Living Well with Epilepsy

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HELLO advocates, volunteers, donors, moms, dads, sisters, brothers and friends,

Wow, that was a mouthful! We are fortunate to have a community of so many people who care about the present and future of people living with epilepsy.

There are many things to love about November – Thanksgiving, the dawn of winter, and the opening of the ski season. November is also National Epilepsy Awareness Month (NEAM). NEAM is about education and awareness of epilepsy and people who live with epilepsy. At the Epilepsy Foundation of Colorado, we strive to educate and raise awareness, but are also constantly being educated and made aware of new data and therapies.

In the spirit of National Epilepsy Awareness Month, we want to share with you something a mother of a child with epilepsy just shared with us. She detected a food additive as one of two triggers for her son’s seizures. Since restricting the chemical from his diet, his seizures have decreased significantly. Will this work for everyone? No. But sharing this information and keeping a seizure log can greatly help to identify potential triggers. It took this mother a long time and a lot of tedious scrutiny to realize the trigger. Can you begin to see a pattern? Don’t give up. Ask another person to examine your seizure log. Call one of our staff who can provide objective input.

Awareness of medical marijuana is on our radars. Medical marijuana as a treatment for epilepsy is a fervent issue since the passing of Amendment 64. Also, the recent CNN story “WEED” about one child’s dramatic decline in seizures after consuming a liquid form of one specific type of marijuana plant has put this issue on the forefront. We want to make our readers aware that the Epilepsy Foundation strongly stands behind - and is helping to fund - more research to substantiate marijuana as a treatment for epilepsy.

Please watch for our next newsletter providing in-depth interviews with two sides of a very important story.

Thank you to those of you who have helped to educate and raise our awareness by passing along your discoveries and knowledge through our Facebook page, chat rooms and support groups. This helps us to do our work more effectively. We would also like to thank all of you who supported us at one of three Strides for Epilepsy 5Ks this year in Colorado Springs, Denver and Fort Collins. Collectively, 3,000 participants and volunteers raised nearly $200,000 to assure the Foundation’s services continue to grow and reach more people. In 2013, we accomplished A LOT including the launch of on-site services and case management at the three area hospitals, the distribution of 800 comprehensive resource kits to newly diagnosed families, seizure response and first aid training to nearly 1,000 law enforcement officers, and delivered accredited school nurse training throughout Colorado.

As we reflect on 2013 and look ahead to 2014, we have a lot of exciting goals and strategies to help serve people living with epilepsy including:

- Expanding the toll-free help line to 24 hours a day, seven days a week
- Increasing support groups from 17 to 25, focusing on rural areas with limited epilepsy resources
- Launching a one-on-one Case Management program, connecting people with personal support
- Developing a second summer camp to accommodate the growing wait list

Join us to continue our efforts and raise awareness for better therapies, support and services. Stay involved. Do what you can, no matter how big or how small. Every day we have BIG successes, small successes and challenges. In the end, we hope to do everything we can to help you be successful.

A special thank you to Kathy Ashenfelter for nine years of board service.

Wow, that was a mouthful! We are fortunate to have a community of so many people who care about the present and future of people living with epilepsy.

In November, you can:

- Organize a training for your school, church or community group to educate people on seizure safety. Contact Marcee Peterson at (303) 377-9774.

- Coordinate a “Purple Day” in your work place or with friends to raise funds and awareness for epilepsy. Contact Allison Bradac at (303) 377-9774.

- Pick your passion, and do it in purple! Be creative, and be yourself in the name of epilepsy awareness. Don’t forget to share your pictures, stories and journeys with us!
Support The Lives We Touch

Some of the remarkable lives touched by the Epilepsy Foundation of Colorado are told on the following pages. We have more stories to tell, so help us reach 500 more people in 2014 by pledging your support in November for National Epilepsy Awareness Month.

Go to www.epilepsycolorado.org.

What’s Your Snapshot?

LIKE US ON FACEBOOK AND POST YOUR PICTURE WITH THE WORDS THAT BEST FRAME YOU.

FACEBOOK.COM/EFCO1

We are so thankful to Hannah Wolfman for bringing together these concepts and ideas for National Epilepsy Awareness Month. Hannah continues to be a leader in our community through her creativity and commitment to bringing awareness to epilepsy.

Thank you, Hannah, for sharing your vision.
Tell me about your greatest passion.
I love to read. I learned to read when I was four, and took to it very quickly. When I was little, my parents didn’t give me a bedtime. They just said I could read until I got tired. But reading excited me too much to be tired!

Has having epilepsy made it more difficult to pursue that passion?
You know, it actually has. You wouldn’t expect a seizure disorder to be triggered by a love of literature, but inadvertently it’s certainly presented its challenges.

How so?
Well for one, the days of reading until the sun comes up are behind me, as we all know lack of sleep can be a huge trigger.

Has living with epilepsy fueled your passion for literature?
I’d say so. I’ve been doing a lot of creative writing about my epilepsy. Of course being such an avid reader lends to being a better writer, but you also tend to pull from your own experiences. And I’ve had a very unique experience.

Has epilepsy held you back?
I was diagnosed with epilepsy when I was in high school. I loved cycling and was racing at a pretty competitive level. After being diagnosed, I couldn’t throw my whole self into it the way I needed to. I stopped pushing myself as hard as I could, because the harder I pushed myself the more seizures I’d end up having. So yes, I guess it has held me back.

How did you adapt to these new limitations?
I still push myself - I’ll always push myself - it’s who I am. I started looking for a new outlet. I took up speech and debate, and ended up going to the state tournament. I also picked up ultimate and joined a league. It was a less vigorous sport to get into, and I could go at my own speed.

What have you gained from this struggle?
Epilepsy is definitely a double-edged sword. On the one hand it keeps me from doing everything I want to do, but it keeps me in check, from going off the deep end. I’ve had to learn to listen to my body more. It’s important to know when to stop, when I need rest and I think more about the decisions I make. It’s kept me grounded.
How has living with epilepsy impacted your art?
Epilepsy hasn’t really inhibited me, but it has given me inspiration. In school there was a project where we had to incorporate five hands. I used pill bottles, clipboards, medical bills, an ambulance - basically the story of my epilepsy.

Are there any ways in which you’ve had to adapt as an artist?
Little things. Routine. My hands tend to get pretty shaky and it’s difficult to paint in fine detail. I don’t think I’ll be a tattoo artist any time soon.

Tell me about your tattoos.
One way or another, my tattoos have all stemmed from my experience living with epilepsy. Of course there’s the purple ribbon on my forearm, but less obvious are the owl and gypsy I have on my back and calf. The owl, made of a dream catcher, is symbolic of holding onto dreams and accomplishments while having the wisdom to achieve them. Gypsies were known for being resilient and tough - they stuck it out!

What is your greatest passion?
I love art – permanent art.
EFCO aids
FAMILIES AND SCHOOLS
Contributed by Misty Eddy

For people living with epilepsy, life transitions, such as entering school, starting a new job and becoming an independent adult can be particularly challenging. The Epilepsy Foundation of Colorado (EFCO) is critical in helping people with epilepsy and their families through these transitions.

Parents of school-aged youth with epilepsy have found navigating the school system and ensuring that the teachers and administrative staff are knowledgeable about epilepsy can be difficult. EFCO can help. We provide educators who know what and how to inform school staff, and have performed various types of trainings in schools.

A recent example ensued when Misty Eddy, Mom of Austin, requested EFCO’s help in educating the staff at her son’s new school. Austin’s case was unique in that he was the first child with epilepsy to attend his charter school. After his teachers recommended that Austin be put on an IEP (Individualized Education Program), Misty reached out to Marcee Peterson, Youth Program Manager with EFCO for guidance. In Misty’s own words;

“I contacted Marcee Peterson, Youth Program Manager, with EFCO for help and support. Marcee was very helpful and supportive each step of the way. She attended our first IEP meeting and helped explain my son’s diagnosis, as I was still learning it myself. She asked the Dean if they would like training for the staff about epilepsy. Our school was very receptive to this and wanted to be educated on Austin’s diagnosis and epilepsy. Marcee and I trained the school on how epilepsy can affect Austin’s learning and school performance. She also explained all types of seizures, warning signs, and what to do if a student has a seizure. I couldn’t be happier with the school’s acceptance these past two years. Each of Austin’s new teachers continues to become educated about Austin and his diagnosis. I am very blessed to have such support from our school and the Epilepsy Foundation of Colorado.”

School trainings can be a key component in your child’s education. EFCO can:
- Attend an IEP/504 meeting to help the evaluators give the most accurate IEP evaluation.
- Instruct the school nurse on how to appropriately handle seizures in school.
- Explain how a child’s seizures can affect learning, behavior and socialization.
- Educate your child’s peers so they are not afraid or unaccepting.

Austin is now eight years old and is doing well on his epilepsy medication. Misty does not let epilepsy slow either of them down and has been empowering Austin through hiking and running. Austin has run four 5ks and finished his first triathlon this year. In March 2014, Misty will be running her first half marathon through the Epilepsy Therapy Project in Los Angeles. “It’s been our outlet and has helped us bond and move forward from the effects of epilepsy. We are okay and we will continue to inspire each other” Says Misty.
EFCO Donation Center

Visit our website at donatecolorado.org for Donation Center drop off locations or to schedule a pick-up at your home. Other ways to support the Donation Center include:

- Coordinate a garage sale and let us pick up leftover, unsold items
- Host a picnic or event in your workplace parking lot
- Organize a donation drive with your boy or girl scout troop

WHERE YOUR money goes

- **Information and Referral**
  - Jason Fleishman Summer Camp
  - Kids Speak Up! Conference
  - Frosty Fun Day
  - Circle of Friends Support Groups
  - Community Education

**Programs & Services** 79.48%

**Management & General Operating** 10.53%

**Fundraising** 9.99%

Thank you to the Friday Aurora Knitters and Crocheters (above), Wednesday Aurora Knitters and Crocheters, St. Michael’s Knitters and Crocheters, and The Mile High Red Hot Mamas. These generous groups knitted and donated 119 scarves and hats that helped to raise money for EFCO and keep our supporters toasty warm!

24 Hours To Raise Support for the Epilepsy Foundation of Colorado

Go to ColoradoGives.org on Dec. 10th
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