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Teenage Angst and Teenage Behavior

ANYONE WHO HAS EVER RAISED A TEENAGER knows that there are emotional ups and downs. They are moody, temperamental, and sometimes, far too much to deal with. How does a parent handle the teenage angst of everyday life? Now ask yourself; how do you handle those overwhelming emotions when that teenager is also cognitively disabled, due to LGS or any other diagnosis?

Imagine the struggle that a teenager with a cognitive disability is going through. Physically, they are adolescents. Their hormones are raging through their bodies every day. But cognitively and emotionally, they are much younger, often times many years younger. They may feel typical teenage frustrations, but may not be able to express themselves properly. Instead of slamming a door like many of us have done at that age, they act out with different behaviors.

What we seem to forget when it comes to the behaviors of special needs individuals, whether they are small children, teenagers, or adults, is that their brain is literally struggling between developmentally appropriate and actually appropriate. The next time we struggle with a behavior of our children with special needs and wonder what we are going to do and how we are going to handle it, we need to first step back and think, “what age is this behavior?” Then, we can handle it appropriate to the age the behavior is. As frustrated as we often get with our kids, imagine the struggle they face with every decision they make. If we all keep that in mind, then sometimes the challenging behaviors that we experience with our kids may not seem so overwhelming.

Bottle of Red, Bottle of White...

Please Join Us for Our 2nd Annual Wine Fundraising Night

On Saturday, May 8th, the LGS Foundation will be hosting our second annual wine reception fundraiser at Martha Clara Vineyards in Riverhead, NY. Join us for wine, hors’devours and live entertainment, as we raise funds for programs and research in LGS.

The Long Island Wine region is home to over three dozen vineyards that produce over 500,000 cases of wine a year. If you are a wine lover and a supporter of the LGS Foundation, this is one event that cannot be missed!

For more information, including tickets and information about the Long Island Wine Region, go to www.lgsfoundation.org/wine.

In the News

NEW CALL FOR PATIENTS FOR STUDY IN LGS

Joseph Gleeson, M.D. and his team at UCSD are looking to identify the genetic causes and pathogenic mechanisms underlying pediatric brain disorders. They have recently expanded their research to include genetic epilepsies and are now recruiting families in order to identify new causes of LGS.

Specifically, they are looking for families with:

- Epilepsy as the primary diagnosis.
- At least 2 members with epilepsy, at least one with LGS
- LGS as a primary diagnosis
- Epilepsy or LGS must be presumed genetic and not be caused by trauma, tumors, stroke, CNS infection, pregnancy or birth complications, or other environmental factors.
- For the LGS family member:
 - o Seizure onset between 2-6 years old
 - o Previous typical development before seizure onset
 - o Must not evolve from infantile spasms

Families will be part of a research study to identify new genetic causes of epilepsy. This study is not affiliated with any other genetic epilepsy studies. The benefit of participating in the research is to be able to share the information with the family's doctor, at their request, if they should find a mutation. For more information, please contact:

Kiley Hill, MA

Gleeson Lab

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GINKGO BILOBA MAY INCREASE SEIZURES IN PEOPLE WITH EPILEPSY

Growing scientific research suggests that Ginkgo biloba, a popular herbal remedy, may increase the risk of seizures in people with epilepsy, a new report concludes. The article appears in ACS' monthly *Journal of Natural Products*. Eckhard Leistner and Christel Drewke reviewed research on the herbal remedy and noted that laboratory studies explain how Ginkgo could have an unwanted effect.

Ginkgotoxin may alter a chemical signaling pathway in ways that trigger epileptic seizures. Additional evidence showed that Ginkgo can interact with anti-seizure medications and reduce their effectiveness.

LGS Patient Spotlight



It is 2:30 am, and Lyndsie is still awake. She has been fussing and crying for more than an hour already, and nothing seems to comfort her. This isn't something new, just another bad night in my 25 year old daughter's life. Not sure if it is some type of seizure, or the emotional side effects of her LGS, but either way, it is not a good night for either of us. This night will dramatically affect her day tomorrow, since she will eventually calm down, and sleep most of the day. That will lead into a similar event at bedtime, since she won't be tired. It is just another day in the life of LGS.

Four weeks after Lyndsie was born, she was hospitalized for "failure to thrive". She had only gained a few ounces, and cried all the time. Little did we know, she'd had a prenatal stroke, which basically wiped out the right side of her brain. She left the hospital four weeks later, with a gastrostomy feeding tube and some valium to help her stay calm. She cried for weeks, but at least she gained weight. Approximately two months later, after a V-P shunt was placed, her crying stopped, and a beautiful happy baby appeared. Over the years, she had developed numerous other issues from her brain injury. A Jejunostomy feeding tube was added due to severe GI reflux. She has a 100% scoliosis curve, numerous contractures, lung problems, GI issues and many others. She can't talk or walk and needs total care. She is a beautiful girl, trapped inside her own body.

Lyndsie's seizures started when she was 9 months, but the term LGS wasn't used much back in the 80's. Over the years, the term 'intractable seizures' was used, but nothing was explained. We truly had no idea what Lyndsie was in for. It took years, but we did achieve reasonable seizure control with Depakote and Klonopin, but eventually as you all know, that didn't last as long as we had wanted. Since that time, Lyndsie has been on almost every seizure drug known, including injectable ACTH and a VNS. We tried for most of Lyndsie's life to get a neurologist to use the Ketogenic diet, and finally found one that would agree. We were so excited, but then the insurance denied it because Lyndsie was one month over the age of 18, and it is only approved for those under 18. Currently, Lyndsie is on Keppra, Lamictal, Klonopin, and Vimpat, as well as the VNS and she has very little seizure control. In a search for info on Vimpat in December of last year, I stumbled upon the LGS website. This was the first time I had ever, in 25 years, heard much about LGS. Eight different neurologists in three different states never gave us the information we needed, or the chance to try some medications that may have made the emotional side effects of LGS a bit more manageable.

Despite Lyndsie's long list of issues, we have tried to give her a quality of life without worrying about the quantity. It must have been a good philosophy, as the doctors said she wouldn't reach adulthood. Lyndsie turns 26 next month! She has traveled around the U.S., been in 26 different states and Canada, all with her two younger sisters and her dad and I. She has even been Canoeing down a river with her class in school, and has been on a whale watching tour in Washington State. Our traveling days with her are probably finished as her medical needs and seizures have severely increased over the years, but we will always have wonderful memories to hold onto. We try to take each day as it comes, knowing that some will be better than others.

I enjoy corresponding with other families who face the challenges of caring for a loved one with LGS. We all have to stick together, support each other and try to get the word out.

-Submitted by Lyndsie's mom Marsha

Helmets for Hope

November 5th, 2009 - The Providence, NYC



Build a Bears with helmets and autographed sportswear by Michael Strahan (NY Giants)



Kari Krause, secretary of the LGS Foundation



Guests of Helmets for Hope



Autographed helmets for the silent auction



The American Epilepsy Outreach Foundation with Mike Yam, sportscaster from ESPN



Guests of Helmets for Hope

Helmets for Hope was a national, one month campaign which aimed to raise awareness of severe epilepsy disorders, including those which are characterized by atonic, or drop-attack seizures. Atonic seizures are often synonymous with Lennox-Gastaut syndrome and are caused by a sudden burst of electricity to the brain and loss of muscle tone, often resulting in a dangerous fall. Children are more commonly affected by drop-attacks than adults, and are usually required to wear a helmet or protective headgear for their safety.

The LGS Foundation developed the Helmets for Hope campaign to raise awareness of Lennox-Gastaut syndrome through the support of professional athletes who wear helmets in their careers. Other accomplishments of the campaign included the distribution of helmets to children with epilepsy, gaining media exposure (both print and broadcast), and raising funds for epilepsy research and programs to benefit families affected by catastrophic or severe forms of epilepsy.

The Helmets for Hope grand finale celebration and fundraiser was held on November 5th, 2009 in New York City. The LGS Foundation would like to sincerely thank all of the attendees, sponsors, supporters, and athletes who contributed greatly to the success of the campaign.

To read more about Helmets for Hope, go to www.lgsfoundation.org/campaign



2010 Walk for Epilepsy

Join us for the 4th Annual "National Walk for Epilepsy" in Washington DC on March 27th, 2010.

Come and meet others who have a connection to epilepsy and Lennox-Gastaut syndrome. Team "LGS Foundation" has been attending since the first walk in 2006, and each year our team has grown. We would love to meet some of our other families and supporters.

The National Mall, where the walk is being held, is home to many museums and monuments, most free of charge. The Cherry Blossoms are in bloom this time of year, and DC is a great place for a vacation, so please consider attending.

The LGS Foundation has reserved a block of rooms at the Residence Inn by Marriott on Vermont Avenue. Reservations can be made by calling 1-888-236-2427, but must be made by March 5th in order to receive a discount. Financial assistance and/or hotel accommodations and discounts may be available on a first-come, first-serve basis.

For more information and to register, go to:
<http://www.lgsfoundation.org/walk.html>

We moved...

Please note our new address and phone number:
PO Box 6948 | New York, NY 10150 | 718-374-3800

American Epilepsy Society's 63rd Annual Meeting

The LGS Foundation had the wonderful opportunity of attending the American Epilepsy Society's annual meeting in Boston, MA.

The Annual Meeting attracts professionals from all over the world including neurologists, epileptologists, neurosurgeons, neuroscientists, and other industry professionals. The American Epilepsy Society promotes research and education for professionals dedicated to the prevention, treatment, and cure of epilepsy.

The next conference is planned for December 3-7th, 2010 in San Antonio, TX.



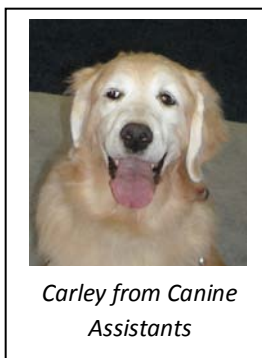
The LGS Foundation and Seizure Tracker Reps at AES in Boston

Donate

To make a donation, please visit www.lgsfoundation.org/donate.html. Your generous support is greatly appreciated.

Seizure Response Dogs

A dog may be known as a man's best friend, but for people with epilepsy, a dog can be so much more. Seizure response dogs, which are typically Golden Retrievers and Labrador Retrievers, are canines trained to respond to a seizure in a variety of ways. Seizure response dogs are able to get help when needed, bring medication, bring a telephone, or lie down and comfort a person as they come out of a seizure.



Many seizure response dogs are also able to alert an individual before a seizure occurs, but cannot be trained to do so. "As far as (a dog) alerting before onset, it isn't something we are able to train a dog to do, but about 85% of our recipients say their dogs are predicting (a seizure) within the first year of having their dog," says Meghan Hopkins of Canine Assistants. "At this point we aren't even positive what it is the dog is picking up on when they alert. It could be a sense of smell or something chemical that they are picking up on, but they seem to know that it is something bad."

In some cases, dogs are able to alert a person before a seizure occurs by nudging them, barking, alerting the parents or caregivers, or bringing them to the floor.

"Dogs form very strong bonds with people and really love to help, they take their jobs very seriously and they know they are getting unconditional love in return," says Hopkins.

More information on seizure response dogs can be found at www.canineassistants.org or www.lgsfoundation.org/services.

Purple Day for Epilepsy

And the Great Purple Cupcake Project

On March 26th annually, people from around the globe wear purple to promote awareness about epilepsy. Purple Day was founded in 2008 by nine-year-old Cassidy Megan of Nova Scotia, Canada. Motivated by her own struggles with epilepsy, Cassidy started the day in an effort to get people talking about the disorder. She named the day after the internationally recognized color for epilepsy, lavender.

To further support Purple Day, the Anita Kauffman Foundation has developed an extra-sweet initiative to promote awareness in epilepsy. Bakeries around the country are invited to create purple cupcakes and donate a portion of the sales to support Purple Day.

For more information, visit www.akfus.org



The LGS Foundation Research Initiative

The LGS Foundation has created a new initiative to help fund different areas of research in epilepsy and Lennox-Gastaut syndrome. To view all of the grants which we are fund raising for, including goals, instructions to apply, and deadlines, go to www.lgsfoundation.org/research. If you would like to receive more information on helping raise funds for a specific grant, or starting your own grant, please email us at info@lgsfoundation.org.

Adults and LGS

Lennox-Gastaut syndrome is a disorder typically diagnosed in childhood.

Therefore, it can be difficult to find information about topics related to LGS and adulthood.

Caregivers of a child with LGS often ask the same questions; what will happen after they turn 18? Where do I find information on group homes? What will happen to their medical benefits? Do seizures get worse as they get older? How independent can I expect them to be?

The LGS Foundation plans to address all of these questions and more, as we develop a new sub-site about adults and LGS.

If you would like us to address a topic related to this subject, please send us an email to info@lgsfoundation.org.

The LGS Community Forum

The LGS Community Forum is a great way to connect with other LGS families, post new topics, reply to existing topics, and make new friends. The Community Forum is free and easy to use. To join, go to www.lgsfoundation.org/communityforum.

LGS Mentor Program

LGS Mentors is a new program which aims to train parents, caregivers, and others interested in educating the public about Lennox-Gastaut Syndrome. Prospective mentors will undergo a training program to become a certified LGS Mentor.

Once complete, an LGS Mentor will share their knowledge and experiences to their community to help educate others about LGS. Each mentor will be given visual teaching aids and other informational materials and handouts.

If you are interested in becoming or scheduling an LGS Mentor, please go to www.lgsfoundation.org/mentor.

The LGS Foundation Welcomes...

We are pleased to announce the addition of two new members to our professional advisory board.

Tracy Dixon-Salazar, PhD & Dr. Michael Chez, M.D.

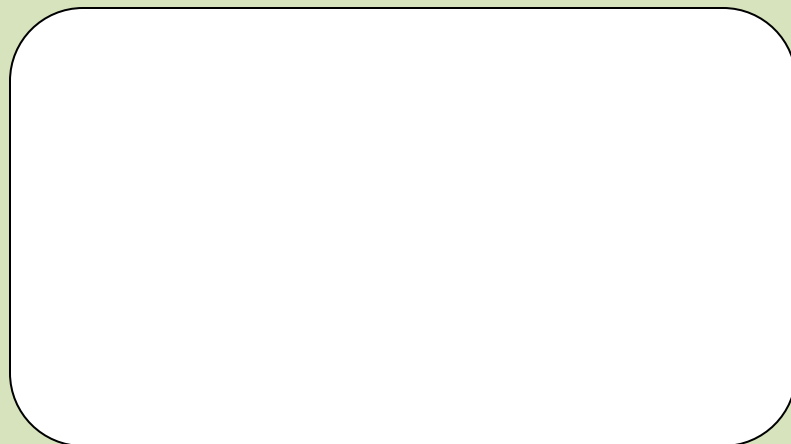
Tracy is not just the mother to a child with LGS, but also a Postdoctoral Fellow at the University of California, San Diego. As both a mom and scientist, she brings passion, purpose and knowledge to the LGS Foundation.

Dr. Michael Chez, M.D. is the director of pediatric neurology at Sutter Neuroscience Group in Sacramento, CA. He has 20 years experience in epilepsy treatment and research, with special competence in Child Neurology. He is also the author of numerous articles and books.

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RAISING AWARENESS. CREATING SUPPORT.

The LGS Foundation is a non-profit organization dedicated to providing information about Lennox-Gastaut syndrome, a rare and debilitating form of childhood-onset epilepsy, while raising funds to help pursue additional research, services and programs for LGS families.