

How You Can Get Involved to **RAISE** Awareness

The Magazine of the Epilepsy Foundation

epilepsyUSA

2012 • ISSUE 2



The R.A.I.S.E. Movement

Advocates RAISED the Bar and RAISED Their Hands for Awareness

For the Love of Yara

Tribute Fund Provides Assistance to the Epilepsy Community



EPILEPSY FOUNDATION®

Not another moment lost to seizures™

www.epilepsyfoundation.org

Published online four times a year by the
Epilepsy Foundation of America, Inc.®
8301 Professional Place
Landover, MD 20785-2353
(301) 459-3700
www.epilepsyfoundation.org

CHAIR

Brien J. Smith, M.D.

IMMEDIATE PAST CHAIR

Joyce A. Bender

SENIOR VICE CHAIR

Mark E. Nini

TREASURER

Julie Desjardins

SECRETARY

Robert N. Pinkerton

CHAIR, PROFESSIONAL ADVISORY BOARD

Joseph P. Sirven, M.D.

EXECUTIVE VICE PRESIDENT

Alexandra K. Finucane, Esq.

MANAGING EDITOR

Shelly Williams

SENIOR ART DIRECTOR

Sara Forhan, Mid-Atlantic Design & Print

epilepsyUSA reports on new developments in a wide range of fields of interest to people with epilepsy and their caregivers. Articles involving medical aspects of epilepsy are not intended to be medical advice, and readers are cautioned not to make any changes in treatment based on such information without consulting a physician. Signed articles, quoted statements, and letters to the editor represent the views of the authors and do not necessarily reflect the positions or policies of the Epilepsy Foundation.



© 2012 Epilepsy Foundation of America

www.epilepsyfoundation.org

1-800-332-1000

Connect With Us:



CONTENTS

2012 • Issue 2



PHOTO: HENRY SHAW

3 / In Brief The latest news briefs on epilepsy research.

5 / The 6th Annual National Walk for Epilepsy RAISED the Bar!

BY SHELLY WILLIAMS
Returning favorites and new features made the 2012 Walk the best one yet!

11 / For the Love of Yara

BY JUDY CURTIS AND SHELLY WILLIAMS
Yara Heston's family established a tribute fund in her memory to provide assistance to the epilepsy community.



14 / Teens RAISED Their Hands to Raise Awareness

BY SHELLY WILLIAMS
Kids Speak Up! and Public Policy Institute advocates visited Washington, D.C. to meet with their representatives.

17 / The RAISE (Raising Awareness and Insight on Seizures and Epilepsy) Resolution

Learn more about the RAISE Resolution and how you can get involved to RAISE awareness.

COVER PHOTO: HENRY SHAW



Yara Heston

» AGING ACCELERATES BRAIN ABNORMALITIES IN CHILDHOOD ONSET EPILEPSY PATIENTS

April 10, 2012 – Study findings published in *Epilepsia*, a peer-reviewed journal of the International League Against Epilepsy (ILAE), show age-accelerated ventricular expansion outside the normal range in this patient population and confirms that childhood onset temporal lobe epilepsy has a significant impact on brain aging.

Epilepsy affects nearly 3 million Americans, and 1 out of every 26 Americans will develop epilepsy sometime over their lifetime according to the recently published [Institute of Medicine study](#). Temporal lobe epilepsy is the most common form of partial epilepsy, with 60% of all patients having this form of the condition. Previous evidence suggests that patients with childhood onset epilepsy have significant cognitive and developmental deficiencies, which continue into adulthood, particularly in those resistant to antiepileptic drugs (AEDs).

Prior imaging studies of patients with temporal lobe epilepsy have shown abnormalities in brain structure in hippocampus, thalamus and other subcortical structures, and also in cortical and white matter volume. However, there is limited knowledge of the effects of aging on these structural changes.

To characterize differences in brain structure and patterns of age-related change, Dr. Bruce Hermann and colleagues from the University of Wisconsin-Madison recruited 55 patients with chronic temporal lobe epilepsy and 53 healthy controls for their study. Participants were between the ages of 14 and 60, with patients having mean age of onset of epilepsy in childhood/adolescence. Magnetic resonance imaging (MRI) was used to measure cortical thickness, area and volume in the brains of all subjects.

In participants with epilepsy, there were extensive abnormalities in brain structure, involving subcortical regions, cerebellum and cortical gray matter thickness and volume in the temporal and extratemporal lobes. Furthermore, researchers found that increasing chronological age was associated with progressive changes in cortical, subcortical and cerebellar regions for both epilepsy subjects and healthy controls. The pattern of change was similar for both groups, but epilepsy patients always showed more extensive abnormalities. In particular, epilepsy patients displayed age-accelerated expansion of the lateral and third ventricles. "The anatomic abnormalities in patients with epilepsy indicate a significant neurodevelopmental impact," said Dr. Hermann.

"Patients with epilepsy are burdened with significant neurodevelopmental challenges due to these cumulative brain abnormalities," concludes Dr. Hermann. "The consequences of these anatomical changes for epilepsy patients as they progress into elder years remain unknown and further study of the adverse effects in those of older chronological age is needed."

» AUTOINJECTORS OFFER WAY TO TREAT PROLONGED SEIZURES

NIH study finds method safe and effective for paramedics

February 15, 2012 – Drug delivery into muscle using an autoinjector, akin to the EpiPen used to treat serious allergic reactions, is faster and may be a more effective way to stop status epilepticus, a prolonged seizure lasting longer than five minutes, according to a study sponsored by the National Institutes of Health. Status epilepticus is a potentially life-threatening emergency that causes 55,000 deaths each year. Anticonvulsant drugs are typically

delivered intravenously (IV) as a first-line treatment.

Starting an IV in a patient experiencing seizures can pose a challenge for paramedics and waste precious time. Giving an intramuscular shot is easier, faster, and more reliable, especially in patients having convulsions. The researchers sought to determine whether an intramuscular injection, which quickly delivers anticonvulsant medicine into a patient's thigh muscle, is as safe and effective as giving medicine directly into a vein. The study, which was carried out by paramedics, compared how well delivery by each method stopped patients' seizures by the time the ambulance arrived at the emergency department.

The investigators compared two medicines known to be effective in controlling seizures, midazolam and lorazepam. Both are benzodiazepines, a class of sedating anticonvulsant drugs. Midazolam was a candidate for injection because it is rapidly absorbed from muscle. But lorazepam must be given by IV. The study found that 73 percent of patients in the group receiving midazolam were seizure-free upon arrival at the hospital, compared to 63 percent of patients who received IV treatment with lorazepam. Patients treated with midazolam were also less likely to require hospitalization than those receiving IV lorazepam. Among those admitted, both groups had similarly low rates of recurrent seizures. The study appears in the Feb. 16, 2012 issue of *The New England Journal of Medicine*.*

"Patients with status epilepticus can suffer severe consequences if seizures are not stopped quickly. This study establishes that rapid intramuscular injection of an anticonvulsant drug is safe and effective," said Walter Koroshetz, M.D., deputy director of the National Institute of Neurological Disorders and Stroke (NINDS), part of the NIH, which funded the study.

The investigators said that while autoinjectors might someday be available for use by epilepsy patients and their family members, more research is required. Because of the strong sedative effect of midazolam, on-site medical supervision is now required for the safety of the patient.

The Rapid Anticonvulsant Medication Prior to Arrival Trial (RAMPART) study was conducted through the NINDS' Neurological Emergencies Treatment Trials (NETT) network. Additional funding was provided by the NIH Countermeasures Against Chemical Threats (NIH CounterACT) program and the Biomedical Advanced Research and Development Authority (BARDA). The Department of Defense's Chemical Biological Medical Systems (CBMS) Joint Project Management Office provided the autoinjectors for the trial under a Memorandum of Agreement with NINDS.

NIH CounterACT, BARDA and CBMS are responsible for enhancing the U.S. government's development of medical countermeasures to natural and intentional public health threats. (Please see full statement below on CBMS). The chemical defense community has a longstanding interest in research on the rapid treatment of nerve agent-induced seizures. As the RAMPART study was being planned, investigators learned that the departments of Defense and Health and Human Services were already working with a midazolam autoinjector and the study was an opportunity to confirm its effectiveness in patients with seizures.

"There was great synergy when we realized that RAMPART was studying a similar problem that was of concern to the chemical defense community. This led to a perfect collaboration between HHS and DoD," said David Jett, Ph.D., program director

for NIH CounterACT and NINDS. "The broader implication of RAMPART is that we now have critical information from studies in humans that a safe and effective tool may one day be available to enhance our public health preparedness. Autoinjectors provide a highly practical way to treat hundreds of people quickly during an emergency."

RAMPART is the first randomized clinical trial to investigate whether intramuscular delivery of midazolam is as effective as IV lorazepam, the current standard of care therapy. The trial started in 2009 and completed enrollment in June, 2011. RAMPART involved more than 79 hospitals, 33 emergency medical services agencies, more than 4,000 paramedics and 893 patients ranging in age from several months old to 103. The network of investigators that designed and carried out the trial was established by NINDS to conduct clinical trials on a variety of acute conditions affecting the brain such as stroke and traumatic brain injury. NETT investigators are organized into a system of 17 major research hospitals each of which is linked to several community hospitals and other medical centers.

Another special aspect of the study was that it was conducted under exception from informed consent for emergency research. This is a federal regulation to protect patients who are involved in research when consent is not possible because of their medical condition. Community consultation is held in advance of the study to raise awareness, ensure transparency, and get input from local residents.

Paramedics in RAMPART used study boxes with a time-stamped voice recorder, designed by the NETT team. This tool allowed paramedics to make quick decisions, indicate the time treatment began and the time the patient's convulsions stopped, all without having to interrupt patient care to record data. The goal of the study was to control the seizures within 10 minutes without having to deliver a second dose of medicine. Prolonged status epilepticus can last for hours and sometimes is controlled only with general anesthesia.

"Few other areas of medicine are as time-dependent as injury to the brain. In epilepsy, even a few minutes can be important.

With every minute the seizure continues, it becomes harder to stop. RAMPART offers first responders an important treatment tool that will have a meaningful impact on the lives of many people with epilepsy," said Robert Silbergleit, M.D., of the University of Michigan in Ann Arbor, first author of the *NEJM* paper.

*SILBERGLEIT, R., ET AL. INTRAMUSCULAR VERSUS INTRAVENOUS THERAPY FOR PREHOSPITAL STATUS EPILEPTICUS. NEW ENGLAND JOURNAL OF MEDICINE, FEBRUARY 16, 2012.

» NEW GENE DISCOVERY UNLOCKS MYSTERY OF EPILEPSY IN INFANTS

January 19, 2012 – Benign familial infantile epilepsy (BFIE) has been recognized for some time as infantile seizures, without fever, that run in families but the cause has so far eluded researchers. However clinical researchers at the University of Melbourne and Florey Neurosciences Institute and molecular geneticists at the University of South Australia have discovered a gene.

BFIE is a disorder that occurs in previously healthy infants who are developing normally. Seizures commence when a baby is about six months old and stop by the age of two years. BFIE is a rare form of epilepsy with the Australian researchers having studied about 40 families from around the world. Some of the children with this gene abnormality develop an unusual movement disorder later in childhood or adolescence called Paroxysmal Kinesigenic Choreoathetosis (PKC).

Families with this condition have now been found to carry a variation in a gene called PRRT2, which may cause the protein the gene encodes to form incorrectly. The function of this gene is not yet known nor is it understood how the changes in this gene cause an infant to have seizures. This gene discovery provides valuable opportunities for learning more about brain function and what causes seizures.

Professor Ingrid Scheffer, Chair of Paediatric Neurology Research said the finding would help families understand why their baby has seizures and will provide reassurance that the baby will grow out of the seizures and not have long term problems. It will also help with early diagnosis and appropriate treatment of the movement disorder.



BE THE FIRST TO KNOW

Subscribe to our FREE eNewsletter and get the latest on epilepsy treatment, research, and activities delivered right to your inbox!

<http://www.epilepsyfoundation.org/resources/eNewsletter/index.cfm>

SIGN UP TODAY



The 6th Annual National Walk

BY SHELLY WILLIAMS, *epilepsyUSA* MANAGING EDITOR

for Epilepsy **RAISED** the Bar!

The 6th Annual National Walk for Epilepsy was bigger and better than ever! Over the past 5 years, the National Walk for Epilepsy has engaged more than 30,000 people and raised more than \$5 million. This year boasted new entertainment, musicians and a completely revamped layout for the event site.

The day started with the Pre-Walk Rally featuring Left on Lincoln, an awesome local band that kick started the day with some classic rock. Then we heard from speakers such as Brien Smith, M.D., chair of the Epilepsy Foundation board who is a neurologist and had epilepsy caused by a brain tumor; and Walk co-chairs Matt Miller and Lisa Moss. Matt has two sons with epilepsy, Nicky and Jordan. Lisa has a daughter, Aria, and a son, Evan, who has tuberous sclerosis. The co-chairs led the Walk council in outreach to companies and individuals to increase participation. It's the dedication of people like them that keep the Walk alive and help it grow year after year.

Jennifer Moore Woods sang the National Anthem and did a spectacular job. She was there supporting her husband Perry Woods who has epilepsy. The Walk began with a ceremonial first step taken by Trenton Gilstrap, a senior in high school who has epilepsy and Asperger's syndrome. Trenton is a great advocate for epilepsy and plays the saxophone in his high school marching band, which performed at the Walk for the third year in a row.

Following the Walk's scenic turn past the Capitol, the Washington monument and the cherry blossoms around the Tidal Basin, there was a post-Walk ceremony. Walk council co-chair

Lisa Moss announced the winning teams in the categories Most Money Raised and Most Walkers, divided by team type: individual team, company/organization team or affiliate team.

After the post-Walk ceremony there was the Ask-the-Experts session, a question and answer session with top neurologists fielding questions from Walk participants. The 2012 panel featured Epilepsy Foundation Professional Advisory Board Chair **Joseph Sirven**, M.D., Epilepsy Foundation Board Chair **Brien Smith**, M.D., and Joan Austin, D.N.S. Joan Austin and Joseph Sirven served on the Institute of Medicine's (IOM) committee on the **Public Health Dimensions of the Epilepsies**, and provided an overview of the IOM study results, released on March 30. In addition, the entire panel provided expert feedback on treatment options, medications and promising research.

In past years, there was one large tent for the Foundation and the Walk sponsors to share. The Foundation passes out informational materials and talks with Walkers about the services

and programs we provide, and Walk sponsors and partner organizations share with the Walkers the work they do.

This year, each organization had their own tent; tents were arranged in a circle, called the Walker's Village. The Epilepsy Foundation had a tent in the center to pass out materials. Also new to the Walk was the Social Media Tent, which was part of the outer ring of tents. This tent originally was established to serve as a space where walkers could meet their online friends they had met through support groups or our social networking site, eCommunities. The Foundation had received feedback that Walk participants would like to have a place to meet their online friends—so they listened and did it! Also at this tent were pieces of the Walk mural, which was painted at a previous year's Walk, and teams were encouraged to stop by the tent to have a team picture taken in front of the mural. All of the team photos were posted the same day on our [Facebook page](#).

Returning to the Walk this year was the Kids Tent, which featured face painting and coloring books; MLB team the Baltimore Orioles mascot, the Oriole Bird; the

Chick-fil-a cow; and the Gwyn Park High School marching band and JROTC. New to the Walk this year was the Buffalo Wild Wings mascot, Blaze, and the Bowie Baysox mascot, Louie. The mascots and characters were a major hit with the crowd!

The Walk is not only a fun, family-friendly event; it's also an awareness event and a support system for people who are affected by epilepsy. Teams come from all over the country to the Walk, the largest epilepsy awareness event in the country. The buzz in the air and the feeling of community at the National Walk for Epilepsy is almost indescribable. Ellen Woods, vice president of development at the Epilepsy Foundation, put it best when she said, "This is a once-a-year event where families from across the country are able to come together and support each other. So many signs and shirts read, 'You are not alone.' That's the positive attitude and enthusiasm we saw all across the Mall that made this Walk so inspiring and inclusive for everyone who participated."

For more about the Walk, visit [WalkforEpilepsy.org](#). "Like" the Foundation on Facebook at [facebook.com/epilepsyfoundationofamerica](#) and follow the Foundation on Twitter at [twitter.com/epilepsyfdn](#).

continued on page 7





Left on Lincoln rocked the crowd with their music.
PHOTO: DAVID ANDERSON PHOTOGRAPHY



PHOTO: HENRY SHAW



PHOTO: DAVID ANDERSON PHOTOGRAPHY

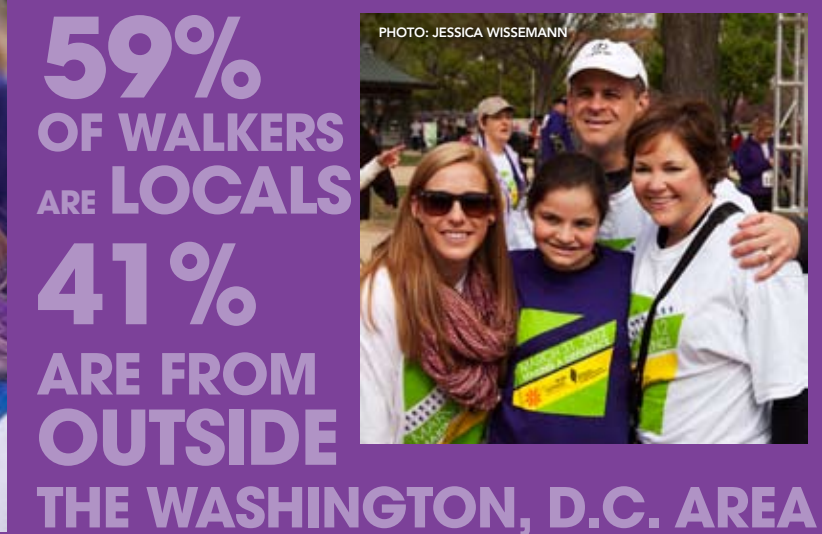


PHOTO: JESSICA WISSEMAN

59%
OF WALKERS
ARE LOCALS
41%
ARE FROM
OUTSIDE
THE WASHINGTON, D.C. AREA



Jennifer Moore Woods singing the National Anthem at the Pre-Walk Rally. PHOTO: HANIFA AYUNISA

63% OF WALKERS ARE FEMALE **37%** ARE MALE



PHOTO: HENRY SHAW



PHOTO: JUDY CARTON



PHOTO: HENRY SHAW



PHOTO: SHELLY WILLIAMS



Lisa Moss, Matt Miller and their children rally the crowd.
PHOTO: DAVID ANDERSON PHOTOGRAPHY

25% OF WALKERS ARE AGES 25-34



PHOTO: HENRY SHAW



PHOTO: HENRY SHAW

18% OF WALKERS IDENTIFIED AS HAVING EPILEPSY



PHOTO: HENRY SHAW



PHOTO: HENRY SHAW



PHOTO: HENRY SHAW

www.epilepsyfoundation.org



Joan Austin, D.N.S., Joseph Sirven, M.D., and Brien Smith, M.D. answer questions from the audience at the Ask-the-Experts forum.
PHOTO: DAVID ANDERSON PHOTOGRAPHY



PHOTO: HENRY SHAW



PHOTO: HENRY SHAW

The 6th Annual National Walk for Epilepsy RAISED the Bar!

Continued from page 8



The Generations of Hope team. PHOTO: DAVID ANDERSON PHOTOGRAPHY



View all of the Social Media Tent photographs on our Facebook!



PHOTOS: SHELLY WILLIAMS



PHOTO: MIKE McEWEN



PHOTO: MIKE McEWEN

You Did It!! The 6th Annual Walk for Epilepsy Would Not Have Been Possible Without YOU!

MOST MONEY RAISED • 2012 National Walk for Epilepsy

INDIVIDUAL/FAMILY TEAM		COMPANY/ORGANIZATION TEAM		AFFILIATE TEAM	
1st	Generations of Hope over \$16,000	1st	American Epilepsy Society (AES) over \$30,000	1st	Epilepsy Foundation Maine/Rhode Island over \$9,000
2nd	Strollin for Sammy	2nd	SCI	2nd	Epilepsy Foundation Virginia
3rd	Seizure Busters	3rd	Supernus Pharmaceuticals	3rd	Epilepsy Foundation New Jersey

MOST WALKERS • 2012 National Walk for Epilepsy

INDIVIDUAL TEAM		COMPANY/ORGANIZATION TEAM		AFFILIATE TEAM	
1st	Fighting Back with Fat 39 members	1st	SCI – Team Dignity 97 members	1st	Epilepsy Foundation Virginia 56 members
2nd	Joshua's Smile	2nd	American Epilepsy Society (AES)	2nd	Epilepsy Foundation Eastern Pennsylvania
3rd	Team "Victoria" us	3rd (tie)	Supernus Pharmaceuticals UCB – Epilepsy Advocates	3rd	Epilepsy Foundation New Jersey



The Epilepsy Foundation thanks all of our participants and supporters in making the 2012 National Walk for Epilepsy a success. The National Walk would not have been possible without the support of the 2012 Walk sponsors:



THE EPILEPSY COMPANY™



Your Partner in Epilepsy



UnitedHealth Group



Anita Kaufmann Foundation

National Association of Epilepsy Centers

LARABAR

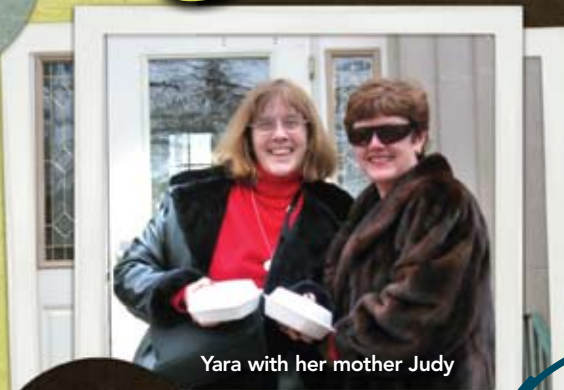
Epilepsy Alliance for Young Adults

Team Epilepsy

Nutricia



For the Love



Yara with her mother Judy

of Yara

AS TOLD BY JUDY CURTIS
EDITED BY SHELLY WILLIAMS, *epilepsyUSA* MANAGING EDITOR

Yara Heston was a kind woman who loved children and was described as "too good for this world." She passed away at the age of 36 on September 30, 2005. In her memory, Yara's Fund was established through the Epilepsy Foundation of Delaware to help other people with epilepsy cover the cost of their medications. This is Yara's story, as told by her mother, Judy Curtis.

Epilepsy was Yara's companion for 30 of her 36 years, but it never once defined her life, nor her attitudes, nor the way she lived her life. She was always positive and optimistic, and probably the most courageous person I ever knew. She was upbeat and very, very interested in living independently. She wanted her own life. That isn't to say that she was in denial. She knew exactly what she was living with and the circumstances under which she lived, but it did not control her.

Yara was born 43 years ago in Denver, Colorado. She was diagnosed as having petit mal seizures when she was six, and then she was put on Zaronitin and things noticeably improved for about four years. The same week she turned ten she had a tonic-clonic seizure,

and most of her seizures thereafter were tonic-clonic.

It's very important to me, and always has been, that epilepsy not be the subject of anything I say about Yara because it did not define her life. She was an exceptional person, but I tried to make her strong. I remember when she was diagnosed, and I went to her first grade teacher. She was a charming, beautiful young lady, and she said, "Oh, I would just be crying and crying." And I said, "Miss Berry, I did; I did that. Now, we have to go about living. We have to meet this and we have to live, and I want Yara to be strong."

Yara said to me when she was ten, "Mommy, why did God give me this?" I said, "Well, Yara, I don't know if He did because I don't believe that He does those things, but if He did, He did it to show His great works through you."

continued on page 12



"She knew exactly what she was living with and the circumstances under which she lived, but it did not control her."

For the Love of Yara

Continued from page 11

I believe that Yara took those words to heart and adopted them. I don't mean to beatify her, by any means. She was a human being and she had her faults, like we all do, but I think she was quite extraordinary.

We moved around a lot until Yara went into high school. I have to say that those four years were among the happiest of her life because she found friends and a wonderful, modified educational program where she flourished. In 1989, she was accepted to National Louis University, into their Professional Assistant Center for Education (PACE) program. While there she did her field study at a daycare and she just loved it. Yara loved children and she chose to major in early childhood.

She never gave birth to a child, did not marry, but she knew exactly what it meant to love children. And she loved children. She had so many in her life through daycare and pre-school, and they loved her because she loved them unconditionally.

In 1994, I remarried and moved to Delaware, and Yara moved to Delaware in 1997. She lived with us for about 17 months, and then she got her own little apartment. She was so happy about that and she continued to work at a day care. Without Bill, Yara's stepfather, she would not have been able to live independently. He gave her a great deal of emotional and financial support.

"She was the kind of person that would give the shirt off her back."



Yara found herself among the people who have trouble sustaining employment. From time to time, she could not work full-time because of her epilepsy, and many times she was fortunate in that she encountered employers who were both sensitive and supportive.

One morning she had a seizure and couldn't go into work, and this man fired her on the spot on the telephone. It was unfair and unjust. And speaking of which, she also had a very strong sense of right and wrong, and of justice. She hated injustice when it was shown to anyone. Her favorite book as a child was *Bambi*, and I could never get her to eat venison.

Once, I heard someone say "the gifts we give to ourselves stay with us and die with us, but the gifts we give to others go out into the world and are immortal." That was Yara; that's the way she lived her life. She thought of others first. She did not set out to make as much money as she could and keep as much money as she could. She shared what she had. She gave it away if someone needed help. She was the kind of person that would give the shirt off her back; very generous, and very loving and giving.

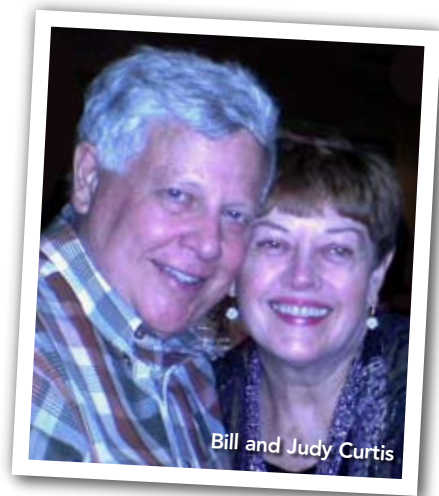
Her smile began in her eyes except for the 15 years she was on Depakote, which did so much harm to her. There was dullness in her eyes, and I noticed slurring of speech. It affected her muscles and her joints. It affected her vision. It produced a tremendous weight gain. Except for those 15 years, she had a sparkle in her eyes from the day she was born, and when she transitioned from Depakote to Lamictal in the year 2000, that returned. She was like Sleeping Beauty; she woke up again. She was full of questions, and she was so alert and so inquisitive, and it was like she had awakened from a 15 year sleep. The things she accomplished in those 15 years while on that medication are just phenomenal to me, and another testament to her perseverance, and her courage and her strength as a person.

Toward the end she fell a lot, and the morning was her most dangerous time of day. Usually she had seizures early in the morning, and I think that's what happened on that last day—she had a seizure.

We had a protocol; I had a plan in place because she was living alone. I would call her every morning about 8:00 her time and I knew that on this morning she had plans to go to the fitness center. By the way, the number of people that knew Yara and loved her was just phenomenal, I mean, the van drivers, her nail technician, the people at the fitness center. In fact, she became very good friends with the gentleman at the center, and that morning when I couldn't reach her, my first call was to him, and he said, "No, she has not come in this morning."

My second call was to the para-transit company, and they said Yara was a "no-show." Then I called her landlord who also has a son who has epilepsy. He and his wife went to her apartment, and they found her. She passed away on September 30th of 2005. That was a terrible day; the worst day in a parent's life, worst day in my life. My neighbor said after Yara passed away that Yara was a gentle soul. She was.

Abraham Lincoln was another parent who lost a child. He lost three children, and I've heard it said that his favorite son was his third son, Willy, who died in the White House. In his grief, Abraham said, "Willy was too good for this world." And that's how I see Yara; she was too good for this world.



She died too young, and she knew it, too. That was something that I found to be quite interesting. We had more than one conversation about the future, about "what-ifs." She did not believe she would live too many years. She was still in high school when she said that.

Yara's Fund was established as a tribute to Yara, as a way of giving to others because that is the way Yara lived. It was established to provide assistance to that 30 percent of the community who find difficulty sustaining employment, and therefore, don't have health insurance,



Yara's Fund was established as a tribute to Yara, as a way of giving to others because that is the way Yara lived.

and have a very difficult time affording their medications which are very expensive. So, this fund provides that support, and every penny in it goes for that. And that makes us feel good that we are able to help other people as a tribute to Yara. It's like she's still with us, and it gives meaning to her life and to ours by doing this.

We hope this fund will continue indefinitely, and we've done different things to try to raise as much money as we can. In 2006, my husband built a beautiful, big, oval-shaped garden in our backyard, and we dedicated it in the spring of 2007. We had friends here, and they brought things to plant and poems. We had a little ceremony, and then we began to take seasonal pictures. My husband is a

very good photographer, and he took pictures of the garden at the four seasons of the year. We created a series of note cards called *The Four Seasons of Yara's Garden* and we sold them. That resulted in \$1,000.00 being donated to the fund. And I still push them off on family and friends. [Laughs]

It's in conjunction with the Epilepsy Foundation of Delaware. And the reason is because that is where Yara lived. That is where she was happy. That is where I lived with my husband for a few years, and that is where I served the affiliate by being on the board and by volunteering. Lastly but not least, I have great respect for Barbara Blair who is the director there. She is one of the hardest working people I have ever met; committed to public awareness, to educating people beginning with teens in high schools, and paramedics, EMTs, bus drivers, van drivers, police officers, firefighters. I just have great respect for that and I like to support that.

Each person has their own individual life to live and their own way of living and meeting challenges. And I would like to say in closing just one more thing about Yara, in an effort to be as positive as she was, and that is it will always be incomprehensible to me that she lived with the challenges. People don't endure; they live in spite of and they live with. It breaks a mother's heart to see these things, but on a positive ending note, I will always remember the grace with which she lived.

She did; she lived with grace, and I don't think there's much more we can expect.

To donate to Yara's Fund and support patients in Delaware who need help paying for their medications, send a check to the Epilepsy Foundation of Delaware. Please make a notation, either on the check or with a separate note, that it is intended for **Yara's Fund**.

For more information, visit <http://old.epilepsyfoundation.org/local/delaware/donations.cfm>

The Epilepsy Foundation of America is a nonprofit, 501(c)3 tax-exempt organization. Contributions are tax deductible as permitted by law. The Epilepsy Foundation has registered in every state in which registration is required. To obtain a copy of our latest annual report, please visit our website www.epilepsyfoundation.org. Our mailing address is Epilepsy Foundation, 8301 Professional Place, Landover, MD 20785-2353 or call 301-459-3700.

Florida: A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL FREE, 1-800-435-7352 WITHIN THE STATE. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. SC-00229. For the cost of copies and postage, documents and information required by the Maryland charitable organizations law can be obtained from the Office of Secretary of State, Charitable Division, State House, Annapolis, MD 21401. Official registration and financial information may be obtained from the Mississippi Secretary of State's Office by calling 1-888-236-6167. Registration by the Secretary of State does not imply endorsement. INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. A copy of the latest annual report can be obtained from the Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271. Kansas license #710-605-7SC. Annual financial report is filed with the Secretary of State, Topeka, KS 66612. In North Carolina, financial information about this organization and a copy of its license are available from the State Solicitation Licensing Section at 1-888-830-4989. The license is not an endorsement from the state. Annual report may be obtained from the Oklahoma Tax Commission. The official registration and financial information of the Epilepsy Foundation of America may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. Virginia residents may obtain a copy of financial documents from the State Division of Consumer Affairs, PO Box 1163, Richmond, VA 23218. The Epilepsy Foundation is registered in Washington with the Charities Division, Office of the Secretary of State, Olympia, WA 98504; toll-free number within state is 1-800-332-4483. West Virginia residents may obtain a summary of registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration does not imply endorsement. Michigan license #MIC-5629.



Teens RAISED Their Hands to RAISE Awareness

Kids Speak Up! Teens Visited Washington, D.C. to Meet with Lawmakers

BY SHELLY WILLIAMS, *epilepsyUSA* MANAGING EDITOR

This past April, teens from all over the country traveled to Washington, D.C. to raise their hands and their voices in the fight for rights, protection and opportunities for people living with epilepsy. These young spokespersons served as a representative of their state as they met with their Senators, Representatives and congressional staff. Their job was to advocate for epilepsy, as part of the Epilepsy Foundation's annual *Kids Speak Up!* program.

Kids Speak Up! (KSU) is a national program that trains young ambassadors with epilepsy between the ages of 13 and 18 to become local and national advocates. KSU is held in tandem with our Public Policy Institute (PPI) for Foundation affiliates and adult volunteers. The teens, affiliates and volunteers' mission is to personally

petition congressional leaders for support of better access to care, improved public awareness and education, and more funding for research toward a cure for epilepsy.

This year, KSU/PPI was focused on the **R.A.I.S.E. Resolution**. The R.A.I.S.E. Resolution stands for **R**aising Awareness and **I**nsight on **S**eizures and **E**pilepsy, and is also known as House Resolution 298, or H Res 298. It was created to promote greater awareness and understanding about epilepsy among government agencies and bodies that come into contact with the nearly 3 million people in this country living with epilepsy.

Forty-four teens participated in the 3-day training to learn more about epilepsy, develop their public speaking skills and learn the importance of advocacy. The highlight of the trip was a meeting on Capitol Hill to urge



Brittany and Tara pose for a picture with their accompanying PPI participants.

support of efforts to improve public understanding of the condition and increase aid to further research for a cure. After the participants return home, they are asked to use their experiences to advocate locally through the Year of Service program, where they design and implement activities that raise awareness year-round.

Special guests this year were **Dr. Frances Jensen** and "Mighty Mike" Simmel. Dr. Jensen is a neuroscientist and professor of neurology at Children's Hospital Boston and Harvard Medical School, and President of the American Epilepsy Society (AES). She addressed the adult participants with a presentation on the latest advances

continued on page 16

Teens RAISED Their Hands

Continued from page 15

in epilepsy research. “Mighty Mike” was diagnosed with epilepsy at age two, and is a professional basketball player with the Harlem Wizards entertainment basketball team and a national spokesperson for epilepsy awareness. Mike is also a motivational speaker, and [blogged about his experience at KSU](#).

New to KSU/PPI this year was the presentation of the Sara Stubblefield Advocacy Award. This award was established in memory of the late Sara Elizabeth Stubblefield and recognizes a person who is a leader in advocating and making a difference for the epilepsy community. Ryan Dillon, member of the national board, was the recipient of the 2012 Sara Stubblefield Advocacy Award because of his dedication to the epilepsy community. Congratulatory videos from Congress Members of Missouri, Ryan’s home state, were shown and Ryan gave a heart-warming acceptance speech.



Board member Tina Westra speaks to the crowd on opening night.



Brandon sends the camera positive vibes.



For more photos and videos, visit www.epilepsyfoundation.org/ksu



Mike Simmel teaches basketball tricks to KSU participants Ian and Chloe.



Sophie and her mother Michelle both have epilepsy and share their experiences with Hill staff.



PPI participants learn how to share their story and speak with their Congress members.

In the United States, epilepsy affects more than 326,000 children under the age of 15. Most of the teens at KSU have epilepsy, but there are some participants who are affected by epilepsy in a different way such as being the sibling or child of someone living with epilepsy. Whether living with epilepsy themselves or being close to someone who has the condition, the personal stories of the teens are amazing. They are honor roll students, athletes, music and arts students, volunteers at their [local affiliates](#), and they never let epilepsy slow them down. Most most importantly, they are the future of the epilepsy community.



Sara Stubblefield's family and the winner of the 2012 Sara Stubblefield Advocacy Award, Ryan Dillon (third from right).



We want to hear from you!

Give us your feedback. Share a personal story. Ask a question.

e-mail: editor@efa.org

mail: epilepsyUSA, 8301 Professional Place, Landover, MD 20785-2353

All letters to epilepsyUSA must include your full name and home address.



Overview

The [RAISE \(Raising Awareness and Insight on Seizures and Epilepsy\) Resolution](#), also known as House Resolution 298 or H Res 298, was created to promote greater awareness and understanding about epilepsy within government agencies that come into contact with the nearly 3 million Americans living with epilepsy. The RAISE Resolution asks for no additional money, just greater effort by the federal government to coordinate the use of epilepsy awareness and educational programs.

By increasing awareness we can improve epilepsy care, access to appropriate services and ultimately build public support for a greater investment in research that leads to a cure. The Epilepsy Foundation strongly supports the RAISE Resolution and urges all members of the House of Representatives to co-sponsor RAISE. The goal is to get at least two RAISE co-sponsors from each state and at least 100 co-sponsors total.

Background

The Epilepsy Foundation works vigorously on Capitol Hill to ensure that epilepsy is a priority in the federal health care system. The RAISE Resolution was introduced in the House of Representatives by JoAnn Emerson (MO), Ed Perlmutter (CO) and Dan Benishek (MI), and has strong bipartisan support.

Nearly than 3 million Americans have epilepsy, yet epilepsy and seizures remain largely misunderstood by the public. The Epilepsy Foundation is particularly concerned about the lack of epilepsy awareness among educators, employers, medical professionals and first responders—as they often come into contact with someone having a seizure. Epilepsy awareness and an understanding of seizures in the workplace, schools and communities would make it safer for students, workers and citizens with epilepsy to access emergency care, continue employment and achieve an education.

Get Involved

Send a Letter to Congress:

[Contact your Representative](#) and ask them to co-sponsor the RAISE Resolution.

RAISE Your Pen:

Sign the [RAISE Petition](#) to help persuade legislators to co-sponsor this resolution and get it passed.

Send a Video to Congress:

Let Congress see your face and hear your voice by creating and posting a short video telling them why you support the RAISE Resolution and why they should, too! You can share your video by:

- posting it on the Foundation's [Facebook page](#)
- tweeting it to the Foundation at [@EpilepsyFdn](#)
- sending it directly to Government Relations & Grassroots Manager, Cornell Woolridge, at cwoolridge@efa.org to be put on the Foundation's YouTube channel

Join the #RAISE Days:

Follow [@EpilepsyFdn](#) on Twitter and be part of the #RAISE Days. On special #RAISE days, the Foundation will send updates about RAISE co-sponsors, action alerts and other events being held in support of RAISE.

Sign Up for Advocacy E-mails:

Join the [Speak Up, Speak Out](#) network to receive action alerts on legislation and advocacy outreach messages.

Browse the Legislative Action Center:

[Find out if your member is a co-sponsor](#) and see the status of the RAISE Resolution.

Learn more about RAISE:

Read the [legislation](#) for the RAISE Resolution.



KSU/PPI participants RAISING their hands for the RAISE Resolution.