

# Living with

LGS • DRAVET • TSC

## IN THIS ISSUE

- ▶ Living With Magazine:  
*made just for you*
- ▶ Advocacy  
*group news*
- ▶ Parents share  
*words to live by*
- ▶ Be prepared  
*no matter where  
you go*
- ▶ Tips with a worksheet  
*to improve your  
parent/teacher  
meetings*

## SIBLINGS Q&A

*7 siblings speak  
from the heart*

Pictured here: Abigaile, with her  
big brother Tommy, living with TSC

### EXCLUSIVE!

*a musical invention  
inspired by a little girl  
living with LGS and TSC.  
See the back cover!*

Brought to you by



AT OUR

# CORE

LGS  
DS  
TSC

It gives us great joy to bring you the first issue of *Living With Magazine*. At Greenwich Biosciences, families living with rare neurological diseases are at the center of everything we do. We're proud to have worked with parents, caregivers, and siblings to help create this resource for families living with Lennox-Gastaut syndrome (LGS), Dravet syndrome (DS), and tuberous sclerosis complex (TSC).

The pages of this magazine hold the words of families like yours to support you on your journey. We've pulled together quotes and insight from interviews.

*In this issue, we're thrilled to share insights and advice from families like yours.*

We have also included 11 Tips with a worksheet to help you establish a solid working relationship with your child's school system and navigate your next Individualized Education Plan (IEP) meeting.

An IEP team—comprising parents, teachers, special educators, and district representatives—evaluates

your child and helps determine which services and support they need.

IEPs can incorporate services ranging from speech therapy to counseling, curriculum modifications, or mobility amenities—all to help children with rare and severe epilepsies, like LGS, Dravet, and TSC, thrive in the general educational environment.

In addition, this issue features siblings! We've heard from many parents about the importance of supporting siblings and wanted to give our siblings a chance to shine and share their insights.

If you'd like other ways to connect with siblings, we encourage you to search for Sibshops in your area. Sibshops are community-run programs designed to provide opportunities for siblings of disabled children to connect and find friendship, support, and solidarity.

Thank you for downloading a copy of *Living With Magazine*. We hope you enjoy this issue!



# DID YOU KNOW?

## ADVOCACY GROUP NEWS



Advocacy groups like these are a great way to connect with families, learn, and get support—and many were started by families just like yours. Here are some of the latest ways to get involved, including educational programs, resources, meetups, support services, and more.

### EPILEPSY FOUNDATION

#### [www.epilepsy.com/living-epilepsy/247-helpline](http://www.epilepsy.com/living-epilepsy/247-helpline)

If you need someone to talk to, from referrals to services, or facts about epilepsy and seizures, the Epilepsy Foundation is here to help 24/7.



@EpilepsyFoundationofAmerica

### TUBEROUS SCLEROSIS ALLIANCE

#### [www.tsalliance.org/events](http://www.tsalliance.org/events)

The TS Alliance is hosting several webinars and virtual town halls. Visit their website for the latest information and news, including a wide range of support resources.



@tsalliance

### DRAVET FOUNDATION

#### [www.dravetfoundation.org/dsf-virtual-meetups-2/](http://www.dravetfoundation.org/dsf-virtual-meetups-2/)

The Dravet Foundation hosts virtual meetups. They are interactive discussions rather than a presentation, and a great way to spend some time with other Dravet parents.



@DravetSyndromeFoundation

### LGS FOUNDATION

#### [www.lgsfoundation.org/for-families](http://www.lgsfoundation.org/for-families)

Join an active community of families living with LGS. There are many ways to get involved and find support resources like virtual conferences and more, all within the LGS Foundation.



@lgsfoundation1

### CURE

#### [www.cureepilepsy.org/events](http://www.cureepilepsy.org/events)

CURE is hosting several exciting events and seminars that support epilepsy research. CURE's video podcast, *Seizing Life*, features stories from the community and is a great way to stay up-to-date on the latest information on epilepsy.



@CUREforEpilepsy



Follow these organizations on Facebook to stay up-to-date with the latest news and events!

# FINDING **INSPIRATION** TOGETHER

## QUOTES AND ADVICE FROM FAMILIES LIVING WITH LGS, DRAVET, OR TSC

Having the opportunity to share your story not only supports others, but uplifts the entire community. Here you'll read a collection of tips from family and friends of those living with forms of epilepsy, like LGS, Dravet, or TSC. Turn to these tips for inspiration on everything from staying supported to finding balance and thriving in the day-to-day.

Michelle W. lists what keeps her going; "Make memories, go places, and live joyfully, without letting the fear of seizures paralyze you. At the end of each day, I ask my son if he had a good day. It's so important. Find a tribe—others who have walked this journey can help shed light on the paths ahead. They will know your thoughts and fears and take your hand. Nurture yourself and your relationships with others—do not isolate."

Nanette S. shares some advice that can often get pushed aside for other things, "Keep social! Get involved with social groups and activities for the person with epilepsy."

Jean S. shares these simple but undeniably important words to live by, "The tips I have learned from my son living with Dravet: 'Stop and smell the roses,' and 'Don't sweat the small stuff.' I have learned that the storms of life help weed out the dead wood (in a tree) and make the roots get stronger."

While reading through these quotes and advice, know that you are not alone and that help, resources, and a supportive community are available to you. Caroline C. shared an important reminder: "Handle each day one day at a time. Tackle one issue at a time."

Thank you to everyone who contributed tips and advice for this article. Check out even more tips from the community on the next 2 pages.





**Join support group(s) because other families who have gone through it are your greatest resource.**

– Christina W.



**Share your emergency plan with the local fire department to help them understand the situation.**

**It can be a valuable time-saving step.**

– Rich M.



**Take a solo or girls' trip every year (minimum 2-3 nights) and a couples' getaway once a year. Even 24 hours away to a hotel 30 minutes from your home with your spouse is effective.**

– Mandee O.



**Choose joy. This journey will take you through many emotional ups and downs but focusing on your hopes and accomplishments will carry you a long way.**

– Sharon G.





**Keep the challenges  
of your life in perspective.**

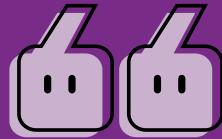
**You can and will  
do whatever is needed  
to provide the best life  
possible. Do not  
let this hold you back.**

**Love life!**

— Greg S.



**When you care for  
others, you sometimes  
forget to take care of  
yourself. Remember to  
find the moments you  
can take for yourself and  
don't forget to tag your  
partner out for a break.** —  
Jim O.



**You will experience  
every emotion and often  
with no rhyme or reason.**

**Find your tribe—people  
who can laugh with you,  
empathize with you,  
cry with you, then help  
you stand strong.**

— Melissa O.



**At the end of the day,  
find something to  
be thankful for: new  
milestones, a smile,  
a nice meal, a sunset.**

**There is always  
something to keep  
your hope going.**

— Cristy G.



# Creating the ultimate Seizure Readiness Kit for Your Child

By Wendy F.

parent of a child living with Dravet syndrome

Seizures bring a level of uncertainty those outside of our community will never know—and in most cases, we parents are the first responders. As unpredictable as our lives can be, there are things we can do to help “control the uncontrollable.” For our family, one of those things was creating our Seizure Readiness Kit.

## Things to include

### ALL CURRENT MEDICATIONS

(at least 1 full day) Helps keep medications on schedule in the event you are not able to get home when planned

### THERMOMETER

Tells you if your child's temperature is too high, potentially triggering a seizure

### SUNGASSES

Helps reduce light-triggered seizures

### FEVER-REDUCING MEDICATION

(both oral and rectal) Lowers temperature to potentially avoid a seizure

### SYRINGES

Administers medication, if needed

### SEIZURE ACTION PLAN

Helps others know what to do when a seizure happens and how to address special medical needs in the event of an emergency

### SEIZURE RESCUE MEDICATION

Helps stop seizures

### FINGERPULSE OXIMETER

Measures oxygen levels in the blood during a seizure

### FOOD/SNACKS

Provides flexibility to feed your child if away from home for an unexpected period of time (particularly important for children following a medical diet)

### BLANKET

Provides a clean surface for your child during a seizure and/or privacy for rectal administration of medication

### COMFORTING ITEM

Provides comfort in the event of an unexpected emergency or hospitalization

### SET OF CLOTHES

Provides a fresh outfit if soiled during a seizure or away from home for an unexpected period of time

### CPR REFERENCE CARD

Gives you a quick guide for resuscitating your child

*Please keep in mind that the items on this list are examples that work for Wendy and her family. Every form of epilepsy is different. Please talk to your doctor to determine what is best based on your or your loved one's unique needs.*



# SIBLINGS SPEAK

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## STORIES AND ADVICE TO SIBLINGS FROM SIBLINGS

On page 4, we shared advice from parents and caregivers, but we also wanted to dedicate part of this issue to give siblings a chance to speak up and share their perspectives and experiences. In this article, we share their stories, memories, life lessons, fears, and advice for other siblings growing up with a brother or sister with special needs.

# meet THE SIBLINGS



**RONAN, 14**

OLDER BROTHER  
OF TRENT, 11

Ronan's brother, Trent, was diagnosed with tuberous sclerosis complex (TSC) as an infant. Ronan is in

8th grade. He loves to play baseball, and Trent is his cheerleader at games.

Ronan spoke to his local government when he was 9 years old to advocate for

Trent and other patients with TSC, so they'd have the chance to pursue gainful employment.



**ABIGAILE, 15**

YOUNGER SISTER  
OF TOMMY, 20

Abigaile's big brother, Tommy, has been living with TSC. Sometimes, things can be scary for Abigaile. She knows it's important to be prepared in case her brother needs help. Abigaile is CPR certified, and is ready to call for help if Tommy is in need.

Despite these moments, Tommy reminds Abigaile to always look at the brighter side of things.



**JUSTIN, 32**

OLDER BROTHER OF HALI, 30

Justin is the oldest of the interviewed siblings. Justin

shares his experience throughout childhood, high school, his adult life, and how his perspective has evolved over the years. His younger sister, Hali, has taught him to not take life so seriously, and to see every situation as a learning opportunity. His little sis also inspired him to pursue a career in social work and dedicate his life to advocating for others.

# meet **THE SIBLINGS**



**PARKER & PEYTON, 17**  
YOUNGER TWIN BROTHERS OF HALEY, 20

The dynamic duo, Parker and Peyton, are fraternal twins and juniors in high school. Their big sister, Haley, is living with Dravet syndrome. Parker's favorite subject is history, and he loves how we can learn through history and see how it repeats itself. Parker and Peyton love the outdoors, and Peyton enjoys sailing and being out on the water. They are both impressed by their big sister's fearlessness—at amusement parks she always wants to ride the biggest roller coasters!



**NATALIE, 16  
& MAKAYLA, 19**  
YOUNGER SISTERS OF MARISSA, 23

Natalie is a sophomore and loves music—she plays in her school's marching band, participates in school musicals, and loves to sing to her sister, Marissa, who is living with Lennox-Gastaut syndrome (LGS). Natalie is learning to drive and can't wait to take her sisters out for a girls' day. Makayla is in college and majoring in neuroscience. Her big sis, Marissa, is the reason why she is so interested in studying the brain.

**On the next 2 pages, these 7 siblings answer questions on connecting, building relationships, and hopes for the future—advice we are thrilled to share with families to support this resilient community.**



# SIBLINGS SPEAK

## 1 How did your family explain your sibling's disability?

My mom explained that not everyone has a sister like Marissa. — **Makayla, 19**

There was never a time where my parents sat us down and told us what the deal was. I always felt something was different. As I got older I started asking more questions like, "Why did she grow up like this?" — **Natalie, 16**

I don't remember sitting down and having that conversation. That was just our normal.  
— **Parker, 17**

## 2 How do you and your sibling spend time together?

I'll go into her room and sit with her and have some music playing. Sometimes I'll sing to her and entertain her while I do my homework. Anything to make her smile. I am going to get a car soon and I want to have a girls' day and just do things sisters would do. We normally don't go out without our parents, so this would be a unique experience for us. Maybe we'd go to the mall or out to eat.

— **Natalie, 16**

Trent is like my cheerleader at baseball games. He comes and supports me. When I strike out, Trent says, "Try again, Ro Ro." Trent always encourages me to try again, just like he has. — **Ronan, 14**



## 3 What life lessons has your sibling taught you?

Hali said, without missing a beat, "It's ok if I say stupid things from time to time." — **Justin, 32**

Haley taught me to be fearless. I've learned to trust the process. Trust that no matter what you are going through, however bad it is, or how painful, keep going. — **Parker, 17**

Have patience, be kind, don't judge, and educate yourself to understand what your sibling has. My parents have taught us everything we know about the disability, and I pick up from what I hear them explaining to others as well. — **Abigaile, 15**

Our parents taught us how to deal with Haley's seizures. We were taking care of her, while my parents were taking care of all of us. It taught me the meaning of family and the importance of supporting and taking care of one another.

— **Peyton, 17**



I learned public speaking. When I was 9, I spoke in front of Congress to tell our story. — **Ronan, 14**

## 4 What things have you done with your parents to strengthen your connection and bond?

I didn't get to see my mom a lot because she was often at the hospital. But we had a journal that we'd pass back and forth, where I was able to better express my emotions. I could take my time to collect my thoughts and write it out. — **Makayla, 19**



## 7

### What advice would you give to your younger self or others who are living a similar experience?

Realize there's going to be some embarrassing moments, but there's going to be a lot more moments of happiness, moments of joy, moments of laughter. That's what you have to focus on.

— **Justin, 32**

It is a big thing understanding that you are not alone. There's a lot of people out there going through the same thing you are. — **Makayla, 19**

Keep it simple and let friends know about the disability. I let my friends know and now they play with him. After my basketball game they let him shoot and everyone cheers him on. — **Abigaile, 15**



When asked questions, answer the best you can. Based on what my friends say, they are generally just curious. It's different to them, and they haven't seen anything like that. And different is not a bad thing. — **Peyton, 17**

It's going to be tough at times, but you're going to get through it. As you help your sibling, they will help you in return. — **Ronan, 14**

*Thank you to all of the siblings who shared their stories with us. Families like yours inspire us every day, and the sibling stories shared here are no exception. Sharing stories is an important way to connect as a community, find support, and know that you're not alone. We encourage you to share this article with a friend, sibling, or parent.*

If you're looking for support or a way to connect with others in your community, consider searching for Sibshops in your area, joining a closed Facebook group or advocacy group page, or talking to someone you can confide in—a friend, family member, coach, or mentor.

## 5

### What's it like telling people in your life about your sibling? Has the way you build relationships changed?

I was pretty selective about who came over to my house. That shaped how I made friends. The biggest struggle was thinking that Hali was embarrassing me by some of the things she did and said. I didn't want to continue to have to explain why she said things the way she said them. It definitely shaped me in my dating life. When talking about my family, I'd say, "My sister can live with us at some point." That's just a conversation I had to have. — **Justin, 32**

When I was younger, I almost felt ashamed and embarrassed for it, and thought, "Would they look at me differently?" Or feeling like I am hiding something. I didn't want them to see what I was actually like because I wanted my lifestyle to seem normal. But as I've grown, I don't need people's approval to boost my confidence. I can do well enough on my own. If people are dragging me down, I don't need that. — **Parker, 17**

## 6

### Do you have any fears for the future?

Eventually, Tommy will be my responsibility, so I have to know what to do and how to help him.

— **Abigaile, 15**

One thing about having a sibling with special needs is that they could go any day. That fear of knowing that each day could be the last is always with you. But in that case, you have to hope and pray for the best. — **Peyton, 17**

# 11 TIPS

## FOR A SUCCESSFUL IEP MEETING

Download and print the worksheet on the next page to fill out during your next IEP meeting.

### WHAT IS AN IEP?

An IEP (Individualized Education Plan) is a collection of support services and annual goals designed for your child's individual needs. It's important to be prepared.

### DOCUMENTS FIRST

Ask for copies of the evaluation and proposed goals and objectives **BEFORE** the scheduled meeting to review and prepare questions.

### TAKE NOTES

If possible, assign one person to take notes while the other listens and asks questions.

### FOCUS ON STRENGTHS

Share strengths and heartwarming stories to keep things positive. After all, we're all here to help a child we care about.

### DYNAMICS AND TEACHER INSIGHTS

Ask teachers about their classroom dynamic. Are there fears, fixations, likes, and dislikes you should know about?

### HYPOTHETICAL QUESTIONS

To avoid a blunt "no" answer, ask hypothetical questions, like "What would you do if this were your child?"

### GO BEYOND GOALS

If the goals are confusing, ask for clarification. Make sure it's clear how progress will be measured, who is responsible, and how you can follow up.

### ASSIGN ROLES

Clarify who is responsible for a specific goal or task. What service does each person provide, and which goal will they focus on specifically?

### HOMEWORK

Ask the team to give you homework, worksheets, and activities for you to practice at home with your child.

### CONTACT INFO

Know how to contact each person involved in the planning and establish how to share information, whether via email or weekly progress reports.

### DIAGNOSIS DETAILS

Share updates, changes to medications, new technology (like seizure tracker apps), and resources with members of the community who help care for your child.

### REMEMBER

You are a member of this committee, too. Everyone in the meeting is there to help your child. And you can always ask questions at any time.

**Reminder: Make sure you have copies of the evaluation, goals, and objectives BEFORE filling out this worksheet**

**Student/teacher dynamic and insights:**

**What is the goal for my child, who will lead it, and how will progress be measured?**

**Goal or task #1:** \_\_\_\_\_

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Person/role: \_\_\_\_\_

How measured: \_\_\_\_\_

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**Goal or task #2:** \_\_\_\_\_

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Person/role: \_\_\_\_\_

How measured: \_\_\_\_\_

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**My child's fears, fixations, likes, and dislikes:**

**Goal or task #3:** \_\_\_\_\_

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Person/role: \_\_\_\_\_

How measured: \_\_\_\_\_

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**Teacher contact info**

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Email: \_\_\_\_\_

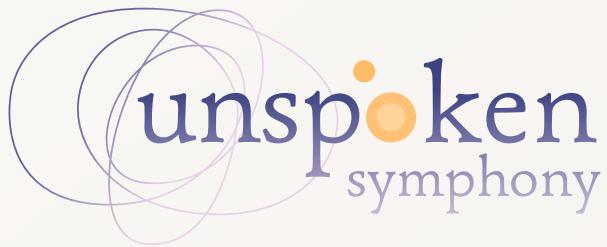
Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

**Homework, worksheets, and activities to practice at home with my child that will support their goals:**



a little girl couldn't speak.  
so we listened.

Inspired by a girl who can't speak, *unspoken symphony* transforms artwork into an original melody, giving the world a chance to communicate and connect with loved ones like never before.

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