

2022

INTERNATIONAL

LGS FOUNDATION

FAMILY & PROFESSIONAL CONFERENCE



SUPPORTING, EMPOWERING, & EDUCATING  
THE LGS COMMUNITY

GAYLORD TEXAN RESORT, DALLAS  
JUNE 17-19, 2022



# A SPECIAL THANK YOU

## FAMILY SCHOLARSHIPS SPONSOR

A very special thank you to Lundbeck for providing attendance scholarships for 157 LGS family members. Without your generous support, these families would not have been able to attend this conference. Thank you!

LUNDBECK PROUDLY SUPPORTS

### The LGS Foundation's National Family & Caregiver Conference



#### Making a Difference... One Patient at a Time

At Lundbeck, we are committed to providing innovative therapies that fulfill unmet medical needs of people with central nervous system disorders and rare diseases, for which few, if any effective treatment options are available. Each year, we participate in hundreds of local events nationwide to support the patient communities we serve — from disease awareness walks to education seminars, and more. Actively engaging with patients and their families fuels our passion to make a difference... one patient at a time.

To learn more about Lundbeck Inc., visit [www.lundbeckinc.com](http://www.lundbeckinc.com).



# WELCOME

Dear Families and Professionals,

On behalf of the LGS Foundation, welcome to the 2022 International Family and Professional Conference! Whether you are attending in-person or virtually, this conference has something for everyone. We are proud to be joined by more than 300 attendees from around the world and more than 45 expert speakers who will present the latest in LGS research, diagnosis, treatment, and management options. This conference has so much to offer including:

- **Main Sessions:** Each day we will all meet in the main sessions to learn about LGS across the lifespan. Topics include LGS 101, causes of LGS, progress in LGS research, existing and emerging treatments, seizure tracking, seizure rescue medications, seizure action plans, mortality in LGS, devices for detecting seizures, LGS Associated Disorders (LAD: e.g. sleep, behavior, etc.), and managing LGS at home, school, and in the community.
- **Caregiver Expert Panels:** We have 3 incredible panels where you will hear from our LGS caregiver experts on navigating the medical aspects of LGS, dealing with LGS Associated Disorders (LAD), and understanding the impact of LGS at home and in the community.
- **Treatment Updates:** These updates will bring you the latest information on new and existing therapies to treat seizures in LGS.
- **Research Updates:** These updates will bring you the latest information on research in LGS, including new studies in LGS and emerging therapies.
- **Sib Camp:** This year we debut our first-ever LGS Sibling Camp. Sibs won't want to miss the fun as they head off to enjoy an escape room, build-a-bear, painting, and so much more!
- **Connect at Designated Tables during Breakfast & Lunch and Meet Other Families:** Be sure to check out our designated breakfast and lunch tables and make lasting connections. Table topics include newly diagnosed, dads, grandparents, families of young children, families of teens, families of adults, international families, and tables by geographical region.
- **Friday Night Reception Dinner:** Join the fun as we get to know either other at this kickoff reception sponsored by our friends at Jazz Pharmaceuticals.
- **Saturday Night Awards Dinner Dance Party:** Our loved ones with LGS love to dance, so get your dancing shoes on and let's jam at this dance sponsored by our friends at Zogenix - Now a Part of UCB. Leader in LGS Awards will be presented during dinner.
- **Exhibit Hall:** Check out our many exhibitors and speak directly to the experts on treatments for LGS, finding the best hospital and care, getting an EEG, specialty beds, genomic testing, and much, much more!
- **Celebration of Life Butterfly Release:** Join us as we honor and remember all we have lost to LGS and as we renew our commitment to finding the cures for LGS.

This incredible conference would not be possible without the generous support of our many speakers, families, doctors, researchers, and industry partners. From the bottom of our hearts, we thank you for making this conference a reality.

We hope this meeting will help support, empower, and educate you, help you make lifelong connections, and layout how we are searching for the cures for LGS.

With gratitude and hope,



Executive Director, LGS Foundation

# GENERAL CONFERENCE INFORMATION

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## General Conference Info

### Registration Hours

Thursday, June 16


4:30–8:30pm table outside of Tate A

June 17, 18, and 19

Opens at 7:00am at table outside of Tate A

### LGS Ambassador & Volunteer Training

This meeting is for ambassadors and volunteers only and requires pre-registration. It will be held at the restaurant on Thursday from 12:00–5:00pm.

Made possible with support by: 

### Exhibit Hall Hours

Friday, June 17

7:00–9:00am Morning and During Breakfast

10:45–11:00am During Morning Break

12:00–1:00pm During Lunch

3:00–3:15pm During Afternoon Break

6:30–8:30pm During Free Time & During Reception

Saturday, June 18

7:00–9:00am Morning and During Breakfast

10:45–11:00am During Morning Break

12:30–1:30pm During Lunch

3:00–5:00pm During Afternoon Break and Until 5pm

Sunday, June 19

7:00–9:00am Morning and During Breakfast

10:20–10:50am During Morning Break

Exhibitor set-up will be June 17, from 5:00–6:45am.

### Virtual Conference & Video Recordings

Main sessions are being video recorded and/or live-streamed. During the conference, attendees may be video recorded or photographed. All conference participants agreed to be video recorded or photographed without compensation. Photos and videos may be used by the LGS Foundation for future publications and promotional materials.

### Community Participation Guidelines

Words and actions matter. While at our conference, please remember to follow the LGS Foundation community guidelines and treat our community and our space with respect. Remember to:

- Be Kind
- Make space
- Be inclusive
- Take responsibility
- Bring solutions
- Lead by example

### Emergencies/First Aid

If you have a minor emergency or need first aid, please go to the LGS Foundation Conference Registration table located just outside the general sessions. For major emergencies, call 911.

### Disclaimers

The information presented during all the sessions is intended for educational purposes only and is not endorsed by the LGS Foundation. Due to unforeseen circumstances, the conference schedule and speakers may change.



# ABOUT THE CONFERENCE

The LGS Foundation is so excited to host the **2022 LGS Foundation Family & Professional Conference** at the Gaylord Texan Resort & Convention Center in Grapevine, Texas. This in-person and virtual conference will bring together more than 350 participants from around the globe to learn from the LGS experts. Topics include diagnosing and treating LGS, the latest in LGS Research, emerging treatments, managing LGS-associated disorders, managing LGS at home and in the community, and much, much more!



## Conference attendees receive:

- The latest and most comprehensive LGS diagnosis, treatment, and research information from the **world's leading LGS clinicians and scientists.**
- Updates on how to manage the many medical, educational, transitional, financial, and emotional challenges of living with LGS **directly from our LGS caregiver experts.**
- The opportunity to meet hundreds of other families and individuals with LGS and **make life-long connections.**
- A better understanding of the **role the LGS Foundation plays** in research, awareness, education, family support, and advocacy.
- Access to a wide range of **exhibitors and service providers.**
- Multiple networking opportunities and "downtime" with **others who share the common bond of LGS.**
- **Q&A Sessions** with the clinicians, scientists, and LGS caregiver experts.
- **Activities** for the entire family.
- Professionally staffed **day camp** for siblings.

**Standing Together.  
Stronger Together.**



# FRIDAY, JUNE 17TH

7 am CT	Registration & Exhibit Hall Open
8 am	<b>Breakfast</b> <i>Special Opportunities to Connect at Designated Tables for:</i> <ul style="list-style-type: none"> <li>Newly Diagnosed</li> <li>Dad's Support Group</li> <li>Grandparents</li> <li>Families of young children with LGS</li> <li>Families of teens with LGS</li> <li>Families of adults with LGS</li> </ul>
8:30 am	<b>Sib Camp, Camper Drop-Off</b> <i>Located in the LGS Sib Camp Fun Room</i>
9 am	<b>Welcome – About the Conference</b> <i>Natalie Gilmore, LGS Foundation Board President &amp; Tracy Dixon-Salazar, PhD, LGS Foundation Executive Director</i>
9:15 am	<b>Our Little Ironman</b> <i>Keynote Speaker: Charles Wagner</i>
9:45 am	<b>LGS 101: Diagnosis, Treatment, &amp; Management Across the Lifespan</b> <i>Kelly Knupp, MD</i>
	<b>Break</b>
11 am	<b>Genetic &amp; Acquired Causes of LGS: Finding Your Cause</b> <i>Brenda Porter, MD, PhD</i>
11:30 am	<b>Solving the Mysteries of LGS with Research</b> <i>Tracy Dixon-Salazar, PhD</i>
	<b>Lunch Break</b> <i>Please pick up your sibling for lunch</i> <b>Special Opportunities to Connect at Designated Tables</b>
1 pm	<b>Seizure Tracker: Empowering You &amp; Your Care Team to Improve Outcomes Through Enhanced Data Collection</b> <i>Rob Moss</i>
1:30 pm	<b>Emergent Seizure Management: How to Safely use Rescue Medication &amp; Create a Seizure Action Plan</b> <i>Michael Chez, MD</i>
2 pm	<b>Mortality &amp; SUDEP in LGS: What We Know &amp; What Can Be Done</b> <i>Melissa Tsuboyama, MD</i>
2:30 pm	<b>Devices &amp; Technology in Epilepsy: Finding the Right Fit</b> <i>Tom Stanton</i>
	<b>Break</b>
3:15 pm	<b>Managing LGS Medical Issues Across the Lifespan</b> <b>Expert Panel:</b> <ul style="list-style-type: none"> <li>Brittany Brown</li> <li>Darla Davison</li> <li>Charles Wagner</li> <li>Jackie Villatoro</li> <li>Colleen Gagnon</li> </ul>
4:15 pm	<b>Closing Remarks</b> <i>Tracy Dixon-Salazar, PhD</i>
4:30 pm	<b>Sib Camp, Camper Pick-Up</b>
4:45 pm	<b>Celebration of Life Butterfly Release</b> <i>Made possible with support by: ZOGENIX</i> <small>Now a part of UCB</small>
6:30 pm	<b>Friday Night Reception Dinner</b> <i>Made possible with support by: Jazz Pharmaceuticals</i>

- Families of older adults with LGS (35+)
- International Families



Friday Night  
Reception:  
Fun Activities  
include; Face  
Painting, Balloon  
Artist, &  
Buffet Dinner



# SATURDAY, JUNE 18TH

7 am CT

Registration & Exhibit Hall Open

8 am

Breakfast

*Special Opportunities to Connect at Designated Tables for:*

- Dad's Support Group
- U.S. North East Region Families
- U.S. Central Region Families
- International Families
- U.S. Southern Region Families
- U.S. Western Region Families

8:30 am

Sib Camp, Camper Drop-Off

*Located in the LGS Sib Camp Fun Room*

9 am

Welcome Back - About the LGS Foundation

*Kathy Leavens, LGS Foundation*

9:15 am

Seizures in LGS & Non-Seizure LGS Associated Disorders

*Sookyong Koh, MD, PhD*

10:15 am

Sleep Issues in LGS

*Gita Gupta, MD, MS*

Break

11 am

Developmental Behaviors in LGS: The Power of Small

*Angela Peterson, MA, LPC*

11:30 am

Making Sense of Your Child's Challenging Behavior with a Brain-First Lens

*Eileen Devine, LCSW*

Lunch Break

*Please pick up your sibling for lunch*

 LGS Community Photo *Please wear your conference t-shirts*

Special Opportunities to Connect at Designated Tables

1:30 pm

Managing LGS Associated Disorders Across the Lifespan

*Expert Panel:*

- Andee Cooper
- Elizabeth Terry
- Jeannie Schnur
- Kayleigh Keen
- Kara Fox

2:30 pm

Research Update: Comparative Effectiveness of Surgery vs. Medication in LGS

*Sandi Lam, MD, MBA*

3:15 pm

Treatment Update: Cannabidiol (Epidiolex)

*Timothy Saurer, PhD, Medical Director, Epilepsy US Medical Affairs - Jazz Pharmaceuticals*

3:30 pm

Treatment Update: Fenfluramine (Fintepla)

*Beck L. Reyes, MSN, CPNP, CNRN*

3:45 pm

Treatment Update: Living with Seizure Clusters: How a Rescue Medication May Be Able To Help

*Michelle Schoonover, PhD - UCB*

4 pm

Treatment Update: Sympazan (Clobazam Oral Film)

*Gary Slatko, MD - Aquestive Pharmaceuticals*

4:15 pm

Research Update: The Skyway Study on Soticlestat

*Yasir Khan Associate Medical Director, Clinical Trial Physician*

4:30 pm

Research Update: The PACIFIC Study on LP352

*Dr. Randall Kaye, CMO - Longboard Pharmaceuticals*

4:45 pm

Closing Remarks

*Tracy Dixon-Salazar, PhD*

5:00 pm

Sib Camp, Camper Pick-Up

6:30 pm

LGS Awards Dinner & Dance Party

*Dance party made possible with support by:* **ZOGENIX**

Now a part of UCB



Family Portraits  
available at LGS  
Dinner & Dance  
Party

# SUNDAY, JUNE 19TH

7 am CT	Exhibit Hall Open
8 am	<b>Breakfast</b> <i>Special Opportunities to Connect at Designated Tables to:</i> <ul style="list-style-type: none"> <li>• Become an Ambassador</li> <li>• Become an Advocate for LGS</li> </ul>
9 am	<b>Welcome Back – About Today's Panels</b> <i>Brittany Brown, LGS Foundation Board Member</i>
9:05 am	<b>Treatment Update: Surgery in LGS</b> <i>Scott Perry, MD</i>
9:35 am	<b>Treatment Update: DBS &amp; RNS in LGS</b> <i>Brenda Porter, MD, PhD</i>
10:05 am	<b>Treatment Q&amp;A: VNS, What we know</b> <i>Panel Discussion:</i> <ul style="list-style-type: none"> <li>• Tracy Dixon-Salazar, PhD</li> <li>• Yunus Ahmadi, MD, MBA</li> <li>• Eliza Hagen, MD, MBA</li> </ul>
<b>Break</b>	
10:50 am	<b>LGS Community Impact Issues</b> <i>Andrea Wilkinson, Sr Director, Patient Advocacy &amp; Public Policy - Zogenix</i>
11:05 am	<b>Home &amp; Family Issues Across the LGS Lifespan: What to Expect</b> <i>Karen Groff, LGS Foundation Board Vice President</i>
11:35 am	<b>School &amp; Community Issues Across the LGS Lifespan: What to Expect</b> <i>Jennifer Griffin, LGS Foundation</i>
12:05 pm	<b>Managing LGS at Home &amp; in the Community Across the Lifespan: Learn from the Experts</b> <i>Expert Panel:</i> <ul style="list-style-type: none"> <li>• Diane Hettasch</li> <li>• Karen Groff</li> <li>• Tifni Cadena</li> <li>• John Gilmore</li> <li>• Fred Roedl</li> </ul>
1:05 pm	<b>Closing Remarks</b> <i>Tracy Dixon-Salazar, PhD</i>



**"A good father is one of the most unsung, unpraised, unnoticed, and yet one of the most valuable assets in our society."**



**LGS is tough. So are we.**





# MEET THE SPEAKERS

The LGS circle of experts comes from a wide variety of backgrounds and includes researchers, clinicians, industry partners, and compassionate, knowledgeable caregivers and family advocates on the frontlines living with LGS. The LGS Foundation is grateful to these individuals for generously sharing their wisdom, experience, and scientific knowledge with a patient family community. Your work and your talks bring hope to the more than 1 million families worldwide living with LGS.



**Natalie Gilmore, Board President**  
LGS Foundation, from Hanover, PA



**Charles Wagner, LGS Caregiver**  
Keynote Speaker, from Fishers, IN



**Kelly Knupp, MD**  
University of Colorado



**Brenda Porter, MD, PhD**  
Lucile Packard Children's Hospital, CA



**Michael Chez, MD**  
Sutter Neuroscience Medical Group, CA



**Melissa Tsuboyama, MD**  
Nicklaus Children's Hospital, FL



**Robert Moss**  
Seizure Tracker



**Tom Stanton, Executive Director**  
Danny Did Foundation



**Tracy Dixon-Salazar, PhD, Executive Director**  
LGS Foundation, from San Diego, CA



**Kathy Leavens, Director of Programs**  
LGS Foundation, from Springhill, FL



**Sookyong Koh, MD, PhD**  
Omaha Children's Hospital, NE



**Gita Gupta, MD, MS**  
University of Michigan



**Angela Peterson, MA, LPC**  
Turn Center, TX



**Eileen Devine, LCSW**  
Portland State University's Child Welfare Partnership



**Brittany Brown, Board Member**  
LGS Foundation, from Clarkston, MI



**Yunus Ahmadi, MD, MBA**  
Liva Nova



**Eliza Hagen, MD, MBA**  
Liva Nova



**Andrea Wilkinson, Sr Director, Patient Advocacy & Public Policy**  
Zogenix - Now part of UCB



**Karen Groff, Board Vice President**  
LGS Foundation, from Columbus, OH



**Jennifer Griffin, Director of Family Support**  
LGS Foundation, from Santa Barbara, CA



**Sandi Lam, MD, MBA**  
Lurie Children's Hospital, IL



**Timothy Saurer, PhD**  
Jazz Pharmaceuticals



**Beck L. Reyes, MSN, CPNP, CNRN**  
Zogenix - Now part of UCB



**Michelle Schoonover, PhD**  
UCB Pharmaceuticals



**Gary Slatko, MD**  
Aquestive Pharmaceuticals



**Dr. Randall Kaye, CMO**  
Longboard Pharmaceuticals



**Scott Perry, MD**  
Cook Children's Hospital, TX

## Caregiver Expert Panelist:

- Brittany Brown
- Darla Davison
- Charles Wagner
- Jackie Villatoro
- Colleen Gagnon
- Andee Cooper
- Elizabeth Terry
- Kara Fox
- Jeannie Schnur
- Kayleigh Keen
- Diane Hettasch
- Karen Groff
- Tifni Cadena
- John Gilmore
- Fred Roedl

## Sib Camp Leaders:

- Mark Wong aka Metal
- Nicole Burgio
- Carla Schad, Sr. Dir, Medical Affairs Advocacy - UCB
- Laurie Bailey, Asst Dir, Medical Affairs Advocacy - UCB

# SIB CAMP

## THURSDAY, JUNE 16TH

4 - 8 pm

### Sib Camp Registration Open

Space is limited. Two ways to sign up for remaining spots: Sign up online at link. or visit the LGS Foundation Registration table.

## FRIDAY, JUNE 17TH

7 am

### Sib Camp Registration Open

Visit the LGS Foundation Table for more information.

8:30 am

### Camper Drop Off

LGS Sib Camp Fun Room

9 am

### Movement Expression

Led by Metal

10:30 am

### Escape Room Challenge

Hotel Atrium

### Lunch Break

Please pick up your sibling for lunch

1 pm

### Camper Drop Off

LGS Sib Camp Fun Room

1:30 pm

### Instructional Painting

Atrium Art Studio

3:30 pm

### Fun Room Free Play

LGS Sib Camp Fun Room

4:30 pm

### Camper Pick-Up

4:45 pm

### LGS Celebration of Life, Butterfly Release

The courtyard

## SATURDAY, JUNE 18TH

8:30 am

### Camper Drop Off

LGS Sib Camp Fun Room

9 am

### VIP Siblings Interactive Workshop

Led by Zogenix

11 am

### Build-A-Bear Workshop

### Lunch Break

Please pick up your sibling for lunch

1 pm

### Camper Drop Off

LGS Sib Camp Fun Room

1:30 pm

### Move with Metal

5:00 pm

### Camper Pick-Up



VIP Siblings are siblings who have a brother or sister with a rare epilepsy. They are often unselfish, dedicated, and demonstrate an amazing ability to see beyond the challenges, exhibiting understanding and compassion beyond their years.

But they need our support.

Thanks to continued collaboration with Zogenix and more than 10 rare epilepsy advocacy groups, we now offer VIP Sibling & Caregiver Kits free to our community.



Request a VIP Kit by  
visiting the LGS  
Foundation website @  
[www.lgsfoundation.org/celebrating-our-rockin-lgs-siblings](http://www.lgsfoundation.org/celebrating-our-rockin-lgs-siblings)

The LGS Sibs Camp was made possible with  
support from our partners at:

**ZOGENIX**

Now a part of UCB

Childcare provided by:  
*trusting connections*  
NANNIES ♥ SITTERS



# EXHIBITORS

**LGS FOUNDATION**  
LENNOX-GASTAUT SYNDROME

Check out the LGSF Gear Store, learn more about the Foundation, find great reads in our book store, and more!

**NEURELIS**

Neurelis is a pharmaceutical company. Check them out to learn more about medication to treat seizure clusters.

**the safety sleeper**  
BY ABRAM'S NATION

Abram's Nation is the maker of the Safety Sleep and more. Check them out to learn more about their products.

**rare genomes project**

Rare Genomes Project is a patient-driven research study led by genomics experts at Harvard and MIT.

**Aquestive**

Aquestive is a pharmaceutical company. Check them out to learn more about medication to treat seizures in LGS.

**Seizure Tracker**  
be aware. track it.

Seizure Tracker is a comprehensive, electronic seizure diary. Check them out to learn more.

**CookChildren's**

Cook Children's Hospital is a nationally recognized pediatric health care organization based in Fort Worth, Texas. Meet our LGS expert, Dr. Scott Perry.

**SK life science**  
a subsidiary of SK biopharmaceuticals

SK Life Science is a pharmaceutical company. Check them out to learn more about medication to treat seizures.

**Courtney BED**  
Helping Families, One Bed At A Time

Courtney Bed is a specialized bed designed to keep loved ones safe and secure. Check them out to learn more.

**Takeda**

Takeda is a pharmaceutical company. Check them out to learn more about medication to treat seizures in LGS.

**EEG TO GO**  
WWW.EEGTOGO.COM

EEG to Go offers patients an alternative to hospitals and inpatient EEG services by offering at home EEG. Check them out to learn more.

**Variantx**

Variantx is a genetic testing company. Check them out to learn more about genetic testing.

**EPILEPSY AWARENESS DAY**  
October 31st - November 2nd, 2022  
HELD AT Disneyland Resort  
epilepsyawarenessday.org

Epilepsy Awareness Day at Disneyland is a 3 day event and expo at Disneyland Resort in CA in November of each year. Check them out.

**ZOGENIX**  
Now a part of UCB

Zogenix, now a part of UCB, is a pharmaceutical company. Check them out to learn more about medication to treat seizures in LGS.

**Jazz Pharmaceuticals**

Jazz is a pharmaceutical company. Check them out to learn more about medication to treat seizures in LGS.

**UCB** Inspired by patients. Driven by science.

UCB is a pharmaceutical company. Check them out to learn more about medication to treat seizure clusters.

**labcorp**

Labcorp provides diagnostic information to help doctors and patients make clear and confident medical decisions.

# A SPECIAL THANK YOU

## PRESENTING SPONSOR

Thank you to our amazing sponsors without whom this meeting would not be possible!

Thank you!

# ZOGENIX

Now a part of UCB



Inspired by **patients.**  
Driven by **science.**



Because nothing  
**else matters**

Our focus is on the moments that matter.  
On seeking out scientific innovations with the greatest  
impact on the lives of people with severe diseases.  
On value that can't be expressed in numbers alone.

To learn more, visit  
[www.ucb-usa.com](http://www.ucb-usa.com)  
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 Inspired by **patients.**  
Driven by **science.**



## HEAR INSPIRING LGS STORIES

Hear these families talk about  
their personal journeys and  
learn about a potential  
treatment option.



Click here to  
watch now at  
**[UnfoldTheirSmiles.com](http://UnfoldTheirSmiles.com)**



UCB welcomes Zogenix, Inc. to UCB.  
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US-LGS-2200012

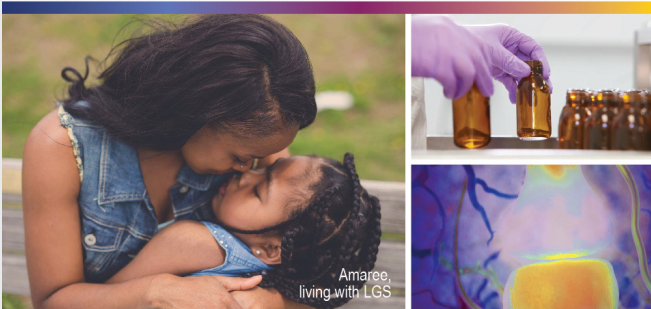


# A SPECIAL THANK YOU

## PREMIER SPONSORS

TRANSFORMING LIVES. REDEFINING POSSIBILITIES.

Jazz Pharmaceuticals is proud to support  
the 8<sup>th</sup> International LGS Foundation  
Family & Professional Conference



Amaree,  
living with LGS

Jazz Pharmaceuticals is a global biopharmaceutical company whose purpose is to innovate to transform the lives of patients and their families. We are dedicated to developing life-changing medicines for people with serious diseases — often with limited or no therapeutic options.



**Jazz Pharmaceuticals.**

[www.jazzpharmaceuticals.com](http://www.jazzpharmaceuticals.com)

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Thank you!



**Jazz Pharmaceuticals.**

Thank you!



### Better Health, Brighter Future

Takeda is a global, R&D-driven biopharmaceutical company committed to discovering and delivering life-changing treatments and vaccines that have a lasting impact on society.

Since our founding in 1781 in a market stall in Osaka, Japan, our values endure by putting patient needs first, building trust with society, strengthening our reputation, and developing the business - in that order.

[www.takeda.com](http://www.takeda.com)



# A SPECIAL THANK YOU



## Partner Sponsor

Thank you!



We are a proud sponsor  
of the LGSF Conference

For more information on the PACIFIC Study  
please visit [longboardpharma.com](https://longboardpharma.com)



## Partner Sponsor

Thank you!



**GOODBYE**  
crushing, mixing  
and measuring  
**CLOBAZAM!**



Learn more at [thealtchoice.com](https://thealtchoice.com)

## Friend Sponsor

Thank you!



## Supporter Sponsor

Thank you!



## Save the Date



**Nashville, TN**

**December 2, 2022**



# LGS FOUNDATION

## LENNOX-GASTAUT SYNDROME



### OUR PROGRAMS

#### EDUCATION

- New Family Welcome Kits
- LGS Learning & Resource Center
- Navigating LGS Video Series
- Advocates for LGS

#### FAMILY SUPPORT

- LGS Online Support Groups
- In-Person Meet Ups
- Elevate Patient Assistance Program
- LGS Navigators & Ambassadors

#### AWARENESS & EDUCATION EVENTS

- Professional & Family Conference
- Walk 'n' Wheel for LGS
- International LGS Awareness Day

#### RESEARCH PROGRAMS

- Cure LGS 365 Research Grants Program
- LGS Research Meeting of the Minds
- LGS Foundation Seminar Series
- LGS Research Roundtable at AES

### Elevate Patient Assistance Program

The LGS Foundation's Elevate Patient Assistance Program was created to provide financial assistance to families impacted by Lennox-Gastaut Syndrome.



[www.LGSFoundation.org](http://www.LGSFoundation.org)

THE LGS FOUNDATION

## MEETING OF THE MINDS



Coming Fall of 2023

ADVANCING CLINICAL  
RESEARCH AND FINDING THE  
BEST CARE FOR LGS

[LGSFoundation.org](http://LGSFoundation.org)

LGS FOUNDATION  
LENNOX-GASTAUT SYNDROME

## LGS FOUNDATION UPCOMING EVENTS

Check Out Our  
Upcoming Events  
this Year!

July  
23

Swing "FORE" a Cure  
*Golf Club of Dublin, OH*

Oct  
31

Halloween Masquerade Ball  
at Epilepsy Awareness Day  
*Disneyland Resort, CA*

Nov  
01

International LGS  
Awareness Day  
*Kicking off Epilepsy Awareness Month,  
Worldwide*

Nov  
05

International LGS  
Awareness Day Every  
Moment Matters Dinner  
Event  
*The Birch Aquarium, CA*

[www.LGSFoundation.org](http://www.LGSFoundation.org)



# LGS FOUNDATION

## LENNOX-GASTAUT SYNDROME



### Our Vision:

To end the suffering and devastation caused by LGS.

### Our Mission:

The Lennox-Gastaut Syndrome (LGS) Foundation is a nonprofit organization dedicated to improving the lives of individuals impacted by LGS through advancing research, awareness, education, and family support.

### Our Pillars:

To accomplish our mission we must:

Support, empower, and educate our community

Accelerate research

Raise awareness and build community

Build and strengthen our organization

### Our Theory of Change:

If we create meaningful, impactful, patient-driven programs guided by our pillars, we will improve the lives of those impacted by LGS.

Get Involved: **Volunteer** **Fundraise** **Donate**

Our work would not be possible without the generous support of our donors. We put your donations to work right away to support our many research and family support programs. Please consider making a tax-deductible gift in support of the LGS Foundation. We must find the cures for LGS! More information on how to donate can be found at [www.LGSFoundation.org](http://www.LGSFoundation.org)

### Stay In Touch

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