

My epilepsy story – The Anita Kaufmann Foundation

Debra Josephs

Epilepsia, **(*)1-2, 2015
doi: 10.1111/epi.12559



I met Anita Kaufmann in third grade. She and her family had just moved to my hometown of Teaneck, New Jersey. My third grade teacher asked me to walk Anita home after the first day of school, and we soon became best friends.

When Anita was 14, she was thrown from a horse while riding and had not been wearing any protective headgear. She was in a coma for several days in the hospital. It was very scary at the time but we thought that Anita had made a full recovery. It was not until much later when Anita's personality began to change and the seizures began that I realized the full extent of a traumatic brain injury.

Anita graduated magna cum laude from the University of Pennsylvania and went on to obtain her law degree from Georgetown Law School. After practicing law for several

years in New York, Anita transitioned into the field of legal recruitment and launched her own search firm in 1986. Under her leadership, Anita Kaufmann Associates became one of the most well-respected firms in the industry. Her clients included Fortune 500 companies, major Wall Street financial institutions, and prestigious international law firms. Anita's career flourished.

But Anita's life would change the day she had her first seizure while taking time away from her firm for a well-earned vacation. After her first seizure, the spa at which Anita was staying insisted she leave. From that moment on, Anita set a plan in motion to establish a foundation to help people with epilepsy and seizures. A compassionate person and a true visionary, Anita understood that the public would be more accepting of people with epilepsy if they were more knowledgeable about the condition.

In 2004, shortly after her death and with the resources she entrusted to me, I created The Anita Kaufmann Foundation (AKF), a nonprofit 501c3 organization with the sole mission of educating the public not to fear epilepsy and seizures. Since 2004, I have been working in Anita's name to let the world know that people with epilepsy can be successful and lead normal lives. Our foundation's goal is to fight the discrimination, which Anita felt was oftentimes a greater burden than the seizures themselves.

Her mission is embodied in everything we do.

Our "Thinking About Epilepsy" program educates fifth graders to recognize seizures, provide first aid, and understand the challenges of living with seizures and epilepsy. The program promotes tolerance and engenders positive attitudes toward people with epilepsy. More than 100,000 fifth graders in the United States have been trained to date. Our goal is to educate every fifth grader in the country.

Seizure recognition and first aid trainings are provided upon request and free of charge. We train our advocates via Skype to administer first aid trainings in their communities. Our advocates have provided these trainings all across the country in schools, restaurants, malls, during hospital symposia, and to police and firemen alike. We consider encouraging our advocates to take an active role in generating awareness in their home communities to be the hallmark of our programs.

Accepted January 8, 2014.

The Anita Kaufmann Foundation, New Milford, New Jersey, U.S.A.

Address correspondence to Debra Josephs, The Anita Kaufmann Foundation, New Milford, NJ 07646, U.S.A. E-mails: debra@akfus.org, www.akfus.org, www.purpledayeveryday.org, www.purpleday.org

Editors Note: *Epilepsia's* Epilepsy Stories is a venue for nonprofit organizations to educate our professional readership about their mission for people with epilepsy from around the world. Many organizations raise awareness about epilepsy including the International League Against Epilepsy's (ILAE's) sister organization, the International Bureau for Epilepsy (IBE) and its chapters. *Epilepsia* does not endorse one organization over another. If you would like to have your nonprofit organization recognized, contact us at epilepsia@epilepsia.com.

Wiley Periodicals, Inc.

© 2015 International League Against Epilepsy

Our “Would You Know What to Do If I Had a Seizure?” campaign introduces the public to people with epilepsy from all walks of life and diverse age groups. Developed specifically by AKF as a tool to educate the community about how to help a person having a seizure, these posters, flyers, and first aid charts can be downloaded from our Website for free at www.akfus.org and www.purpledayeveryday.org. Our materials hang in local coffee houses, supermarkets, department stores, malls, and bakeries, and are handed out to participants of our walks and training sessions.

Our “Heads Up for Vets” program is a collaboration between AKF and the U.S. Department of Veterans Affairs (VA) Epilepsy Centers of Excellence (ECoE). We recognize that many of our brave servicemen and servicewomen are returning home from active duty with a new war to wage: a battle to control seizures and epilepsy. Together with the ECoE we developed educational materials and established a support network that provides epilepsy education to veterans and their families and connects them to services and benefits within the VA and in their hometown communities.

But the platform that has had the greatest impact on people with epilepsy in the United States and around the world is Purple Day—World Epilepsy Day. In 2008, 9-year-old Cassidy Megan of Nova Scotia, Canada created Purple Day. Motivated by her own struggles with epilepsy, Cassidy’s goal is to get people talking about the condition in an effort to dispel myths and inform those with seizures that they are not alone. She named the day Purple Day after the internationally recognized color for epilepsy, lavender.

Since 2008, Purple Day, celebrated annually on March 26th, has become an international movement and is now celebrated in more than 80 countries and in just about every U.S. State. The Anita Kaufmann Foundation and its partner, the Epilepsy Foundation of Nova Scotia, have led

the march to empower people with epilepsy to take control of demystifying the condition and to create a more accepting global environment for those who struggle with its consequences each and every day by incorporating purple into their awareness activities. Inclusion and collaboration are key. Through social media, Purple Day has connected thousands of people from around the world who are living with epilepsy and has created a support network for our advocates worldwide.

We are branding purple with epilepsy to create more awareness for the condition. During the week of Purple Day—World Epilepsy Day, AKF sponsors The Great Purple Cupcake Project, where bakeries and individuals worldwide bake and sell purple cupcakes to raise funds and awareness for epilepsy. In addition, we have a special purple nail polish and encourage everyone to polish their nails purple. Interestingly enough, the purple nail polish has been an incredibly popular vehicle to raise awareness. Inclusion and collaboration are key, as active partnerships have grown in Spain, Brazil, and Australia, with Japan hosting the first International Purple Day tour this July. Outreach continues to connect epilepsy organizations under the purple umbrella that affected persons have themselves chosen as their instrument of change.

We invite you to participate. Reach out to me personally. Visit our Websites. Learn how you can contribute. Please join our team and help us make this world a kinder place for people living with epilepsy.

DISCLOSURE

The author declares no conflicts of interest. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.