"There is a collective ignorance about epilepsy," says Ginny Grady. "It's not intentional. It's just a lack of opportunity to spark that interest -- until it touches your life." She speaks with a confident intelligence that one would expect from an experienced trial attorney whose career has been devoted to giving voice to others. But now, talking about epilepsy, she's speaking for herself.

As is typical for adults whose lives have been interrupted by epilepsy, Ginny can tell you precisely the date, time and circumstances of her first seizure. The seizure itself, however, does not hold a place in her memory. "It was an alignment of the stars that my son was home and able to help. I had my first seizure in his arms," she recalls. "The next thing I remember, a paramedic was standing over me, 'Ginny, you had a seizure.'"

Ginny's epilepsy is stable now; but she quickly acknowledges it was a long road to get where she is today. "It's such an interesting thing to have epilepsy. You have a lot of time to think about these things as you progress through it, and I was interested about the science of what was going on in my brain. For me, I think that curiosity took the place of fear."

Her seizures remained uncontrolled for many months, and Ginny set out to learn as much as she could about her epilepsy. "I did my research and quickly realized that nobody really knows that much about seizures," she said.

"Lawyers think they know everything about everything right away, and we don't," Ginny said with a smile. "It's the same way with epilepsy. Now my perspective looking back is a little bit clearer every day for me. Now I know I'll never stop learning about it."

To help deepen her understanding of the seizures she was having, Ginny developed a clear visual representation of the activity in her brain, likening a seizure to a bolt of lightning with all of nature's variables. "Seeing my seizures in this way is how I process their existence, for me and for everyone around me," Ginny explains. "I need to have a visual, because no one else can 'see' it happening. And nobody wants to talk about something they can't see."

Ginny is more than willing to talk about seizures, and has adopted an adventurous attitude that is sure to spark some interesting discussions. "I look at the brain as one of the last great frontiers, and here I am experiencing the activity of one of the last great frontiers. It is fascinating. I am a personal witness to a science that other people can never be a personal witness to. What an interesting experience to have in life."

CONTINUED ON PAGE 7
FORWARD LIVING
NEWS FROM THE MEDICAL COMMUNITY

EFCO PILOTS NEW PROGRAMS TO EXTEND REACH OF CARE MANAGEMENT RESOURCES

The Care Management program of the Epilepsy Foundation of Colorado is an extension beyond medical care to help people of all ages meet the day-to-day challenges of living with epilepsy. Designed to empower, support, educate, and connect those impacted by epilepsy and their families, EFCO is now piloting new methods to work directly with epilepsy clinics at Children’s Hospital, Kaiser Permanente, and Lutheran Medical Center, bringing these essential services to more people who need them.

Typically, patients seeking help would find the foundation through their own research, or perhaps an informal referral from their physician. The new pilot programs will test the effectiveness of a proactive system that reaches into the epilepsy community, with the direct partnership of healthcare providers.

The program is basically a resource conduit; providing patients with information about the services that are available to help them successfully manage their healthcare, and giving them a direct opportunity to connect with the EFCO Care Manager. Patient information is always voluntary, and is treated with a professional level of privacy and sensitivity.

“I want my patients to know there is a strong, caring community of people living with epilepsy right outside my office door, so to speak,” commented Danielle McDermott, M.D., Epileptologist for Kaiser and medical director of the EMU at Saint Joseph Hospital. “Our new partnership with the Epilepsy Foundation of Colorado connects sooner rather than later, to help patients to manage the complex aspects of living with chronic illness.”

EFCO’s Care Management menu includes education, active follow-up from our Direct Care Manager to provide support and guidance, information and referral for various community resources, as well as the foundation’s own empowerment workshops such as Studio E, Beyond Medication, and Circle of Friends support groups. The service is offered free of charge. For more information visit epilepsycolorado.org, or call 303.377.9774.

GALA
Save the Date for the 2015 Gala:
Colors of the Mind
Saturday, March 14, 2014
Sports Authority Field at Mile High.

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STUDIO E EXPRESSES THE EMOTIONS OF EPILEPSY

One picture is worth a thousand words. That statement has never been more relevant than it is for Studio E, an innovative art therapy course available through the Epilepsy Foundation of Colorado. The program is designed especially for people living with epilepsy and allows participants to strengthen their artistic voices, explore their creativity, express emotions through art, and share experiences within a safe and supportive group setting.

A recent Studio E session was facilitated by Erica Jacknin, a board certified art therapist and licensed psychotherapist. Over a six-week period, she uses a variety of artistic mediums to guide her group with sensitivity and compassion. “It’s always exciting to see how people open up through the process,” Jacknin commented. “I can help them connect with the images they create and know they are essentially connecting with themselves in a way they wouldn’t have done verbally.”

Studio E is not about the art itself, but rather the process of self-expression. No artistic skill or experience is needed and in fact, Jacknin notes, “Often those who enter the program claiming no artistic ability benefit the most.”

“I was so excited all week about coming to Studio E. I knew I could be myself there, and find creative ways to express myself.” Studio E participant

Dual Faces is a stunning example of the power of Studio E. Created by a recent participant, Jacknin recalls the process as a perfect example of art therapy. “The painter did not set out to create a picture of the two faces of her life,” she said. “But when given an opportunity to create something purely as a form of self-expression, she experienced the freedom to connect with her emotional self. As that process continued the two faces in the painting emerged. It was quite a breakthrough.”
BROOMFIELD FAMILY RALLIES TOP SUPPORT FOR STRIDES 5K

March 1st, 2013 is a day seared into Shana Bairrington’s memory. She was picking up her youngest son, Nolan, from preschool. “I lifted him up to put him in the car, and he just went limp in my arms,” Shana recalled. “I was completely terrified and panicked. I had no idea what was happening.”

The mother and son took their first ambulance ride that afternoon, but ended-up leaving the hospital with no explanation. “We were told that sometimes, children have seizures and we don’t know why,” said Shana.

Things were starting to get back to normal, when on the way home from Nolan’s fourth birthday party, he experienced another seizure. At the hospital following their second ambulance ride in as many weeks, and after more exhaustive medical testing, a doctor first mentioned that Nolan might have epilepsy.

“Epilepsy was not something we had considered among the worst possible scenarios,” Shana said. “At the time it was almost a relief. I figured with epilepsy, we’ll get some medicine, and we’ll move on. We had a lot to learn.”

And so the Bairrington family began their son’s journey with epilepsy, an arduous and unpredictable scenario of trial and error to get the right medications and the correct dosages. Through it all they remained positive, and sought to educate themselves about epilepsy. It is through that process they first came in contact with the Epilepsy Foundation of Colorado.

The family learned about the annual Strides for Epilepsy 5k, and thought it would be a fun activity with a special purpose. Shana remembers “It was a great event for all of us; Ty, Nolan’s big brother ran his first 5k at Strides, which makes it an extra special memory.”

The Bairrington’s participation in the event was so positive, they decided to put a team together for the 2014 event. “We wanted to help raise awareness and make something good out of what we were going through,” she said. From that inspiration, the family team, Nolan’s Crew, took off and raised $14,787, the most money among more than 150 Strides teams.

The outpouring of generosity inspired by Nolan’s journey humbles Shana. “As we watched the total go higher and higher, we were just amazed and we are so grateful to our friends, our family, and the Epilepsy Foundation,” she said tearfully. “It gives us strength.”

The 2014 Strides for Epilepsy 5k brought a record of more than 2,000 people together at Denver’s City Park, and raised $168,000 to help fund the many programs and services EFCO provides to the epilepsy community in Colorado.

The Strides 5k is an annual event, held in Denver each spring, and in Colorado Springs every fall. For more information please visit the Events tab at epilepsycolorado.org.
Dear Friends,

The programs, services and personal stories we share in this newsletter are vibrant examples of our organization in action. Perhaps you also log-on to our website, or follow us on Facebook. However you stay informed you know we are the primary source of information and support beyond your medical office.

I often think, what would Colorado look like if the Epilepsy Foundation of Colorado didn’t exist? As I have mentioned before, I am the father of a teenager with epilepsy, and we’ve utilized the Foundation’s services on numerous occasions. I can tell you without hesitation: my daughter and my family are healthier because of this dedicated organization. I want every family in Colorado who has been touched by epilepsy to have access to the same resources, which is why I commit my volunteer time and my financial resources to this caring organization.

I am asking from the bottom of my heart, for you to do the same thing, now, today. Stronger Together is not just a tag line for us; it is the very essence of our existence. Whether raising our collective voice to eliminate misunderstanding about epilepsy, or providing one-on-one support for someone in need, only WE can make this happen.

Why give? Did you know every year over 1,500 people call the Foundation to connect with one of their care managers for help during a difficult time in their journey with epilepsy? Just last month the Foundation provided a specialized training for 60 new school nurses, changing the landscape for children with epilepsy in the classroom. And most of us are very familiar with the incredible empowering effect of the Foundation’s summer camps for youth.

Our goal is simple; to be an ally in your journey with epilepsy. It is important to me that we have every opportunity to bring that goal to fruition. Please let us know that it is important to you, too.

Steve Franzen
President, EFCO Board of Directors
Lisa Marie Maxson is a self-described serial entrepreneur. She has successfully launched and managed several businesses, from software engineering to e-commerce, and an Ice Hockey Rink. Her highly successful track record is fueled by a passion for people and a fearless attitude, in part due to the fact that Lisa Marie has lived with epilepsy since childhood.

Based on her own experience with seizures, Lisa Marie sought to channel her philanthropy to an organization that had a deep and effective reach into the epilepsy community. The Epilepsy Foundation of Colorado was her clear choice.

“I believe giving back is a critical component of success, and that means giving my time and financial support,” Lisa Marie said.

Within that spirit of giving, Lisa Marie found a creative way to extend her generosity through one of her businesses, 10X People. The software engineering firm is centered on a culture that encourages a work-life balance, while maintaining a high level of accountability and productivity.

“We’ve developed a unique, interactive way to work that keeps us connected and moving forward as a team,” Maxson explained. “As I learned more about EFCO’s mission to maximize quality service, I saw an opportunity to put the 10X principles to work.”

Since adopting the 10X method, the staff at EFCO is indeed operating at an even higher level. “With all that we do in the epilepsy community throughout Colorado, people are often surprised to learn that we operate with a full-time staff of only six,” said executive director, Gail Pundsack. “10X has raised the bar in terms of how we work, how we communicate with each other, and ultimately how well we serve our stakeholders.”

The results are especially gratifying to Lisa Marie, who is a shining example of how to live well with epilepsy. “My business success is due in part to the fact that I’m not afraid to fail,” she said. “I have that same attitude about my epilepsy. I won’t let it stop me from achieving the things I want to do. It’s just part of who I am.”
Corporate partners of the Epilepsy Foundation of Colorado understand that investing in the communities where their employees live and work is a strong business decision, but they also value the importance of providing individuals living with epilepsy with the services and resources they need to lead fulfilling lives. Every year, EFCO proudly partners with numerous local and national businesses to help make a positive difference.

Continued from page 1

Following her initial diagnosis, Ginny craved normalcy and returned to work, admittedly “way too soon.” She immediately told everyone in her office what was going on, in part because she knew she worked with intelligent people who wouldn’t judge or penalize her for a health condition. “There was no way I wasn’t going to plow through it, and I knew it would be important for everyone working alongside me to be comfortable. That can only happen if we talk about it.”

“...I was interested about the science of what was going on in my brain. For me, I think that curiosity took the place of fear.”

She continued to have smaller, “partials and auras”, but having not yet begun treatment with an epileptologist, Ginny wasn’t really aware that the interruptions she was experiencing four or five times every day were indeed seizures. “I suspected it, but no one had validated that for me. The aura would be like a fog rolling in.”

Along with the new challenges Ginny was facing with the sudden onset of epilepsy, she was also presented with the professional opportunity to which she had aspired for 20 years. Persistence – not to mention a stellar tenure as a defense attorney – landed her the job, and she now serves as the Federal Public Defender for the Districts of Colorado and Wyoming. “My epilepsy didn’t change how I did my job, and it hasn’t changed my ability to do it.

In fact, Ginny believes that in an unexpected way, being a defense attorney prepared her to deal with epilepsy. “I’ve spent 30 years explaining the human condition. I wouldn’t have spent my career doing that if I wasn’t interested in it. So now it’s sort of a natural turn of perspective for me. Now it’s about my human condition.”

Unceasingly optimistic, Ginny has benefitted from her naturally positive disposition, and has advice for others who may still be searching for answers. “I just deal with it. I am a problem solver. If you’re not, you’ve got to find somebody around you who is,” she asserts. “The one thing I think you can do is be willing to look at it. Really see your epilepsy. The more you know, the less there is to fear. And if you lessen the fear for yourself, you will lessen the fear for everyone around you.”

Ginny Grady takes a stroll with her dog, Wilson.
STRONGER TOGETHER
GET INVOLVED

COMING IN NOVEMBER:
NATIONAL EPILEPSY AWARENESS MONTH

Join us in November and help create a wave of awareness and positive change for the epilepsy community in Colorado.

Here are four easy ways to get involved, talk about epilepsy, and help support EFCO...

Thanks a Latte!
Instead of that morning latte at your favorite coffee shop, switch to water or bring your coffee from home and allocate the money saved to EFCO. Thirty days of savings will really add-up!

Gifts from the Heart.
In lieu of gifts for that special birthday or holiday, ask your family and friends to consider making a donation to EFCO.

Party with a Purpose!
Host a party for family, business associates or friends in your community, and instead of letting them bring a dish or bottle of wine, ask them to make a donation to EFCO.

The Color Purple.
Simply by wearing or displaying our signature color, you can open the door to conversations that will educate people about epilepsy and build understanding in the community.

Let us help you design creative and engaging activities for you and your company, neighborhood, or school. Visit us at epilepsycolorado.org for more information and to pledge your participation.