

LGS FOUNDATION MEETING OF THE MINDS REPORT

IN SEPTEMBER 2021, THE LGS FOUNDATION HOSTED THE FIRST-EVER LGS RESEARCH MEETING OF THE MINDS.



RESEARCH CONFERENCE

This 2-day discussion by LGS Experts focused on finding Disease-Modifying Therapies in LGS and consisted of 19 presentations and 4 panel discussions.

EXCELLENT ATTENDANCE

Nearly 250 researchers and family members from 7 different countries attended this virtual research conference.



244 Individuals
7 Countries



MAIN OUTPUTS

Scientific Talks & Conference Program can be found at: lgsmeetingoftheminds.org

GREAT FEEDBACK

"You should be feeling good! Really Good.
FANTASTIC MEETING!"
-Clinician Scientist

KEY LEARNINGS

LEARNING 1:

- PATIENT FAMILIES WANT A TRANSFORMATIVE TREATMENT. THERE IS AN UNDERLYING, UNIFYING LGS EPILEPTIC NETWORK WHICH IS AN ANATOMICAL STRUCTURE MADE OF GROUPS OF CELLS, CHANNELS, AND MOLECULES. WE NEED TO UNDERSTAND AND TREAT THE LGS NETWORK.

NEXT STEPS:

- LGS FOUNDATION WILL CONTINUE THE CONVERSATION AS PART OF THE MEETING OF THE MINDS SEMINAR SERIES.
- LGS FOUNDATION WILL RELEASE A NEW REQUEST FOR APPLICATIONS (RFA) IN 2022 TO ADDRESS KEY LEARNINGS FROM THE MEETING.

LEARNING 2:

- PATIENT FAMILIES COMPARE CURRENT LGS TREATMENT TO THROWING DARTS AT A DARTBOARD, BUT WE ARE NOT LEARNING FROM THE DART PATTERNS. WE NEED TO LEARN FROM EVERY PATIENT AND UNDERSTAND HOW TO TREAT LGS TODAY.

"I HAVE LEARNED A LOT ABOUT LGS. I HAD NEVER REALLY APPRECIATED HOW UNIQUE IT IS. THE DEVELOPMENTAL COMPONENT IS FASCINATING AND MOTIVATES ME TO LOOK AT OUR MICE OVER TIME TO SEE HOW THE PHENOTYPES EVOLVE."

- Basic Scientist

LGS FOUNDATION
LENNOX GASTAUT SYNDROME

Standing Together. Stronger Together.

LGS FOUNDATION MEETING OF THE MINDS REPORT

THIS MEETING ALSO HOSTED A DAY OF LGS PATIENT FAMILY EXPERTS WHO DISCUSSED WHAT A DISEASE-MODIFYING THERAPY WOULD LOOK LIKE IF ONE EXISTED.



FAMILY EXPERTS DAY

A recap of the research talks from days 1 & 2 was giving to the attendees and then they broke out to discuss what they want in an LGS treatment.

EXCELLENT ATTENDANCE

Over 80 family members from 3 different countries attended the one-day, virtual discussion for family experts.

 83 Individuals
 3 Countries



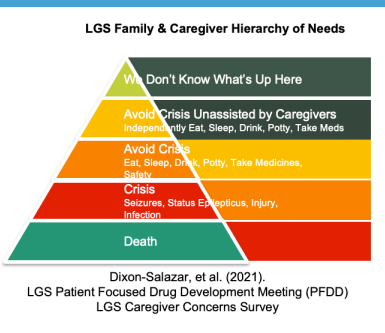
MAIN OUTPUTS

Watch Family Expert Day Talks:
lgsmeetingoftheminds.org

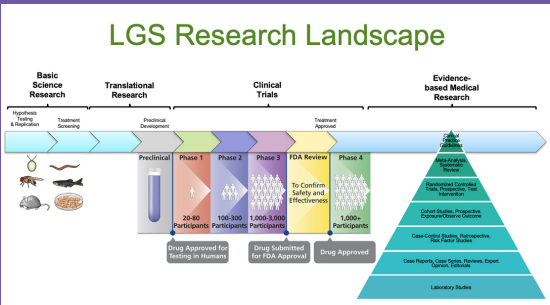
GREAT FEEDBACK

"We appreciate the opportunity to learn more about LGS therapies and research today and to share our family's voice!"
-Mom of an adult daughter with LGS

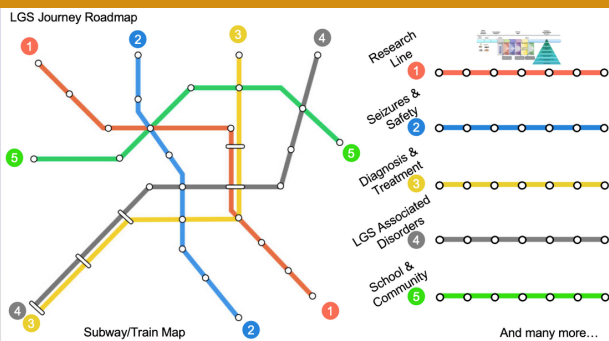
KEY LEARNINGS



LGS Families are living in constant crisis and most with LGS require help with every aspect of their daily lives. We need a transformative treatment!



We've been treating LGS the same way for 30+ years. We treat seizures and hope for the best. We need to change this! We need to treat the whole syndrome, not just one symptom.



Research is only a tiny part of the LGS Journey (see the research line above). LGS Families need help in all of these areas!

"THIS MEETING WAS CRITICAL! IT NOT ONLY BROUGHT THE RESEARCH AND FAMILY COMMUNITIES TOGETHER BUT IT HAS HELPED GUIDE THE LGS FOUNDATION'S SUPPORT AND RESEARCH FUNDING STRATEGY MOVING FORWARD."
- Tracy Dixon-Salazar, PhD

60% OF FAMILIES POLLED ABOUT WHAT AN IDEAL LGS TREATMENT WOULD LOOK LIKE SAID IT WOULD STOP THE PROGRESSION OF LGS & IMPROVE SEIZURES AND AT LEAST SOME OF THE OTHER LGS-ASSOCIATED ISSUES.
- Family Member Survey

Thank you to our wonderful partners!

Partner



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As
One

Gold Supporters



Silver Supporters



This meeting would not have been possible without your generous support!