### **EXHIBIT L**



2340 E Meyer, Ste. 300 B, Kansas City, MO 64132

May 10, 2018

Dear Representative Hammer,

A March, 2012 report by the Institute of Medicine entitled *Epilepsy Across the Spectrum* is a culmination of an 18-month study by 24 federal agencies and nonprofit organizations. This group came together with a vision for advancing the field of epilepsy and improving the lives of individuals with epilepsy by focusing this study on the public health dimensions of the disorder. This study is instrumental in guiding the Epilepsy Foundation of Missouri and Kansas' (EFMK) programs. The recommendations from this report influence EFMK's activities.

Epilepsy is a spectrum of disorders with a range of severities, widely differing seizure types and causes, and varying impacts on individuals and their families. Beyond actually living with epilepsy, its seizures, and coexisting health conditions, the challenges facing people living with epilepsy include access to high-quality health care, learning about and coordinating health care, and awareness of educational and community services (*Epilepsy Across the Spectrum*, March 2012). Epilepsy comprises more than 25 syndromes and many types of seizures that vary in severity. The impacts on physical health and quality of life encompass a spectrum as well, with people with epilepsy experiencing different health outcomes and having a range of activities of daily living that may be affected, including achievement and social interactions. The many complexities of the epilepsies make it a challenging health condition to convey to the general public to promote understanding and to alleviate stigma.

On average, 50% percent of people with epilepsy have complete seizure control on medication. Another 25% have very good control and the remaining 25% of the individuals have uncontrolled seizures. Seizure control is improved by providing current and accurate information about epilepsy in an attempt to change the belief that epilepsy is a result of sins, demonic possession and substance abuse. Epilepsy is a widely recognized health condition, but one that is poorly understood, even among people who have the disorder. Lack of knowledge about the causes of epilepsy has been associated with negative attitudes, misconceptions and stigma. Lack of understanding about epilepsy is a leading cause of discrimination.

Because of ignorance about the disorder, the diagnosis of epilepsy has a profound social and psychological impact on people with epilepsy and their families. Many people believe that epilepsy is a mental illness, that people swallow their tongues during seizures, or that epilepsy is contagious. Children with epilepsy are at an increased risk for educational underachievement, learning disabilities, mental health problems, social isolation and poor self-concept.

### WHAT DOES THE EPILEPSY FOUNDATION INTEND TO DO ABOUT THIS?

First – Education in the schools:

Epilepsy education that will change misconceptions must begin at an early age and be repetitive and continuous (*Elsevier: Epilepsy and Behavior*, "Kids Perception of Epilepsy", Paula T. Fernandes, June, 2005). Epilepsy education helps to eradicate misconceptions, misinformation and poor attitudes toward children with epilepsy. Education also provides parents and school personnel with the necessary tools to recognize seizure activity in children. When a child has epilepsy, parents and school personnel need to understand seizure types, the effects of the medications, how to work with the medical team and, most of all, what is happening to the child.

30 education presentations reaching 1000 people at \$300 - \$2,000 depending on presentation

Second - Education for EMTs, Fire Fighters, Police

The Complex Partial Seizure is the most common type of seizure. This seizure clouds awareness, blocks normal communication and produces a variety of undirected, involuntary and unorganized movements. It is this type of seizure that is associated with symptoms that may be erroneously perceived as combativeness. These symptoms may include screaming, running, flailing or unnatural looking movements of the arms or legs, spitting, shouting and abusive statements. Again, all of these are involuntary and unconscious manifestations of seizures.

As normal brain function returns following a seizure, a person typically is fatigued and dazed. It is during this period, which may last for an hour or more, that one may become belligerent or aggressive, especially when approached or threatened; one is also easily frightened or upset and unable to communicate. Accordingly, restraint of persons soon after a seizure may exacerbate or precipitate combativeness – the opposite of the intended result. As one's resistance to restraint increases, the threat to his or her life similarly increases. These are the issues addressed in the Epilepsy Foundation's *Take Another Look* training materials.

15 presentations reaching 150 people at \$500 per presentation

Third – Support for Veterans

Recent prevalence data from the Centers for Disease Control reports that 1.3% of Americans have active seizures. The Veterans Health Administration (VHA) estimated that the prevalence of veterans with epilepsy under treatment at VA facilities was 13.8 per 1000 in 2015. The VHA data show that about 13% of veterans with seizures were less than 45 years old, 39% were between 45-65 years old, and about 8% were female.

Because having active epilepsy will almost always prevent someone from being accepted into the military, epilepsy usually develops in veterans during or following military service. Veterans are at higher risk of developing epilepsy than the public because they are more likely to have traumatic brain

<u>injuries</u> (TBI) and post-traumatic stress disorder (PTSD). TBI and PTSD are also associated with psychogenic non-epileptic seizures (PNES). PNES look like seizures but are not associated with abnormal electrical activity in the brain and are caused by psychological (mental or emotional) distress. PNES cannot be treated with medication. Non-epileptic episodes are treated by counselors and/or psychologists. The Epilepsy Foundation provides resources within the Managing Epilepsy Well (MEW) network that is most effective in reducing seizures in veterans who experience PNES.

10 veterans with epilepsy reaching 50 people \$250 - \$1,000 per person with epilepsy depending on time spent

### Fourth – Support of the person with epilepsy

An Epilepsy Foundation staff member will be a member of the community and will assist individuals to adopt healthy behaviors. Staff members will facilitate improvements in health status and quality of life. With Epilepsy Foundation staff in Arkansas the impact is remarkable in the areas of:

- Assisting people with epilepsy to access healthcare and social services systems
- Gathering information for medical providers
- Working with clinicians
- Educating social services providers on community/population needs
- Teaching concepts of disease prevention and health promotion to lay populations
- Managing epilepsy, including training on lifestyle strategies, risk factors, self-monitoring and medications
- Engaging in health prevention and promotion activities
- Understanding liability issues
- Understanding community prejudices
- Safety
- Mental health
- Utilizing technology, including mobile applications
- Responsive to the community
- Trained in context of health interventions

There will be significant changes in health status, knowledge, beliefs, and actions for people with epilepsy living in Arkansas which translates into lowered cost to the state for treatment.

Patients with uncontrolled epilepsy racked up nearly \$10,000 a year in direct medical costs, while patients with controlled cases had a tab of only about \$2,000 a year. Study author Charles Begley, PhD, a health economist and associate professor of public health at the University of Texas in Austin, says controlling seizures may help reduce costs. The high concentration of costs in patients with difficult to manage epilepsy emphasizes the importance of seizure control," says Begley

These people, and others who have uncontrolled <u>epilepsy</u>, contribute disproportionately to the cost of treating the chronic disease, say researchers who found that patients with poor seizure control represented 25% of all cases, but accounted for up to 86% of all costs.

Investing \$75,000 from the State of Arkansas has the potential to reduce health care costs by 900 times that amount. (8658 people with uncontrolled epilepsy in Arkansas times the \$8000 per person noted above equals \$69,264,000).

**50 people with epilepsy reaching 250 people** \$250 - \$1,000 per person with epilepsy depending on time spent

Please consider the Epilepsy Foundation's request for an allocation of \$75,000.

Sincerely,

Bridgit Patterson
Program Director
Epilepsy Foundation of Missouri & Kansas
816-444-2800 X 192
bpatterson@efmk.org

### OF MISSOURI AND KANSAS EPILEPSY FOUNDATION



### MISSION

The Epilepsy Foundation of Missouri and Kansas leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

recognized nationally as the first-ever awarded Affiliate of the Year and Program, Marketing, Newsletter, Staff Member and others related to has received 12 additional awards including Executive, Volunteer, The Epilepsy Foundation was founded in 1961. EFMK has been specific program excellence.

EFMK is the ONLY affiliate that has received International awards for excellence.



### NOISIN

- sustained through coordinated healthcare and convenient services The health of people with epilepsy within Missouri and Kansas is
- People with epilepsy participate in their care (or health) by being well-informed and empowered to use this information to make
- People with epilepsy and their families are supported and safe, and experience opportunities resulting from public understanding and acceptance
- Community health is promoted through prevention and lower incidence of seizure disorders



# COMMUNITY NEED - Prevalence

- 1.8% of adults 18 years and older have active epilepsy or 41,040 in Arkansas
- 6% of youth 17 years and younger have active epilepsy or 43,200 in Arkansas
- 1 in 10 people will have a seizure sometime in their lifetime or 300,000 in Arkansas
- The lack of understanding about epilepsy is the leading cause of discrimination



# COMMUNITY NEED - Prevalence

- People with epilepsy run twice the national average of unemployment
- People with epilepsy run five times the national average of underemployment
- 59% of people with active seizures are unemployed
- 79% of people with active seizures coupled with psychiatric condition are unemployed



# Community Need - Co-Occurring Conditions, Risk & Cost

- 75% of people with epilepsy have complete or good control
- 25% of people with epilepsy do not have good control these people make-up the majority of the EFMK target population
- depression, anxiety, memory loss, cognitive impairment, stoke, heart 30% of people with epilepsy have co-occurring conditions such as disease and developmental delays



# Community Need - co-Occurring Conditions, Risk & Cost

- The leading identifiable cause of epilepsy is trauma to the head
- Risk of death increases for people with epilepsy by 11 years of life lost
- The #1 unnecessary trip to the emergency room is seizures
- \$9.6 billion is spent yearly in the US on medical care related to epilepsy



### **EDUCATION PROGRAMS**



## **EDUCATION PRESENTATIONS**

- Education Presentations inform different audiences about seizures, prepare with first-aid techniques and appropriately respond in emergency situations
- Target school personnel, students, employers, nurses, veterans, seniors, child and adult care providers, police, EMTs
- Epilepsy staff makes 200 presentation annually across both states to approximately 5000 people
- EFMK receives referrals from neurologists, the Department of Health and Senior Services, school personnel and other NFP agencies and places where we have made presentations in the past



### EDUCATION IMPORTANCE



Carol M. Ulloa, MD, FAES
Director, Comprehensive Epilepsy Center
Director, Epilepsy Division
University of Kansas Medical Center

a disease that is commonly misdiagnosed, misunderstood and mistreated. Unfortunately, these deficits often of the most common neurologic illnesses, and I am still astonished at the lack of community awareness. It is Quote: "I have dedicated my medical career to the diagnosis and treatment of people with epilepsy. It is one the community about epilepsy and all of its facets. The Epilepsy Foundation is a necessary ally and partner apply to medical professionals as well. I have countless stories of patients that have lived with seizures for these barriers can be successfully addressed. A big part of my job is to educate medical professionals and much broader reach than I ever could. They are able to tackle the common misconceptions about epilepsy compounded by the ingrained stigma of the disease. I strongly believe that education is the only way all of decades, either with no diagnosis despite seeking medical attention, or with inadequate treatment. This is in this job. The Epilepsy Foundation provides many educational resources to the community; they have a and there are so many. People whose lives are touched by epilepsy in some way or another need the Epilepsy Foundation."

- residency at Boston University, she subspecialized in the fields of clinical neurophysiology and epilepsy during a two-year fellowship at New York Presbyterian Hospital--Weill Cornell Medical Center. Dr. Ulloa then joined the faculty at Geisinger Health System in Pennsylvania for five years, where she served as Associate Director of Neurology. As a Dr. Carol Ulloa is the Director of the Comprehensive Epilepsy Center. She attended medical school at the University of Missouri-Kansas City. After completing her neurology Missouri native, she returned to her roots in the Midwest and joined the University of Kansas Medical Center in 2015.
- Dr. Ulloa is a board-certified neurologist with subspecialty certification in epilepsy by the American Board of Neurology and Psychiatry. Her main clinical interests are seizures, neurosurgeons, radiologists, and neuropsychologists that provides state-of-the-art comprehensive care to epilepsy patients at the University of Kansas Medical Center. epilepsy, intractable epilepsy, video EEG monitoring and surgical interventions for the treatment of epilepsy. Dr. Ulloa leads a multidisciplinary team of epileptologists,
- She is a Fellow of the American Epilepsy Society



## EDUCATION IMPORTANCE



Deb Cook, RN President, Missouri Association of School Nurses Quote: "School nurses throughout the state have benefited immeasurably from the resources and training of the Epilepsy Foundation of Missouri & Kansas ("EFMK") coordinated with the Missouri State School Nurse Consultant. Information from EFMK has been invaluable in providing training, updates, assistance with individual education plans, seizure action plans and parental support. EFMK's resources help school nurses to better understand epilepsy and allow them to provide quality education to staff, students, and parents. EFMK staff is always very responsive and professional. Based on my 24 years of experience with EFMK and witnessing the achieved outcomes, I highly recommend a similar program in Arkansas."

ly 31, 2018

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ansas House of Representatives

Representative Ham

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I have been a school must for 24 years and a member of the Missouri Association
I Havk been a school must for 24 years and a member of the Missouri Association
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as the Protestions. Excloding the state has been been been determined and training and state of Eliabory Foundation of Nissouri & Association Missouri (EMKI) coordinates with
schooling of Eliabory Foundation from ERM has been invaluable in providing
assistance with introduction proceeding in place, before action propose and support and eliabory and allow them to provide quality and
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and, such or dependent who tiff MMR and witherstag the activities discontinued in Table.

ious consideration of this program is greatly appreciated

Sincerely,

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resident

EPILEPSY FOUNDATION July 31, 2018



The Honorable Representative Kim Hammer Arkansas House of Representatives 1411 Edgehill Benton, AR 72015

Dear Representative Hammer,

I have been a school nurse for 24 years and a member of the Missouri Association of School Nurses ("MASN"). For a majority of my tenure, I have served on MASN's Board of Directors and currently serve as the President. School nurses throughout the state have benefited immeasurably from the resources and training of Epilepsy Foundation of Missouri & Kansas ("EFMK") coordinated with the Missouri State School Nurse Consultant. Information from EFMK has been invaluable in providing training, updates, assistance with individual education plans, seizure action plans and parental support. EFMK's resources help school nurses to better understand epilepsy and allow them to provide quality education to school staff, students, and parents. EFMK staff is always very responsive and professional. Based on my 24 years of experience with EFMK and witnessing the achieved outcomes, I highly recommend a similar program in Arkansas.

Your serious consideration of this program is greatly appreciated.

Sincerely,

Deb Cook, RN

President

Missouri Association of School Nurses



4406 St. Vincent • St. Louis MO 63119 • Phone: (314) 781-4949 • Fax: (314) 781-4907 2340 E Meyer Blvd, Bld 1, Suite 300 B • Kansas City, MO 64132 • Phone: (816) 444-2800

### **EDUCATION PROGRAM EVALUATION**

Date o	Presentation:		
1)	Name of Facility:		
2)	Address:		
3)	County		
4)	Name of Facility Contact Person:		
5)	Contact Person's Email:		
6)	Audience:  a Social Service b Business c School	ol (specify)	
71	dOther		
7)	Number of People Attending:		
8)	Did the attendees learn something new about epilepsy?	YES	NO
9)	Do the attendees know when a seizure is an emergency situation?	YES	NO
10)	Were you satisfied with the presentation?	YES	NO
When v	vould you like to be contacted to schedule additional epilepsy educati	on programs?	
СОММ	ENTS:	2	

For more information, or to schedule additional programs, Call (314) 781-4949 (St. Louis) or (816) 444-2800 (Kansas City)

## INFORMATION & REFERRAL

- information to individuals with epilepsy, their family and friends Individual Consultation (information and referral) – to provide
- Epilepsy staff provides services to 1500 annually in Missouri and Kansas
- These individuals call, email, or make an in-person appointment when requesting information





### OUTCOME RESULTS

- 80% of clients gain knowledge about healthy lifestyle habits
- 82% of clients experience fewer mental, emotional and/or behavioral symptoms







# INDEPENDENT LIVING PROGRAMS

- to obtain and/or retain employment. We use the Charting the Course Employment Preparedness – assists people with epilepsy who desire under the direction of the Department of Labor, to help participants develop specific skills to be more prepared in dealing with epilepsy curriculum, designed by the Epilepsy Foundation's National office specific conditions (such as triggers, seizure action plans)
- situation. Such assistance includes: medication compliance, access to good medical care, socialization, relaxation and stress management Residential Living Preparedness – assists people with epilepsy who desire to live independently or improve their independent living



### OUTCOME RESULTS

80% of the people with epilepsy in the EFMK job training program found a job and maintained it for 6 months or more The state and federal taxes paid by those who were employed through the EFMK job training program, cumulative, over a five year period, was 2 times greater than the cost of running the program.

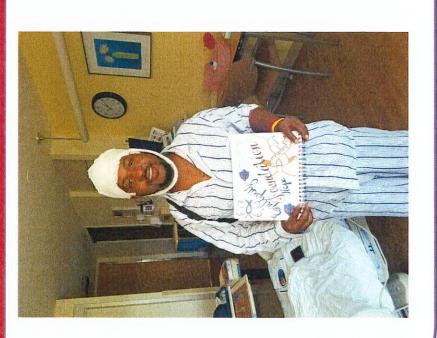
Program cost/year: \$100,000 (\$500,000)

Taxes paid by individuals who gained employment through the EFMK employment training program: \$1,000,000 75% of clients are successfully able to manage physical health conditions

62% of clients develop coping and stress management skills



## DANNY PREPARING FOR EEG



Danny drew this picture to show appreciation for helping him obtain needed testing

### **EXECUTIVE REVIEW**

### June 2018

You know – it is pretty ominous to have the words "saving lives" in the agency's mission. Goodness! I have to assure the agency is financially stable, steward volunteers, manage programs, support staff, report to boards AND save lives?

Well, OK.

Danny's grandmother called. She was concerned about Danny. He was incarcerated, having lots of seizures and she didn't know what to do. "Do you know the people at the jail house?", she asked in desperation. Staff member Michelle got right on it. She called an agency that works with developmentally disabled individuals who are incarcerated. Danny was released the next day.

Michelle talked at length with Danny. His grandmother gave him a comfortable home with love and care, as grandmothers do. Danny has had seizures all his life. When he turned 18 he was no longer eligible for insurance. He wasn't taking medication. He had active seizures. He had no job because of his seizures. He had few friends. He was reluctant to leave his house.

Whew. Save Lives. Where do you begin?

Michelle advised Danny to register for Gateway to Better Health. She was sure he would qualify because he has no insurance and no money. Danny

followed through and was accepted. Danny made an appointment to see a physician. Danny had no records or test results from previous appointments to take with him. He did remember that his medication was Dilantin. The physician wrote him a script for Dilantin and told him he needed to see a specialist and get an EEG. Gateway to Better Health does not employ specialists nor do testing but they did fill his script. Danny felt positive and encouraged that he was back on medication.

Michelle knew that getting a current EEG and consulting with a specialist was a MUST! She advised Danny to apply for an EEG at Barnes Hospital. Again, Danny complied. This was a long, laborious process. Michelle encouraged him to stick with it.

In the meantime, Grandmother needed support and moved in with other family members. Danny was without a place to stay. He moved in with his mother. His mother is hyper-sensitive about seizures because Danny's brother died from complications from seizures. Every time Danny has a seizure, Mom calls the ambulance. Although Danny is compliant, the Dilantin was not controlling his seizures. Danny's frustration with Mom's behavior was contributing to increased seizure activity. Michelle helped by providing Epilepsy 101 to Mom but the frustration continued. Danny wanted to get his own job and live on his own.

Michelle capitalized on Danny's motivation and referred him to a job training program. The job training program wouldn't take him without income. The next step was to apply to the state Department of Mental Health that would provide funding for job training. Danny was on it!

Danny was finally approved at Barnes Hospital for the EEG. Both Danny and Michelle were thrilled. When they read the acceptance letter, Michelle realized that the approval was for only the test. The nurses, technicians and ancillary expenses were not covered. There was no way Danny could afford the test.

Danny was accepted by the Department of Mental Health. The department was willing to pay for Danny's job training.



Both Danny and Michelle were discouraged about the test but excited to begin job training.

Michelle looked into resources to pay for the expenses of the test. Danny went to his first job training class. The instructor of the class referred Danny to administration. There he was told that he couldn't start the class because there was a warrant for his arrest. Danny admitted that there was restitution that was required when he was released from jail and he hadn't paid it.

### Saving Lives is tough business!

Danny began doing odd jobs around the neighborhood to raise money to pay his restitution.

Michelle found a program at Washington University that would pay for the ancillary expenses of the EEG. Danny applied and was accepted.

Last week Danny paid his restitution.

Last week Danny completed his EEG.

Last week Danny visited with a specialist and was put on different medication.

This week Danny will begin his job training class.

Let's see:

√ Financial stability

√ Steward volunteers

 $\sqrt{}$  Manage programs

 $\sqrt{}$  Support staff

√ Report to boards

√ Save Lives

Thanks, Michelle, for your stellar work.



### SOCIAL SERVICES

 Social Service Programs – provide people with epilepsy, their family and friends opportunities for group interaction, support, education and socialization. This is provided through face to face gatherings, telephone, video chat and webinars.



### SEMINARS & WEBINARS

- woman's issues, co-occurring conditions, CBD oil, surgical and non- Seminars – provide information regarding seizures in seniors, surgical treatment options
- Professional Advisory Board member makes 1.5 hour presentation in an evening session with Q & A. The PAB member is an expert in the subject matter selected
- participants. We gather specific information on each person to follow Six presentations annually, including 3 in St. Louis area to 150 direct up and provide updates
- Four webinars have been added this year with the same format as seminars, but with the capability of reaching a broader audience



# SEMINARS & WEBINARS - Cont.

### Seminars

- 2/20 Trends in Epilepsy Treatments Patrick Landazuri, MD
- 3/20 Starting a Family with Epilepsy Nancy Hammond, MD
- 4/17 Tips for Transitioning Back to Work Bridgit Patterson, Epilepsy Foundation of MO and KS
- 5/15 Community Event Includes panel discussion with physicians
- 6/19 Caregiver support group Machele Haskins, mother of patient with epilepsy
- 7/17 Healthy Eating, Modified Atkins Nicolette Jones, RD, LD, Clinical Dietitian Nutritionist
- 8/21 Memory and Cognition in Epilepsy Caleb Pearson, PsyD
- 9/18 Community Event Includes panel discussion with physicians
- 10/16 Living with Epilepsy, A Patient Perspective Christine Haskew, Brad McGee, Jessica Rostock
- 11/20 Tips for a Happy Holiday Season Kelsey Sewell, PhD
- 12/18 Caregiver support group Bridgit Patterson, Epilepsy Foundation of MO and KS



# SEMINARS & WEBINARS - Cont.

### Webinars

Surgical Treatment Options for Epilepsy – Wednesday June 20 | 6:30 – 7:30 PM CST

Watch recording at: https://bit.ly/2v6IRHz

 SUDEP (Sudden Unexplained Death in Epilepsy) – Wednesday August 14 | 6:30 – 7:30 PM CST Watch recording at: https://bit.ly/2wgMtKy Neuropsychology and Epilepsy: The Role of Neuropsychology In Assessing Memory at a Level 4 Epilepsy Center Tuesday October 9 | 6:30 – 7:30 PM CST

The Effects of Epilepsy Beyond Seizures – Tuesday December 11 | 6:30 – 7:30 PM CST



### Epilepsy Webinar Series

resented by Epilepsy Foundation Missouri and Kansas and NeuroPace

Saint Luke's Hospital Stephen E Griffith, MD



Watch recording at: https://bit.ly/2v6LRHz Surgical Treatment Options for Epilepsy

Washington University Kwee Liu Lin Thio, MD



Epilepsy) SUDEP (Sudden Unexplained Death in

Watch recording at: https://bit.ly/2wgMtKy

Kansas Hospital The University of Caleb Pearson, PsyD



Epilepsy Center Assessing Memory at a Level 4 The Role of Meuropsychology in

Tuesday October 9 | 6:30 - 7:30 PM CST

and Wellness Resolve Counseling LMSW, CPT Lori Cull-Deshmukh,



Tuesday December 11 | 6:30 - 7:30 PM CST The Effects of Epilepsy Beyond Seizures

Lectures followed by Q&A sessions.

www.neuropace.com/efmk-webinars For more information and to register for the next free webinar, please visit:

**EpilepsyFoundationMOKS** You can also watch live on Facebook at www.facebook.com/

Questions? Contact: sedington@neuropace.com





### OUTCOME RESULTS

- 75% of clients feel less isolated
- 90% of clients gain knowledge about healthy lifestyle habits







## SOCIAL SERVICES ACTIVITIES









22

## GOVERNANCE - Board Mix

Number:

Location:

• Gender:

11 Board Members

6 from Kansas City, 5 from St. Louis

6 males, 5 females

• Tenure:

Average 5 years

Racial Diversity:

18%

63% Family member with epilepsy:

10%

Person with epilepsy:

\*5 additional Board of Directors would be assembled from Arkansas



# GOVERNANCE - Board of Directors

- Michael Zaitz (President) Director of Accounting, Affinity Law Group, LLC
- Matthew Sogard (Vice President) President & CEO, Lee's Summit Medical
- Justin Whitworth (Treasurer) Assoc. General Counsel, Stella-Jones Corp
- Hollie Caupp (Secretary) VP of Patient Access, Express Scripts
- Edeen Martin-Nichols (Past President) Chaplain

# GOVERNANCE - Board of Directors-Cont.

- Ahmed Abdelmoity, MD Epileptologist, Children's Mercy Hospital
- Donna Baringer Missouri State Representative
- Ed Stout Managing Partner, Grant Cooper
- Keating Mohrman Enterprise Fleet Management
- Lindsay Serrano- Senior Wealth Consultant, Mariner Wealth Advisors
- Shelley Edington Sales Executive, NeuroPace, Inc.



# Professional Advisory Board - 33 Members

- · Abdelmoity, Ahmed, M.D. (Chair), Epileptologist, Directory of Child Neurology, Children's Mercy Hospital, Kansas City, MO
- Block, Margo, M.D., Epileptologist, Centerpoint Medical Center, Independence, MO
- Bucholz, Richard, M.D., Neurosurgeon, St. Louis University
- Chaudhry, Frasat, M.D., Neurologist, St. Luke's Hospital, Chesterfield, MO
- Croom, John, M.D., Epileptologist, St. Luke's Hospital, Kansas City, MO
- Deck, Dayna, J.D., Litigation Attorney EEOC, Kansas City, KS
- Gibbons, Vincent, M.D., Neurologist, St. Louis University
- Goretzke, Sean, M.D., Neurologist, St. Louis University
- Gurnett, Christina, M.D. (Past Chair), Neurologist, St. Louis Children's
- Gustafson, Meagan, MSN, RN, CPNP, Epilepsy Section Coordinator, Children's Mercy Hospital, Kansas City, MO



# Professional Advisory Board - Cont.

- Hall, Josh, Ph.D., Neuropsychologist, Children's Mercy Hospital, Kansas City, MO
- Hammond, Nancy, M.D., Epileptologist, University of Kansas Medical Center
- Harker, Lisa, PsyD, Neuropsychologist, St. Louis Children's
- Hegazy, Mohammed, M.D., Epileptologist, University of Kansas Medical Center
- Kayyali, Husam, M.D., Neurologist, Children's Mercy Hospital, Kansas City, MO
- Landazuri, Patrick, M.D., Epileptologist, Director of Comprehensive Epilepsy Center, University of Kansas Medical Center
- Ledo, Christi, R.N., Registered Nurse, St. Luke's Hospital, Kansas City, MO
- Lee, Ricky, M.D., Epileptologist, Via Christi, Wichita, KS
- Leuthardt, Eric, M.D., Neurosurgeon, Washington University, St. Louis, MO
- · Limbrick, David, M.D., Neurosurgeon, St. Louis Children's



# Professional Advisory Board - Cont.

- Maccotta, Luigi, M.D., Ph.D., Neurologist, Washington University, St. Louis, MO
- Meyer, Tom, RPh., Registered Pharmacist, St. Louis, MO
- Michael, Sarah, Neurology Fellow at St. Louis Children's
- Myers, Tara, MSN, RN, SPNP, APRN Manager, Children's Mercy Hospital, Kansas City, MO
- Oghlakian, Roger, M.D., Epileptologist, Mercy Hospital, Springfield, MO
- · Pawar, Kailash, M.D., Neurologist, Children's Mercy Hospital, Kansas City, MO
- Rashid, Samiya, D.O., Neurologist, Washington University, St. Louis, MO
- Seeley, Mike, M.D., Epileptologist, Johnson County Neurology, Overland Park, KS
- Thio, Liu Lin, M.D., Neurologist, Washington University, St. Louis, MO



# Professional Advisory Board - Cont.

- Ulloa, Carol, M.D., Epileptologist, Director Comprehensive Epilepsy Center & Epilepsy Division, University of Kansas Medical Center
- Uysal, Utku, M.D., Epileptologist, University of Kansas Medical Center
- Weisenberg, Judith, M.D., Neurologist, St. Louis Children's
- Willmore, L. James, M.D., Epileptologist, St. Louis University

#### \* Additional PAB Members will be assembled from Arkansas

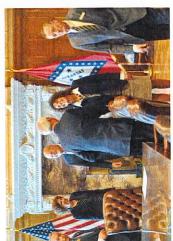


## ADVOCACY IN ARKANSAS





Staff member,
Bridgit Patterson,
with Arkansas
Governor Asa
Hutchinson



## ADVOCACY IN ARKANSAS



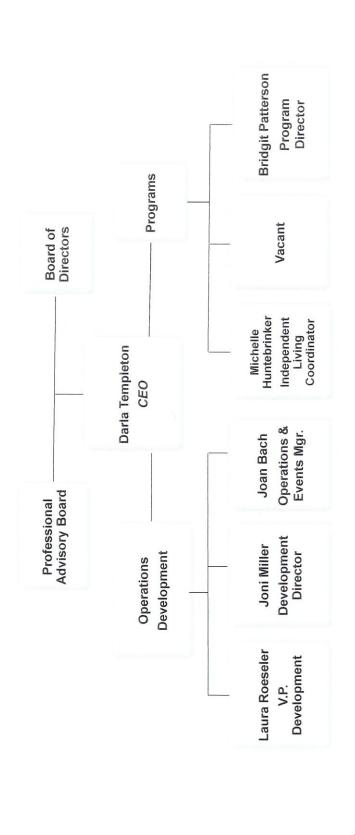
Staff member,
Bridgit Patterson,
with Arkansas
Governor Asa
Hutchinson in
Warren, Arkansas

#### CREDENTIALS

- EFMK is a member of and meets all standards for the Better **Business Bureau**
- EFMK meets all standards of The United Way
- EFMK meets all standards of the Epilepsy Foundation of America
- EFMK posts the annual summary of programs and outcomes on the website annually
- EFMK posts Form 990 (Financials for NFP) on the website annually



## ORGANIZATIONAL CHART





# **EPILEPSY FOUNDATION OF ARKANSAS**

- proven-effective programs and services to compliment the medical care for EFMK would like to expand into Arkansas and bring the well established, those with epilepsy
- EFMK is asking for \$75,000 that would be a purchase of service program getting paid only if the services are provided in Arkansas at the audited hourly rate of service
- EFMK is an <u>affiliate</u> of the Epilepsy Foundation of America, holding our own 501 (c) 3, paying 3% of our revenue in dues (approximately \$16,000/year)



# EPILEPSY FOUNDATION OF ARKANSAS

- EFMK has our own governing board of 11 who provide governance and oversite of EFMK; 5 additional Board of Directors will be added from Arkansas
- medical and legal consultation and advice; additional PAB members will EFMK has a Professional Advisory Board (33 members) who provide be added from Arkansas
- 20 of the 28 affiliates receive state funds to support epilepsy programs from their states ranging from \$50,000 to \$26,000,000



#### THANK YOU



### EPILESPY FOUNDATION Missouri & Kansas

1 INTERIM STUDY PROPOSAL 2017-126 2 3 REQUESTING THAT THE HOUSE COMMITTEE ON PUBLIC HEALTH, WELFARE, 4 AND LABOR STUDY THE NEED FOR THE TRAINING AND EDUCATION OF THOSE 5 WHO INTERACT WITH INDIVIDUALS WITH EPILEPSY ON SEIZURE 6 RECOGNITION AND WAYS TO EFFECTIVELY MANAGE AND SUPPORT 7 INDIVIDUALS WITH EPILEPSY, AND TO PROVIDE COMMUNITY SUPPORT FOR 8 INDIVIDUALS WITH EPILEPSY. 9 10 11 WHEREAS, epilepsy comprises more than twenty-five (25) syndromes. 12 with a range of symptom severities and widely differing seizure types 13 and causes; and 14 15 WHEREAS, the impacts on physical health and quality of life 16 encompass a spectrum as well, with individuals with epilepsy 17 experiencing different health outcomes and varied consequences to their 18 activities of daily living, including academic or professional 19 achievement and social interactions; and 20 21 WHEREAS, the many complexities of all forms of epilepsy and the 22 numerous challenges to health and wellbeing that epilepsy presents make 23 it difficult for the general public to fully understand the challenges 24 the disorder poses and appreciate the stigma that may be associated 25 with its symptoms and diagnosis; and 26 27 WHEREAS, on average, fifty percent (50%) of people who have 28 epilepsy have complete seizure control on medication, twenty-five 29 percent (25%) have very good control, and the remaining twenty-five 30 percent (25%) have uncontrolled seizures; and 31 WHEREAS, seizure control is improved by providing current and 32 33 accurate information about epilepsy in an attempt to change the belief 34 that epilepsy is a result of sins, demonic possession, or substance abuse; and 35

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1	WHEREAS, epilepsy is a widely recognized health condition, but			
2	one that is poorly understood, even among people who have the disorder;			
3	and			
4	WHEREAS, lack of knowledge about the causes of epilepsy has been			
5	associated with negative attitudes, misconceptions, and stigma; and			
6				
7	WHEREAS, lack of understanding about epilepsy is a leading cause			
8	of discrimination against individuals with epilepsy; and			
9				
10	WHEREAS, because of ignorance about the disorder, the diagnosis			
11	of epilepsy has a profound social and psychological impact on			
12	individuals with epilepsy and their families; and			
13				
14	WHEREAS, delayed recognition of seizures and inadequate treatment			
15	greatly increase the risk of subsequent seizures, brain damage,			
16	disability, and death from injuries incurred during a seizure; and			
17				
18	WHEREAS, epilepsy education helps to eradicate misconceptions,			
19	misinformation, and poor attitudes toward individuals with epilepsy and			
20	provides those who interact with individuals with epilepsy with the			
21	necessary tools to recognize seizure activity; and			
22				
23	WHEREAS, those who interact with individuals with epilepsy need			
24	to understand epileptic seizure types, the effects of medications,			
25	including without limitation cannabidiol (CBD) oil, and how to work			
26	with the medical team of an individual with epilepsy; and			
27				
28	WHEREAS, epilepsy is the most common neurological problem of			
29	childhood and its incidence is highest in the first decade of life, a			
30	period during which children begin and complete a critical part of			
31	their social and educational development; and			
32				
33	WHEREAS, children spend much of their first decade of life in a			
34	school environment; and			
35				

1 WHEREAS, one (1) out of every twenty (20) students will have 2 epilepsy before eighteen (18) years of age, meaning that forty-three 3 thousand two hundred (43,200) Arkansas students will face the impact of 4 epilepsy; and 5 WHEREAS, it is important for parents and school personnel to 6 7 recognize seizure activity early, refer the child to medical 8 professionals for treatment, and assure accommodation within the 9 school; and 10 11 WHEREAS, teachers' knowledge about and attitudes toward epilepsy can have a direct impact on students who have epilepsy in terms of 12 13 school performance, social development, and post-school success; and 14 15 WHEREAS, epilepsy education for police officers, emergency 16 medical technicians, and firefighters is crucial to avert misunderstandings between a first responder and an individual who may 17 18 be having an epileptic seizure; 19 20 WHEREAS, the complex partial seizure, the most common type of 21 seizure, clouds awareness, blocks normal communication, and produces a 22 variety of undirected, involuntary, and unorganized movements; and 23 WHEREAS, this type of seizure may include screaming, running, 24 25 flailing, unnatural-looking movements of the arms or legs, spitting, 26 shouting, and abusive statements, all of which may be erroneously 27 perceived as combativeness; and 28 29 WHEREAS, as normal brain function returns following a seizure, an 30 individual recovering from a seizure typically is fatigued and dazed 31 for one (1) hour or more, and the individual may become belligerent, 32 aggressive, easily frightened, upset, or unable to communicate, especially when approached or threatened; and 33 34 35 WHEREAS, restraint of an individual soon after a seizure may

exacerbate or precipitate combativeness, and as the individual's

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1 resistance to restraint increases, the threat to his or her life 2 similarly increases as a result of a potential misunderstanding of the 3 individual's behavior; and 4 5 WHEREAS, additional support for veterans who have epilepsy is needed as veterans are at higher risk of developing epilepsy than the 6 7 public because they are more likely to have traumatic brain injuries 8 and post-traumatic stress disorder; and 9 10 WHEREAS, individuals with epilepsy and who have poor seizure control incur significantly more healthcare costs than those with 11 12 better controlled epilepsy; and 13 14 WHEREAS, providing epilepsy training and education for those who interact with individuals with epilepsy and providing support, 15 16 including community support, for individuals with epilepsy may not only 17 improve the quality of life of individuals with epilepsy but also 18 considerably reduce their healthcare costs, 19 20 NOW THEREFORE, 21 BE IT PROPOSED BY THE HOUSE COMMITTEE ON PUBLIC HEALTH, WELFARE, AND LABOR OF 22 THE NINETY-FIRST GENERAL ASSEMBLY OF THE STATE OF ARKANSAS: 23 24 THAT the House Committee on Public Health, Welfare, and Labor study the need for training and education of those who interact with individuals with 25 26 epilepsy on seizure recognition and ways to effectively manage and support 27 individuals with epilepsy. 28 BE IT FURTHER PROPOSED THAT the House Committee on Public Health, 29 30 Welfare, and Labor study the need for providing community support for 31 individuals with epilepsy. 32 33 Respectfully submitted, 34 35

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Representative Kim Hammer

#### I.S.P. 2017-126

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