain areas of the brain? Dysfunction of serotonergic system?
- Modeling relationship between depression, memory dysfunction, hippocampal atrophy
- Anxiety: Analysis of TLE patients; Brain imaging for biomarkers of people with epilepsy
- Suicide: Neurobiology through functional MRI
- Antidepressant drugs: Do they slow or stop seizures?
- Epilepsy's effects on amygdalar activity, governing emotions

► **Cognitive Functioning:**

- Role in risk for depression?
- Memory in Pediatric Epilepsy: Contributing factors

► **Social Cognition and Psychosocial Functioning:**

- Stigma in epilepsy
- Temporal lobe epilepsy

EF Programs in Co-Morbidities

- ▶ **Focusing on awareness/treatment since 2005:**
 - Cognitive delays
 - Mood disorders
 - Depression
- ▶ **Booklet for consumers: “About Depression”**
- ▶ **Screening tool/checklist: NDDI-E (Neurological Disorders Depression Inventory for Epilepsy)**
- ▶ **Fact Sheets:** Effects of meds; school and employment issues; ADD and LD in epilepsy
- ▶ **Webinar: “Non-Epileptic Seizures (NES)”**

EF Web Page on Clinical Trials

- ▶ Web page access to ongoing clinical trials
- ▶ Educational, patient involvement, living w/epilepsy
- ▶ From lay person's perspective
- ▶ Selected stories shared Facebook, NIH trials
- ▶ Location:
 - ***Off of main EF site (epilepsyfoundation.org):***
'Research' and button on 'Participate in...':

Partnership: Amer Epilepsy Society

- ▶ Share common application w/AES for pre- and post-doctoral research grants
- ▶ Infrastructure grants (co-funded w/AES)
 - Clinical and basic science awards
 - Supports pilot programs w/multi-center sites
- ▶ EGAD (Epilepsy Grant Award Database):
 - Evaluate impact of grant awards on career development
 - Most recipients progress to NIH R01 grant awards

Partnerships, cont.

▶ ***Epilepsy Research Foundation:***

- **New Therapy Grants Program**
 - Co-funded with Epilepsy Therapy Project
 - Intended for translational research by experienced investigators, for ‘commercializable’ projects

▶ ***Susan S. Spencer Clinical Research Training Fellowship***

- Supported by the EF, AES, and AANF (American Academy of Neurology Foundation)
- Intended for clinical research methodology

Epilepsy Foundation Research Grants Target Rare Oravet Syndrome

"This is huge!" said Mary Anne Meskis on hearing the Epilepsy Foundation had awarded three grants totaling nearly \$100,000 to study one of the most severe forms of epilepsy: Dravet Syndrome. "We haven't seen that many grants for that much money at once. I'm just amazed."

Meskis' son was diagnosed with Dravet Syndrome in 2004. "back when there were only about three hits about it on Google," she explains.

Like many other parents whose children have severe epilepsies—West. Lennox-Gastaut, Othara Syndrome among others—Meskis took up the cause for a cure, co-founding and now directing the [Dravet Syndrome Foundation](#) in Connecticut.

Otherwise known as Severe Myoclonic Epilepsy of Infancy, Dravet Syndrome usually appears before a child's first year. Characterized by the French neurologist Charlotte Dravet in 1978, the syndrome has clear genetic causes and well-defined treatments.



But Dravet Syndrome is rare—it "maybe affects

Dravet Syndrome: The Importance of Awareness

After Grapevine, Texas resident Chuck Sparks published a 2007 In My Own Words column about his daughter Shelby in EpilepsyUSA, he and wife Lauren heard from Jennifer May, who told the Sparks that Shelby sounded like her son.

Chuck had written of feeling "helpless" as he described seizures without a diagnosis.

May's call—which Lauren says she "initially blew off" because "I felt like we had run every test and looked under every rock we could for Shelby"—turned over the biggest rock of all by

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