

7TH INTERNATIONAL LGS FOUNDATION FAMILY CONFERENCE



SEPTEMBER 25-27, 2020

The LGS Foundation is excited to host our 7th International LGS Foundation Family Conference!

Join our journey toward a bright future during this 3-day virtual event right from the comfort of your home!

Presented by:

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

www.LGSFconference2020.org

2020 LGSF FAMILY CONFERENCE

Table of Contents

Table of Contents.....page 2

Welcome Letter.....page 3

LGSF Staff & Leadership.....page 4

Meet the Speakers.....page 5

Code of Conduct.....page 6

LGSF Conference Agenda.....page 7-8

Sponsors.....page 9-10

Acknowledgements.....page 11

2020 LGSF FAMILY CONFERENCE

Welcome



Welcome to the 7th International LGS Foundation Family Conference, our first ever virtual conference! While we are all learning to navigate a world impacted by COVID-19, our virtual conference allows participation from the comfort and safety of your own home. This ensures that the conference, collaboration, and resources are available to

EVERYONE worldwide. If you've never been to an LGSF conference, one of the first things you will notice is that there is an entire community that understands YOUR LGS journey. Standing in the (virtual) room with another LGS family member for the first time is an experience most of us never forget. Resources, experts, and information are abundant and there is a spirit of hope in the air.

Conference highlights include:

- Treatment options
- Research updates
- Managing disruptive and harmful behaviors
- Stress, resilience, and LGS
- Breakout sessions in smaller groups with other families
- Exhibit Hall
- Opportunities for laughter, fun, interaction

Your LGS Foundation remains steady as we navigate the world pandemic and social change. We remain committed to improving the lives of those affected by LGS through our family support programs, research, education, and community building. We are paving the way for a bright future, one journey at a time!

Natalie Gilmore

LGS Foundation Board President

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LGS FOUNDATION STAFF



Tracy Dixon-Salazar, PhD

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LGS FOUNDATION BOARD OF DIRECTORS



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Speakers



Elaine Wirrell, MD
Director of Pediatric Epilepsy

Mayo Clinic, MN

Dr. Wirrell studies pediatric epilepsy with a focus on early diagnosis, treatment, causes and outcomes. She is co-founder of the Pediatric Epilepsy Research Consortium, a multicenter U.S. group of clinicians that focuses on epilepsy in children.



Katherine Junger, PhD
Assistant Professor, UC

Department of Pediatrics

Cincinnati Children's Hospital, OH

Dr. Junger is a clinical psychologist for Behavioral Medicine and Clinical Psychology. Her focus is improving behavioral and mental health for all and to improve quality of life in children with epilepsy.



Scott Perry, MD
Medical Director, Neurology & Genetics Epilepsy Center

Cook Children's Hospital, TX

Dr. Perry is a pediatric neurologist specializing in caring for children, teens and young adults with neurologic conditions with a focus on rare forms of epilepsy and intractable or drug-resistant seizures.



Nathan Call, PhD,
BCBA-D

Associate Professor

Emory University School of Medicine, GA

Dr. Call is the clinical director of the Marcus Autism Center and studies the assessment and treatment of severe behavioral disorders in children and adults.



Tracy Dixon-Salazar, PhD
Director of Research & Strategy

LGS Foundation

Dr. Dixon-Salazar is a neuroscientist, geneticist, and, patient advocate. Her desire to get her Ph.D. was inspired by her daughter, who developed Lennox-Gastaut Syndrome (LGS) at the age of 2. She works to promote research into better treatments and cures for LGS.

Peer Expert Panel

Brittany Brown, mother to Amaree
Emma Nott, mother to Charlie
Kimberley Hanterman, mother to Kai
Shaye McLeod, sibling to Deven
Ruben Salazar, father to Savannah
Gloria Kramer Shotz, mother to Jacob

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Code of Conduct

We know that LGS does not discriminate. It may be diagnosed in any family regardless of race, color, religion, national origin, disability, sexual orientation, gender identity or socio-economic status. Thus, the LGS Foundation strives to create an inclusive and welcoming environment for everyone affected by LGS.

Participants in LGS Foundation forums, activities, and events agree to:

- Treat other participants with kindness, compassion, and respect. Aggression, harassment, intimidation, and discrimination will not be tolerated.
- Respect the boundaries and policies of the platform, venue, and facilitators.
- Speak up! Should you observe or experience an incident in violation of the Code of Conduct, any dangerous situation, or a person in distress, please report it as soon as possible to:

Info@LGSFoundation.org OR
Dale Todd (319) 389-6071
dale@hatchdevelopment.com

Conference Agenda

– Friday, September 25th, 2020

6:00-7:30 pm EDT

LGS Family Fun Night

Victoria Strong, Executive Director and founder of the Gwendolyn Strong Foundation will kick off our evening with an inspirational talk about her rare disease journey. Followed by interactive family fun breakout sessions



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- DAY 1 Saturday, September 26th

12:00-12:30 pm EDT

LGSF Welcome Introductions & Conference Kickoff

- **Natalie Gilmore**
- **Kayleigh Keen**
- **Kathy Leavens**
- **Tracy Dixon-Salazar, PhD**

12:30-1:20 pm EDT

LGS: What we know. What we are learning.

Elaine Wirrell, MD

During this session, Dr Wirrell will discuss what LGS is, how diagnosis and treatment have changed over the years, the importance of understanding both LGS your loved one's cause of LGS, and hope on the horizon.



1:20-2:10 pm EDT

Latest Treatment Options for LGS

Scott Perry, MD

During this session, Dr Perry provides an overview of treatment options available for LGS, what's new, and how you know what's right for your loved one.

Followed by Breakout Discussions

2:10- 3:10 pm EDT

Guided Discussion

Connect with other families in similar walks of life.

- Open Chat
- LGS Friends & Family
- Newly Diagnosed
- Caregivers of Children w/LGS
- Caregivers of Teens w/LGS
- Caregivers of Adults w/LGS

TAKE A BREAK

Visit Our Virtual Exhibit Hall

3:40-4:30 pm EDT

Latest in LGS Research

Tracy Dixon-Salazar, PhD

During this session, Dr. Dixon-Salazar will discuss the latest research in LGS, what listening to LGS families has taught us, and how your voice matters for the future of LGS research.

Followed by Breakout Discussions

4:30-5:30 pm EDT

Guided Discussion

What is your LGS research wish? Share your story & hopes for the future.

5:30 pm EDT

Talk with the Doctor

Live Q&A with Dr. Scott Perry

*Visit our Virtual Exhibit Hall (open till 7:30pm)
Meet us in the Lounge at 5:30pm for another night of fun.*

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- DAY 2 Sunday, September 27th

10:30 am-12:00 pm EDT

Virtual Exhibit Hall

Visit our virtual exhibit hall. Be sure to stop by the LGSF booth.

12:00-12:20 pm EDT

Welcome Back

- Karen Groff
- Jennifer Griffin
- Dale Todd
- Kara Fox

12:20-1:10 pm EDT

Managing Disruptive & Harmful Behaviors

Nathan Call, MD

During this session, Dr Call will discuss behavioral challenges in those with LGS and how to intervene.

1:10-2:00 pm EDT

Medical Traumatic Stress & Family Adjustment in LGS

Katherine Junger, PhD

During this session, Dr Junger discusses medical traumatic stress, family adjustment, and strategies to help.

Followed by Breakout Discussions

2:00pm-3:00 pm EDT

Guided Discussion

Join us for an open discussion about today's sessions. Share your thoughts, insights, and any takeaways.

TAKE A BREAK

Visit Our Virtual Exhibit Hall

3:15-4:30pm EDT

Taking Care of the Whole Family

What does "family care" look like?
Join our panel of peer experts as they discuss personal issues that affect us all and how they overcome everyday obstacles.

4:30-5:30 pm EDT

Happy Hour

Join Us for Cocktails & Conversation



Visit Our Virtual Exhibit Hall (open till 5:30pm)

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Lilly W.
Actual Patient



YESTERDAY

A legacy rooted in unlocking the potential of cannabinoid medicines to address rare conditions with limited treatment options.

TODAY

An enduring commitment to scientific rigor and bringing forward plant-derived cannabinoid prescription medicines for patients.

TOMORROW

A promise to continue advancing cannabinoid science and providing medications that have the potential to address the unmet needs of patients.

GREENWICH Biosciences is a biopharmaceutical company focused on discovering, developing, and commercializing novel therapeutics from its proprietary cannabinoid product platform. It is our passion and purpose to continually seek solutions that transform the lives of those living with rare and severe neurological diseases.

To learn more, visit www.GreenwichBiosciences.com.

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CREATING HOPE THROUGH INNOVATION

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At Eisai, everything we do is guided by a simple principle: patients and their families come first. We spend time with them. We listen and we learn about their lives, their desires and their greatest needs. *We call this human health care or hhc*, giving first thoughts to patients and their families and helping increase the benefits health care provides.

Our hhc mission is what drives us to discover innovative solutions and therapies that help address unmet needs within the communities that we seek to serve.

Eisai is proud to support the Lennox-Gastaut Syndrome (LGS) Foundation.

hhc
human health care

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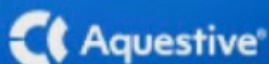


Ovid Therapeutics is honored and thankful to be part of the LGS community. More than ever, together we are strong, and our team is inspired by every LGS family and the work of the LGS Foundation. Thanks for including Ovid in this important event.

OUR QUEST

to advance treatments, solve problems, and help improve the lives of people with Epilepsy.

TheAltChoice.com



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Together, we can bring hope and support to families impacted by rare diseases.

At Zogenix, patients and their families are central to everything we do. We strive to rapidly deliver treatments that address unmet medical needs, in order to change the lives of patients and their communities.

ZOGENIX

zogenix.com



For more information, please visit [NEURELIS.COM](https://www.neurelis.com)

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please visit www.lgsfoundation.org

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The LGS Foundation is a non-profit organization dedicated to improving the lives of individuals affected by Lennox-Gastaut Syndrome (LGS) through research, family support programs, and education.

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