

Stronger Together



2013 ANNUAL REPORT



EPILEPSY
FOUNDATION®



epilepsy
therapy project

Stronger Together

About Epilepsy

When a person has two or more unprovoked seizures, they have epilepsy, which affects more than 2 million people in the United States and 65 million people worldwide. This year, another 200,000 people in our country will be diagnosed with epilepsy. Despite all available treatments, four out of 10 people with epilepsy continue to experience uncontrolled seizures while many more experience less than optimal seizure control.

About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with 47 affiliated organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The Foundation works to prevent, control and cure epilepsy through community services; public education; federal and local advocacy; and supporting research into new treatments and therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit www.epilepsy.com.

“Like” the Epilepsy Foundation on Facebook at www.facebook.com/epilepsyfoundationofamerica and follow us on Twitter at www.twitter.com/epilepsyfdn.

How Can You Make a Difference?

Giving to the Epilepsy Foundation means you make the world a better, easier, more manageable place for the more than 2 million people in the U.S. who are living with epilepsy and seizures.

DONATE NOW

Make a donation and help ensure that not another moment is lost to seizures for those living with epilepsy by:

Phone: (800) 213-5821

Email: RDev@efa.org

Online: www.epilepsy.com

Other Ways to Give

Honor & Memorial Gift

Pay tribute to a loved one and make a gift in their honor or their memory.

Monthly Gift

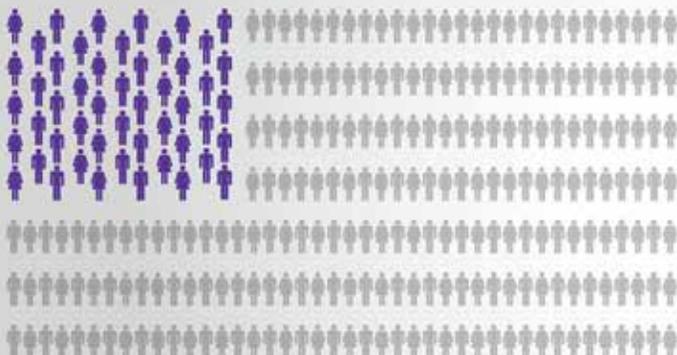
Give a recurring monthly donation to support the Epilepsy Foundation. Set up is easy, plus your ongoing support offers strong and steady funding.

Clothing Donations

Give gently used items and the Epilepsy Foundation will benefit from your generosity. The Epilepsy Foundation has partnered with Savers, Inc., a leading privately held thrift store chain with more than 320 locations. Contributions of slightly used items are part of a simple, convenient, yet impactful way for people to support the Epilepsy Foundation. Within this partnership, Savers pays the Epilepsy Foundation for every donation.

Vehicle Donation

Donate an automobile, RV, truck, boat or trailer to the Epilepsy Foundation and you can earn a charitable income tax deduction. You'll avoid the costs and hassle of selling a used vehicle and we'll tow your vehicle for free. You must own a clear title to donate a vehicle.



More than

2,000,000

PEOPLE in the United States have epilepsy.

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Letter from the President and Chair

Dear friends,

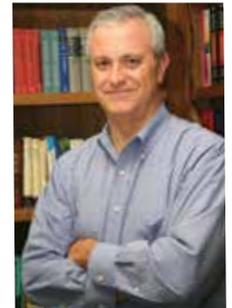
2013 represents a new beginning for the Epilepsy Foundation that will have enduring benefits for individuals living with seizures and for the entire epilepsy community. The Epilepsy Foundation and Epilepsy Therapy Project, after a successful, decade-long partnership in the funding of new therapies, have come together to form one organization with a stronger voice in education and awareness and with a greater ability to improve the lives of people with epilepsy and to accelerate new therapies to market in a timeframe that matters.

Together, our time is now.

The Epilepsy Foundation is pushing forward to improve the lives of the more than 2 million Americans living with epilepsy. A full one-third of people with epilepsy have seizures that cannot be controlled by currently available therapies. For many more, side effects of treatments including fatigue and dizziness have a dramatic impact on quality of life. Epilepsy, being a spectrum condition, is different for each and every person who lives with it. Some have their seizures controlled with medication; some live with hundreds of seizures a day. For others, epilepsy robs them of their lives.

The Epilepsy Foundation is a family-led organization dedicated to being an unwavering ally for all people impacted by epilepsy and seizures.

Phil's Story: When our 4-year-old son Philip had his first seizure, Jill and I didn't know what was happening and we were very frightened. Philip was in intensive care for four days. The hospital staff told us that Philip may be among the one in 10 Americans who have one seizure during their lifetime. We were devastated to find just a few weeks later, our son was having multiple seizures a day. Our son had recurrent seizures, epilepsy. And, our family began a journey that was heartbreaking at first, but not without promise and hope.



In our journey to find answers, we found a parent support group through the Epilepsy Foundation of Greater Chicago. The Epilepsy Foundation helped us find an epilepsy center that had medical professionals committed solely to helping individuals living with seizures. It was our association with the Epilepsy Foundation and with Philip's medical team that began to make the difference. In many ways, Philip and our family were lucky to find good care for his seizures.

Warren's Story: Our daughter Sylvie's first two seizures came out of the blue one afternoon when she was nine months old and led into an episode of status lasting more than 30 minutes that evening, a two week stay in the ICU, and a journey into the challenging world of uncontrolled seizures and Dravet's. Our family was fortunate to find caring, knowledgeable doctors in Denver and then New York and Boston but unfortunate to learn that for Sylvie, as for so many people with seizures and epilepsies, the best doctors did not have answers for her seizures. And yet we were blessed to have the opportunity to work with many of those doctors, and with other families and caregivers, to embark with the Epilepsy Therapy Project family and soon the Epilepsy Foundation family on a quest to find those answers and therapies that could make a difference for Sylvie and for millions living with seizures and epilepsies around the world.



At the Epilepsy Foundation, we believe that no individual or family should have to be "lucky" to find good care for their seizures, and we believe that no individual or family should have to live with uncontrolled seizures, debilitating side-effects or the loss of a loved one to seizures and epilepsy.

In the last year, the Epilepsy Foundation's staff and volunteers across our network of 47 affiliates provided supportive care, public education, outreach and services, all at no cost, to more individuals and families than ever before.

We are building on the incredible strength and reach of epilepsy.com, creating the most comprehensive consumer information and public education website in the world.

We are focused more than ever on advancing new therapies in a timeframe that matters for all people living with epilepsy today and to strengthening our ability to fund the very best research that will advance our mission.

We are working with strong partners, allies and friends to help build public awareness, so all people will know how to recognize a seizure and what to do if they see someone having a seizure.

We are advocating for and protecting the rights of all people living with seizures, so they can have the opportunity to participate fully and without discrimination in their communities, schools or places of work.

We invite you to read through our annual report, review the highlights from this past year and celebrate with us as we begin this new and exciting chapter in our organization's history. With your continued support, we will accelerate our shared vision and work together to see a day when we all live in a world without seizures.

Thank you,

Phil Gattone

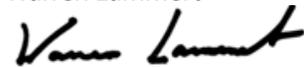


President and CEO



Stronger Together

Warren Lammert



Chair, Board of Directors

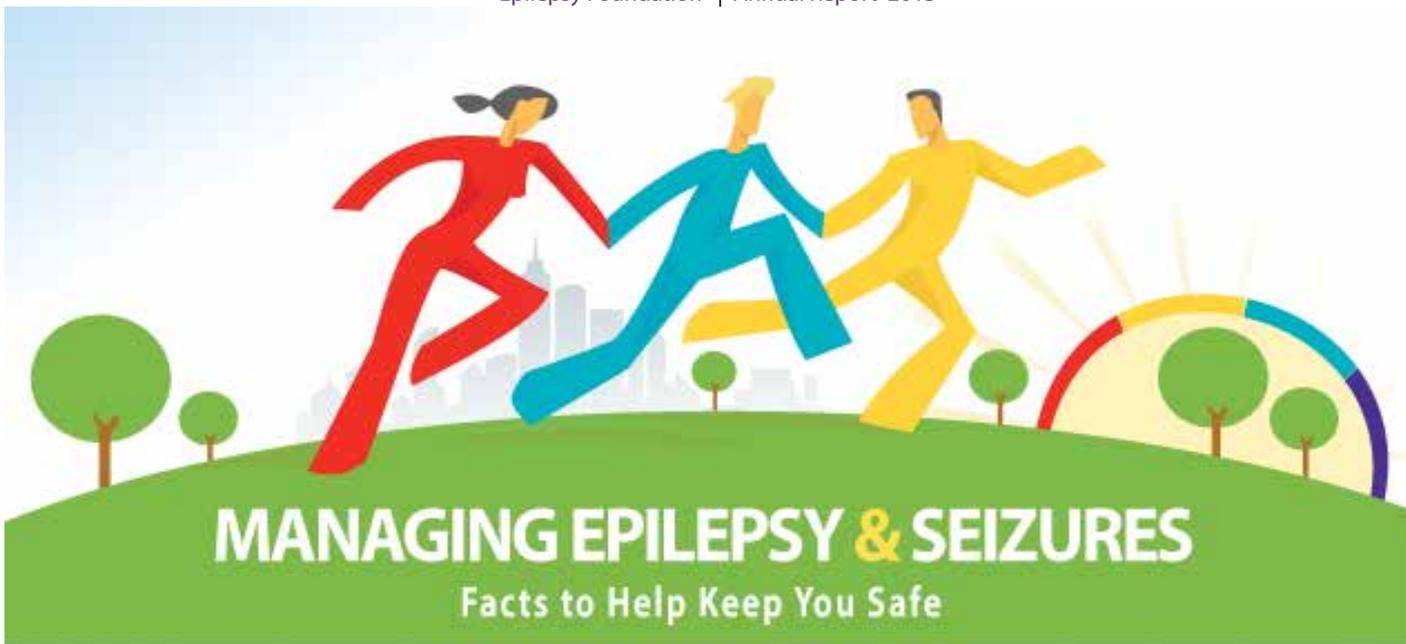


"Unmasking Epilepsy" by Angel

studio  The Epilepsy Art Therapy Program



Stronger Together



Communication is key for others to help you

Work with your doctor to understand your risks and make a plan

Get answers to these questions:



What type of seizures (or epilepsy) do I have?



What should I do if I have another seizure?



How can I prevent future seizures?



What are common side effects of my medicines?



What should I do if I forget to take my medicine?



If my medicines aren't working, what other treatment options do I have?



What is my risk of Sudden Unexpected Death in Epilepsy (SUDEP)?

Each year SUDEP happens to about 1 in every 1,000 people diagnosed with epilepsy. Some people are at more risk than others. To lower your risk, work with your doctor to create a seizure management plan that leads to as few seizures as possible.

Brought to you by



Visit www.epilepsy.com or call 800.332.1000 to learn more about support and services in your area.

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Source: Information and statistics are based on data from The Centers for Disease Control and Prevention

STRONGER TOGETHER



“Healer” by Angie Bryant

studio  The
Epilepsy
Art Therapy
Program



Stronger Together

Epilepsy Foundation and Epilepsy Therapy Project Finalize Merge to Create Strong, Unified Organization to Support People with Epilepsy

New Foundation drives awareness, provides supportive care and accelerates new therapies for millions of people living with seizures.

Washington, D.C., December 26, 2012 – The Epilepsy Foundation (EF) and the Epilepsy Therapy Project (ETP) announced today that their Boards of Directors have unanimously approved the merger of the two organizations. The new organization, known as the Epilepsy Foundation, fights for more than 2 million Americans and their families living with epilepsy today and the one in 26 Americans who will develop epilepsy at some point in their lives. The new mission of the Foundation is to stop seizures and SUDEP, find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies. This strategic merger of EF and ETP has garnered tremendous support from leaders in the healthcare advocacy and research communities.

“The Epilepsy Community has an obligation and now an opportunity to step forward with a strong unified voice to bring greater resources to bear at the national and at the local level to improve the lives of people with epilepsy,” said Warren Lammert, chairman and co-founder of the Epilepsy Therapy Project. “The merger of EF and ETP creates an opportunity, working together with the 47 local affiliates of the Epilepsy Foundation, to make a real difference through a comprehensive agenda that includes education, advocacy, awareness, local services and supporting research and the development of new therapies in a time frame that matters to people living with epilepsy today.”

“Across all diseases and life-threatening conditions, patient-focused organizations – and patients themselves – are leading the way toward better treatments,” said Michael Milken, chairman of FasterCures. “The merged resources of the Epilepsy Therapy Project and Epilepsy Foundation will give individuals living with the condition – and their families – an even stronger advocate and partner working to accelerate research and discovery.” Since 1998, the Milken



Phil Gattone, Epilepsy Foundation president and CEO, shakes hands with Warren Lammert, chairman and co-founder of the Epilepsy Therapy Project, in celebration of the organizations' merger

Family Foundation has worked alongside the Epilepsy Therapy Project and Epilepsy Foundation, providing funding to young investigators focused on developing more effective treatments for the condition.

Under the agreement, the Epilepsy Therapy Project will continue supporting scientific and clinical research with an emphasis on translational medicine and new product development under the Epilepsy Foundation umbrella. Phil Gattone, EF president and CEO, will continue to lead the Epilepsy Foundation. Warren Lammert, ETP chairman and co-founder, will serve on the board of directors of the new organization and play a crucial role during the merger transition period. Members of both boards, representing some of the most renowned researchers and practitioners in epilepsy, will hold seats on a newly formed board of directors. The award-winning patient care website www.epilepsy.com will serve as the premier source of accurate information regarding epilepsy and seizures. The new organization will be headquartered in Landover, Maryland, with 47 regional affiliate offices located throughout the United States.

“Epilepsy is more prevalent than autism, multiple sclerosis, cerebral palsy and Parkinson’s disease combined – and takes thousands of lives each year. This is why we need to advance the cause of epilepsy together and forcefully,” said Gattone, also the father of a child with epilepsy. “This Foundation and our affiliates are at the forefront of transforming how we comprehend, treat and support people with epilepsy – from



(l-r) Brien J. Smith, MD, FAAN, 2012-2013 Epilepsy Foundation chairman; Warren Lammert, chairman and co-founder of the Epilepsy Therapy Project; Joyce A. Bender, Epilepsy Foundation board member; Greg Grunberg, actor and Epilepsy Foundation spokesperson; and Phil Gattone, Epilepsy Foundation president and CEO

government lobbying at the national level to supporting the child and family in your community. Our affiliated chapters around the country provide free services to all. We are dedicated to helping address the public health dimensions associated with seizure disorders, including access to care, challenges in school, Sudden Unexpected Death in Epilepsy (SUDEP) and other devastating consequences of uncontrolled seizures, furthering opportunities for gainful employment and independent living.”

The new Epilepsy Foundation brings together the mission and assets of both organizations:

- epilepsy.com, the leading portal for people, caregivers and professionals dealing with epilepsy;
- 47 affiliated Epilepsy Foundations around the country dedicated to providing free programs and services to people living with epilepsy and their loved ones;
- Scientific, Professional and Business Advisory Boards comprised of leading epilepsy physicians, health care professionals and researchers, industry professionals and investors with experience in clinical care, as well as in the evaluation and commercialization of new therapies;
- A track record of identifying and supporting important new science, translational research programs, and the most promising new therapies;
- The Epilepsy Pipeline Conference, a leading global forum organized in partnership with the Epilepsy Study Consortium that showcases the most exciting new drugs, devices and therapies, and includes the Epilepsy Shark Tank; and
- A professional advocacy network focused on increasing epilepsy government and military funding and initiatives at the federal, state and local levels.

Epilepsy Across the Spectrum: Recommendations from the Institute of Medicine's report to promote health and understanding in the epilepsies

by Patricia Osborne Shafer RN, MN
and Joan K. Austin, RN, PhD, FAAN

One of the most exciting events in epilepsy occurred last year with the release of the Institute of Medicine (IOM) report *Epilepsy Across the Spectrum: Promoting Health and Understanding*, published in March 2012 (1). The IOM is a nonprofit organization that works outside the government to help those in government and the private sector make informed health decisions based on reliable evidence. The IOM uses a rigorous process in the development of reports.

In 2010, 24 organizations including federal agencies and nonprofit epilepsy organizations came together and asked the IOM to study the public health aspects and problems of epilepsy and to develop recommendations for change. The impetus for this request was clear. While progress in biomedical research has been made, despite repeated calls for action, large gaps in health care and social services for people with epilepsy remain. The committee was asked to study four main areas in epilepsy:

- public health surveillance and data collection
- population and public health research
- health policy, health care and human services
- education of people with epilepsy, families, health care providers and the public



The Institute of Medicine helps those in government and the private sector make informed health decisions based on reliable evidence.

The IOM study, conducted between January 2011 and March 2012, included public workshops and committee meetings. Two articles covering the 13 recommendations and research priorities, as well as some of the public testimonies, have been published (2, 3). In this article, we briefly summarize the findings that led to the recommendations (see IOM Recommendations sidebar) and highlight those that are especially relevant to the work of the Epilepsy Foundation.

IOM Recommendations

Surveillance and Prevention

1. Validate and implement standard definitions and criteria for epilepsy case ascertainment, healthcare and community services use and costs, and quality-of-life measurement
2. Continue and expand collaborative surveillance and data collection efforts
3. Develop and evaluate prevention efforts for epilepsy and its consequences

Health Care

4. Improve the early identification of epilepsy and its comorbid health conditions
5. Develop and implement a national quality measurement and improvement strategy for epilepsy care
6. Establish accreditation of epilepsy centers and an Epilepsy Care Network

Health Professional Education

7. Improve health professional education about the epilepsies

Quality of Life

8. Improve the delivery and coordination of community services

Education for Patients and Families

9. Improve and expand educational opportunities for patients and families

Public Awareness

10. Inform media to improve awareness and eliminate stigma
11. Coordinate public awareness efforts

Stakeholder Collaboration

12. Continue and expand Vision 20-20 working groups and collaborative partnerships
13. Engage in education, dissemination, and advocacy for improved epilepsy care and services

Surveillance and Prevention

The committee found significant gaps in information about the numbers of people who have epilepsy, their health care, and the other services they use. They also found gaps in knowledge about the risk factors for epilepsy, the other conditions associated with epilepsy or comorbidities, and outcomes. These gaps limit the opportunities for preventing epilepsy and its range of consequences.

The IOM committee had three recommendations in this area and called for expansion of surveillance methods and data collection by the Centers for Disease Control and Prevention (CDC) in collaboration with other agencies and stakeholders involved in this type of research. While people with epilepsy and the general public may not conduct this research, they must recognize how important it is to have real data to make changes. People can help by advocating for this type of research funding and participating in public health research when opportunities arise.

Health Care and Education of Health Care Professionals

Many gaps and problems in health care for people with epilepsy were noted during the course of this study. Large numbers of people are not getting the care they need at the right time or wait too long to get the right care. Reports of people living with seizures for more than 15 years before being evaluated at a specialized epilepsy center were found. These delays in treatment can be costly, on a personal level as well as financially. Care for epilepsy can also be fragmented and difficult to navigate with many differences among those who are treated by primary care providers, neurologists, or epilepsy specialists. Care needs also vary widely among people with epilepsy because epilepsy occurs across a spectrum with some having lives that are relatively unchanged and others that are severely affected by uncontrolled seizures and comorbidities.

While some people may have access to nurses, mental health professionals or other health care professionals to help in managing epilepsy and the way it affects one's life, others have limited or no access to these professionals. No one reason was found for these discrepancies, and it was clear that much work needs to be done to understand the current barriers and opportunities for care and how these may be changed to improve the delivery and quality of health care for people with epilepsy. The committee also found that many health care professionals were receiving very limited information about epilepsy in their educational programs.

The IOM committee had three recommendations on improving health care, including the need for early identification of epilepsy and other conditions associated with epilepsy, more attention to the quality of health care for people with epilepsy, and establishing accreditation of epilepsy centers emphasizing a patient-centered care

model. A fourth recommendation proposes strategies to improve the education of health care professionals.

Building on the understanding that epilepsy is more than just seizures and the need for earlier access to care, the committee recommended that screening methods be developed and validated in the following areas: identifying epilepsy early in those at risk for seizures; identifying comorbid conditions in people with epilepsy; and identifying persistent seizures in people with epilepsy. While this recommendation was targeted to professional organizations (such as the American Epilepsy Society and American Academy of Neurology), a collaboration of professional and patient driven epilepsy groups have come together to develop a tool for people with epilepsy/family members to identify when a higher level of care may be needed. This initiative strives to seek common messages for one of the most important issues for people with epilepsy – when and where people who continue to have seizures can get the care they need.



People can help by advocating for this type of research funding and participating in public health research when opportunities arise.

The health care recommendations will involve efforts by the Epilepsy Foundation network and other epilepsy groups in collaboration with

professional organizations and relevant stakeholders. The Epilepsy Foundation and affiliates are active in professional education initiatives to non-epilepsy specialists, for example school nurses, first responders, and other health care professionals. The recommendations encourage all organizations involved in professional education to evaluate outcomes from educational offerings and to disseminate best practices and programs more broadly. The Foundation has already begun a major effort to reach more school nurses over the next two years using a program for school nurses funded by the CDC.

Quality of Life

The committee reviewed substantial testimony and literature supporting the need to improve the quality of life of people with epilepsy. As people with epilepsy know, living with epilepsy is about much more than dealing with seizures. Many children have challenges at school and adults often have uncertainties about social and employment

situations. Certainly, many people with epilepsy face difficulties associated with limitations on driving a car and living independently. At the same time, people with epilepsy and their families are faced with health care and community services that are often fragmented, uncoordinated, and difficult to obtain.

To address these issues the committee recommended that the delivery and coordination of community resources and services for people with epilepsy be improved. For example, it is critical to have services readily available to help children with epilepsy with learning and other school problems and to help adults with employment, transportation and independent living concerns. Other proposed strategies include developing innovative partnerships with relevant organizations, developing educational opportunities for community service providers, and providing a 24/7 nonmedical help line.

The Foundation and its network of 47 affiliates throughout the country are especially poised to lead these efforts for change and growth in our communities. For example, the information and referral program is being revised to meet the needs of affiliates and people with epilepsy throughout the United States. While education and training programs for some community service providers (e.g. police officers, teachers, and adult day care providers) have been created by the Foundation with CDC support, many groups have no consistent training emphasizing the scope of work to be done.

Educating Patients and Families

People with epilepsy have significant information needs about epilepsy and its management. The committee found that when people with epilepsy were provided information about their condition and how to best live with epilepsy, they had subsequent improvements in quality of life. However, the committee found that access to resources and programs that are accurate, up-to-date, easy to understand, and linguistically and culturally appropriate is inconsistent. Many people with epilepsy experience difficulty in getting their questions answered.

The committee recommended that educational opportunities for people with epilepsy and their families be improved and expanded. Proposed strategies encourage the evaluation of existing programs and websites, dissemination of best practices, provision of accurate and timely information, and centralized online efforts to link people to appropriate resources. Epilepsy self-management needs and programs were examined as part of the committee's recommendations to improve health care and education for people with epilepsy and their families. Because epilepsy self-management takes place over time, both health care providers and community-based organizations and providers are encouraged to incorporate self-management programs and resources into their offerings and go beyond traditional information giving strategies.



The merger of the Epilepsy Foundation and Epilepsy Therapy Project provides a unique opportunity to evaluate and update their website content and materials, combine educational materials and activities to prevent unnecessary duplication, and use their combined expertise to address unmet epilepsy educational needs.

The recommendations for patient and family education are critical to efforts of the Foundation's network. The merger of the Epilepsy Foundation and Epilepsy Therapy Project provides a unique opportunity to evaluate and update their website content and materials, combine educational materials and activities to prevent unnecessary duplication, and use their combined expertise to address unmet epilepsy educational needs. For example, online information for African American and Hispanic audiences

has been developed with plans to reach out to Asian Americans over the next few years.

Public Awareness

The committee found that public misperceptions and misinformation about epilepsy continue to exist in our society. Moreover, perceptions of stigma and fears of discrimination and prejudice continue to negatively affect the quality of life of people with epilepsy. The committee recommendations in this area included steps to help engage and collaborate with the media to improve awareness about epilepsy and eliminate stigma. For example, efforts include promoting more accurate and positive story lines about epilepsy, disseminating regular updates on research and medical advances to the media, and establishing partnerships with groups of people with conditions that are

also associated with stigma. To enhance the effectiveness of epilepsy awareness, the committee also recommended that epilepsy organizations coordinate their public awareness efforts with common messages when appropriate and address the spectrum and seriousness of epilepsy. Reaching the youth of our nation will also be critical in changing attitudes and eliminating stigma.

Stakeholder Collaboration

The final recommendations highlight the importance for everyone in the epilepsy field to be a united front and work together to create a stronger, united voice for change. The committee found that people with epilepsy and their families were among the most persuasive advocates. The committee recommends that people with epilepsy who are willing to speak be actively engaged in education, dissemination, and advocacy for improved epilepsy care and services. Additionally, epilepsy non-profit and federal organizations should continue to collaborate on common goals, strategic plans, and ways to disseminate and implement the IOM recommendations.

One example of this collaboration can be seen in the advocacy network that encourages participation from all epilepsy organizations and the general public. The Foundation is committed to the expansion of the Speak Up Speak Out network and the Kids Speak Up Public Policy Institute that engages families and professionals in epilepsy to learn and participate in advocacy efforts.



Other proposed strategies include developing innovative partnerships with relevant organizations, developing educational opportunities for community service providers, and providing a 24/7 nonmedical help line.

Summary

The IOM report on the epilepsies provides an in-depth view of the current needs of people with epilepsy and their families and the critical impact on individuals, families, health care, and communities. While the report raised concerns about the gaps and lack of progress in many areas, it also highlighted opportunities for change. Central to this effort were the testimonies from families and the epilepsy community that highlighted concerns, problems and strategies. Much work remains to be done. To be successful, we must continue to be patient-centered, be cognizant of the diversity and spectrum of epilepsy, work collaboratively, and use lessons learned from the past to move into the future.

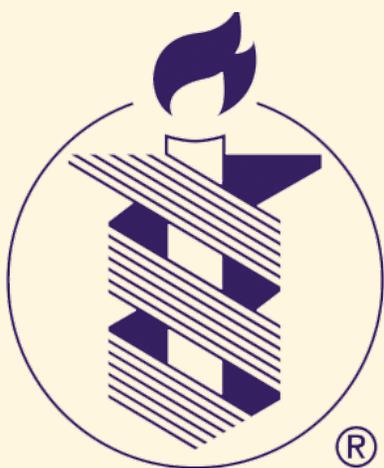


The committee found that people with epilepsy and their families were among the most persuasive advocates.

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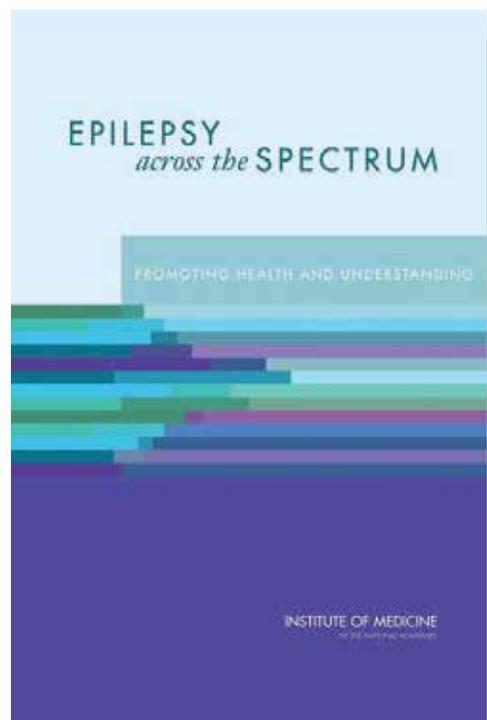
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Joan Ressler Austin, PhD, RN, FAAN, is a distinguished professor emerita at the Indiana University School of Nursing in Indianapolis. She is a consultant for the Intramural Program of the National Institute of Nursing Research at the National Institutes of Health (NIH). She has held leadership positions and has been a member of numerous professional associations, including the American Epilepsy Society (AES) (where she was president in 2005), the Epilepsy Foundation (where she served four terms on the Professional Advisory Board), and the IOM (since 2000).



Patricia Osborne Shafer, RN, MN, is an epilepsy clinical nurse specialist at the Comprehensive Epilepsy Center, Beth Israel Deaconess Medical Center in Boston, Massachusetts, and a resource specialist with the Epilepsy Foundation. She is a past member and chair of the Epilepsy Foundation’s Professional Advisory Board, a past member of the board of directors of the Epilepsy Foundation, and a current member of the Epilepsy Foundation’s Professional Advisory Board of Massachusetts, Rhode Island, New Hampshire, and Maine. She has served on the AES board of directors and numerous committees and work groups.

The Institute of Medicine’s report, *Epilepsy across the spectrum: Promoting health and understanding*, is available online at http://books.nap.edu/catalog.php?record_id=13379.





"El Negro del Caballo"

by Giovanny Paucar Cucalon



Seventh Annual National Walk for Epilepsy

Thousands of people cheered, laughed, and hugged as they gathered on April 20, 2013, on the Washington Monument grounds in Washington, D.C., for the Seventh Annual National Walk for Epilepsy. During the opening ceremony, Actor Greg Grunberg, whose son has epilepsy, described what many people were feeling when he said, "Being here for me is such a motivating thing. It's so empowering." Joining Greg in the three-mile walk around the Tidal Basin's Franklin Delano Roosevelt, Martin Luther King, Jr. and Jefferson Memorials were Tony Coelho, former U.S. Congressman from California; Geoffrey Pope, former New York Giants cornerback; Chanda Gunn, U.S. Olympic hockey player; and Zach McGinnis, Virginia Tech swimmer.



**"Today is about you!
It's about the people you
love and it's about you."**

—Philip M. Gattone,
President & Chief Executive Officer
of the Epilepsy Foundation

Just a few feet from the starting line and main stage, participants found Walker's Village, a ring of sponsors' booths packed with fun activities, giveaways and educational information. In the Village's Social Media Tent, participants had their pictures taken and shared on the Epilepsy Foundation's

Facebook page throughout the day. The Foundation's educational tent served as the setting for the "Ask the Experts" session where a panel of top neurologists answered questions about managing seizures, treatment options, stress, pregnancy, research, and more.

The nearly \$1 million raised during this energetic and heartwarming event will help create essential programs for people living with epilepsy and help fund research toward better treatment options and a cure.



(top) Smiles were abundant as people set off to begin the National Walk for Epilepsy. (center) Many people made signs at the walk to show support for a loved one with epilepsy and to raise awareness. (bottom) Walkers crossed the finish line with arms locked and spirits high.



**"It's great to be with a community of people
who understand."**

—Michelle Westover from Chantilly, Virginia

2013 Hero of Epilepsy - Jacqueline A. French, MD



Actor Greg Grunberg, his son Jake and Dr. Jackie French at the VIP Reception for the 2013 National Walk for Epilepsy

In announcing the award, Philip M. Gattone, president and CEO of the Epilepsy Foundation, said, "Jackie's extensive research and clinical contributions, as well as her commitment to improving the lives of those in the epilepsy community, make her an obvious choice for this year's award. As a pioneer in the clinical care of seizures, her research has led to groundbreaking treatments in epilepsy."

Dr. French is the director of the Epilepsy Study Consortium, director of clinical trials at NYU's Comprehensive Epilepsy Center and current president of the American Epilepsy Society. Her research focuses on finding new therapeutic interventions for people with epilepsy and on clinical trial methodology. Her work has been featured in Lancet Neurology and The New England Journal of Medicine, among other respected publications. Dr. French has also worked with the U.S. Food and Drug Administration to develop new trial designs for antiepilepsy drug (AED) approval. She has been a key leader in the global conversation on epilepsy and seizure conditions, lecturing around the world on topics related to AED therapeutics and working closely with the Foundation to build the annual AED Pipeline Conference, which focuses on bringing together industry and experts to present the latest information and innovations in epilepsy therapies.

This year, the Epilepsy Foundation was proud to present its Hero of Epilepsy Award to Jacqueline A. French, MD, in recognition of her longtime contributions to epilepsy research and clinical trials. The Hero of Epilepsy Award honors individuals and organizations that have made a deep impact on the epilepsy community. Recipients of the Hero Award exemplify the Foundation's mission to stop seizures and SUDEP (Sudden Unexpected Death in Epilepsy), find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies.

We asked some of Jackie's friends to describe her in one word...



Steve Collins "Committed"



Rebecca and Ben French "Visionary"



Roger Porter "Phenomenal"



Phil Gattone "Friend"



Howard Soule
"Best Compassionate Doctor Ever"



Joe Sirven "Endearing"

The Next Step for a Successful Marathon Program: Athletes vs. Epilepsy

Beginning in Fall 2011, the Epilepsy Therapy Project established the TEAM ETP endurance race program. In year one, 31 TEAM ETP runners took to the streets of Washington, D.C., to tackle the Marine Corps Marathon. This inaugural team raised more than \$35,000 to accelerate new therapies, setting the stage for a growing and enduring program.

In 2012, TEAM ETP made major strides in the number of races, participants, funds raised and ultimately greater awareness of epilepsy. In addition to the Marine Corps Marathon, TEAM ETP ran in the Bank of America Chicago Marathon, ING New York City Marathon, and Philadelphia Marathon / Half Marathon / 8K. The increase from one to four races resulted in a 180% increase in participation and 158% increase in funds raised.

The program and our athletes are not stopping there.



Athletes vs Epilepsy: Women's Ice Hockey player Chanda Gunn, Super Bowl Champion Geoff Pope, Jake Grunberg and All-American Zach McGinnis



Geoff, Chanda and Zach join Epilepsy Foundation President & CEO Phil Gattone at the National Walk for Epilepsy

With the merger of the Epilepsy Therapy Project and Epilepsy Foundation in January 2013, the vision and scope of an awareness and fund-raising campaign around athletics blossomed even further. No longer just TEAM ETP, the program evolved into Athletes vs. Epilepsy.

The Athletes vs. Epilepsy initiative strives to bring greater awareness to epilepsy through appearances and participation by athletes of all levels—from little league to professional athletes.

In 2013 athletes will again take on marathon events in Los Angeles, Washington, D.C., New York City and Philadelphia. In addition, participants compete all over the country in their chosen sport as Athletes vs. Epilepsy by promoting awareness and encouraging support for the Epilepsy Foundation.

Along the way, the Foundation has recruited notable athletes such as Super Bowl Champion Geoff Pope, three-time Olympic gold medalist Women's Ice Hockey player Chanda Gunn, and five-time Honorable Mention All-American NCAA swimmer Zach McGinnis to lead the initiative as spokespeople.

To join the Athletes vs. Epilepsy program, visit www.epilepsy.com/AthletesvsEpilepsy.



Zach swimming

Hidden Truths, The Mind Unraveled

On Saturday, October 6, 2012, the Epilepsy Therapy Project celebrated the opening of "Hidden Truths, the Mind Unraveled," an art show at the Susan Nelson Gallery in Newport Beach, California. The event featured reproductions of artwork from Dr. Steven Schachter's portfolio of artists living with epilepsy, as well as pieces from well-known southern California artist Nancy Mladenoff, event host Susan Nelson, and event chair Dr. Julie Thompson-Dobkin.

During the evening, Dr. Thompson-Dobkin, who is a neurologist and self-taught artist, spoke about the art that was on display, its creators and her son, who lives with epilepsy and who is her biggest inspiration. "Art became a means of therapy," she said. "It allows [people with epilepsy] to finally communicate and express themselves in ways they couldn't before."

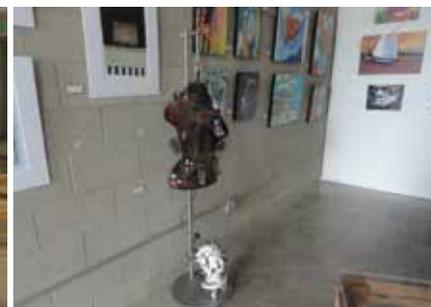
In attendance were Sara and her husband Steven, who had a friend in high school with epilepsy. Describing when his friend had a seizure in class, Steven said, "I was first to him, because I knew what was happening right away." He added that he had always known about epilepsy, but never knew how widespread it is until the art show. "I have to, honestly, admit that I was not aware of some of the statistics I was reading," said Sara, referring to the fact that one in 26 individuals will develop epilepsy at some point in their lives.

A huge success, the event created awareness about the incidence and prevalence of epilepsy and seizures and raised more than \$10,000 that was used to fund translational research.

HIDDEN TRUTHS



THE MIND
UNRAVELED



The Epilepsy Therapy Project's 2nd Annual Night Out in New York



Friends and supporters of the Epilepsy Therapy Project and people who love jazz gathered on November 27th in New York City to change lives by raising funds to accelerate new therapies. The event was held at the Jazz Standard in New York City and featured the music of Grammy Award winning jazz musician Arturo Sandoval.



World Changers Honored at Gala

Nine impressive, deserving honorees were celebrated at the 2012 Epilepsy Foundation gala for being “world changers,” people that exemplify excellence in key aspects of the Foundation’s mission to serve people living with epilepsy. The honorees included The Honorable Steve Bartlett, Senator Roy Blunt, Dr. Orrin Devinsky, Dr. Eli Mizrahi, Dr. Antonio V. Delgado-Escueta, Congressman Steny Hoyer, Dr. Timothy Pedley, Reese Terry, and The Baltimore Sun. The event, chaired by Warren Lammert, co-founder of the Epilepsy Therapy Project, and Terry Lierman, chair of CSGI Inc., took place in the historic Mellon Auditorium in Washington, D.C., on September 12, 2012.

2012 World Changers Awards Gala program

With more than 300 supporters in attendance, the gala raised more than \$350,000 to support the work of the Epilepsy Foundation around awareness, supportive care and research. Support at the highest levels came from two key sponsors: SCI (Service Corporation International) and UCB Pharma, Inc.

Throughout the evening, guests were entertained by the performance of America’s Got Talent finalist and indoor kite flier Connor Doran. Connor credits his unique talent with helping him manage his life with epilepsy. The night culminated with remarks from the Honorable Steny Hoyer. It was truly an evening to highlight what is possible when so many invest their time and energy to research solutions, provide care and advocate on behalf of the more than 2 million people living with epilepsy.



Epilepsy Foundation President and CEO Philip M. Gattone and Epilepsy Therapy Project Co-Founder Warren Lammert

FACT

\$9.6 BILLION: The annual direct medical care cost of epilepsy in the U.S. This does not consider community service costs or indirect costs from losses in quality of life and productivity (these indirect costs are estimated to constitute the majority of the cost burden of epilepsy).

FACT

ONE-THIRD: Number of people with epilepsy who live with uncontrollable seizures because no available treatment works for them.



America’s Got Talent finalist and indoor kite flier Connor Doran



studio  The Epilepsy Art Therapy Program

“Neronas” by Nicolas Vangi



Advocacy - Motivate, Activate & Champion



Kids Speak Up! volunteers on Capitol Hill

2013 Public Policy Conference

The Epilepsy Foundation's annual Public Policy Institute and Kids Speak Up! Conference was held April 21 to 23 in Washington, D.C. Representatives from 35 affiliates participated in the conference and Hill day, which brought together more than 200 teens, parents, affiliates, and volunteers for a day and a half of learning and advocacy training that culminated with visits to the Capitol. Families and affiliates shared their personal stories and advocated in support of the Epilepsy Foundation's legislative goals through more than 170 congressional meetings.

Families who attended this year's Public Policy Institute and Kids Speak Up! Conference learned about the importance of speaking up to raise awareness about the challenges of living with epilepsy. Teens and advocates were inspired by hearing from individuals who are living with epilepsy, including Tony Coelho, a former Member of Congress and the lead author of

the Americans With Disabilities Act; "Mighty Mike" Simmel of the Harlem Wizards; and Chanda Gunn, Team USA's goaltender at the 2006 Winter Olympics.

Teens, families, and affiliate volunteers learned how each of us can take a role in educating policymakers at all levels about our needs, and now return home ready to be epilepsy advocates in their communities.

Regulatory Advocacy at FDA

The Epilepsy Foundation has been a leading voice for the epilepsy community with the Food and Drug Administration (FDA) on issues ranging from bioequivalence research and medication switching, to patient-centered risk-benefit analysis and epilepsy treatment approvals. The Foundation's sustained advocacy with the FDA should continue to yield victories for the epilepsy community as the drug and device review process becomes more receptive to patient's needs. Epilepsy continues to be a priority for the federal investment in bioequivalence research, and new treatments and devices are moving through the approval process at the FDA.

Epilepsy Research and Programs

The Epilepsy Foundation is a long-standing advocate in the fight for increased funding for critical epilepsy programs at the Centers for Disease Control and Prevention (CDC) and research initiatives at the National Institutes of Health (NIH). Epilepsy programs at CDC, which provided education and direct training to more than 6,700 nurses, 10,000 veterans, 8,500 school personnel, 660,000 first responders and 208,000 students, are delivering critical services and model programs to our communities.

The Epilepsy Foundation supports other innovative approaches to research that can translate into new treatment options for people living with epilepsy. One of those initiatives is the MODERN Cures Act, legislation that would encourage innovation by opening up patent pathways for unused or expiring patents that show promise of treating medical conditions that have limited to no treatment options. MODERN creates a pathway to hope especially for those living with uncontrolled seizures, significant side effects, or with rare epilepsies.

Convention on the Rights of Persons with Disabilities

The Epilepsy Foundation is a historic advocate for disability rights and a champion for the Convention on the Rights of Persons with Disabilities (CRPD), which suffered an unfortunate setback during the 112th Congress when ratification by the U.S. Senate failed by only six votes. Undeterred, the Epilepsy Foundation has continued to fight for reintroduction and ratification of the CRPD. The treaty, based on the Americans with Disabilities Act, is designed to ensure equal rights for those living with disabilities, including epilepsy, throughout the world and reflects U.S. leadership in the area of disability rights. The CRPD is consistent with U.S. laws and has already been ratified by 133 countries, including important U.S. allies.

VA Epilepsy Centers of Excellence

The Epilepsy Foundation worked hard to secure continued funding for the Veterans Affairs (VA) Epilepsy Centers of Excellence (ECoE). Created in 2008 through legislation championed by Rep. Ed Perlmutter (CO), the centers have proved an invaluable service to our veterans and have saved millions of dollars a year in epilepsy care while furthering research and treatments options.

Veterans are at an increased risk for epilepsy because many have suffered traumatic brain injuries (TBI) during their service. TBIs are one of the most common injuries of the Iraq and Afghanistan wars, and experts believe 30 to 50 percent of military personnel affected by TBIs will develop epilepsy. Advances in epilepsy diagnosis, treatment and research being made at the VA's ECoEs will ultimately help all Americans affected by epilepsy.



Kids Speak Up! participants at the Public Policy Institute

Advocacy Across the States

The Epilepsy Foundation and its affiliate network across the country remain vigilant on the legislative and regulatory battles taking place at the state level to preserve meaningful access to quality care and treatment for people living with epilepsy and to provide support for epilepsy programs at the state level. The Foundation and its affiliates have been a voice for the epilepsy community at state houses and state agencies. Through expert and patient testimony, public comments and letters, we've shared with policymakers the story of people living with epilepsy, their needs, challenges, and achievements.

Legal Defense Fund

The Jeanne A. Carpenter Legal Defense Fund is a national legal advocacy program with the mission to end epilepsy-based discrimination through education and increased access to legal services for individuals with epilepsy. We educate people with epilepsy, affiliates, and attorneys about legal issues affecting people with epilepsy. In 2013, we have educated hundreds of consumers concerning their legal rights as people with epilepsy. Through the Epilepsy Foundation's legal advocacy program, we provided direct legal resources to assist criminal attorneys in at least three criminal cases where clients with epilepsy were arrested for seizure related behavior. With the assistance of the Fund, these attorneys were successful at getting criminal charges against their clients dismissed.

In 2013, our volunteer network of attorneys has grown more than 10 percent. This year, we launched efforts to increase the network even more through dedicated outreach to the National Legal Aid & Defender Association. This effort will help promote our legal rights information regarding arrest for seizure related behavior and epilepsy resources to a key legal service organization that represents more than 200 public defender offices across the nation.

A D V O C A C Y T R A I N I N G



Kids Speak Up! volunteers participated in advocacy training to prepare for their meetings on Capitol Hill

O N T H E H I L L



Kids Speak Up! families come to Capitol Hill annually to meet with their legislators to tell their personal stories about living with epilepsy and seizures

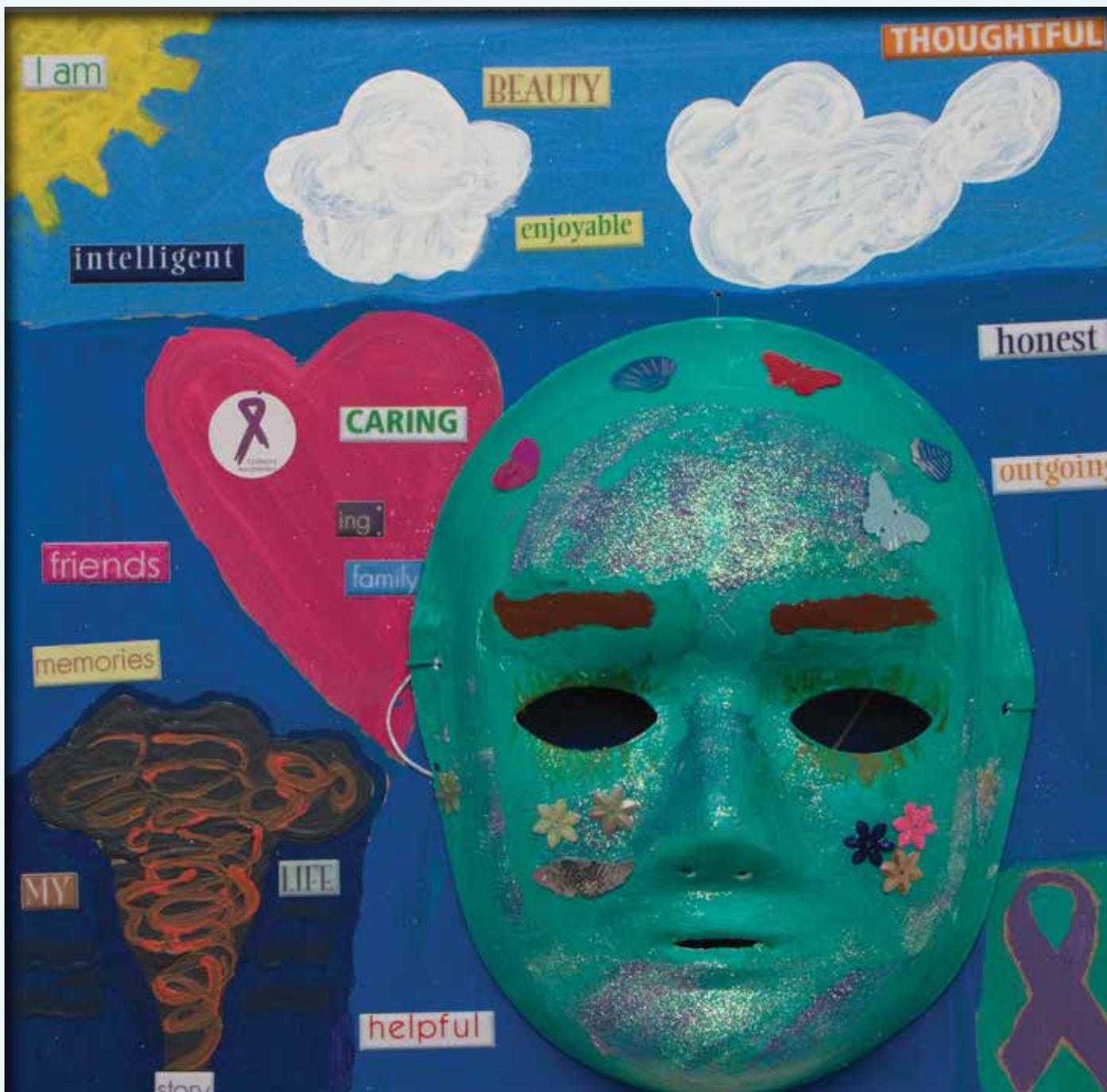
P O R T R A I T S



Our Kids Speak Up! Volunteers

All photos by Hartzman Photography

RESEARCH & NEW THERAPIES



studio  The Epilepsy Art Therapy Program

"Unmasking Epilepsy" by Veronica

The Epilepsy Foundation: Research Update on New Therapies

by Roger J. Porter, MD and Jacqueline French, MD

The Web Pipeline

In the final self-standing annual report of the Epilepsy Therapy Project (ETP), now merged into the Epilepsy Foundation, we described the creation of the Epilepsy Therapy Pipeline, a listing available on www.epilepsy.com. This list describes potential new therapies for epilepsy and categorizes each by stage of development. Since that report of 2011, the pipeline has expanded to 120 projects. Epilepsy is fortunate to have preclinical models in which to test new therapies, and the fruits of this availability are demonstrated in the robust pipeline. Even more remarkable, the Foundation, including the ETP, has contributed to 60 of these projects, an astonishing 50 percent. Although more resources are needed for translational research, the Foundation is committed to increasing its impact in research in the coming years. For those projects which are beyond the current financial reach of the Foundation, a new award, the Epilepsy Innovation Seal of Excellence launched in the spring to attract the private sector to outstanding opportunities.

The Pipeline Conferences

In addition to keeping tally of potential new epilepsy therapies with the web pipeline, ETP and now the Foundation, have been busy with conferences to highlight the latest advances. Most of you are aware of the Epilepsy Pipeline Update held every other year in San Francisco—the last was in February 2012 and the next is in early June 2014. You may not be aware that we have sponsored a day-long pipeline session held on alternate years at the Antiepileptic Drug and Device Trials (ADDT) meetings in Florida. The most recent of these meetings was in May 2013 and was highly successful.

Highlights of the Most Recent ADDT Meeting

On May 15 through 17, 2013, we collaborated with New York University and the Epilepsy Study Consortium to convene the 12th Antiepileptic Drug and Development conference in Aventura, Florida. The meeting was attended by more than 200 scientists, clinicians, trialists, representatives of pharmaceutical companies and advocates for epilepsy. In addition, there were representatives from government agencies such as the National Institutes of Health and the Food and Drug Administration. The purpose of the meeting was to bring together all of the stakeholders involved in delivering new therapies and devices to the epilepsy community and to discuss advances, roadblocks, and new initiatives. The meeting was followed by a review of many of the new drugs and devices currently in development (“The Pipeline”).

Also, the second “Shark Tank” competition was held. This competition seeks out entrepreneurs working in the epilepsy therapeutics and device area and offers a \$100,000 prize to the person who is deemed the most likely to improve the lives of patients with epilepsy in the near term. The top five finalists presented their ideas live at the conference, and a panel, along with the audience, voted on the winner.

What was on the mind of the conference presenters and participants? One thing was one of the most grievous problems with current therapies, namely adverse effects of the medications used to control seizures. Several scientists discussed new ways to identify how likely new drugs might be to cause side effects, before the drugs are ever used in people. Using new techniques for measuring behavioral abnormalities in animal models may reduce the possibility of advancing drugs to the market with unpleasant adverse effects. Possible measures include a variety of tests under the headings of general behavior, anxiety, depression, mood, and cognition. Just watching animals, and determining how they move in their cages, can indicate sedation and incoordination. In an effort to quantify the current experience with adverse effects, an ILAE (International League Against Epilepsy) working group asked leading expert clinicians to rate (admittedly in subjective manner) current medications with “smiley faces.” If the drug was less harmful than most in a particular area, a white smile was indicated; worse adverse effects were categorized as orange and the very worst as red—see the chart below.

Perceived Adverse Events of AEDs

Drug	Ataxia/ Incoordination	Dizziness	Sedation	Irritability / Agitation	Cognitive Disturbance	Depression/ mood issues
Phenytoin	1.8	1.4	1.1	0.5	1.1	1.0
Carbamazepine	1.5	1.8	1.1	0.5	1.4	0.4
Valproic Acid	0.8	0.9	1.0	0.1	1.0	0.1
Ethosuximide	0.8	0.9	1.0	0.8	0.8	0.8
Phenobarbital	1.4	1.1	2.6	1.3	2.0	1.8
Zonisamide	0.6	1.0	1.3	1.5	1.4	0.8
Gabapentin	0.5	0.8	1.1	0.1	0.8	0.3
Lamotrigine	0.9	1.3	0.4	0.6	0.3	0.0
Topiramate	0.9	0.9	1.0	1.0	1.5	1.3
Tiagabine	0.6	1.3	1.5	0.8	1.3	1.4
Oxcarbazepine	1.5	1.6	1.1	0.5	0.8	0.3
Levetiracetam	0.3	0.6	1.1	1.9	0.3	1.4
Felbamate	1.0	0.8	0.8	1.0	0.6	0.8
Pregabalin	1.0	1.5	1.5	0.4	1.1	0.6

Modified slide courtesy of Jacqueline French, MD & Working Group 1 of London meeting

The challenge, of course, is that virtually all anti-seizure drugs have adverse effects at high doses; eliminating otherwise promising drugs from further development on the basis of these behavioral tests will not be risk-free. Nevertheless, the effort to confront this issue is now front and center.

Another hot topic was the increasing partnership with the Food and Drug Administration (FDA) in the design of trials for new therapies. One of the most interesting—and provocative—observations at the meeting was an analysis of the impact of being on the placebo arm of a controlled trial. Specifically, in an analysis of 112 trials, the incidence of SUDEP (Sudden Unexpected Death in Epilepsy) in patients taking placebo was between 5 and 10 times higher than patients taking the active drug under test. To further address this, the FDA has asked for an independent review of SUDEP in placebo arms of most pivotal trials to determine whether being on add-on placebo in a randomized controlled trial is safe. Several alternative trial designs that would limit placebo exposure were discussed. The FDA is also considering eliminating the need for both monotherapy (using the drug alone) and adjunctive therapy (using the drug combined with others) indications for

antiepileptic drugs—reflecting not only the difficulty of demonstrating effectiveness of monotherapy in a clinical trial setting but also recognizing the growing expert opinion that drugs proven effective as adjunctive therapy would also be effective when used alone, and this may not require independent proof.

Finally, new seizure detection and alerting devices are coming forward in new and impressive ways. Each new device has its own advantages and shortcomings, but better delineation of seizures seems destined to help not only individual patients but also contribute greatly to the quality of our clinical trials. Some of the notable devices are shown below.

Many other exciting advances were apparent at the AADD meeting; the few highlighted here give only a brief glimpse into the spectrum of the meeting.

We hope to see you at the next Epilepsy Pipeline Update in San Francisco, California, June 5 to 7, 2014!

Seizure Detection/Alerting



SAMi



Brain Sentinel



Epiband



EEG Patch



Smartwatch

About the Authors

Roger J. Porter, MD, is chief scientific officer of the Epilepsy Foundation and a consultant to the pharmaceutical industry, primarily in the development of antiepilepsy drugs. He is also adjunct professor of neurology at the University of Pennsylvania and adjunct professor of pharmacology at Uniformed Services University of the Health Sciences. He has served as chairman of the White House Committee on Brain and Behavioral Sciences, president of American Epilepsy Society, secretary general of the International League Against Epilepsy and secretary of the College of Physicians of Philadelphia.

Jacqueline A. French, MD, is a professor in the Department of Neurology at New York University in the Comprehensive Epilepsy Center and director of the Clinical Trials Consortium. She is the former assistant dean for Clinical trials at the University of Pennsylvania. She has served on the board of the American Epilepsy Society and the American Society of Experimental Therapeutics. In addition, she is the head of the scientific advisory board of the Epilepsy Foundation.



2013 SHARK TANK WINNER

Disposable Microfluidic Chips to Detect Antiepileptic Drug Serum Concentrations at the Point of Care and the Moment of Need

Antiepilepsy drugs (AEDs) are the mainstay of treatment for persons with epilepsy (PWE)^{1,2}. Optimizing the effectiveness of AEDs involves adjusting dosages and timing of dosages to minimize side effects and maximize seizure control. Utilizing AED serum concentrations can guide this process, but obtaining blood tests is presently impractical due to the associated inconvenience and costs, as well as the often long latency between side effects and/or seizures and when blood tests are obtained. However, as many as two out of three PWE suffer from recurrent seizures or AED-related side effects.

In either case, optimization of AED dosages is clinically important and often guided by measuring AED serum concentrations. AED serum concentrations are typically quantified by High Performance Liquid Chromatography (HPLC) in conjunction with UV and photodiode arrays³. However, these methods are lab-based and not point of care (POC) nor obtained at the moment of need (for example after a seizure or when side effects are occurring), because they rely on

expensive equipment and skilled technicians⁴ (Figure 1). Thus, there is a great need for simple, rapid, reliable and disposable tests for AED measurements that can be performed at the doctor's office or by the patient or a family member.

Here, we propose to develop a micro-a-fluidic based disposable AED detection that can be performed anywhere and automated to handle 100 μ L of blood obtained with a fingerprick, such as used for blood glucose monitoring. The proposed system will require a cell phone and an inexpensive micro-a-fluidic chip (<\$2) for detection that can give results in approximately 15 minutes. A version of this device could be made with readouts that the patient or family member can see, to report to the physician or to implement actions that the physician provided them in advance.

Importance of Your Project

Epilepsy is a medical condition that affects the brain and causes a person to have seizures. A seizure happens when nerve cells in the brain work abnormally, affecting consciousness or movement. Epilepsy affects 65 million people worldwide and 2.2 million people in the U.S., including about 60,000 people in Massachusetts. It is most common among the very young and the very old, although anyone can develop epilepsy at any age.

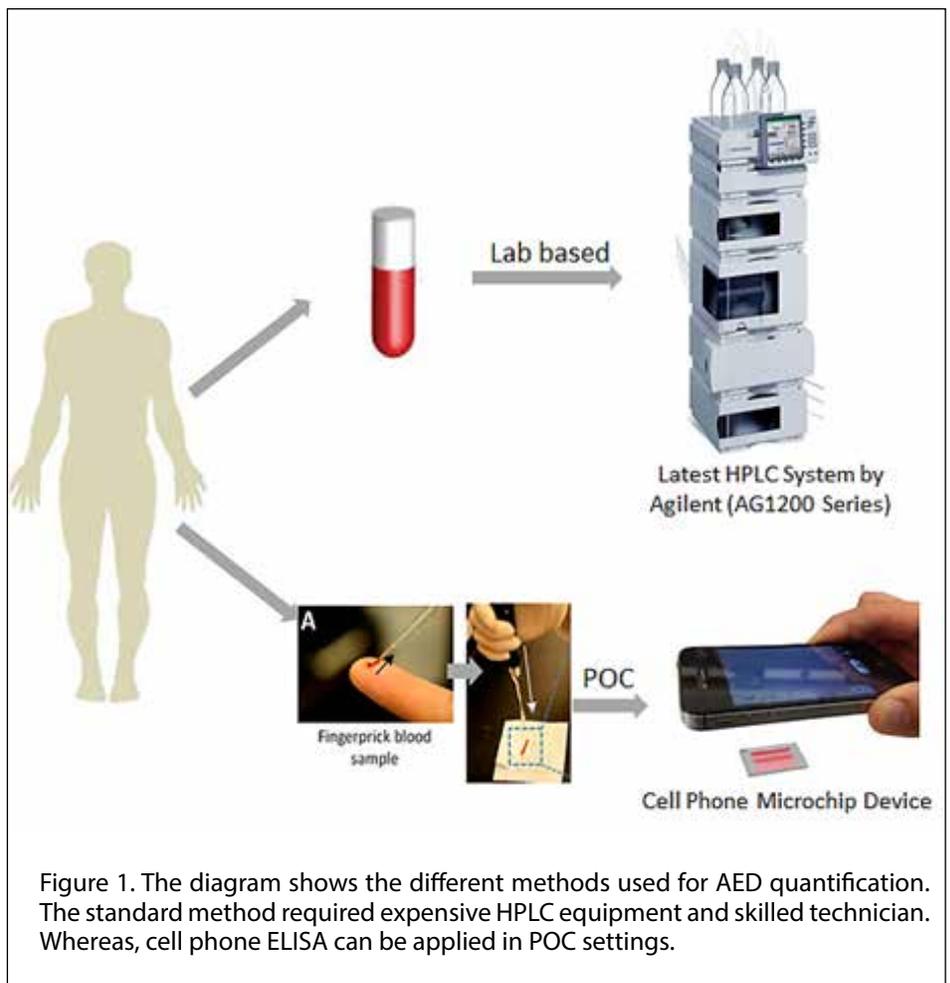


Figure 1. The diagram shows the different methods used for AED quantification. The standard method required expensive HPLC equipment and skilled technician. Whereas, cell phone ELISA can be applied in POC settings.



FACT

BETWEEN 4 AND 10 OUT OF 1,000: Number of people on earth who live with active seizures at any one time.

Experiencing seizures or their disabling side effects can severely limit patients' educational achievements, employment prospects and participation in all of life's experiences. Seizures can even be life-threatening. And, our device can save lives.

In U.S., there are several treatment centers for epilepsy; however, the current treatment procedure can be burdensome for epilepsy patients. Medications need to be taken every day, sometimes several times a day. Physicians often use blood tests to measure the levels of medications to be sure the dosage is just right—to prevent seizures without causing drug-related side effects. The problem is that people with epilepsy have to visit a laboratory or hospital for these blood tests. This is difficult, especially because many people with epilepsy are not allowed to drive. Additionally, the timing of blood tests is very important.

What is hoped to be accomplished?

Our project seeks to help patients and their doctors take control over when and where these blood tests are done. We are designing a device that patients can use to test their blood at home, which will help their doctors better manage their medications to prevent seizures, emergency room visits and side effects.

How will this therapy be of help?

Our platform will be the first POC test to measure blood levels of seizure drugs. We are designing an easy testing device that adult patients or parents of children with epilepsy can carry in a pocket or a purse. This test can be performed anywhere, anytime.

By translating enzyme-linked immunosorbent assay (ELISA) to localized surface plasmon resonance (LSPR) platform, the device contains very tiny sensors called nanoplasmonics—like the ones inspired by the tiny hand-held machines in the “Star Trek” movies. Patients provide a very small drop of blood through a fingerprick, like in a glucose-meter. The device checks the blood sample and gives results in fewer than 10 minutes. Easy and safe.

When will it be available?

This platform aims to develop an inexpensive, disposable and easy to use AED quantification chips for POC testing. First we will develop the test prototype. We intend to make the microchip operation automatic once the sample is introduced to the chip.

What patient group may benefit from this new therapy?

The device gives results quickly, so when patients call their doctors or nurses for advice on how to manage their epilepsy, they can give these results to their doctor and get help immediately, when they need it.



FACT

MORE THAN 65 MILLION: The number of people worldwide who have epilepsy

Our device can improve the quality of life for anyone affected by epilepsy and can even help save lives in emergency settings, such as an ambulance ride or a hospital emergency room.

References:

¹“Epilepsy” Fact Sheets. *World Health Organization*. (October 2012).

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³ Bhatti, M. M., Hanson, G. D. & Schultz, L. Simultaneous determination of phenytoin, carbamazepine, and 10, 11-carbamazepine epoxide in human plasma by high-performance liquid chromatography with ultraviolet detection. *Journal of pharmaceutical and biomedical analysis* **16**, 1233-1240 (1998).

⁴ Patsalos, P. N. et al. Antiepileptic drugs-best practice guidelines for therapeutic drug monitoring: a position paper by the subcommission on therapeutic drug monitoring, ILAE Commission on Therapeutic Strategies. *Epilepsia* **49**, 1239-1276 (2008).

ACROSS THE FINISH LINE

The Epilepsy Foundation has provided funding for more than 60 of the 120 products currently in the epilepsy pipeline. Here are updates on the projects we have helped fund that are now available for people living with epilepsy.

Bringing New Therapies to Life in a Timeframe that Matters: An Update on a Pilot Study to Evaluate MR-guided Laser Ablation of Epilepsy Foci

Importance of the project?

There are clearly a large number of people with epilepsy that are excellent candidates for traditional open resective surgery to remove the area of brain responsible for seizure generation, but this type of procedure remains underutilized, owing largely to the invasive nature of the procedure. We believe a minimally invasive surgical option could increase the number of patients that qualify and seek out such a procedure.

What is hoped to be accomplished?

The goal of our Epilepsy Therapy Project-supported project was to complete pilot clinical studies using minimally invasive, MRI-guided laser ablation to thermally destroy epileptogenic seizure foci. Our work was aimed at determining whether this technique would provide results warranting more wide-spread use of this novel surgical tool.

How will this therapy be of help?

There are currently few treatment options between continued drug trials and highly invasive surgical procedures for people with epilepsy who don't respond to initial drug therapies. If successful, our minimally invasive laser technology could fill that void and offer a new minimally invasive surgical tool for eliminating seizure foci.

When will it be available?

The Visualase Technology is already cleared by the U.S. Food and Drug Administration (FDA) as a surgical tool for soft tissue ablation (thermal destruction of tissue) in various medical specialties, including neurosurgery. Physicians are currently employing the system for procedures that previously would have been performed through a much larger opening in the skull (open craniotomy). Placement of our small (1.6mm, pencil lead size) fiber optic probes into target brain tissue requires only a 3.2mm diameter skull opening and has even been performed on awake patients using only local anesthetics. People undergoing minimally invasive laser ablation typically have much faster recoveries than traditional surgery with average hospital stays of only 24 to 48 hours and almost no signs of having gone through a surgical procedure at all.

Who will benefit from this new therapy?

Our pilot work investigated use of the system in both children and adults with well defined areas of the brain, typically visualized as lesions on imaging exams that were able to be safely targeted for ablation. Advances in imaging technology and diagnostic procedures are increasing the number of people in which the precise area of the brain responsible for initiating seizures can be determined, and therefore similar increases in the number of people which might be amenable to this procedure should emerge. Furthermore, many people with multiple lesions in the brain, which may have previously been excluded from standard surgeries, or those that wish to avoid more invasive "open" brain surgeries might now have a minimally invasive surgical option for destroying these lesions.

Why was it important that your project received funding?

During the course of our project, we exceeded our original goals of completing 10 procedures, and eventually enrolled 20 people into a pilot study at Texas Children's Hospital. People with various lesions associated with epileptic foci were treated with the Visualase system, including Tuberous Sclerosis (n=2), Mesial Temporal Sclerosis (n=2), Hypothalamic Hamartoma (n=12), and Focal Cortical Dysplasia (n=4). To date people achieving seizure freedom from the laser procedure

have compared favorably to traditional open surgical resection in similar patient populations. Our initial pilot results were critical in our ability to generate interest and support for adoption at additional sites. These exciting results were in large part enabled by the Epilepsy Therapy Project's funding and support. To date, over 200 epileptic foci ablation procedures have been performed among more than 25 Visualase sites, with results that continue to show promise for minimally invasive laser surgery in patients with epileptic foci refractory to other therapies. Additional post-approval studies and expanded installations of the system are planned, which will build upon the great foundation we achieved through our early ETP funding.



Physicians at Texas Children's Hospital, Dr. Angus Wilfong and Dr. Daniel Curry, performed the first minimally invasive laser ablation of epileptogenic lesions using the Visualase system. (Top-left) The laser probe is placed through a small 3.2mm opening in the skull and into the target lesion. (Bottom-left) Patient ready for transport to MRI for treatment. (Top-right) Real-time monitoring of the ablation process in MRI allows physicians to precisely control the area and amount of damage. Patients are typically released from the hospital within 24 to 48 hours with no signs of having undergone a surgery at all.



FACT

10: The estimated number of years of life lost for people whose epilepsy has a known cause



FACT

6 OUT OF 10: Number of people with epilepsy where the cause is unknown.

ACROSS THE FINISH LINE

External Trigeminal Nerve Stimulation for Drug Resistant Seizures

by Christopher M. DeGiorgio, MD

Professor, UCLA Department of Neurology

The Epilepsy Therapy Project provided funding commencing in 2008 to Dr. Christopher DeGiorgio and UCLA for a 50 subject randomized double blind controlled trial of external Trigeminal nerve stimulation for drug resistant seizures. External Trigeminal nerve stimulation is a non-invasive therapy, designed to deliver neuromodulation without the risk of invasive devices or electrodes placed in the brain. The results of this clinical trial were published in the leading journal *Neurology*.

The primary findings of this Phase 2 clinical trial were:

1. External Trigeminal nerve stimulation was associated with significant within-groups improvement in responder rate, which increased to 40.5% at the conclusion of the double blind treatment period ($p = 0.01$, GEE).
2. External Trigeminal nerve stimulation was associated with significant improvements in mood, as measured by the Beck Depression Inventory ($p = 0.03$, Wilcoxon).

The results of this Phase 2 study were extremely promising, given improvements in both seizures and mood. NeuroSigma, the exclusive licensee and manufacturer of the Monarch™ eTNS™ System, has received European approval for the treatment of epilepsy (CE mark) in adults and children 9 years and older, as well as Canadian approval.

eTNS is still investigational in the U.S. NeuroSigma has received approval from the Food and Drug Administration (FDA) of its Investigational Device Exemption (IDE) to perform a large, multicenter pivotal Phase 3 trial for partial seizures with or without secondary generalization in people with epilepsy ages 12 to 65. NeuroSigma is now in the planning stages of the Phase 3 trial and expects to begin the trial in the first quarter of 2014.



Monarch™ eTNS™ System

by NeuroSigma



ACROSS THE FINISH LINE

An Update on SmartWatch: An Innovative Monitoring, Detection, and Reporting Solution for Seizures



On Christmas Day a few years ago, a single mother reached out to Smart Monitor founder Anoo Nathan to share a frustrating story. Her teenage son suffered from epilepsy, and she desperately sought a way to monitor him while he slept and while she worked. Until then, she had set an alarm to go off hourly – day and night – to check on him.

Ms. Nathan heard from several more parents and family members who were in need of an automated solution for detecting unusual movements from various conditions. She launched Smart Monitor with the mission to develop an easy-to-use monitoring device that would immediately notify a family member when the user needed help.

About SmartWatch

SmartWatch, Smart Monitor's flagship product, is a patented, intelligent and non-invasive wristwatch that continuously monitors the user and instantly alerts family members and caregivers upon the onset of abnormal movement patterns similar to those caused by generalized tonic-clonic (GTC) seizures. When the SmartWatch detects repetitive shaking motion, it automatically sends the user's Bluetooth-connected Android phone text and phone call alerts to designated alert

recipients. Within seconds, family members receive the SmartWatch alerts, which include the date, time, GPS location and duration of the event.

SmartWatch is fully portable and can be worn in and out of bed, during sleeping and waking hours, as the wearers go about their regular activities in their homes, schools, offices and elsewhere. SmartWatch provides caregivers peace of mind, as they know they will be alerted upon the occurrence of excessive movements, which may be indicative of a seizure. SmartWatch also gives wearers independence, allowing them to go about their normal daily activities without worrying whether they'll be able to get help if they have a seizure.

More Than Just Monitoring

SmartWatch has several ancillary features that can help improve the safety and treatment of users. The Medication Reminders feature allows users to set customized medication reminders and other useful notifications. For the many people with epilepsy who may find it challenging to stay on a daily medication routine, Medication Reminders can be valuable and potentially lifesaving.

Another useful feature is the "Get Help" button, which allows users to immediately notify parents or caregivers and, if necessary, quickly direct them to their exact location using SmartWatch's GPS functionality. With this feature, users can also get help when they have non-GTC seizures that SmartWatch won't detect.

SmartWatch's data reporting capabilities can provide significant value to both users and clinicians. The device records the date and time, location, duration and intensity of every alerted event. Users can securely access this data and share it with their physicians, providing valuable insight that can lead to more proactive and better-informed care decisions.

FACT

1 OF EVERY 10,000: The number of newly diagnosed people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP).

Success Stories

Smart Monitor has heard from dozens of families about how SmartWatch has helped improve their lives. Here are just three of SmartWatch's many notable success stories:

- Jill G, Michigan - Late one night, the SmartWatch of Jill's young daughter alerted Jill to a seizure she was having while asleep. Without SmartWatch, Jill's daughter could possibly have died.
- Rebecca Y, Nebraska - Rebecca's SmartWatch alerted her partner after she fell down the stairs following a drop seizure, allowing her to quickly send for help.
- Connor D, Oregon - SmartWatch provides Connor with the independence he needs to succeed as an indoor kite flier. Connor's impressive resume includes making it to the final eight on America's Got Talent!



SmartWatch User

photo: Lori S. Robinson

Clinical Studies

The ability of the SmartWatch to detect and alert upon repetitive shaking motion similar to those caused by convulsive seizures has been validated via clinical studies at leading medical institutions.

- Stanford University Medical Center (Jan 2009 – June 2010) - In this study, conducted with adult patients for more than a year, the SmartWatch was able to detect all but one generalized tonic-clonic seizure during the study. The one seizure was missed due to a process error – an aide inadvertently put a watch that was not charged on the patient who had the seizure.
- University of California, San Francisco Pediatric Epilepsy Center (July 2011 - Jan 2013) - The UCSF studies were conducted for over a year with pediatric patients and concluded very successfully earlier this year. The SmartWatch was used in patients as young as 3 years. In over 500+ hours of testing, the SmartWatch did not miss a single seizure. There was one false positive during the entire testing period. This demonstrates a tremendous improvement in accuracy based on the algorithm improvements made after the Stanford studies.
- St. Jude's Le Bonheur Children's Hospital (Jan 2013 - Present) - Clinical studies are currently underway at St. Jude's Hospital in Memphis, TN. The studies are focusing on the SmartWatch's data reporting and aggregating capabilities. The studies began in January 2013 and will be completed by year's end.

SmartWatch Grants

The Epilepsy Foundation and Epilepsy Therapy Project provided grants that were absolutely crucial in helping to bring SmartWatch to market. These grants also allowed Smart Monitor to complete the Stanford University study and a series of in-home tests to validate the efficacy of the SmartWatch. Smart Monitor is tremendously grateful to both organizations for the support and funding they've provided.

Purchasing SmartWatch

SmartWatch is available to purchase through an affordable monthly subscription plan. SmartWatch subscriptions include firmware and software upgrades, customer support, choice of one of 12 watch band colors, and a full product warranty for as long as the account remains active. A new, intuitive user interface and "My SmartWatch" cloud portal will soon be available for all SmartWatch users as well.

To learn more about SmartWatch and view subscription plan options, please visit www.smartmonitor.com.

ACROSS THE FINISH LINE



An Update on our 2012 Shark Tank Winner – SAMi: The Smart Activity Monitor for Individuals

by Charles W. Anderson



SAMi (Smart Activity Monitor for individuals) is an infrared camera based nighttime monitoring and recording system for home use. SAMi continuously looks for motion. When motion is detected, the camera creates time stamped files that are automatically transferred to the SAMi app running on

an iPhone or iPad. These files can be quickly reviewed, and recordings showing abnormal activity are clearly marked for later review with medical personnel. Optionally, SAMi can also be configured to sound an alarm and provide a live video or audio display to a nearby caregiver when such motion is detected.

Seizures can happen at any time. Those that happen during the day can be quite dangerous, but those that happen at night present unique challenges. Nighttime seizures are often never witnessed. In our case, we noticed that our son often had seizures at night when we went on family vacations. Our assumption was they were associated with the stress of travel. It turns out he was regularly having seizures at night even at home, we just never knew it. Tracking seizure frequency is critical for assessing the efficacy of medication and other treatments. With SAMi in place, we had recordings of the nighttime seizures and could provide our doctors with accurate information.

Once we knew he was having seizures at night, we needed to not just record them, but be alerted to when they happened. Our options were co-sleeping, a baby monitor, or a movement detector. No solutions are 100% reliable, and all involve compromises. Co-sleeping was a last resort, especially with a teenager. We tried a baby monitor but found we were waking multiple times a night on minor sounds. A movement detector can work well for seizures with rhythmic movement, but our son's often looked a lot like sleepwalking.

We built SAMi in 2009 and ran it on a dedicated laptop computer. SAMi silently watches, running on the nightstand next to our bed looking like a digital clock. Minor movements such as turning over and even entering/leaving the room are ignored. If movement continues for a selectable period of time it sounds an alarm, followed by a live video. In our case, even minor motion continuing for more than 20 seconds usually indicated a seizure.

The impact of this on our ability to manage our son's epilepsy and the entire family's general quality of life cannot be overstated.

Winning the first Epilepsy Foundation Shark Tank Competition in 2011 allowed me to transform SAMi from an expensive custom solution for us into a refined, much less costly tool for others. I immediately put the funds to work. Specifically, I used the award to purchase the computer and software necessary to write the iOS app. I then purchased and distributed SAMi cameras to other families for testing. Finally, the funds were used to purchase inventory, build the www.samialert.com website, and pay attorney fees for incorporation of HiPass Design Ltd and a patent application.



SAMi Smart Monitor

The product testing we did convinced me that this was something many others can use. Here is some of the feedback:

“Today we had an appointment with T---’s neurologist. I went armed with my iPod. I had videos of the last two days. This is the same doctor [who] 3 months ago said, ‘You do not need a baby monitor. Go home treat him like a normal child.’ He was extremely impressed. Thank You A Million Times Over!!!”

—Susan D., Florida

“It has been eye opening to playback the recordings of the seizures made by SAMi; they have been very helpful when reviewing/analyzing the seizures and our seizure dog’s response.”

—Cindy M., California

“I have had the SAMi monitor for over a year. I never would have imagined that I would get peace of mind at night with my son’s seizures. We have tried many other monitors and none have worked for him. I love the fact that not only can you adjust the sensitivity, but you can also adjust how long before it alerts you. I would recommend this monitor to anyone with a loved one who suffers with seizures.”

—Stacy B., Colorado

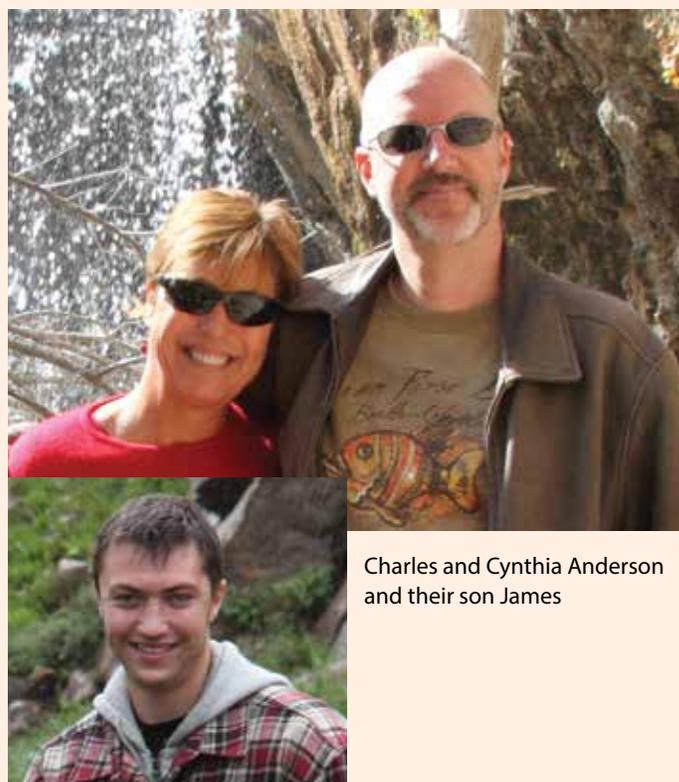
This summer we have started shipping SAMi cameras and systems to customers. We would like to thank the Chelsea Hutchinson Foundation and the Danny Did Foundation

for their support; they have started purchasing SAMi for the families and individuals they serve in the epilepsy community. We would also like to thank the Epilepsy Foundation of Colorado for their continued advice and support.

About the Author

I have spent the last 30 years designing digital products and leading engineering teams. I have an established track record in entrepreneurial organizations including founding, building, and selling a highly successful engineering R&D company. My blend of technical, business and marketing knowledge gave me the tools I needed to put together a solution to our monitoring problem and turn that solution into the one we are now making available to help others.

I graduated in 1983 from Tufts University with a bachelor of science degree in electrical engineering and computer science. For the last 26 years I’ve lived and worked in Boulder, Colorado, and am the father of two sons, both now attending college, one with temporal lobe epilepsy. He has been seizure free for over a year now after excellent care and surgery at the Cleveland Clinic. My wife Cynthia and I are the owners and founders of HiPass Design Limited, which manufactures and markets SAMi.



Charles and Cynthia Anderson and their son James

Grants, Fellowships & Research Initiatives



Research is the key to the future for people with hard to control seizures — as many as 600,000 Americans of all ages. The future of epilepsy research depends on attracting the best scientific minds to the study of seizures and funding innovative research. To do just that, the Epilepsy Foundation offers a series of grants and fellowships in basic, clinical and behavioral science to scientists at the start of their careers. The Foundation also offers funding opportunities to established investigators for targeted research initiatives and for the development of new therapies for epilepsy, accelerating the advancement of research from the laboratory to the patient.

EPILEPSY FOUNDATION – NEW THERAPY COMMERCIALIZATION GRANT PROGRAM

Looking back on the progress in the last generation, it is not surprising that the leaders in epilepsy research believe that a cure may be in sight. For the first time, we can think in terms of “cure”—not just “control.” Now is the time to build on the remarkable progress of the past few years. And we can do it by investing more money in scientific research than we ever have before.

The mission of the Epilepsy Foundation New Therapy Commercialization Grants Program is to drive the development of new therapies for epilepsy, accelerating the advancement of research from the laboratory to the person with epilepsy. The Foundation funds innovative senior level research projects led by the nation’s leading scientists with the potential to discover new treatment options and ultimately a cure.

The program focuses on the following:

- Research with potential to discover new therapies and a cure for seizure disorders.
- Meaningful grants to senior level scientific and clinical investigators on the brink of new discoveries, working at the nation’s leading academic and research institutions, and in industry.
- Innovative cutting edge projects that could lead to breakthrough discoveries.
- Research programs that might not otherwise be funded through traditional sources.
- Projects that encourage collaboration among scientists and industry.

FALL 2012 AWARDS – \$63,643

HE3286 Treatment of Drug Resistant Epilepsy

Clarence Ahlem, MS, Vice President

Harbor Therapeutics, Inc., San Diego, CA

HE3286 is an anti-inflammatory drug in clinical trials for other diseases, which may provide a novel treatment for epilepsy seizures that are resistant to currently approved drugs. Because brain inflammation is linked to epilepsy, we will test HE3286 in mice with epilepsy to see if it decreases the number or duration of chronic seizures.

SPRING 2013 AWARDS – \$250,000

Factors Determining Placebo Response in Drug-resistant Focal Epilepsy

Emilia Bagliella, PhD

Icahn School of Medicine at Mount Sinai, New York, NY

The magnitude of placebo response is an important factor in the outcome of clinical trials, and an inflated placebo response can obscure true drug-placebo differences. Failure to demonstrate drug-placebo differences where true differences exist encourages sponsors to terminate drug development programs prematurely, thus preventing access to effective treatments. In this project, we propose to analyze a large sample of data to determine the factors that affect placebo response in clinical trials.

Two Open-label Studies of CBD in Dravet and Lennox-Gastaut Syndromes*Orrin Devinsky, MD**New York University School of Medicine, New York, NY*

This is a joint project to investigate the safety and tolerability of a novel antiepilepsy drug, Cannabidiol (CBD). Further, the two studies outlined in this proposal will provide a first look at efficacy in seizure control in two severe childhood epilepsy syndromes – Dravet and Lennox-Gastaut.

MR-guided Focused Ultrasound for Treatment of Mesial TLE*Ryder Gwinn, MD**Swedish Neuroscience Institute, Seattle, WA*

This project aims to be the world's first clinical investigation of MR-guided focused ultrasound as a potential completely noninvasive and radiation-free treatment alternative for medication refractory people with mesial temporal lobe epilepsy.

Minimally Invasive Mapping and Ablation to Treat Epilepsy*Gregory Worrell, MD, PhD**Mayo Clinic, Rochester, MN*

Minimally invasive surgical techniques have revolutionized many areas of medicine; however, open surgery for epilepsy has remained unchanged for decades. We propose minimally invasive catheter-based methods to replicate excellent outcomes of epilepsy surgery. Our goals are improved outcomes, lower morbidity, lower cost and greater access to epilepsy diagnosis and treatment.

POSTDOCTORAL RESEARCH AND TRAINING FELLOWSHIP

The Postdoctoral Research Fellowship program develops academic physicians and scientists committed to research related to epilepsy. Applications are considered equally from individuals interested in acquiring experience either in basic laboratory research or in the conduct of human clinical studies. Physicians or PhD neuroscientists who desire postdoctoral research experience are eligible to apply.

FALL 2012 AWARDS – \$495,000**Sudden Cardiac Death in a Severe Form of Childhood Epilepsy: Mice & Men***David Scott Auerbach, PhD, Postdoctoral Research Fellow**The Regents of the University of Michigan, Ann Arbor, MI*

People with Dravet Syndrome experience uncontrollable electrical disturbances in the brain known as seizures. Many young people die suddenly, yet often the cause of death remains unknown. Seizures can be traced back to mutations in one of the sodium channel genes. Interestingly, these mutated sodium channels are also present in the heart. This project will explore whether mutated sodium channels cause electrical disturbances in the heart, called arrhythmias. Arrhythmias may provide an explanation for sudden death in people with Dravet Syndrome. The mechanism(s) for the initiation of these electrical disturbances in the heart will be explored. Funding for this grant was supported by the American Epilepsy Society and Eisai, Inc.

Defining ECoG Resting State Networks Associated with Focal Epilepsy*Sarah Bandt, Resident Physician**Washington University in St. Louis, St. Louis, MO*

Epilepsy affects more than 2 million Americans at an estimated yearly cost of \$15.5 billion. A third of these people never achieve seizure control with medication alone. Surgery may help some. There have not been many recent advances in the way we treat epilepsy with surgery. The purpose of this project is to analyze seizures directly from the surface of the human brain

to try to better understand the relationships between the cells causing the individual's seizures and the surrounding brain tissue to guide surgical resections to maximize seizure control with minimal injury to normal brain function. Funding for this grant was supported by the American Epilepsy Society.

A Role for Interleukin-6 in Epileptogenesis

Jeff Boychuk, Postdoctoral Scholar

University of Kentucky Research Foundation, Lexington, KY

Traumatic head injury is a leading cause of acquired temporal lobe epilepsy (TLE). This work intends to help understand the process whereby brain injury promotes the development of chronic seizure disorders. Head injury results in massive inflammatory responses in the brain. This project examines how the body's natural inflammatory response to brain injury may influence chronic changes in brain function leading to epilepsy. The focus here is whether one inflammatory protein, Interleukin-6, signals brain cell networks to become permanently in a manner consistent with the development of TLE. Experiments here study how Interleukin-6 affects both excitatory and inhibitory brain networks. Funding for this grant was supported by the American Epilepsy Society and Lennox & Lombroso Trust for Epilepsy Research and Training.

The Pathogenic Role of Activated Microglia in Epilepsy

Zhihong Chen, Postdoctoral Fellow

Cleveland Clinic Foundation, Cleveland, OH

Epilepsy is a persistent and devastating neurological disease characterized by repeated seizures. It is among the least understood chronic disorders and current medications are only effective in a fraction of people with epilepsy. This project will inspect brain inflammation for its potential roles in the development of epilepsy. Well established animal models and modern technologies will be used to understand the underlying mechanisms of epilepsy-associated inflammations. This work will help advance our knowledge about epilepsy and offer insight into the designing of effective treatment. Funding for this grant was supported by the American Epilepsy Society and Sunovion Pharmaceuticals, Inc.

Restoring Consciousness during Seizures Using Optogenetic Stimulation

Moran Furman, PhD, Postdoctoral Associate

Yale University, New Haven, CT

Loss of consciousness in epilepsy is a major burden for people with epilepsy and for society. Even small seizures in brain regions devoted to memory can cause loss of consciousness, and currently, there are no effective therapies to prevent this debilitating side-effect of epilepsy. Seizures in rats, like in humans, cause impaired consciousness. We will use two brain stimulation techniques, electrical stimulation and optogenetics (a novel technique based on activation of neurons by laser light), to prevent loss of consciousness in rats with epilepsy. This research will hopefully pave the way for novel therapies to prevent loss of consciousness during seizures in humans.

Reelin Signaling Mediates Aberrant Neurogenesis in Temporal Lobe Epilepsy

Matthew Joseph Korn, PhD, Postdoctoral Research Fellow

The Regents of the University of Michigan, Ann Arbor, MI

Mesial temporal lobe epilepsy (mTLE) is a common and often intractable form of epilepsy. Many of the pathological changes take place in the hippocampus where the disruption of the circuit results in persistent hyperexcitability. Adult-born neurons are prone to developing abnormalities that may contribute to chronic spontaneous seizures. Despite advances in understanding the pathogenesis of epilepsy, few therapeutic targets are available. This project investigates how changes to the reelin signaling pathway, known to be disrupted in mTLE, impact the development of immature neurons in the hippocampus. If spontaneous seizures develop, it would offer reelin signaling as a target for treatment.

Investigating the Mechanism of Stress Induced Seizure Susceptibility

Georgina MacKenzie, PhD, Postdoctoral Associate

Tufts University, Boston, MA

The majority of people with epilepsy report that stressful situations exacerbate their seizures. However, the complex relationship between stress and epilepsy is still not fully understood. This project investigates a novel mechanism linking stress to increased neuronal excitability and seizure susceptibility with the goal of identifying new therapeutic targets for the treatment of epilepsy. Funding for this grant was supported by the American Epilepsy Society and Sunovion Pharmaceuticals, Inc.

Detection and Prediction of Human Seizures Using Intracortical Neural Signals

Yun Sang Park, Postdoctoral Research Associate

Brown University, Providence, RI

One of the most debilitating aspects of epilepsy is the seemingly unpredictable nature of seizures. Reliable early-detection or even prediction of seizures could bring tremendous benefits to people with epilepsy, including a significant improvement in therapeutic possibilities. The project aims to develop and test a novel framework for early detection and prediction of seizures in people with epilepsy using experimental intracortical neural signals. The long-term goal is to develop a closed-loop system for seizure warning, prediction, and control and ultimately to conduct a human pilot clinical trial with the system.

Screening for Seizure Modifiers in a Drosophila Knock-in Model of SMEI

Lei Sun, Postdoctoral Fellow

The Regents of the University of California (Irvine), Irvine, CA

Dravet Syndrome, also known as severe myoclonic epilepsy of infancy (SMEI), is a catastrophic form of intractable epilepsy that begins in infancy. Over 300 different mutations in SCN1A sodium channel gene have been linked to SMEI, and the limited ability to evaluate disease mechanisms hampers development of effective therapeutics. We will use a Drosophila model of human SMEI to study the underlying mechanisms of SMEI and to screen for novel therapeutic targets. The Drosophila models of SMEI provide a rapid, low cost platform for categorizing SMEI mutations by function and developing therapies for personalized treatment. Funding for this grant was supported by the American Epilepsy Society and Sunovion Pharmaceuticals, Inc.

mTOR, Epilepsy and Synaptic Transmission

Matthew Weston, PhD, Postdoctoral Fellow

Baylor College of Medicine, Houston, TX

In both humans and mice, mutations in genes that control mammalian target of rapamycin (mTOR) signaling lead to epilepsy. In some cases of epilepsy, changes in how nerve cells communicate with each other are thought to be a cause. Discovering ways in which communication between nerve cells are altered in mice that have mutations affecting mTOR signaling will lead to a better understanding of the development of epilepsy. Funding for this grant was supported by the American Epilepsy Society and Lennox & Lombroso Trust for Epilepsy Research and Training.

Innate and Adaptive Immunity in Epileptogenesis of Childhood Epilepsy

Dan Xu, Postdoctoral Trainee

Northwestern University-Chicago Campus, Chicago, IL

The goal of this project is to determine if the presence of inflammation in the seizing brain of young children would increase the likelihood of recurrent seizures and eventually lead to epilepsy. Approximately one in every 25 children will have at least one febrile seizure, which is convulsion brought on by a fever. One-third of these children will have additional febrile seizures, which is intrinsically associated with inflammation. This project adopts a mouse model that recapitulates human epilepsy to study whether manipulation of the inflammation can prevent the development of epilepsy and to identify novel targets for improved therapy.

RESEARCH GRANT PROGRAM

The Research Grant Program stimulates epilepsy research by providing funding for investigators in the early stages of their careers. One- and two-year seed grants are awarded to clinical investigators or basic scientists for support of biological or behavioral research that will advance the understanding, treatment, and prevention of epilepsy. Applications from established investigators (Associate Professor or above) are ineligible.

FALL 2012 AWARDS – \$300,000

Neurotrophins and Fetal Anticonvulsant Syndrome

Kevin Bath, PhD, Assistant Professor

Brown University, Providence, RI

This project will use preclinical models of early life exposure to anti-seizure medications to test the hypothesis that multiple anti-epilepsy drugs (AEDs) contribute to a common disruption in brain development underlying many of the observed AED side effects.

The Role of miRNA-Mediated Regulation of Kv4.2 during Status Epilepticus

Christina Gross, PhD, Assistant Professor

Emory University, Atlanta, GA

A major challenge in epilepsy research is the identification of therapeutic strategies that are beneficial for people with epilepsy disorders of different etiologies. Potassium channels play an important role in controlling neuronal activity and excitability in the brain and might be promising therapeutic targets. This research will analyze how a specific potassium channel, Kv4.2, a major player in limiting brain activity, is controlled by a group of small RNAs. In the future, these small RNAs might be used as therapeutic tools to manipulate Kv4.2 function and modulate brain activity in epilepsy of different etiologies.

Contribution of Cortical Interneurons to Epilepsy

Illya Kruglikov, PhD, Research Assistant Professor

New York University, School of Medicine, New York, NY

Healthy brain function depends on a precise balance of excitation and inhibition. Decreasing inhibition causes runaway excitation and consequently epilepsy. Inhibition is provided by a small and diverse group of neurons called interneurons. This project addresses the contribution of different cortical interneuron types to the development of epilepsy by genetically removing a protein, which when mutated is known to cause epilepsy in humans. One goal of this project is to study the type of epilepsy seizures produced by affecting specific interneuron populations. Another is to understand the wiring of cortical circuits leading to seizure generation. This project will advance our understanding of the cellular and circuit mechanisms of epilepsy.

Interaction between TrkB Signaling in Interneurons and Epilepsy

Keri Martinowich, PhD, Investigator

Lieber Institute, Baltimore, MD

Epilepsy is a disorder characterized by recurrent seizures that arise from disruptions in neuron firing patterns that lead to excessive excitation. Understanding the cellular and molecular mechanisms that lead to hyperexcitability and spontaneous seizures is crucial to identify targets for drug development. Investigations of the cellular and molecular origins of brain hyperexcitability leading to epilepsy have identified the brain-derived neurotrophic factor (BDNF). There is extensive evidence that BDNF, signaling through its receptor TrkB, is involved in epilepsy. However, both proepileptogenic and antiepileptogenic effects have been attributed to BDNF/TrkB signaling. This study characterizes the less well-understood mechanisms by which reductions in BDNF potentiate seizure development by influencing inhibitory transmission.

Potential for Seizure Control of Isovaline in Epilepsy*Damian Shin, PhD, Assistant Professor**Albany Medical College, Albany, NY*

While many people with epilepsy are treatable with anti-epilepsy drugs (AEDs), some do not respond and others experience adverse effects. Therefore, there is considerable interest in identifying novel candidates for AED development. This study will assess whether isovaline, an amino acid with a unique structure that attenuates seizure-like events in brain slices, has utility as a new AED in acutely and chronically seizing animals. If so, then a new class of drugs may revolve around the unique properties of this amino acid.

Ultra High Resolution DTI of the Hippocampus in Epilepsy*Michael Zeineh, PhD, Assistant Professor**Stanford University, Stanford, CA*

Epilepsy is when someone has frequent seizures. Often, there is a defect in a part of the brain causing these seizures. If the defect can be found, surgery can eliminate the seizures. However, current techniques often cannot find the defect. Diffusion imaging is a new method that looks at the microscopic motion of water in the brain. This project will use high-definition diffusion imaging in people with epilepsy to identify with greater accuracy the parts of the brain that are causing the seizures.

PREDOCTORAL RESEARCH AND TRAINING FELLOWSHIP

The Predoctoral Research and Training Fellowship supports predoctoral students with dissertation research related to epilepsy, thus strengthening their interest in establishing epilepsy research as a career direction. Graduate students must be matriculating in a full-time doctoral (PhD) program with an academic career focus. Areas of interest considered include, but are not limited to, neuroscience, physiology, pharmacology, psychology, biochemistry, genetics, nursing, or pharmacy.

FALL 2012 AWARDS – \$220,000**Circuit Contributions of Adult and Seizure-Induced Neurogenesis***Christopher Dengler, BS, BA, PhD Candidate**The Children's Hospital of Philadelphia, Philadelphia, PA*

The birth of new neurons is a natural feature of the adult brain, but this process is profoundly dysregulated after brain injuries that precipitate epilepsy. The exact circuit contributions of new neurons in both the healthy brain and the brain of a person with epilepsy are unknown. The proposed studies employ optical and electrical recording techniques, as well as transgenic strategies, to investigate the physiological contributions of neurogenesis to hippocampal circuit function in health and in epilepsy. Elucidation of the role of newborn neurons in epilepsy should enhance our understanding of the disease and contribute to the development of new therapeutic avenues and insights. Funding for this grant was supported by the American Epilepsy Society.

Contribution of Cilia Defects to Neuronal Activity in Developing Cortex*Sarah Guadiana, BS, Doctoral Candidate**University of Florida, Gainesville, FL*

Virtually every neuron in the brain grows a primary cilium, a "cellular antennae" that surveys the cell's local extracellular environment. How cilia regulate CNS neuronal development and function is unclear despite a growing body of literature that links mutations in cilia genes with various manifestations such as cognitive disorders, autism and seizures. The overall goal is to bridge the gap between our understanding of ciliogenesis defects and abnormal neuronal activity and excitability underlying neuronal differentiation changes. Results from these experiments will provide insight into manifestations seen in people with ciliopathies and may provide novel therapy targets for these human disorders. Funding for this grant was supported by the American Epilepsy Society.

Effects of TRIP8b Phosphorylation on HCN Channel Trafficking in Epilepsy

Robert John Heuermann, BA, Graduate Student

Northwestern University - Chicago Campus, Chicago, IL

Ion channels are specialized proteins that enable nerve cells to generate electrical signals. Our lab focuses on one particular family of ion channels named hyperpolarization-activated cyclic-nucleotide-gated (HCN) channels. These channels serve a variety of functions in different regions of the brain. In the hippocampus, an area we are particularly interested in that governs learning and memory, HCN channels have an inhibitory effect that reduces overall activity. Furthermore, in forms of epilepsy that affect the hippocampus, the amount of HCN channels is reduced, which contributes to the increased excitability and recurrent seizures that characterize epilepsy syndromes. Our goal is to understand the changes that occur in HCN channels during epilepsy, which may lead to preventive therapies for this debilitating disorder.

Physiological Consequence of an Epilepsy Mutation in the VGSC Beta1 Subunit

Larisa Kruger, PhD Graduate Student

The Regents of the University of Michigan, Ann Arbor, MI

Voltage-gated Na⁺ channels are ion channel pores in the brain that are essential for proper neuronal firing. These channels are composed of alpha subunits that form the pore and beta subunits that modulate the pore. The SCN1B gene encodes the beta1 subunit. Mutations in SCN1B are associated with Genetic Epilepsy with Febrile Seizures Plus (GEFS+). This project will compare two mouse models of GEFS+, both with mutations in SCN1B, to determine their mechanisms of epilepsy. This project will also use the induced pluripotent stem cell technique to study human neurons derived from a GEFS+ patient's skin biopsy. The long-term goal is to develop new epilepsy therapies. Funding for this grant was supported by the American Epilepsy Society.



FACT

2: The estimated number of years of life lost for people with epilepsy from an unknown cause.

Optogenetic Medial Septal Neuromodulation to Control Hippocampal Seizures

Nealen Laxpati, Predoctoral Researcher

Emory University, Atlanta, GA

Many of the 65 million people with epilepsy worldwide lack effective therapy, and new deep brain stimulation techniques have only had partial success. This is in part due to the non-specificity of electrical stimulation and inefficient stimulation parameters and anatomical targets. This project aims to control hippocampal seizures by addressing these issues. Novel optogenetic techniques enable more specific neuronal control. This technology will be leveraged in the tetanus toxin rat model of epilepsy. It will be targeted to the medial septum, which projects onto the seizing hippocampus, to modulate focal hippocampal seizures with a known antiepilepsy oscillatory rhythm, theta. Funding for this grant was supported by the American Epilepsy Society.

Inflammation in Epilepsy Associated with Cortical Dysplasia

Lena Hoan Nguyen, BS, Predoctoral Fellow

Baylor College of Medicine, Houston, TX

Cortical dysplasia (CD), a disorder characterized by malformations of the cortex, is commonly associated with drug-resistant epilepsy. Although dysregulation of specific signaling pathways has been identified in cortical dysplasia, the mechanism underlying the associated epilepsy phenotype is not understood. Emerging evidence, including recent identification of increased inflammation in human cortical dysplasia tissue, supports an important role for brain inflammation in drug-resistant epilepsy. The purpose of this research is to investigate how brain inflammation modulates epilepsy in cortical dysplasia. A better understanding of the role of inflammation in epilepsy may lead to new treatment strategies.

Inflammation Mechanisms in Epileptogenesis after Febrile Status Epilepticus

Katelin Patterson, BA, Graduate Student

The Regents of the University of California (Irvine), Irvine, CA

The most common type of seizure amongst children and infants are known as febrile seizures (seizures that arise with fever). Human data and animal studies suggest that febrile seizures lasting longer than 30 minutes (known as febrile status epilepticus or FSE) may lead to temporal lobe epilepsy (TLE). Therefore, understanding the processes in which a healthy brain develops epilepsy will allow for therapeutic interventions to prevent epilepsy. Inflammation has been implicated in the generation of epilepsy post FSE. We want to determine if inflammation is necessary for the generation of epilepsy after FSE by blocking it and testing for the presence of later seizures.

Seizures Beget Seizures: Role of Blood-brain Barrier Leakage in Epilepsy

Emma Soldner, BS, BA, Graduate Research Assistant

Regents of the University of Minnesota - Twin Cities, Duluth, MN

Approximately 40 percent of people with epilepsy respond poorly or not at all to current therapies. Thus, understanding the causes and triggers of seizures may direct us to the development of new epilepsy treatments. Recently, it has been shown that seizure-induced blood-brain barrier leakage promotes further seizure activity and that restoring barrier function reduces seizure burden in rodent models of epilepsy. Currently, however, the cause of barrier leakage following seizures is unknown. The goal of this project is to understand the mechanism by which seizures alter blood-brain barrier permeability and to restore its function to help reduce seizure activity in epilepsy. Funding for this grant was supported by the American Epilepsy Society.

Characterizing KCNQ2 Mutations in Severe Neonatal Epilepsy Encephalopathy

Baouyen Tran, Graduate Student

Baylor College of Medicine, Houston, TX

Benign familial neonatal seizure (BFNS) is a rare inherited disease linked to mutations in the gene encoding the protein Kv7.2 and generally does not lead to developmental abnormalities. However, novel mutations in this gene lead to less favorable outcomes for affected individuals that suffer from mild to severe psycho-motor impairment. The purpose of this research is to characterize the mutations that may help pinpoint other risk factors, leading to better therapies to reduce motor and cognitive decline. Funding for this grant was supported by the American Epilepsy Society and The Pediatric Epilepsy Research Foundation.

Proneurotrophin Signaling in Epilepsy

Ajay Thomas, BS, MD/PhD Candidate

University of Colorado Denver, AMC and DC, Aurora, CO

This work could impact positively our knowledge in the field of epilepsy since there is little known about the role of proBDNF signaling in development of epilepsy and could lead to new ways of approaching therapeutic interventions for epilepsy.

The Role of BDNF in the Maturation of Axo-axonal Synapses

Xinjun Wang, PhD Student

University of Wyoming, Laramie, WY

Chandelier cells play a key role in the regulation of neural oscillation and epileptogenesis. This study will investigate on axo-axonic innervations in a model system for epileptogenesis. First, we will characterize the properties of axo-axonic inhibition in the piriform cortex of mice using the optogenetic approach and in vitro slice electrophysiology. Second, we will examine the role of activity-dependent brain-derived neurotrophic factor (BDNF) in the maturation of axo-axonic innervations using a knock-in mouse model. Funding for this grant was supported by the American Epilepsy Society.

Research and Training Fellowship for Clinicians

The Research and Training Fellowship for Clinicians is for clinically trained professionals. This fellowship is one-year of supervised study and research. Individuals with an MD or DO who will have completed residency training in neurology, neurosurgery, pediatrics, internal medicine, or psychiatry by the time the fellowship commences may apply. Other clinically trained professionals (i.e., PharmD, Doctor of Nursing) are also eligible to apply.

FALL 2012 AWARDS – \$100,000

Automatic Intraoperative Mapping of Epilepsy Networks

Mesha Gay Brown, MD, Resident

The Trustees of the University of Pennsylvania, Philadelphia, PA

Less than 50 percent of people with nonlesional extratemporal epilepsy achieve seizure freedom after epilepsy surgery. It has recently been discovered that high frequency oscillations (HFOs) within the brain may be biomarkers of epilepsy networks. To test whether resecting HFO-generating brain regions improves outcome from epilepsy surgery, it is vital that intracranial electrodes be placed to capture major HFO-generating regions. The goal of this project is to develop methods to map and localize interictal HFOs effectively, both intraoperatively and during video-EEG monitoring with intracranial electrodes, to define HFO-generating regions and minimize sampling error during electrode placement. These methods will be used in a preliminary study to determine if supplementary electrodes placed intraoperatively based on real-time HFO detection may more accurately localize epilepsy networks during continuous inpatient recording outside of the operating room, potentially improving the outcome from epilepsy surgery.

Ictal Cores, Penumbra, and High Frequency Oscillations

Robert Connors, Fellow in Clinical Neurophysiology

Columbia University Medical Center, New York, NY

This project studies a new interpretation of high-frequency electrical signals generated during an epilepsy seizure and examines their relationship with a patient's clinical symptoms. Our work will help to localize the part of the brain generating seizures more precisely and will one day lead to more precise therapies for partial epilepsy.



FACT

150,000: The number of new cases of epilepsy diagnosed in the U.S. annually

Research Infrastructure Grant

The American Epilepsy Society (AES) and the Epilepsy Foundation are partnering to provide an opportunity for scientists to obtain support for nationwide or international networks of clinical or basic science researchers focused on understanding the causes, consequences and treatment of epilepsy. Multicenter research programs are viewed as an important venue through which investigators from around the world can establish centralized databases, common protocols, shared resources and core laboratories and can exchange rapidly developing techniques and technologies. Such cooperative efforts are anticipated to hasten the speed of discovery. These funds are meant to be used to support pilot projects and to

hold organizational and planning sessions with representatives from each center in the planned network. These planning sessions should also be used to develop the research effort and collect results that would be used to prepare and submit a larger application for support from the federal government and to establish the multicenter research program over the long term.

FALL 2012 AWARDS – \$100,000

Rational Intervention for KCNQ2 Epilepsy Encephalopathy (RIKEE) Network

*Edward Cooper, MD, PhD, Associate Professor of Neurology and Neuroscience
Baylor College of Medicine, Houston, TX*

Pediatric Status Epilepticus Research Group (pSERG)

*Tobias Loddenkemper
Children's Hospital Boston, Boston, MA*

Establishment of a Multicenter Pediatric Epilepsy Group (PEG) to Facilitate Collaborative Research in Epilepsy Encephalopathies of Infancy and Childhood

*Elaine Wirrell, MD, Mayo Clinic Rochester
Kelly Knupp, MD, University of Colorado*

This project seeks to establish a functional, multicenter network of U.S. pediatric epileptologists to further study causes, best treatments, and outcomes of epilepsy encephalopathies in infants and children. Epilepsy encephalopathies are among the most severe childhood brain disorders and include many of the rare epilepsies, including Dravet syndrome; Landau-Kleffner syndrome; Lennox-Gastaut syndrome; and West syndrome. Intractable seizures and extreme cognitive deficits are frequent symptoms and often progress relentlessly to early death. Grant recipients also propose to demonstrate that the PEG network can collaborate effectively in clinical research.

HEALTH SCIENCES STUDENT FELLOWSHIP

The Health Sciences Student Fellowship stimulates individuals to pursue careers in epilepsy in either research or practice settings. Predoctoral training students in the health sciences may be accepted at any point in their schooling, following acceptance but before beginning the first year, or in the period immediately following their final year.

SPRING 2013 AWARDS – \$15,000

Efficacy and Cost Analysis of Antiepilepsy Drugs in Malignant Glioma

*Jennifer Kang
Duke University Medical Center, Durham, NC*

A common presenting symptom of brain tumors is seizures, and out of all people with primary brain tumors, those diagnosed with malignant glioblastoma experience preoperative seizures the most. There is a current lack of consensus in the medical literature and no national guidelines on the use of anti-epilepsy drugs for primary malignant glioblastoma. People with malignant glioblastoma have dismal outcomes. Those with the highest grade of malignant glioblastoma have a survival of about 12 to 14 months if they are able to tolerate maximum therapy of surgical resection, radiation therapy, and at least six months of chemotherapy. Uncontrolled seizures can be very debilitating to people with a limited quality of life due to a terminal disease. Therefore, any understanding we can gain to prevent and treat seizures in people with malignant glioblastoma may greatly improve their quality of life and potentially improve survival. The complex and lengthy treatment of malignant glioblastoma is costly. Understanding the economic impact on people with epilepsy and society when recommending additional treatments is a critical part of healthcare.

Calcium Imaging of Intra-reticular Thalamic Signaling in Absence Epilepsy

Peter Klein

The Rector and Visitors of the University of Virginia, Charlottesville, VA

Epilepsy is a very common disorder affecting nearly 70 million people globally. Absence epilepsy is a type of epilepsy where people experience brief impairments of consciousness rather than convulsions, show a specific pattern of brain activity and are more likely to have cognitive and linguistic deficits. Absence seizures occur when a part of the brain called the thalamus is overly active. The thalamus has two distinct clusters of neurons that fire back and forth with a reciprocal pattern of activity. Normally all of this activity is deliberately not very synchronized, but when all of these neurons fire at the same time it generates an absence seizure. This study examines the mechanisms that keep this activity desynchronized and how the pattern of firing transitions from normal activity to producing a seizure. Knowing the way in which activity in the thalamus produces seizures could help with the development of better drugs to treat absence epilepsy.

Tuber Evolution and Epilepsy in Tuberous Sclerosis Complex

Anna Kathleen Prohl

Children's Hospital Boston, Boston, MA

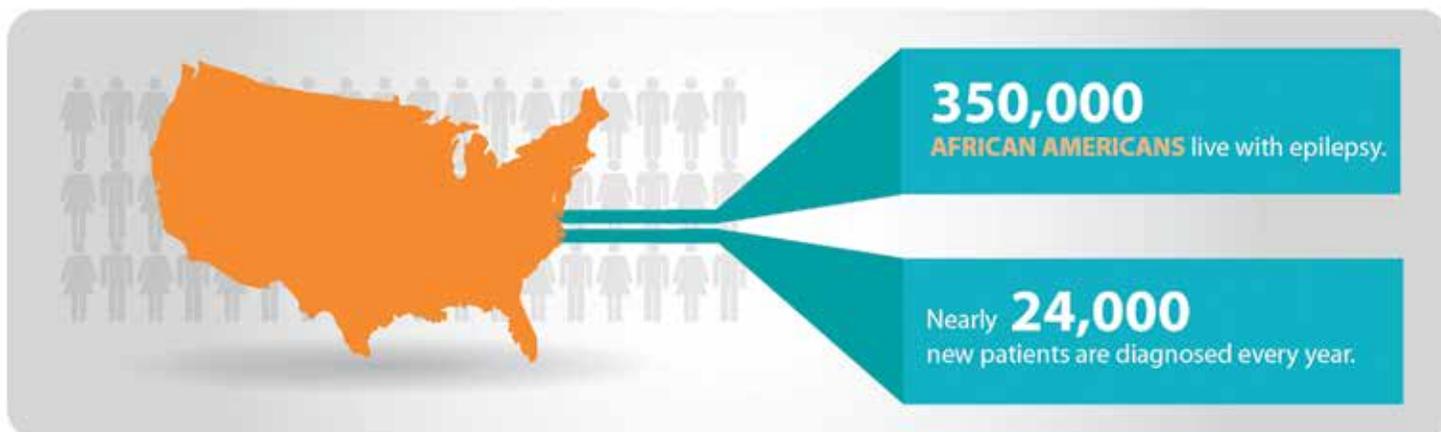
Tuberous Sclerosis Complex (SC) is a genetic disorder that is characterized by growth of benign tumors in many organs, including the brain where they are called "tubers." However, the relationship between these tubers and seizures is not well understood. Previous research has shown that poorly formed tissue in and around the tuber can show abnormal electrical activity, suggesting they are responsible for seizures. The purpose of the present study is to determine if there is a relationship between the structure of the tuber tissue and epilepsy severity in SC patients, to determine if the tuber tissue becomes more abnormal over time and to look for a relationship between tissue changes and epilepsy. This work would allow for a better understanding of the cause of epilepsy in SC.

Corticoid-cortical Connections and Dominant Interdict Spike Initiation Sites

Daniel Vitantonio

Georgetown University, Washington, DC

The contralateral cortex is known to generate a "mirror focus" of secondary seizure activity opposite to an existing seizure focus, but how early mirror sites form prior to emergence of seizures, and whether they promote development of seizure activity, remains unknown. Interdict spikes occur in epilepsy tissue prior to and in between episodes of seizure activity and are correlated with the area of seizure activity. We hypothesize that mirror sites of the interdict spike initiation sites interact to promote dominant initiation sites at fixed spatial areas. Frequent interdict spikes initiating from a dominant site in the brain may accumulate to promote seizure activity originating from the same site. In this study, interdict spike initiation sites are imaged in a whole animal model using voltage-sensitive dye imaging, and the formation of dominant initiation sites over time is examined. Electrical stimulation of the contralateral cortex will be performed to manipulate the dominant initiation sites. The proposed study will contribute to understanding the spatial property of interdict spikes, which is important because fixed spatial patterns of frequent interdict spikes may accumulate over time to promote seizures.



BEHAVIORAL SCIENCES STUDENT FELLOWSHIP

The Behavioral Sciences Student Fellowship stimulates individuals to pursue careers in epilepsy in either research or practice settings. Appropriate fields include sociology, social work, psychology, anthropology, nursing, economics, vocational rehabilitation, counseling, political science, and others relevant to epilepsy research or practice. Both graduate and undergraduate students are eligible.

SPRING 2013 AWARDS – \$3,000

Working Memory Intervention in People with Temporal Lobe Epilepsy

Mark Fischer

University of Cincinnati, Cincinnati, OH

One of the most common difficulties that individuals with temporal lobe epilepsy report is impairment during tasks dependent on memory functioning. The proposed research will investigate the efficacy of a web-based training program for people with temporal lobe epilepsy to strengthen a component of memory performance known as working memory, which refers to the ability to hold new information in mind and manipulate that information.

BEHAVIORAL SCIENCES POST-DOCTORAL FELLOWSHIP

The Behavioral Sciences Post-Doctoral Fellowship develops excellent behavioral scientists to teach the appropriate psychosocial intervention techniques used in working with people with epilepsy and contributes to the body of behavioral research in epilepsy. Individuals who will have received their doctoral degrees in a field of the social sciences by the time the fellowship commences and desire additional postdoctoral research experience may apply.

SPRING 2013 AWARDS – \$80,000

Naming Assessment for Spanish-speakers with Epilepsy

Kirsty Bortnik, PhD

The Trustees of Columbia University, New York, NY

Word-finding or “naming” is an important language skill that is often compromised in people with temporal lobe epilepsy (TLE). Historically, naming has been assessed via visual object naming, yet this task has failed to consistently identify true naming difficulties. The development of auditory description naming has improved the sensitivity of naming assessment and has proven useful in identifying brain areas that are important for language. However, these naming measures are not available in Spanish, which compromises assessment and treatment for a significant proportion of the epilepsy population. There are significant limitations to existing visual naming measures for Spanish speakers (e.g., inclusion of culturally unfamiliar test items), and no Spanish auditory naming measures have been developed. This project will develop a set of standardized, culturally-appropriate naming measures for native Spanish-speaking adults. Study findings will lead to better diagnosis of naming deficits in Spanish-speaking adults with epilepsy, which will ultimately assist in their epilepsy treatment and care.

Can Resting-state Networks Predict Cognitive Change after Epilepsy Surgery?

Gaelle Doucet, PhD

Thomas Jefferson University, Philadelphia, PA

Developing tools to prevent cognitive co-morbidity following epilepsy brain surgery is an elusive, but critical clinical goal. While the deficits in episodic memory are well understood, the reasons for deficits in functions such as attention and

working memory are not clear in this largely mesial temporal disorder. The purpose of this study is to assess the integrity of key well-defined resting-state networks on a pre-surgical basis and determine their ability to predict neurocognitive outcomes after brain surgery. For this project, people with epilepsy will all have realized both pre- and post-surgical neuropsychological evaluations to assess cognitive changes. Also, they will have undergone a resting-state functional magnetic resonance imaging condition, pre-surgery. This will allow mapping the brain networks involved in the major functions (episodic memory, working memory, executive control, language and attention). Overall, the goal of the project is to provide maps of cognitive networks relevant for cognition, so they might be preserved during surgery and further help people with epilepsy maintain their quality of life post-surgery.

TARGETED RESEARCH INITIATIVE FOR SEVERE SYMPTOMATIC EPILEPSIES

The Epilepsy Foundation announced its first annual Targeted Research Initiative for Severe Symptomatic Epilepsies Grant program. This program seeks to better understand, diagnose, identify co morbidities, and treat these rare but devastating epilepsy syndromes. The catastrophic epilepsies of childhood commonly include Othara's syndrome, severe myoclonic epilepsy in infancy (Dravet), infantile spasm, progressive myoclonic epilepsies, Lennox-Gastaut syndrome, Doose syndrome, Sturge-Weber syndrome, Rasmussen encephalitis and, in later childhood, Landau-Kleffner syndrome (LKS) and continuous spike and wave in slow-wave sleep (CSWSS).

SPRING 2013 AWARDS – \$50,000

Mechanisms of KCNQ2 Mutations Associated with Epilepsy Encephalopathy

Hee Jung Chung, PhD

The Board of Trustees of the University of Illinois at Urbana-Champaign, Urbana, IL

Neurons generate electrical signals called action potentials in their morphologically distinct processes named axons. KCNQ channels concentrated at the axonal surface allow potassium ions to move from inside to outside of the neurons. Such current through these channels prevents “repetitive firing of action potentials,” which is a hallmark of excessive neuronal activity leading to seizures. Mutations in KCNQ2 subunit protein of these channels recently were found in people with epilepsy encephalopathy, severe epilepsies of childhood characterized by drug-resistant seizures and psychomotor impairment. Some of these mutations are clustered in the cytoplasmic tail of KCNQ2 subunit, which is important for surface expression or opening and closing of the channels. The research will investigate whether these mutations reduce potassium current and/or axonal localization of KCNQ channels, leading to excessive action potential firing. Two small molecule compounds will also be explored for their ability to enhance the channel surface expression. These studies should provide insights into the pathogenesis of this disease and facilitate the development of novel therapy that could correct the loss of channel surface expression.



TARGETED RESEARCH INITIATIVE FOR WOMEN

The Targeted Research Initiative for Women with Epilepsy program was developed to support research that generates initial data leading to more extensive projects that will have direct relevance to the care of women with epilepsy. Research should focus on investigating one of the many areas that preferentially affect women with epilepsy during the reproductive life cycle. This initiative recognizes the need for research and new insights into these scientific areas. The research may target any point along the reproductive spectrum, including puberty through menopause. Examples of topics of interest include, but are not limited to, the following areas: neuroendocrine disorders, hormone influence on seizure susceptibility, infertility, polycystic ovarian syndrome, contraceptive strategies, complications during pregnancy, and pregnancy outcomes.

SPRING 2013 AWARDS – \$50,000

NR2D Subunit: Novel Treatment Target for Status Epilepticus in Women

Jana Veliskova, MD, PhD

New York Medical College, Valhalla, NY

About 50 percent of people with epilepsy are women. Epilepsy in women is often associated with reproductive disorders and early menopause due to imbalances in reproductive hormones (estrogen and progesterone). Estrogen has neuroprotective effects against status epilepticus (SE)-induced neuronal damage, while progesterone has only anti-seizure but not neuroprotective properties. In contrast to men, women undergo profound hormonal changes during their lifespan that can interfere with seizures and seizure-induced neuronal damage. NMDA receptors (NMDAR) play a critical role in seizure generation and maintenance. Depending on subunit composition and/or subcellular localization, NMDAR mediate both neurotoxic and neuroprotective effects. Estrogen modulates NMDAR-mediated transmission by regulating composition, distribution and functional properties of NMDAR. Whether estrogen's neuroprotective effects against SE-induced damage involve a shift of balance to beneficial pro-survival in contrast to neurotoxic and pro-epileptogenic NMDAR effects in females lacking estrogen is unknown and will be the focus of this grant. Results will serve as a ground for personalized treatment strategies in women with epilepsy depending on their hormonal status.

THE TARGETED RESEARCH INITIATIVE FOR YOUTH

The Targeted Research Initiative for Youth recognizes the increasing need for epilepsy and seizure research in populations from children through adolescence involving pathophysiology, epidemiology, diagnosis, behavioral manifestations, medication therapy, and quality-of-life issues.

The Foundation invites research grant applications from investigators interested in psychosocial problems and comorbidities of children and adolescents with epilepsy including, but not limited to, topics such as psychiatric comorbidity; treatment of behavioral and cognitive comorbidities, including innovative techniques such as utilization of internet or computer based technologies; studies of the impact of impaired social cognition on educational and occupational outcomes; difficulties and treatment gaps for adolescents transitioning to adulthood; social supports for adolescents with epilepsy; health access and literacy including family communication with health care professionals; the impact of other health conditions (e.g., sleep difficulties, migraines, etc.) on epilepsy treatment and outcome. Investigators must hold a relevant advanced degree (MD, PhD, MS, PharmD) and have completed all research training appropriate to the project proposed. Open to investigators at academic/university settings and others in the public and private sectors.

SPRING 2013 AWARDS – \$50,000

Effect of Impression Management on Hireability of Youth with Epilepsy

Ying Yuk (Connie) Sung, PhD

Michigan State University, East Lansing, MI

The impact on youth with epilepsy is substantial - lifestyle, school, and limitations on employment are major problems. Employment is fundamental to individual's psychological well-being and quality of life. The strongest predictor of adult employment has been attributed to gaining employment experience during adolescence and yet, the employment experiences of youth with epilepsy remain unstudied. Traditionally, considerable efforts have been devoted to help people with disabilities develop work-related skills specific to a job position. However, little research effort has been directed toward helping people with disabilities develop "job-getting skills." Research indicates that interviewers' evaluations of applicants is less influenced by academic credentials and work skill factors than by interviewers' subjective opinions. Therefore, the use of impression management (IM) tactics among people with non-visible disabilities should be considered. The purpose of this study is to determine the effect of IM tactics on interviewers' evaluation of youth with epilepsy. Results of this study will provide insights on the use of IM tactics and inform the development of job interviewing skills for youth with epilepsy.

TARGETED RESEARCH INITIATIVE FOR MORBIDITY AND MORTALITY

The Targeted Research Initiative for Morbidity and Mortality supports research that generates initial data leading to more extensive projects that will generate knowledge that will ultimately improve the lives of persons with epilepsy. This initiative recognizes the need for research and new insights into these scientific areas.

The broad focus of the morbidity portion of this program includes identification of somatic comorbidities in epilepsy that occur more than expected among controls (including but not limited to diabetes, gastrointestinal bleeding, chronic lung disease, congenital cardiac abnormalities, heart failure, and pneumonia) and identification of associations between somatic comorbidities in epilepsy and epilepsy outcomes (including quality of life in epilepsy, seizure remission, stigma and other outcomes).

The mortality portion of the program is focused upon potentially preventable causes of death in epilepsy, such as accidents, suicide and sudden unexpected death in epilepsy (SUDEP). Applicants are encouraged to examine risk factors for these causes of death in epilepsy, as well as interventions to decrease the presence of risk factors for these causes of death where risk factors have been identified.

SPRING 2013 AWARDS – \$50,000

SUDEP Prevention: Mediators of Post-Ictal Respiratory Control

Carl L. Faingold, PhD

Southern Illinois University School of Medicine, Springfield, IL

Sudden unexpected death in epilepsy (SUDEP) is a devastating consequence of seizures and is thought to be caused by abnormal breathing, heart, and brain activity after seizure. SUDEP is the major cause of death in people with epilepsy, and DBA mice are an important animal model of SUDEP. This project will evaluate the changes in breathing and heart and brain activity after seizure to determine the contribution of these abnormalities to SUDEP in DBA mice. Discovering a treatment to prevent SUDEP is an important goal of epilepsy research, since there is no current treatment. Several chemicals are released during seizures that may contribute to SUDEP, including opiate-like agents and adenosine. This project will measure these chemicals in the blood of DBA mice and people after seizures to determine if they are potentially important to SUDEP.

A drug that blocks the effects of adenosine appears to block SUDEP in DBA mice, and this will be verified along with evaluating the effects of drugs that block opiate effects in this proposal in mice to establish the potential use of these drugs for prevention of SUDEP.

TARGETED RESEARCH INITIATIVE FOR COGNITIVE AND PSYCHIATRIC ASPECTS OF EPILEPSY

The Targeted Research Initiative for Cognitive and Psychiatric Aspects of Epilepsy supports research leading to new insights into the diagnosis etiology, complications and treatment of persons with epilepsy and mood disorders including comorbid depression, anxiety, suicidality, other psychiatric symptoms; and psychogenic non-epilepsy seizures.

SPRING 2013 AWARDS – \$50,000

Neuroimaging Features of Cognitive Dysfunction in Focal Cortical Dysplasia

Karen Blackmon, PhD

New York University School of Medicine, New York, NY

Focal Cortical Dysplasia (FCD) is a common cause of treatment-resistant epilepsy. It is associated with subtle brain lesions that are often located in or near areas that are important for performing everyday functions, such as speech and learning new tasks. However, very little is known about which features of FCD might disrupt these crucial functions and increase the risk of developing a cognitive disorder. The most common feature on brain scans of FCD patients is a loss in sharp contrast between the white and grey matter borders of the brain – a feature called blurring. A previous study found an association between regional blurring and reduced language abilities in healthy individuals. The current study plans to assess whether abnormalities in blurring are associated with cognitive impairments in people with FCD. Findings from this investigation will determine whether blurring can: (1) be used as a non-invasive probe to investigate the functional vulnerability of tissue both within and outside of the visually identifiable lesion; (2) identify individuals at greater risk for cognitive impairments; and (3) be combined with neuropsychological test results to better localize regional tissue vulnerability in focal epilepsy.



9 OF EVERY 1,000: The number of candidates for epilepsy surgery who die of sudden unexpected death in epilepsy (SUDEP).



THE EPILEPSY INNOVATION SEAL OF EXCELLENCE

In the spring of 2013, the Epilepsy Foundation launched the Epilepsy Innovation Seal of Excellence (SEAL) to recognize groundbreaking and innovative product development programs deemed by the Foundation as deserving of significant and urgent support. The launch of the SEAL was part of the Foundation's strategic mandate to recognize critical advancements in the field of epilepsy. The SEAL is designed to facilitate access to funding and resources that will carry the recipient's work through proof of concept (PoC) and beyond, which typically costs from \$1 million to \$5 million dollars.

The award, which will be presented biannually, is given after intense scrutiny by the Scientific and Business Advisory Boards of the Epilepsy Foundation's Epilepsy Therapy Project (ETP) Initiative. ETP is focused on identifying and accelerating the most innovative epilepsy products in development. The SEAL includes a prize of \$25,000 and the privilege of using the Foundation's Epilepsy Innovation Seal of Excellence in advancing their efforts.

SPRING 2013 AWARDS – \$50,000

Anti-seizure Drug AMP-X-0079

AurimMed Pharma

Park City, Utah

AurimMed Pharma is advancing an exciting anti-seizure drug AMP-X-0079 that has already demonstrated promising early-stage data in the National Institute of Neurological Disorders and Stroke (NINDS) Anticonvulsant Screening Program. The company is currently seeking \$1.9 million to prepare AMP-X-0079 for an Investigational New Drug (IND) Application with the U.S. Food and Drug Administration, taking this program into human clinical studies.

Airbag Helmet

Hövding

Malmö, Sweden

The revolutionary airbag helmet created by Hövding was originally designed to protect cyclists, but also has the potential to offer significant safety features for people with epilepsy. The goal for Hövding is to obtain \$4 million to adapt the bicycle device for falls during seizures and to make the airbag reusable.





STRONGER TOGETHER



EPILEPSY PIPELINE UPDATE - 2014

SAN FRANCISCO, CALIFORNIA - JUNE 5-7, 2014

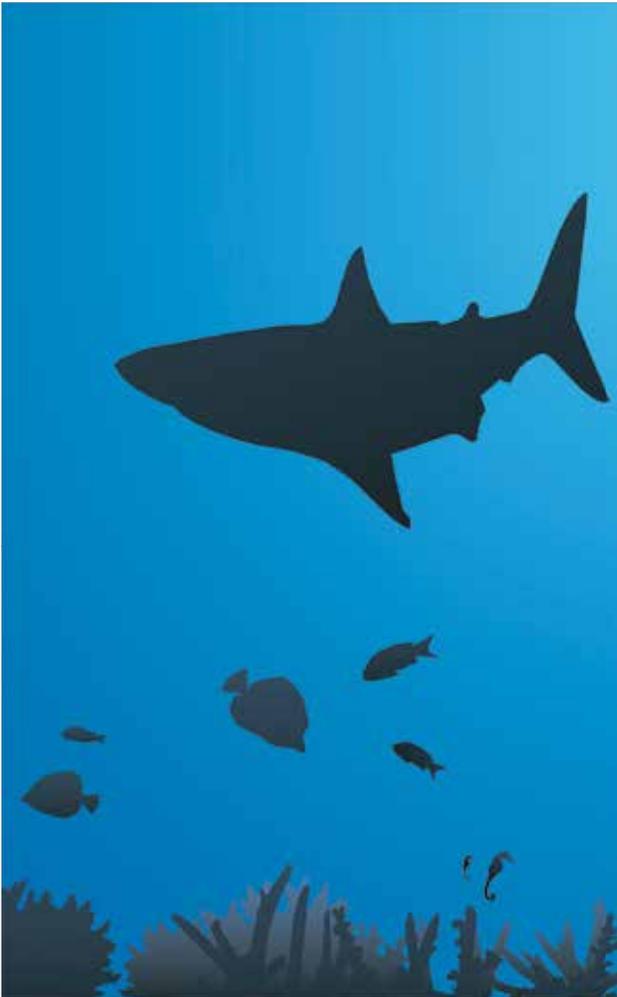
2014 EPILEPSY PIPELINE CONFERENCE

Save the Date!

June 5-7, 2014

Hyatt Regency

5 Embarcadero Center
San Francisco, California



Don't Go in the Water!

Join us for our 3rd Shark Tank Competition

The ETP Shark Tank is a competition created to help identify a new idea or technology that will benefit persons with epilepsy. Proposals are submitted in the form of Letters of Intent, of which, five proposals will be selected and invited to present to a panel of Sharks and audience participants at the 2014 Epilepsy Pipeline Conference.

The Shark Tank is a terrifyingly important competition and great fun too! As a member of the epilepsy community, we hope you will alert appropriate candidates about the Shark Tank competition to participate by submitting an LOI, or experience the excitement in person at the Epilepsy Pipeline Conference. Total Shark Tank prize package this year will be \$200,000!

Details and submission deadlines will be available soon. Keep watch...

For questions about the Pipeline Conference, Shark Tank, and activities, please contact: kmacher@efa.org

CARE & SUPPORT SERVICES



“To Be Real” by Gustavo Noguera



Stronger Together

Care & Support Services

The Epilepsy Foundation works to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, people living with epilepsy and seizures throughout the U.S. are served by 47 Epilepsy Foundation affiliates around the country.

Typical of the Foundation's national programs are its public awareness programs; school personnel and first responders training programs; outreach to families, youth and African American, Hispanic and Asian American communities; and self-management programs. Services commonly provided in local communities are information and referral, counseling, patient and family advocacy, school and community education, art therapy and support groups, and camps for children. Some of these care and support services are described below.

Seizure Training in Schools

"Managing Students with Seizures: A Training for School Nurses" is a continuing education program designed to provide school nurses with the information, strategies and resources to better manage students with seizures. After completing this training through one

of the Epilepsy Foundation's 47 local affiliates, school nurses are able to support positive treatment outcomes, maximize educational and developmental opportunities, and create a safe and supportive environment for students with seizures.



This year, the Foundation trained nearly 6,000 school nurses, moving closer to reaching its goal of training 10,000 school nurses in a year. Integral to this progress was the formation of the Epilepsy Awareness Management (EAM) Collaborative, a mentoring network that helps local Foundation affiliates carry out this national program. In 2014, the Foundation hopes to expand the number of nurses reached to 15,000 and plans to update program materials with information about new treatment therapies and strategies for supporting students with epilepsy.

Expanding the seizure training program beyond school nurses, the Foundation formed a new partnership with the Centers for Disease Control and Prevention to create the "Seizure Training for School Personnel" program. This continuing education program brings seizure management training to teachers, administrators, cafeteria workers, security guards, custodians, and anyone else who comes in contact with students with seizures.

Epilepsy and Seizure Response for Law Enforcement and EMS

The Epilepsy Foundation continues to offer free online training courses on epilepsy and seizure response to law enforcement personnel, emergency medical services (EMS) personnel, students and other healthcare professionals who may be responsible for the health and safety of people living with seizures. Additionally, Foundation affiliates provide training to law enforcement personnel through online, class and train-the-trainer sessions.

The Law Enforcement and EMS program is promoted through multiple media outlets and outreach has expanded to local, county, state and campus personnel. Last year, approximately 3,000 first responders were trained. Nearly 90% of the EMS participants received continuing education units.



Stronger Together



Studio E Program Continues to Grow

Studio E: The Epilepsy Art Therapy Program expanded its reach to 31 affiliate cities across the country this year as participants created art using a variety of mediums, such as painting, sketching, collaging, and sculpting. The resulting art work has been showcased at national convenings like the American Epilepsy Society annual meeting and on the Internet by Studio E sponsor Lundbeck at YourPartnerInEpilepsy.com. The website also offers prints for sale with a portion of the proceeds donated to the local Epilepsy Foundation that hosted the program of the artist.

The overwhelming majority of Studio E participants express that they

- Enjoyed the program and found it to be a valuable experience
- Would recommend the program to others with similar needs
- Felt more confident after the art therapy group sessions
- Indicated improved social skills

Looking toward the future, in addition to further expansion of the program, research will be conducted to measure the quality of life and self-esteem of participants after completing the sessions.

“This experience was amazing. I believe I learned a lot about myself and from others as well. To hear and come into contact with others that have epilepsy made me feel like I’m not alone. Thank you for this experience, and I will be able to keep this with me forever.”
 —Participant from the Epilepsy Foundation Michigan



“Man In Despair” by Gustavo Noguera



“Just My Imagination” by Marveil Oneal



“Hope” by Marcia Hunter

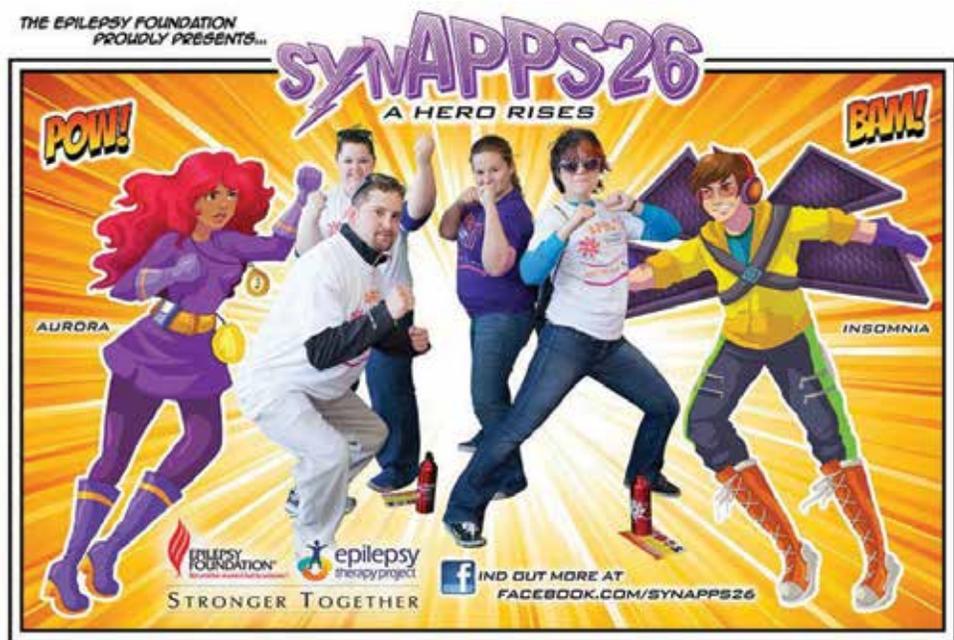
Youth Education and Awareness

The National Youth Council developed a new initiative for youth ages 16 to 24; “P2P! P2P” is a series of two separate programs that speak to education and awareness of epilepsy. The programs are geared toward both youth who have and those who have not been diagnosed with epilepsy. The program seeks to create leaders that are comfortable discussing epilepsy with their peers.

The first program is a peer-to-peer education program that uses a facilitator, who has been trained by a member of the National Youth Council, to direct educational sessions. The eight program sessions cover topics including how to be a good peer educator, transitioning from childhood to adulthood, medication management, and socializing. The program can be implemented in a way that is convenient for the facilitator and the peers to be educated. This new program is a great way for youth to learn in a way that doesn't involve a teacher-student model. Instead, it provides the opportunity for youth to be educated and communicate with their peers, which has been found to be a very effective way of delivering messages to youth.

The second program is the Transition Mentoring Program, which is an educational program that uses a one-on-one mentoring model. Designed to serve the same population as the peer to peer program, the mentor is also trained by a member of the National Youth Council. However, instead of being educated through group sessions, mentoring is done through a series of individual meetings, using a guide with talking points on subjects important to youth with epilepsy. This program allows dialogue about epilepsy to take place in a more informal way that mimics the Big Brother/Big Sister mentoring model.

Unveiled at the 2013 National Walk for Epilepsy, Synapps26 is a new and innovative public awareness campaign geared to promoting epilepsy awareness among youth high-school-age and older. Through the use of social media, a website that includes a character blog and comic strips, and gaming mobile apps (still in development), SynAPPS 26 tells the story of students at the fictional Fairmont High, including Tyler, a 16 year old with epilepsy, and his 15 year old girlfriend Ava. During his time at Fairmont, Tyler encounters both friends and foes of people with epilepsy. With superheroes and villains such as Aurora and Insomnia, Synapps26 aims to educate youth around epilepsy in an adventurous way!



Participants in the 2013 National Walk for Epilepsy could have their photos taken with Aurora and Insomnia, characters from Synapps26



FACT

Children and older adults are the fastest-growing segments of the population with new cases of epilepsy

Creating Awareness Across Cultures

Culminating in September 2012, the first phase of the CDC program for African American and Hispanic outreach on college campuses was designed to spread messages of inclusion and to emphasize that people with epilepsy can live, learn, work, play, thrive and participate in life's experiences. Conducted by six Epilepsy Foundation local affiliates, the program reached more than 11,000 people (about half were students) at 17 universities and 11 technical schools using tools and tactics including banners, door hangers, brochures, participation in campus events, and engaging with professors, fraternities and sororities, and other students. Affiliates that participated concluded that "campus outreach is transformative" and that it produces positive impacts on audiences, increasing awareness and knowledge and promoting healthy behaviors and practices.

Local Epilepsy Foundations Involved in the 2012 African American and Hispanic Campus Outreach

- Epilepsy Foundation Arizona
- Epilepsy Foundation Central and South Texas
- Epilepsy Foundation Greater Cincinnati & Columbus
- Epilepsy Foundation Kentuckiana
- Epilepsy Foundation San Diego County
- Sociedad Puertorriqueña de Epilepsia

Some of the affiliates that participated in the first phase agreed to continue working together as an advisory group to the Foundation's multicultural affairs team, providing advice and counsel to the affiliates taking part in the next round of outreach activities, which is underway now.

Local Epilepsy Foundations Involved in the 2013 African American and Hispanic Campus Outreach

- Epilepsy Foundation Central and South Texas
- Epilepsy Foundation Greater Chicago
- Epilepsy Foundation Greater Cincinnati & Columbus
- Epilepsy Foundation Kentuckiana
- Epilepsy Foundation Northwest
- Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas
- Epilepsy Foundation Virginia
- Sociedad Puertorriqueña de Epilepsia

The Foundation's multicultural affairs team also has begun working with four affiliates on a new outreach campaign to Asian American young adults. The affiliates are partnering with Asian and Asian-serving leaders and organizations in their communities and using tactics including ethnic and social media. This campaign will conclude in the next fiscal year.

To further enhance outreach efforts to diverse audiences, the Foundation's multicultural affairs team created customized training on diversity and cross-cultural awareness for epilepsy. A dozen affiliates completed the training over the last year. Delivered by experienced master trainers, the program educates and informs participants about epilepsy to reduce stigma and promotes collaboration and partnership among

individuals and families impacted by epilepsy, their service providers, community advocates and policymakers to help people living with epilepsy access culturally and linguistically appropriate services. This training program addresses the Institute of Medicine's recommendation to improve and expand educational opportunities for patients and families (#9).

The Foundation's multicultural affairs team also presented at several national conferences to raise awareness and reduce stigma about epilepsy in diverse populations.

Local Epilepsy Foundations Involved in the 2013 Asian American Young Adult Outreach

- Epilepsy Foundation Central & South Texas
- Epilepsy Foundation Greater Cincinnati and Columbus
- Epilepsy Foundation Hawaii
- Epilepsy Foundation Northwest

Project Access: Striving for Comprehensive, Coordinated Care

Since its inception more than 10 years ago, the National Center for Project Access has been committed to bringing together state and local agencies, doctors and other health care providers, families, schools, and community resources to improve access to comprehensive, coordinated healthcare for children and youth living with epilepsy in rural and underserved areas.

In April 2013, the Project Access team hosted a two-day grantee meeting bringing together parents, young people living with epilepsy, and professionals for a series of panel discussions and networking opportunities.

In addition, five Care Coordination trainings were held at community health centers in North Carolina, Louisiana, Georgia, Alabama, and Texas over the past year to help improve the system of services for children and youth with epilepsy at Community Health Centers in those regions.

In five underserved communities (Louisiana, Texas, Alabama, North Carolina, and Tennessee), Project Access has also worked to promote better access to care and improve the delivery of health care services to children and youth living with epilepsy by establishing working relationships between Federally Qualified Health Centers and Epilepsy Foundation affiliate offices. As part of the work, the affiliate offices have expanded community outreach to families and professionals to reduce stigma and increase public and professional awareness about epilepsy and seizures.

In order to reach the largest possible audience, several electronic materials were made available on the Internet and via e-mail. The Project Access team revised the Epilepsy and My Child tool kit and provided the National Council for Farmworkers Health with a revised Spanish version that is currently in final review. Finally, five e-newsletters were produced that explained the work of the Epilepsy Foundation to Project Access grantees, parents, and others who are interested in the mission of the initiative.

Local Epilepsy Foundations Involved in Project Access Community Outreach

- Epilepsy Foundation Texas – Houston/Dallas – Fort Worth/West Texas
- Epilepsy Foundation North Carolina
- Epilepsy Foundation Central and South Texas
- Epilepsy Foundation Louisiana
- Epilepsy Foundation East Tennessee
- Epilepsy Foundation Alabama

NATIONAL CENTER FOR PROJECT ACCESS
QUARTERLY NEWSLETTER
SPRING 2013
VOLUME 1 - ISSUE 2

Message from the Editor

I recently attended a conference on transitioning students with disabilities. One of the sessions focused on the challenges of minority students with disabilities in higher education, including issues with misdiagnosis, over-medication, attention disorders, depression, and anxiety. There was also some discussion about self-empowerment and self-advocacy and awareness building in education systems. I began wondering about the associated behavioral health of children and youth managing disabilities and chronic medical conditions like epilepsy. We know that in some instances, difficult to control seizures in children and adolescents might be due to psychological causes or stressors. Recent studies suggest that some people, whether they have epilepsy or not, have events that look like seizures but are not actually seizures or epilepsy. These are called non-epileptic seizures. For more information about non-epileptic seizures please visit, www.bit.ly/NEWebinar.

In this issue, I provide information about a consortium of disability professionals and highlight available resources, such as the Epilepsy Art Therapy Program, to help individuals with epilepsy and their caregivers. There is an experiential commentary on how pediatric psychologists can contribute their clinical and research expertise to addressing behavioral health comorbidities, adherence, and quality of life for children and youth with epilepsy. I also share updates from the most recent annual Epilepsy Foundation Public Policy Institute and Kids Speak Up! Conference and the 7th Annual Walk for Epilepsy. On the epilepsy research front,

there is an excerpt about a study in which scientists continue to make significant strides in understanding, treating and improving the lives of children and youth with epilepsy.

The Project Access team has been making inroads to improving access to care for medically underserved children and youth with epilepsy. We are continually updating our website with information and resources for you, our readers! Please visit our website at www.epilepsyfoundation.org/projectaccess/ find a resource to see what's new!

Thank you for your continued support in serving children and youth with epilepsy.

Kindest Regards,
Gloria Uchegbu
Gloria Uchegbu

Historically Black Colleges and Universities Disability Consortium

by HBCU Disability Consortium Team

Black and African-American students with disabilities are over-represented in special education and under-represented in higher education, and very little is known about what works for students with epilepsy or other disabilities as they move through the transition process into college. Likewise, most research on college-level teaching and disability services have assumed that what works for white students with disabilities will work for all students with disabilities, even though that may not be the case.

continued page 2

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- Message from the Editor
- Historically Black Colleges and Universities Disability Consortium
- 7th Annual National Walk for Epilepsy
- Studio E: The Epilepsy Art Therapy Program
- National Conference on Pediatric Psychology
- Annual Policy Conference and Hill Day Brings Together Epilepsy Awareness Supporters
- Epilepsy Cure in Mice Provides Hope

Making Progress to Build Awareness for SUDEP



SUDEP Institute Leadership: (From left) Elson So, MD (American Epilepsy Society); Vicky Whittemore, PhD (NINDS/NIH); Steve Wulchin (Freewave Technologies); Orrin Devinsky, MD (NYU Epilepsy Center); Cyndi Wright (SUDEP Institute); Warren Lammert (Epilepsy Foundation); Gardiner Laphan, RN (CURE); Phil Gattone (Epilepsy Foundation); Tom Stanton (Danny Did Foundation).

Much progress has been made since the Epilepsy Foundation SUDEP (Sudden Unexpected Death in Epilepsy) Institute was launched in February 2013.

At its kick-off meeting, the SUDEP Institute sought feedback and suggestions on how the Institute could best address gaps in three focus areas: education and awareness, research, and supportive care.

So far, the SUDEP Institute has accomplished the following:

- Updated the SUDEP content in print publications, on www.epilepsy.com, and through partners like the Managing Epilepsy Well (MEW) Network
- Supported SUDEP Legislation that has now been signed into law in New Jersey and Illinois.

- Hosted a SUDEP Surveillance Workshop to determine best practices and build awareness of SUDEP in the death investigation community.
- Lead the development and management of the Partners Against Mortality in Epilepsy (PAME) webinar series.

The Epilepsy Foundation thanks our staff, partners, board, advisors and supporters for making our progress possible. The Foundation pledges to continue to build awareness. Together we are making a difference in honor of those who have been lost to SUDEP.

Improving Quality of Life through Self-Management Programs

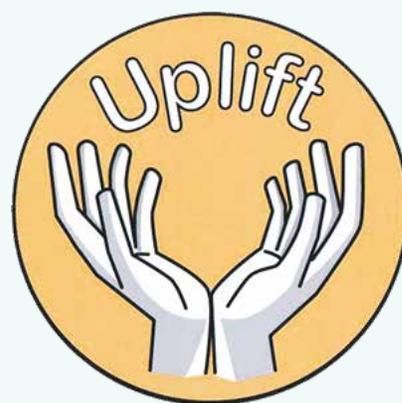
The Managing Epilepsy Well (MEW) Network is composed of individuals interested in the care of people with epilepsy, including representatives from U.S. universities, community-based organizations and the Centers for Disease Control and Prevention (CDC). MEW Network members work together to promote epilepsy self-management research and improve the quality of life for people living with epilepsy. While the Foundation is a liaison to the MEW Network, Emory University serves as the coordinating center and the Universities of Michigan, Texas, Washington, Case Western Reserve, and Dartmouth contribute as collaborating members.

In the last year, the MEW Network has made significant progress in developing self-management skills in people with epilepsy and their caregivers through the following initiatives.

- WebEase (Epilepsy Awareness, Support & Education) is a free, on-line, science-based program designed to assist people living with epilepsy who need help taking their medication on schedule, reducing stress or improving their sleep.
- Project UPLIFT (Using Practice and Learning to Create Favorable Thoughts) is a home-based, science-based program designed to treat depression in people with epilepsy.
- PEARLS (Program to Encourage Active, Rewarding Lives for Seniors) for Epilepsy is designed to reduce depression and improve quality of life in all-age adults with epilepsy.

Several other programs were piloted through the Epilepsy Foundation affiliate network, including the FOCUS on Epilepsy program. In addition, the Foundation has contributed to several working groups within the MEW Network that are studying e-self-management tools and self-management skills in the pediatric population.

In addition to the MEW Network, the Foundation also offers Texting 4 Control, a texting medication reminder service for people with epilepsy aged 13 and older. The program also provides motivational messaging, an online seizure diary, and the option for a caregiver to receive text messages to support the person with epilepsy in their self-management efforts. Close to 400 people signed up in the first year of the program.



Celebrating Success: A Sample of Highlights from Our Affiliate Network

"Epilepsy Foundation Michigan's 1st annual Celebrating Abilities event showcased the many talents of people with epilepsy. It was a magical evening of music, artwork, and creative expression that built confidence, forged new friendships based on shared interests, raised awareness, and inspired others to discover and develop their own abilities."

—Arlene S. Gorelick, MPH, President, **Epilepsy Foundation Michigan**



Cassandra Emmerson

Cassandra's Story

The **Epilepsy Foundation Michigan** first met Cassandra Emerson through the Studio E Art Therapy program, during which her frustration with epilepsy, along with her boundless creativity, became apparent to everyone she met. Despite her love for music, she had stopped performing because of feeling embarrassed about her memory and out of fear of having a seizure.

In addition to Studio E, Cassandra attended the Wellness & Epilepsy Conference and was one of the first enrollees in the six-month PROGRESS Toward Wellness self-management program. After participating in this program, Cassandra reported improvements

in quality of life, social and emotional well-being, memory, stress, physical symptoms, body mass index, confidence, knowledge, and self-management skills. She credits many of these positive changes to the coaching calls that were part of the program.

When asked about the impact of the program, she said, "I've become more accepting of living with epilepsy and more outspoken about living with epilepsy, letting other people know there is hope. It made me want to be a better advocate for people living with epilepsy, especially minorities with epilepsy." And to top it off, she is back on stage performing. At the Epilepsy Foundation Michigan's first Celebrating Abilities event, she inspired the audience with two poems and an original song called "Don't Count Me Out."

Reaching Out Across Alabama

The **Epilepsy Foundation Alabama** is partnering with the University of Alabama in a joint research project to determine the impact of epilepsy on the families with children aged 1 to 12. Director of Client Services David Toenes is coordinating the program and is working with Angelia M. Paschal, PhD, associate professor in the Department of Health Science at the University of Alabama, Tuscaloosa, on the endeavor.

The study seeks to determine how parents obtain, understand, and use health information about their children through personal interviews with parents. Starting in June 2013, the initiative will cover all 67 counties of the state. Toenes is excited about the opportunity that this project presents stating, "This survey effort will help us put the image of the Epilepsy Foundation Alabama and our broad range of programs into every county in Alabama in a strong, positive posture."



1 in 26: The number of people in the U.S. who will develop epilepsy at some point in their lifetime.

Michaela's Story

In late March 2013, while **Epilepsy Foundation Indiana** President Sandy Pollard was getting ready for the Foundation's "Paint for Purple" fundraising event, she received an email from Heather, the mother of a young lady with epilepsy named Michaela. Heather was inviting Sandy to their home for a "Purple Day" celebration and to give her the money Michaela raised designing and selling epilepsy awareness t-shirts. Although Sandy had planned to attend the painting event, something pulled her to attend the party instead.

At the celebration, Sandy learned that Michaela was struggling with being accepted at school after suffering a seizure in class. She was being subjected to so much bullying that she began suffering from depression and eventually withdrew from school. "Her story struck a nerve with me and I invited her to participate in our Studio E program," said Sandy. "Her face lit up and she told me that she loved art because it helped her express emotions."

Sandy reports that Michaela is a vibrant part of the Studio E program, and Heather has become a great advocate for the Foundation. Michaela will enroll in a new school in the fall, and, hopefully, she will feel more accepted and supported from her peers in the Studio E program. "I am blessed and filled with hope for the future when I see her beautiful smile as she proudly shows me her project," said Sandy.



Michaela



Erin Vander Pas

Erin's Story

Erin Vander Pas, who has epilepsy, attended Camp Blackhawk as a camper for five years. She loved the camp so much that in 2013 she became a camp lifeguard.

The Epilepsy Foundation Greater Chicago's Camp Blackhawk is a week-long summer camp for kids ages 6 to 17 with epilepsy. It's a place where children with epilepsy can be themselves and enjoy fun activities like swimming and rock climbing, make lasting friendships, and leave behind the challenges and worries that epilepsy can bring to their daily lives.

Erin uses her time at the camp to be open about her epilepsy, something she hopes will give courage to the other campers. "I feel like I'm kinda changing the world a little bit, just one person's world, maybe more," she said. "But I feel like I'm really helping out with what I can do and that's just an amazing feeling."

Erin does not limit her public speaking to camp. With an eye on advocacy as a future career, her enthusiasm and commitment made her an ideal spokesperson about epilepsy when she served as a Kids Speak Up! Representative in 2012.



Jessica's Story

When Jessica Waters (pictured second from the left) was diagnosed with epilepsy five years ago, she didn't want to talk about her seizures and thought there were things she couldn't do anymore. She says all of that changed when she went to a camp for children with epilepsy.

Located on the wooded grounds of Camp Kern in Warren County, Ohio, Camp Flame Catcher is run by the **Epilepsy Foundation Greater Cincinnati and Columbus**. The camp gives children with epilepsy the typical camping experience that their peers enjoy with the added guidance of trained epilepsy specialists to care for their specific needs.

"I came to camp and was able to do the giant swing, and to canoe and rock climb. And those are things I never thought I'd be able to do again. And that was life changing for me, and I knew I wanted to help people and for their lives to be changed from this," says Jessica. Since that first trip to camp, Jessica returned two times as a camper and two more times as a camp counselor.

A few years ago, she created "Cupcakes for Camp" to raise money to send other children with epilepsy to the camp she loves so much. In 2013, she raised enough to send six kids to camp. Now 16 years old, Jessica also speaks out about epilepsy and tells others about seizure first aid in schools and for civic groups and has used it as her platform in beauty pageants.

Sharon's Ride.Run.Walk for Epilepsy

The 9th annual Sharon's Ride.Run.Walk for Epilepsy was held on May 5, 2013. The event is dedicated to Sharon Rosenfeld, a nurse and teacher who cared deeply about epilepsy and who advocated helmet safety. After she was killed on a cross country ride in 1993, Dr. William Rosenfeld and Susan Lippman, neurologists who specialize in epilepsy, created the event in honor of Dr. Rosenfeld's sister.

This year's event had more than 450 participants and raised a record \$55,500 that the **Epilepsy Foundation Connecticut** will use to raise the quality of life for people living with epilepsy and to educate the community about the importance of wearing a helmet.

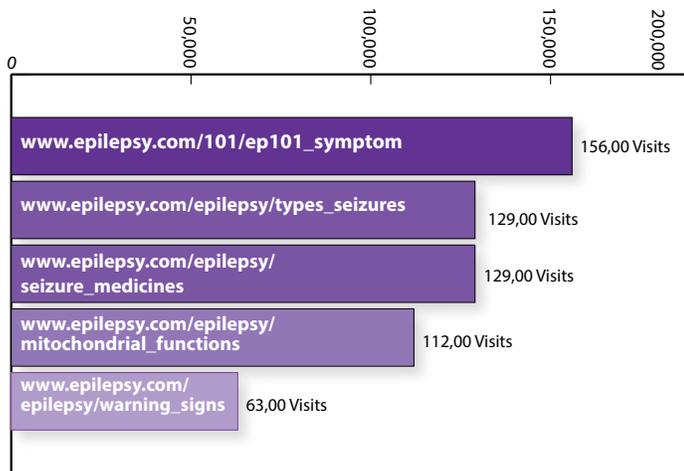
A leading identifiable cause of epilepsy is trauma to the head due to accidents. Wearing a helmet while participating in any head injury prone sport can reduce the number of new cases significantly.



Our Website & Social Media Reach Continues to Grow

Combined, our three main websites (*EpilepsyFoundation.org*, *Professionals.Epilepsy.com*, and *Epilepsy.com*) were visited 7.7 million times in the past year with *Epilepsy.com* leading the way with almost 4.8 million visits.

The Top-5 Most Visited Epilepsy.com Landing Pages



Epilepsy.com reached visitors in 228 countries.

The top-5 countries were:

- United States = 64% of visits
- United Kingdom = 9% of visits
- Canada = 6% of visits
- Australia = 4% of visits
- India = 3.5% of visits



Our social media audiences continue to grow!

Social Media Account	Number of Followers/Likes (As of 11/1/13)
Epilepsy Foundation Twitter	10,527 followers
Epilepsy Therapy Project Twitter	1,127 followers
Epilepsy Professionals Twitter	1,371 followers
Talk About It Twitter	2,820 followers
Epilepsy Foundation Facebook	31,841 likes
Talk About It Facebook	2,147 likes
Epilepsy Therapy Project Facebook	17,787 likes

Our Epilepsy Foundation Facebook page has become our most versatile and popular social media outlet as our communications team continues to break records for number of likes, shares, and total reach of posts.

In addition to daily posts about various foundation events or initiatives like the National Walk for Epilepsy and Athletes vs. Epilepsy, Facebook also provides the national office with the ability to share the activities, campaigns, and photos of the affiliate network to a much larger audience.

Social media also became a crucial part of our information and referral program as visitors often ask questions through direct messages or post public thoughts and ideas, asking for assistance from our Foundation staff as well as from each other. When a webpage is available to answer any questions, it is shared as a resource or, at minimum, the person is referred to the I&R hotline for further assistance.



Our signature weekly epilepsy newsletter currently has more than 60,000 subscribers, while our more specialized professionals newsletter reaches more than 3,200 subscribers per week.



Joseph I. Sirven, MD, is a professor of neurology and chair of the department of neurology at the College of Medicine of the Mayo Clinic in Arizona. Dr. Sirven has published extensively on epilepsy and its treatment. His interests in epilepsy include status epilepticus, surgical therapy, epilepsy in older adults, and psychosocial issues, particularly those involving Hispanic populations and transportation.

Joe I. Sirven, MD
Epilepsy.com Editor-in-Chief

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“Untitled” by Lisa Nygaard



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Did you know you can earn a charitable income tax deduction by donating an automobile, RV, truck, boat or trailer to the Epilepsy Foundation? You'll avoid the costs and hassle of selling a used vehicle and we'll tow your vehicle for free. You must own a clear title to donate a vehicle.

It's Easy!

- Simply access our car donation wizard or call (877) EFCARS7. You'll receive an e-mail acknowledgment confirming your intention to donate your vehicle.
- Within four business days of receiving your paperwork, you will be contacted to schedule a pick up time for your vehicle.
- When the vehicle is towed, you'll receive a receipt for tax purposes within 10 business days.
- To help determine the value of your vehicle, you may want to visit www.nadaguides.com or www.kbb.com.

It's that simple! And you can count on us to put your vehicle to good use empowering people with epilepsy and their families.

CFC/CHC

The Epilepsy Foundation participates in the world's largest workplace charity campaign, the Combined Federal Campaign (CFC). Through the CFC, government workers and those in the military can support the work of the Epilepsy Foundation through payroll deductions. If you are a federal government employee and are interested in giving to the Epilepsy Foundation through the CFC, please designate code #10568 on your pledge card.



Many private sector companies also participate in workplace giving campaigns. Check to see if your employer allows charitable giving through payroll deductions today! You can designate the Epilepsy Foundation using #10568 on your pledge card or give through Community Health Charities online at www.healthcharities.org.

Monthly Gift

As a monthly partner in the Epilepsy Foundation's efforts to make the world a better, more manageable place for the more than 2 million people living with epilepsy, you are one of our most dedicated supporters. By providing steadfast income throughout the year, you help fund high-impact research, education and advocacy.

Making a monthly gift is an easy way for you to make a difference every day. By making an automatic tax-deductible gift each month on your credit or debit card, you provide strong and steady funding to help those who need it most.

How does monthly giving work? After signing up on our website, your specified donation amount will be charged to your credit or debit card. Moving forward, your card will be charged each month. You choose the amount of your gift and can modify or cancel your donation at any time. Your monthly gift allows us to limit our overhead costs and apply your contribution where it is needed most. Monthly contributions are critical to the success of our work.

Corporate and Foundation Partners

Corporations and foundations that partner with the Epilepsy Foundation distinguish their organizations as socially responsible and earn the gratitude and loyalty of people living with epilepsy, their families, friends and caregivers.

Matching Gifts

You Can Double the Impact of Your Gift! Many corporations have matching gift programs and will match your donation to accredited charitable organizations such as the Epilepsy Foundation. It's an easy way to double or even triple the impact of your personal contribution to find a cure and overcome the challenges created by epilepsy. Ask your employer if they participate in a matching gift program and complete the necessary paperwork to have your gift matched.

Do-It-Yourself (DIY) Fundraising

Host and fundraise for any event through Epilepsy Foundation's DIY program. Epilepsy Foundation supporters are hosting theme parties, concerts, art auctions, and much more — all to bring awareness to epilepsy. Start your own fundraising endeavor today.

Stock Gifts

Do you own stock or mutual fund shares that have increased in value?

Donating securities to the Epilepsy Foundation is a way to help us move closer to improving the lives of those living with epilepsy and ultimately finding a cure. Giving appreciated assets is one of the most tax-efficient ways to make charitable donations. If you transfer the shares before December 31st, you may claim the charitable deduction in the same year.

Wire Instructions

DTC Delivery:

A/C Name: Epilepsy Foundation - Contingency Account

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If you have stock certificates, and you wish to transfer the physical securities, please send the certificates to:

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Estate Planning

Make an Impact! A bequest from a will or a living trust lets you make a gift of any size to the Epilepsy Foundation. When making a planned gift, you allow us to invest in new endeavors to support those living with epilepsy and help to ensure the Foundation is here for decades to come. By doing so you are able to receive a current income tax deduction and reduce your potential estate taxes in the future.

Clothing Donation

The Epilepsy Foundation and Savers, Inc., a leading privately held thrift store chain with more than 320 locations, are working together to advance access to care and raise much needed funds for the more than 2 million Americans living with epilepsy. Contributions of gently used items are part of the simple, convenient, yet impactful way for people to support the Epilepsy Foundation. The partnership means Savers pays the Epilepsy Foundation for every donation of clothing, housewares, furniture and much more.



Special Events

Have fun, be inspired and get engaged with the Epilepsy Foundation's special events. The Foundation hosts various events throughout the year that provide an opportunity to actively show your commitment and raise funds to make a difference in the lives of people living with epilepsy.

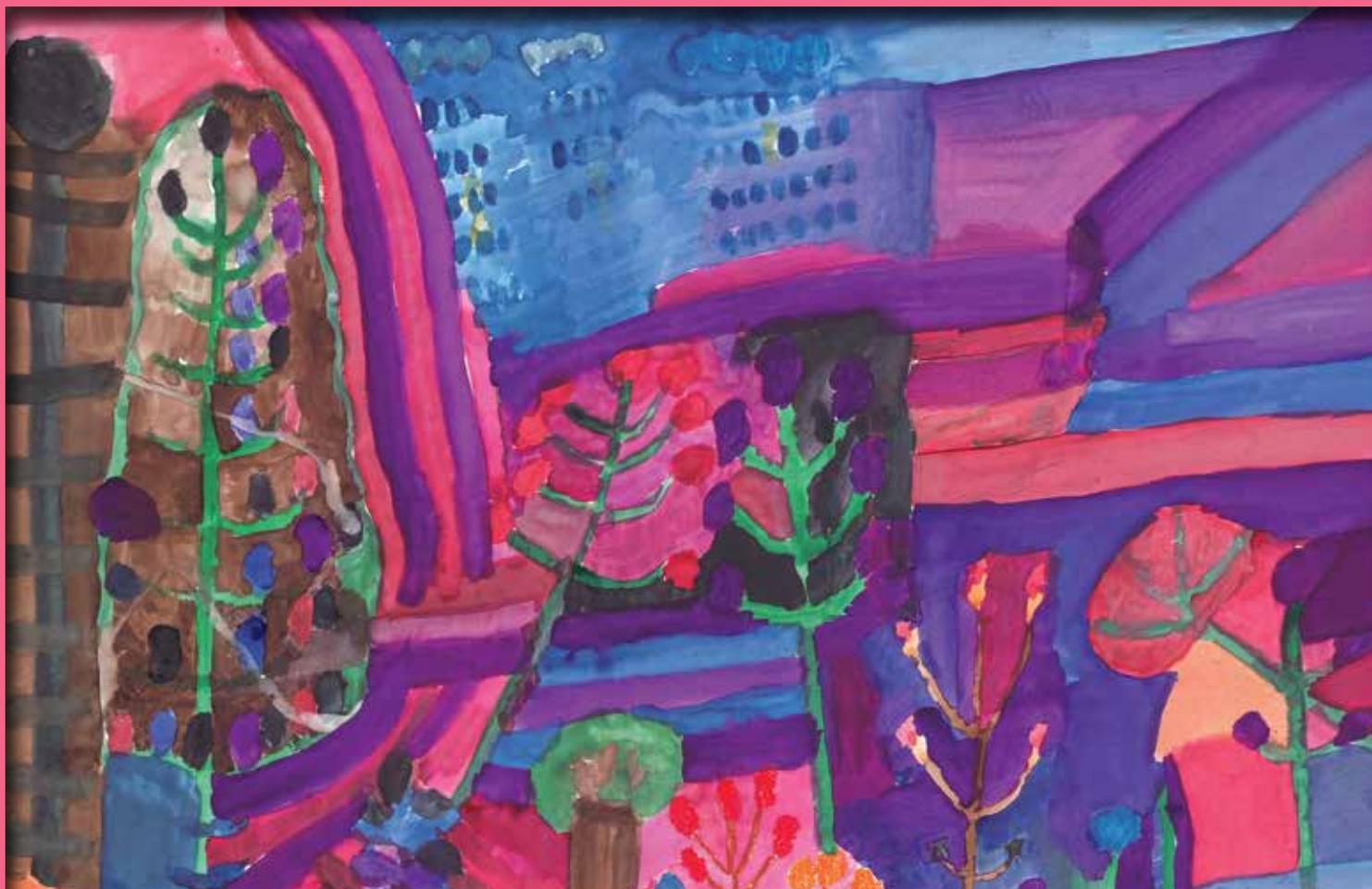
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For more information about any of these ways to give, contact Donor Services at (800) 213-5821 or email rdev@efa.org.

2013 NATIONAL WALK FOR EPILEPSY



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“Wildlife of Plants” by Aijana Carr



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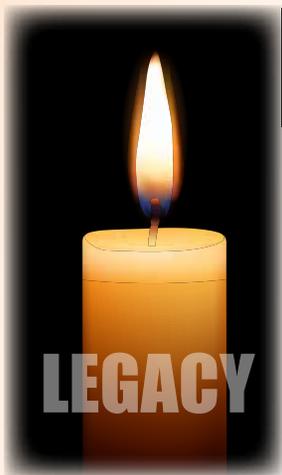
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** Deceased Donors*



Creating a Legacy of Hope for Those Living with Epilepsy

The Candle of Light Society is our community of committed individuals who have invested in building a brighter future for people living with epilepsy. By making an estate gift, these individuals have become part of the Foundation's future. It will serve as a permanent reminder of their generosity to the Epilepsy Foundation.

If you would like to become a member of the Candle of Light Society, please call 1-800-213-5821 or email chartman@efa.org.

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Corporate Partners for Fiscal Year 2013

The Epilepsy Foundation is pleased to recognize the following corporations for their generous support to the newly merged organization. The following companies further our mission of providing education and research grants to fund activities that help people with epilepsy and their families.

\$250,000 +

- Lundbeck, Inc.
- Sunovion Pharmaceuticals, Inc.

\$100,000-\$249,000

- Cyberonics
- Eisai Corporation
- GlaxoSmithKline
- Pfizer, Inc.
- UCB Pharma, Inc.
- Upsher-Smith Laboratories

\$50,000-\$99,000

- AbbVie, Inc.
- SAVERS, Inc.

\$10,000-\$49,000

- Bender Consulting Services
- Comcast
- Coca Cola
- Digitas
- Highmark
- MacAndrews & Forbes Holdings Inc.
- Neuro Pace, Inc.
- SCI (Service Corporation International)
- Supernus Pharmaceuticals, Inc.
- United Health Group

\$1,000-\$9,999

- Access to Patients, LLC
- American Airlines
- BB&T
- CSC, Computer Sciences Corporation
- Nutricia North America, Inc.
- Questcor Pharmaceuticals, Inc.
- Walgreens
- The Wine Institute

National Partnership with Savers Benefits People Living with Epilepsy and Seizures

This year, the Epilepsy Foundation expanded its partnership with Savers, Inc., a privately held for-profit global thrift retailer offering clothing and accessories for men, women and children and household goods under the Savers, Value Village, Village des Valeurs, Unique Thrift Store and Valu Thrift Store brands.

Savers previously partnered with individual Epilepsy Foundations in Chicago, Colorado, Minnesota, New England (serving Massachusetts, Rhode Island, New Hampshire and Maine) and New York. In early 2013, the partnership expanded to the national level, bringing on board Arizona, California, Kansas, and Missouri with more Savers locations coming in 2013 and 2014.

Savers was founded on the core principle of supporting local communities and has embraced that value by partnering with local nonprofit organizations since 1954. Through its unique business model of purchasing, reselling and recycling secondhand merchandise, the Savers family of thrift stores benefits more than 150 nonprofit organizations, gives local consumers a smart way to shop, and saves more than 600 million pounds of quality used goods from landfills each year. Savers has paid more than \$1.5 billion to its nonprofit partners over the last 10 years, turning otherwise unused items into sustainable funding that supports vital community programs and services.

It's truly a win-win situation and, with valuable partners and friends like Savers, the Foundation will be able to help people living with epilepsy throughout the country and advance new therapies and treatments.

savers
Good deeds. Great deals.

Special Thanks

We are grateful to all of the many companies that donate their time and talent to helping us serve the epilepsy community. In particular, we would like to recognize the following for their service in 2012-2013.



Weil, Gotshal & Manges LLP

www.weil.com

Weil represented the Epilepsy Foundation in its merger with the Epilepsy Therapy Project to create the leading US not-for-profit organization dedicated to fighting epilepsy. The boards of directors of both organizations unanimously approved the merger on December 18, 2012, and the merger took effect on January 1, 2013.

The Epilepsy Foundation was founded in 1968. Among its many services, the national organization, along with a nationwide network of local affiliates, provides a supportive care network for patients and families, public awareness campaigns, and educational programs. The Epilepsy Therapy Project has focused on the goal of accelerating the clinical development of innovative therapies for people with epilepsy. Through the success of an existing joint venture, the two organizations together have provided funding for 42 of the 85 known drugs and devices in active development, resulting in the introduction of three new epilepsy products in the past year. The merger will enable the new organization, under the name of the Epilepsy Foundation, to combine the strengths of each to become a stronger, more unified leader on the issues that are most important to epilepsy patients and their families.

Excerpt from Weil, Gotshal & Manges' report "Our Finest Hours: Pro Bono 2013" (page 25)



Accenture

www.accenture.com

Accenture partnered with the Epilepsy Foundation to develop a data and donor management strategic plan and assisted with the analysis of our national database system. Throughout this process, Accenture offered recommendations of how to better support our affiliate network. The level of support and level of expertise they shared was phenomenal. Accenture has committed significant resources to the Epilepsy Foundation to support our 2013 development initiatives. As we continue on our way to being the preeminent organization to support and serve people with epilepsy, it is critical that we are able to capture and serve our donors and constituents and to better understand their connection and future involvement with our organization.

Accenture (www.accenture.com) is a global management consulting, technology services and outsourcing company, with approximately 275,000 people serving clients in more than 120 countries. Combining unparalleled experience and comprehensive capabilities across all industries and business functions with extensive research on the world's most successful companies, Accenture collaborates with clients to help them become high-performance businesses and governments.

FINANCIAL STATEMENTS



“Pastel of Lighthouse” by Michael Donnelly



Stronger Together

Treasurer's Report

The Epilepsy Foundation's Fiscal Year 2013 marked a stabilization of the organization's financial health after a period of deterioration resulting from leadership transitions and the after-effects of the economic circumstances of prior years, commonly known as the "Great Recession."

Revenues increased by \$5 million over Fiscal Year 2012 driven by higher contributions, up \$2.6 million, in part due to an enhanced donor base resulting from the merger with the Epilepsy Therapy Project as well as success in other initiatives. Government grant revenue also improved year-to-year, up \$1.7 million. Expenses were also higher by \$1.5 million. The expense growth reflected a buildup of the Foundation's fundraising development capability that added \$0.6 million. Also driving the expense growth was increased support of Community Services by \$1.2 million and increased Public Health Education activity, up \$0.5 million, both primarily driven by the enhanced government grant funding for the year.

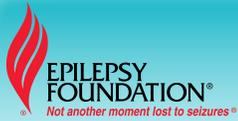
While the year-to-year improvement was welcome, there is much work to be done. The Foundation's leadership is focused on efforts to significantly grow revenues in the coming year to support and achieve the vision of the Foundation's future capabilities discussed throughout this report.



EPILEPSY FOUNDATION AND EPILEPSY RESEARCH FOUNDATION**Summary Combined Financial Statements****\$ in Thousands**

COMBINED STATEMENTS OF FINANCIAL POSITION	As of June 30:	
	<u>2013</u>	<u>2012</u>
ASSETS		
Current assets	5,463	3,654
Non-current contributions receivable	399	57
Beneficial interest in perpetual trusts	3,266	3,042
Investments	8,455	12,432
Property and equipment, net	506	421
Total assets	<u>18,089</u>	<u>19,606</u>
LIABILITIES AND NET ASSETS		
Current Liabilities	5,135	5,719
Non-current grants payable	169	776
Net assets	<u>12,785</u>	<u>13,111</u>
Total liabilities and net assets	<u>18,089</u>	<u>19,606</u>
COMBINED STATEMENTS OF ACTIVITIES	For the year ended June 30:	
	<u>2013</u>	<u>2012</u>
REVENUE		
Contributions	7,448	4,884
Government grants	5,448	3,731
Affiliate dues	482	458
Special events, net of direct cost	450	380
Investment income	888	272
Other	435	111
Total revenue	<u>15,151</u>	<u>9,836</u>
EXPENSES		
Program Services		
Research	3,518	3,996
Public health education	2,457	1,990
Professional education	53	134
Community services	5,004	3,820
Patient services	863	718
Supporting services		
Management and general	1,610	2,013
Fundraising	1,972	1,315
Total expenses	<u>15,477</u>	<u>13,986</u>
Change in net assets	(326)	(4,150)
Net assets beginning of year	<u>13,111</u>	<u>17,261</u>
Net assets end of year	<u>12,785</u>	<u>13,111</u>





STRONGER TOGETHER

EPILEPSY & SEIZURES 24/7 Helpline

What do we do?

The helpline has trained information specialists standing by to answer your questions about epilepsy and seizures and provide you with support, guidance, and referrals to national and local resources.

Who do we help?

We can help anyone interested in or affected by epilepsy. This includes:

- People living with epilepsy
- Caregivers and friends of someone with epilepsy
- Anyone who simply wants to learn more about epilepsy

How can we help you?

The 24/7 Helpline provides compassionate telephone support, answers emails and replies to forum posts on the Foundation's online community site.

Some of the topics our information specialists respond to most often include:

- Current treatments and alternative therapy options
- Available medicines
- Support groups
- Seizure first aid and safety issues
- Employment and discrimination issues
- Emotional issues
- Getting connected with local Epilepsy Foundation affiliates
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Free information packets



1-800-332-1000
www.epilepsy.com

Para obtener información adicional y materiales impresos con información detallada y actualizada comuníquese con nuestra línea gratuita 1-866-748-8008 o visita nuestro sitio web: www.laepilepsia.org.

Providing help, hope and support to people with epilepsy and seizures and their families nationwide.

8301 Professional Place - East | Landover, MD 20785

Rev. 11/14/2013

Coming in 2014

The New Epilepsy.com

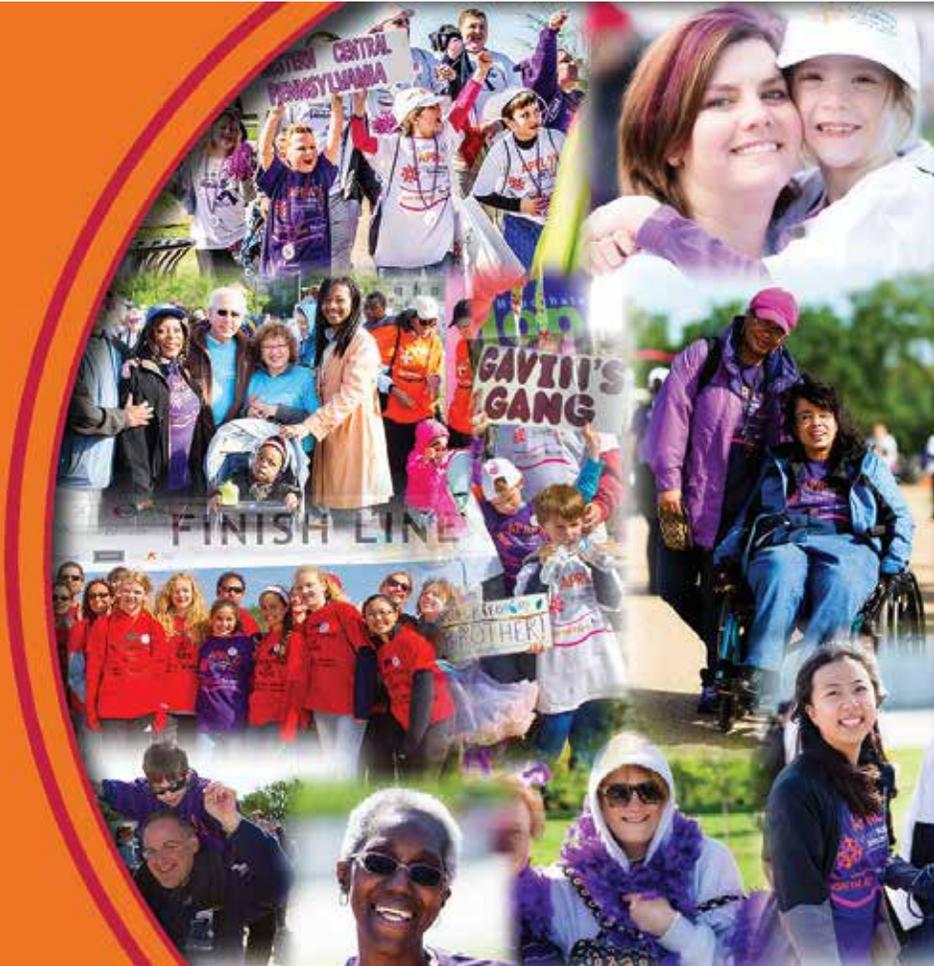
In Fiscal Year 2014, the Epilepsy Foundation will unveil a new website that merges two of the largest and most comprehensive websites for epilepsy-related content—epilepsyfoundation.org and the previous epilepsy.com — into one dynamic and engaging site.

Meeting a key recommendation of the Institutes of Medicine 2012 report, “Epilepsy Across the Spectrum: Promoting health and understanding,” the new website will create a stronger, centralized source for all epilepsy-related information and support services. The new state-of-the-art website will react and scale itself to where the user is viewing the web, whether that’s a PC, tablet or mobile phone. Fully integrated with social media, users will be able to log on with an existing identity from Facebook, Google, or Twitter to comment on content, participate in conversations and easily share pages to their social media profiles. Combined together, these new features will empower visitors to become ambassadors for epilepsy and seizure awareness like never before.

SAVE the DATE

The 8th Annual
National Walk for Epilepsy

Saturday, March 22, 2014
Washington, DC



Stronger Together





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2 0 1 3

A N N U A L R E P O R T

July 2012 - June 2013



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