MEET Larissa

DU DIVER BREAKING BARRIERS

Larissa Grammer Dives Into College Life at DU

Larissa Grammer, a freshman at The University of Denver, looks completely at home on campus, blending into college life with a maturity and sense of purpose that belies her 18 years. She is an exceptional student, and a promising member of the school’s Division I women’s diving team. And she has epilepsy.

Diagnosed at the age of nine, Larissa admits she didn’t really understand it at first but it wasn’t long before her natural curiosity took over. “I’ve always wanted to understand what is happening in my own head. When I was first diagnosed I remember going on to the Epilepsy Foundation website, and watching the videos to learn about the different parts of the brain, and what takes place when a seizure occurs. I find that so fascinating.”

However, by the time she was 10, she became self-conscious about her seizures and didn’t want anyone to know. “I’ve always been a perfectionist. When I was diagnosed I felt as though I had to be perfect in every other aspect of my life – in everything I do. I wanted to prove that I was no different than anybody else.”

Since then Larissa has found a balance that allows her to live her life on her own terms, without the stress of trying to hide her diagnosis. Nor does she hide behind it. “I’m very lucky that I’ve been able to just carry on with my life as I want to live it. It’s been an interesting path.”

Larissa was just starting to figure that out on her own, when she went to the Jason Fleishman Summer Camp, a youth program offered by the Epilepsy Foundation of Colorado. “That’s when life really changed for me,” said Larissa. “I learned there are lots of other kids like me, and it’s okay to talk about it.”

Talking about it opened the door to a support system that ultimately empowered her to stay in charge of her own life. Now Larissa manages her epilepsy and hopes that sharing her story will help other kids who may be struggling with the same issues she’s been... life really changed for me,” said Larissa. “I learned there are lots of other kids like me, and it’s okay to talk about it.”

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Neurofeedback Finding Increased Acceptance in the Treatment of Epilepsy

Although the practice of neurofeedback was discovered more than 40 years ago, it is currently gaining renewed acceptance as a treatment for epilepsy in otherwise traditional neurological medical practices. It has been well studied in patients with epilepsy, as well as patients with other neurological conditions. The potential for neurofeedback as an anti-seizure therapy was discovered by chance in animal studies of seizures, and the technology was quickly tried in humans with seizures.

Neurofeedback is a form of biofeedback that uses EEG sensors to sample, analyze and “feedback” information about the brain’s electrical activity. Your brainwaves are very complex signals. Low frequency, or “slow”, waves and high frequency, or “fast”, waves have different functions in different regions of the brain. During neurofeedback, people learn to change their brainwaves by exercising and strengthening balanced neural pathways.

“While in training sessions, people work towards increasing healthy brain rhythms while suppressing unhealthy rhythms,” explains Dr. Lauren Frey, Associate Professor of Neurology at the University of Colorado, and a staff epileptologist at University Health. “The more you exercise your brain and produce healthy brainwaves, the stronger those rhythms will become.”

Multiple medical studies have shown that neurofeedback can reduce seizure frequency, even in patients whose seizures are not controlled by currently available anti-seizure medications. Although individual results may vary, with sufficient training, improvements can be long lasting.

Dr. Frey is encouraged by the results she is seeing in her practice. “I believe that anyone with medically refractory seizures should consider neurofeedback training,” she said. “Some of my work suggests that there are also non-seizure and quality of life benefits to be realized through training.”

For more information about whether neurofeedback is appropriate for you, a family member or friend, start online at the Biofeedback Certification International Alliance website (www.bcia.org). This website has more information about neurofeedback, and has a listing of certified neurofeedback providers in your area.

COMING SOON:
EFCO Report to the Community on Medical Marijuana and Epilepsy

The use of a marijuana derivative for children with epilepsy has been big news since CNN broke the story about Charlotte Figi last August. Charlotte is a Colorado child with Dravet’s Syndrome, whose previously intractable seizures declined dramatically after she began taking a medication (now known as “Charlotte’s Web”) made from marijuana plants. This case has placed Colorado at the epicenter of this phenomenon, as families from around the United States are moving to Colorado to access Charlotte’s Web for their children who are suffering from uncontrolled seizures.

In keeping with our mission to provide accurate information about all therapies and treatments, The Epilepsy Foundation of Colorado will release a comprehensive report to the community on this topic on or before March 1st. It is designed to answer questions about the compound, the legal aspects as they currently exist, and potential research on the horizon.

This report will be available by March 1st, on our website, and via direct email upon request. If you would like to receive a copy, please call 303.377.9774.

The Epilepsy Foundation of Colorado does not endorse or discourage the use of medical marijuana. We are providing this carefully researched report as an educational service to our community. We expect that patients will consider all available therapies through consultation with their own physicians.
Rich Joiner is a self-described techie. He is a level two IT operations technician for First Data, a global leader in credit card transaction processing. During his twelve hours shifts, Rich applies steely focus on the four computer monitors on his desk, making split-second decisions to quickly correct computer glitches that arise during transactions. It is a stressful and demanding job that Rich enjoys, in spite of the fact that he has epilepsy.

Rich began having seizures when he was 23. The result of a brain tumor, the seizures continued long after the tumor was successfully removed. His life was shaped by the challenges of living with epilepsy for the next 17 years, until he and his doctors found the right medication. “I’ve been pretty lucky,” Rich said. “My seizures have been controlled for the past ten years now, and I’ve been able to get on with my life.”

Rich volunteers his time to lead a support group in Aurora for adults living with epilepsy. He hopes to share the benefit of his experience, not to mention his positive outlook on life, with others who are navigating the same challenges that he has faced.

“You never really get over it – but you can learn to live with it,” Rich explains. “That’s what I want to share with others who may be struggling with the challenges of epilepsy. It’s different for everyone, but by sharing our experiences, I think we can help each other find that road that will take us to better lives.”

Rich is working with the Epilepsy Foundation of Colorado, which facilitates a total of 16 support groups in the area. Volunteers like Rich, who are themselves living with epilepsy, and have made a commitment to help educate and support their community, lead the groups. “We want to provide an opportunity for people impacted by epilepsy to meet, learn more about the medical condition, and receive support in a safe and social environment,” said Gail Pundsack, the foundation’s executive director.

The support group in Aurora meets on the third Tuesday evening of each month, from 7 – 8:30, at the Hoffman Heights Fire Station #2. For more information about this group, as well as others, please call the Epilepsy Foundation of Colorado at 303.377.9774, or visit us on the web at epilepsycolorado.org.
The Epilepsy Foundation of Colorado will present its annual fund raising Gala on Saturday, March 8th, 2014 at the historic Brown Palace Hotel in downtown Denver. The evening will begin at 6:00 p.m. with hosted cocktails and a silent auction, followed by dinner, a live auction, and dancing to Moment’s Notice.

The black-tie optional evening will elegantly convey the French era of innovation and invention in a modern-day setting, while honoring all those who live with epilepsy, as well as those who are making strides to find a cure.

“This year’s Gala will be a truly beautiful evening,” commented chairwoman Kate Petrocco. “Our committee is hard at work to create a memorable event that will be enjoyable and informative.”

Joining Petrocco on the committee this year are Cynthia Anderson, Kathleen Beram, Terri Davis, Marcia Forman, Tracy Murray, Candy Palazzo, Brandon Speer, Dana Stehno, Maria Terry, and last year’s honorary chair, Brooke Gordon. “We are all touched in some way by epilepsy,” Petrocco continued. “I think that common thread is what distinguishes this Gala. Everyone on this committee is driven by their own personal passion to improve the lives of people with epilepsy.”

The event’s Honorary Chairman is Warren Lammert, a well-known businessman and a leader in the national epilepsy community. A former Denver resident, Mr. Lammert is the chairman of the board for the Epilepsy Foundation of America, and co-founder of the Epilepsy Therapy Project and Epilepsy.com. He also serves on the board of directors of FACES (Finding a Cure for Epilepsy and Seizures) at New York University.

The Gala is one of the foundation’s key fund raising events, and raises more than $240,000 each year. Proceeds from the Gala support EFCO’s programs including education and outreach efforts, support and referral services, new and integrative therapies, and the Jason Fleishman Summer Camp.

For more information on sponsorships, tables and ticket availability, please contact Allison Bradac at 303.377.9774, allisonbradac@epliepsycolorado.org, or visit epilepsycolorado.org.

Kate Petrocco, 2014 Gala Chair

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Epilepsy Foundation Colorado
LOCAL YOUTH IS FIRST TO REPRESENT COLORADO ON NATIONAL YOUTH COUNCIL

Brandon Speer relishes the opportunity to talk about epilepsy. “There is an inadvertent air of discrimination,” he explains. “There’s so much misinformation and assumption connected to epilepsy, and people tend to be afraid of what they don’t understand. I like to turn that fear into curiosity so I can set the record straight.”

Diagnosed with epilepsy at the age of 12, he wasn’t always so willing to share his story. In fact, there was a period in his life in which he referred to the seizures that interrupted his childhood as “my dirty little secret.”

The turning point for Brandon was the year he first attended the Jason Fleishman Summer Camp, an EFCO program designed to give kids like Brandon an opportunity to enjoy the simple pleasures of a summer camp experience with others who are living with the same challenges. “Just knowing I wasn’t the only kid dealing with seizures was a huge step for me,” Brandon said. “It was absolutely life changing.”

Since that first year, Brandon has become increasingly involved at camp, and as an active participant in the EFCO Youth Council, a group of young men and women, ages 15 to 22, whose lives have been directly impacted by epilepsy. The group is committed to work collaboratively and individually on projects designed to educate the public about epilepsy, dispel myths and stigma attached to the condition, and to advocate for their young peers who need support.

Brandon’s dedication and passion for the cause have been rewarded with a recent appointment to the National Epilepsy Youth Council, the first such appointment from Colorado. Brandon is excited to take his message to the national stage.

“Epilepsy is something that makes me unique — no better or worse than anyone else,” Brandon says. “Being able to understand and truly accept that about yourself, you need the support of others who are dealing with the same thing. That’s my goal with this work; figuring out ways that we can come together and talk about how to live our best lives and just keep moving forward.”

Now a sophomore at University Colorado, Brandon is studying molecular, cellular and development biology, and has a long-term eye on attending law school. Wherever his career takes him, educating others about epilepsy will certainly hold an important place in his life.

EFCO Youth Council meets regularly and works together on endeavors such as Project Backpack, which provides information and comfort to newly diagnosed patients at Children’s Hospital. To get involved, or support the efforts of our outstanding young volunteers, please contact Marcee Peterson, 303.377.9774, marcee@epilepsycolorado.org; or visit epilepsycolorado.org.
TEKsystems Partnership Driven by Employees’ Generous Spirit

TEKsystems, an international leader in IT staffing and services, has been a corporate sponsor of EFCO since 2008. The TEKsystems model of charitable giving is one that has been especially valuable, providing not only financial support but also direct employee involvement.

The relationship began at the urging of TEKsystems director of business operations, Steve Franzen, who first joined the EFCO family because of his daughter, Claire. Diagnosed with epilepsy as a toddler, Claire is now a “pretty typical 15 year old high school sophomore”, thanks in large part, according to Franzen, “to the support, education and advocacy we received from the foundation.”

As Claire blossomed from her involvement with EFCO programs, the sponsor relationship also deepened, resulting in thousands of dollars donated and thousands more raised through extended employee participation.

The company is always well represented at the foundation’s annual Gala, but perhaps the most meaningful corporate involvement occurs with the annual Strides for Epilepsy 5k Walk/Run. The TEKsystems team at the Strides 5k has become an annual summer tradition for employees, their families, and friends, and is now one of the largest annual events attended by the company’s Denver office.

“Our participation in the Strides event helps us build the right culture that represents the core values of our company,” commented Steve Franzen. “We have a very competitive staff of people, but building a great business is not just about providing great customer service, increasing market share and making money; it’s also about serving the community and developing people who are balanced with the right business acumen, character and a desire to help others.”

“TEKsystems, and their parent company, Allegis Group, are to be commended for their outstanding community leadership,” noted EFCO executive director, Gail Pundsack. “We are very grateful for their support, and look forward to working with the TEKsystems family at our events for many years to come.”
through. “It’s okay,” Larrissa says. “We’re all so afraid of being judged, but people will like you for who you are. When I decided to start telling my friends and teachers, every one of them was accepting and wanted to know how to help.”

Statistically, there are likely many such kids, and adults. In fact, more people are living with the challenges of epilepsy than those with MS, Cerebral Palsy, and Parkinson’s disease, combined.

“It is definitely a scary thing. And I get why other people get freaked out. But if we’re going to change that, we have to be more open and willing to talk about it and support each other.”

Larissa brought that open and honest approach to her diving coach and teammates at DU.

“Our team is like a big family, so I told everyone straight-up, right from the beginning.” Channing Kimball, DU’s head diving coach, has been a huge support and made a point of learning as much as she could about epilepsy.

To anyone who might assume that epilepsy should keep her away from the sport she loves, Larissa says, “For me, diving is what I love and it gives me joy every day. You have to follow your passion, or risk feeling worthless. That’s true for anyone – with or without epilepsy.”

As to her future, Larissa wants to do “something big!” Majoring in biology with a neuroscience concentration, she hopes to become a neurologist, or perhaps an attorney specializing in neurolaw – an emerging field that deals with the application of neuroscience on legal rules and standards. “I’m really lucky. I can do a lot more than I ever thought. I just want to be that happy person who lives my life in a way that can make other people happy, too.”

Contact: 303.377.9774 1.888.378.9779 info@epilepsycolorado.org
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Online registration is now open for the annual Stride 5k Run/Walk for Epilepsy.

Sunday, June 8th
Denver’s City Park

Start organizing your team, and join us for the largest epilepsy awareness event in Colorado!

For sponsorship information and more details, please contact Allison Bradac, 303.377.9774, allisonbradac@epilepsycolorado.org; or visit us on the web at epilepsycolorado.org.

WE WANT TO KNOW WHAT YOU WANT TO KNOW

Please take a few minutes to tell us what you want and need to know by taking our short online survey at www.surveymonkey.com/s/LIVINGWELLFEB14.

Thank You