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Issue 4

# Living with <sup>TM</sup>

LGS • DRAVET • TSC



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Pictured here: Bobby, father of Haley, living with Dravet syndrome



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## AT OUR CORE

We are delighted to share the fourth issue of *Living With Magazine*—created for and by families living with epilepsy.

Jazz Pharmaceuticals has always been committed to putting patients first, and we continue to place families living with rare neurological diseases at the heart of everything we do. The information and stories shared in this magazine are all created in close collaboration with parents, caregivers, and siblings for those living with rare forms of epilepsy like Lennox-Gastaut syndrome (LGS), Dravet syndrome, or tuberous sclerosis complex (TSC).

The theme of this issue is communication in its many forms and its importance when caring for a loved one. Every family is unique, and that means good communication will look different from one family to the next. We hope the stories, experiences, and advice from other families will empower you to continue communicating in the best way possible.

*Love & Commitment* is written by Bobby. He and his wife, Lisa, have been caregivers for their daughter for over 20 years. He shares their story, reflecting on how their communication has changed over the years and gives some advice on what he has learned along the way.



*Fighting for Change* is all about communicating—and enacting—the change that is needed to make the world a safer, more inclusive place for our loved ones living with epilepsy. The article highlights the Seizure Safe Schools movement and gives you information on how you can partner with advocacy groups to make an impact.

In our *Words of Advice and Sibling Reflections* features, parents and siblings to loved ones living with epilepsy share their advice on how to communicate about difficult topics, such as reaching out for help, setting boundaries, and more.

We hope this issue of *Living With* gives you valuable insights and fosters a sense of connection to the larger epilepsy community. Remember, you are not alone on your journey.



To download previous issues or select future topics, visit [LivingWithMag.com](http://LivingWithMag.com)



# Caregiver Spotlight

Meet the caregivers sharing their stories and advice. We are grateful for their time, passion, and dedication in making this issue possible.



## Lauren S.

Mother of Brynleigh, living with TSC

### My family includes:

My husband, Sean, and our daughters, Brynleigh, age 9, and Kaelyn, age 4.

### The toughest part of our journey was:

During the time we couldn't get Brynleigh's seizures under control even after trying several medications. While at the hotel one night, we first realized she was having seizures during the night as well as during the day. It was a very scary time, and it was so difficult to watch her have more than 25 seizures in a 24-hour period. We just wanted to get them to stop and give her a better quality of life. We spent a lot of time away from home getting tests done and meeting with the medical team, ultimately making the decision that surgery was her best option.

Another tough part of our journey to pass Brynleigh's Act, also known as the Maryland Seizure Safe School Act, was when the COVID-19 pandemic shut down our state's General Assembly. Ending the session early stopped our legislation in its tracks and there wasn't anything we could do about it. It was difficult to process that everything we had done up to that point came to a screeching halt and that we would have to completely start over again the next session. We did our best to rally our advocates and encourage them to keep spreading awareness and reaching out to their legislators to let them know we would be back soon! We were determined not to let anything get in our way or prevent us from making our schools seizure safe, even though we knew it would take longer than we had originally planned or anticipated.

### Our family mantra is:

Together we can take our struggles from adversity and turn them into actions through advocacy!



**READ MORE**  
about Seizure Safe Schools on [page 16](#)



## Ashley W.

Mother of Piper, living with Dravet syndrome

### My family includes:

My husband, Tim, and our 3 children, Owen, age 17, Piper, age 14, and Mimi, age 14. We also have a retired service dog, Rafe, and two cats, Bingo and Boxer.

### The toughest part of our journey was:

Thinking we could get to zero seizures. This put so much pressure on my husband and me. I don't know when we realized 100% seizure control was unlikely, but when we accepted this, it allowed us to really focus on how to care for Piper through her seizures. I take time each day to practice mindful breathing to calm my nerves.

Grieving the loss of the path of parenting I thought I was going to have continues to be hard for me. Some days, I am at peace and experience so many blessings. On other days, I am sad, angry, lonely, and scared. After years of operating from a place of flight/fight/freeze due to the alertness that is often needed as a caregiver to someone living with epilepsy, my grief piled up and felt like a clog in my system. With the help of therapists and dear friends, I remind myself that life is hard and grief will come and go. It doesn't last forever. In fact, when I pass through a period of darkness and grief, I'm often surprised by the amount of light I experience on the other side.

### Our family mantra is:

We think about how to include Piper in experiences rather than splitting up our family. We have gotten brave and creative in how we travel and the adventures we are willing to try with Piper.





### Bobby S.

Father of Haley, living with Dravet syndrome

#### My family includes:

My wife, Lisa, our daughter, Haley, age 22, and our twin boys, Peyton and Parker, age 19. We also have 2 chocolate Labrador retrievers, Gracie and Lulu.

#### The toughest part of our journey was:

Overcoming the loss of our freedom of movement. Ever since Haley began having seizures, Lisa and I have navigated our lives around the question, "Who will be with Haley?" Anything we do, even a walk outside, requires us to make sure someone is with Haley. Life is not "normal," and it is probably hard for someone who doesn't have a family member who requires 24/7 care to know what this is like. It is difficult to overcome the loss of the freedom to go places, but Lisa and I have found ways to adjust to our "normal." This is what our life is going to be like and we make the most of it. On our twenty-fifth wedding anniversary, we took a trip to the Florida Keys and brought Haley with us. It was a different trip for us, but we created some of our fondest memories as a family.

#### Our family mantra is:

Family first. We try to meet the unique needs of our children. Haley has her needs because of Dravet syndrome, but our twins have their own unique needs too. Our main priority in life is to make sure all of our children are getting the individual attention they deserve.



Leslie, a program speaker and caregiver

### Epidialogues

Conversations about rare epilepsy

Join a **30-minute webinar** featuring an HCP speaker and a caregiver ambassador for:

- Information about seizures
- Tips on partnering with your healthcare team
- An overview of a treatment option
- An opportunity to ask questions during a Q&A after the session



REGISTER FOR A PROGRAM  
Scan the QR code or visit [Epidialogues.com](http://Epidialogues.com)



# Words of ADVICE

Effective communication is an ongoing process and can be even more complicated for those in the epilepsy community! Here are some examples from caregivers of what they have learned through either professional or lived experiences about the importance of effective communication.



**Ashley W.**

**Mother of Piper, living with Dravet syndrome**

## As a licensed therapist, how do you help caregivers who struggle with or are reluctant to ask others for help?

Through talking and working with many families, I've learned that caregivers, including myself, often feel a sense of guilt about asking for help from others or are afraid to be a burden. What helps me, and the advice I give to others, is to ask, "When is the last time someone asked you for help?" or, "Would you help a friend who was in your position?" Most of the time, the answer is yes. So then, if you would do it for them, they most likely would do it for you. You are not a burden for asking for help from your family or friends—they are your support system. People genuinely want to feel useful and helpful—so don't be afraid to ask for what you need. Asking for help is not easy. It's hard for me, too.

## What do you tell families after they receive a diagnosis to help normalize their feelings?

Everyone reacts differently—there is no one size fits all. I think what we all have in common is shock and a remarkable story that goes with the first time our child has a seizure. Some of us freeze and have a hard time

doing anything because we are so overwhelmed and devastated. Some of us cope by pouring our energy and attention into all there is to learn about epilepsy and our child's diagnosis. For me, this looked like keeping my work/family routine and adding hours of time researching her diagnosis, taking a class to learn the ketogenic diet, attending epilepsy events, and fundraising for research.

Some of us are so overwhelmed and cope with that through avoidance. This might look like hiding at work, more time on technological devices, an uptick in substance use—anything to take the pain away. After shock, devastation, and near-crippling fear, grief surfaces. It is so hard and so painful for a while. And then, it shifts.

If you have a spouse or partner, you may find yourselves on different pages with your emotions. When my husband and I were adjusting, the hardest part for me was how differently we coped. I know I did a bit of all the coping styles depending on the day. This created distance between us, and I didn't know how to connect with him and accept our differences. Therapy helped us bridge the gap and find our way back as a team.

## What advice do you have for parents about sharing their child's epilepsy diagnosis with siblings?

Whispering and secrets can be hard on kids. They sense and pick up on so much. Information can be quite grounding, even if painful. I believe it's helpful to share information with siblings and speak in age-appropriate language so they are informed about what is going on. I was operating from a state of trauma and missed doing this with Piper's siblings. It wasn't until they were 5-7 years old that I began to communicate honestly and openly with them. They were living in our home, experiencing all of the stress and trauma, too. Once they got more information, their anxiety went down.





## Lauren S.

**Mother of Brynleigh, living with TSC**

### **As an advocate in the legislative space, how have you communicated to others when you need their support?**

We have always been very open and have often asked others for support! Asking for help was another way to spread awareness about Brynleigh’s Act. It helped us find more people with a connection to epilepsy who really wanted to know how to help and what else they could do to support our efforts. Even something as simple as asking someone to complete an online “action alert” to their legislator can make a huge impact during the legislative process. You also never know the new connections you will uncover when asking for support.

Asking others to help or provide support has even helped us find more families who could benefit from the Seizure Safe Schools legislation. The harsh reality of epilepsy is that every day, more children are having their very first seizure and/or being diagnosed with epilepsy. Most people want to help—they just need direction on exactly what to do. By providing clear talking points, example scripts/emails, and sending electronic action alerts, we made it very quick and easy for others in our community to help.

### **Can you share with us ways that you have partnered with advocacy and organizations for support?**

We have partnered with so many organizations, both locally and nationally, for continued support along our journey. We are stronger together and can make a much larger impact when we come together with joint support for the legislation. We quickly realized that one of the best ways to advocate was to join forces with as many local and federal organizations as possible. We collaborated with more than 60 organizations that signed a joint letter of support that we sent to our legislators, and committee leaders/staff provided written testimony, all in support of Brynleigh’s Act and

Seizure Safe Schools in our state. We also could get out information to the community by having these organizations reach out to their members for help. We will be forever grateful to each and every organization that supported this project and assisted us in finally getting Brynleigh’s Act passed.



## Bobby S.

**Father of Haley, living with Dravet syndrome**

### **How have you successfully communicated to others that you need support with Haley?**

This is something we’re still working on. As a family, we struggle to ask for help. We’ve always been of the mindset that we can just do it ourselves. While our boys are older and Haley is in an “OK” place, we still struggle with allowing someone else to watch her. Since her seizures are at night, we have a lot of fears about leaving her alone. Maybe one day we’ll get there, but we’re just not there yet.

### **How does your style of communication vary to support your sons’ different emotional needs?**

We have good relationships with Peyton and Parker and have always seen them as individuals. We still take the time to do one-on-one things with them. Peyton lives with us still, and we appreciate all the help he gives us. We make it known he is appreciated. Parker is away at college in Florida, and I don’t think a day goes by without us chatting. We know that Haley’s life has impacted the twins negatively and positively. We allow them to vent and share everything without judgment. They both have looked to the future and how it will impact their lives. We always support them in their choices.





# PATIENT ADVOCACY

## GROUP NEWS

Patient advocacy groups are a way to connect with other families and find support. These organizations were created with one thing in mind: to help support families living with epilepsy. They offer expertise, resources, support, help raise awareness, and even advocate for healthcare reform.

The groups featured in Issue 3 were the Epilepsy Foundation, the LGS Foundation, the Dravet Syndrome Foundation, and the TSC Alliance.

 You can download Issue 3 at [LivingWithMag.com](http://LivingWithMag.com)



### EPILEPSY ALLIANCE AMERICA

Epilepsy Alliance America is here to support you and your family. Founded in 2018, Epilepsy Alliance America is a growing national organization. They have local, regional, state, and even national agencies that serve and support the everyday needs of individuals living with epilepsy.

Learn more about Epilepsy Alliance America and how they can help support you or your loved one. Visit [epilepsyallianceamerica.org](http://epilepsyallianceamerica.org)



**Together, they work to meet the specific needs of families in their own community.** They can help provide real solutions to real problems that families may be facing. Families affected by epilepsy need strong, service-minded organizations in their local communities doing their best work.

Epilepsy Alliance America has been collectively supporting people with epilepsy for decades through support services, information, education, advocacy, and public awareness. As a result, Epilepsy Alliance America provides real epilepsy help to approximately 1 million Americans living with epilepsy.





To learn more about the AKF, their initiatives, and the support they offer the epilepsy community, please visit [purpledayeveryday.org](http://purpledayeveryday.org)



## ANITA KAUFMANN FOUNDATION

The Anita Kaufmann Foundation (AKF) is a 501(c)(3) public charity whose mission is to make the world a kinder place for people living with epilepsy and brain trauma through seizure first aid training, education, and advocacy efforts. The AKF was established by a bequest from Anita Kaufmann, a brilliant lawyer and businessperson with epilepsy who wanted to help others deal with the discrimination she faced. **The AKF is all about education and fighting discrimination.** The AKF produces and distributes free seizure first-aid material worldwide.

The AKF is the global sponsor of PURPLE DAY®, the largest grassroots epilepsy awareness initiative in the world, started 14 years ago by an 8-year-old girl with epilepsy. She wanted there to be one day when everyone with epilepsy would not feel alone. PURPLE DAY® is celebrated on March 26 every year. For PURPLE DAY®, people arrange for buildings, bridges, and landmarks to be lit up in purple, the internationally recognized color of epilepsy. People affected by epilepsy hold celebratory events to educate their community about epilepsy and seizures. Many governmental proclamations have been issued recognizing PURPLE DAY®. Walks, bike rides, cupcake sales, and art shows are held worldwide.



To learn more about the DDF, and how they may assist you, visit [www.dannydid.org/](http://www.dannydid.org/)



## DANNY DID FOUNDATION

The Danny Did Foundation (DDF) was founded by Mariann and Mike Stanton. They lived with their son, Danny, in the north side of Chicago on a street packed with young children, enjoying many kickball games on their front lawn. Danny passed away at age 4 from sudden unexpected death in epilepsy, or SUDEP. His mom and dad started the DDF to help other parents avoid their tragic outcome by way of improved communication.

The DDF wants to make an immediate impact for families, and they have given nearly 2,500 grants to patients and caregivers so they can purchase a seizure alerting device. The peace of mind from knowing you can intervene during a seizure is meaningful.

Collaborations are key to the DDF. They work with and support many other patient advocacy groups, and they are also a founding member of Partners Against Mortality in Epilepsy (PAME), a multi-stakeholder initiative that engages families, doctors, industry and public health officials worldwide.

The DDF believes that communicating with families about the full range of potential risks that accompany epilepsy, including SUDEP, will empower their decision-making. That information-sharing is what families living with epilepsy want and deserve.

Many families ask about the name of the foundation. It comes from the last line of Danny's obituary, "Please go and enjoy your life. Danny did." **The DDF celebrates Danny's spirit in every person they reach.**





# SEIZURES™ ARE SIGNS

*“Having a specific diagnosis is very important. It helps with your treatments. Certain syndromes have specific medications out there for them.”*

*- Natalie*



Lili, living with LGS, with her mom, Natalie

## Seizures Are Signs may help your family find a diagnosis behind uncontrolled seizures

A general epilepsy diagnosis may not be a complete diagnosis for your loved one. The resources on the Seizures Are Signs website were created in partnership with patient advocacy groups, epilepsy experts, and other families living with epilepsy.

You will find:



A short assessment to create a customized discussion guide to share with your doctor



Stories from other families who received a more specific diagnosis



A doctor/specialist locator, seizure action plan (SAP), individualized education plan (IEP), and more!

SCAN THE QR CODE to learn more,



or visit [SeizuresAreSigns.com/assessment](https://SeizuresAreSigns.com/assessment)



# LOVE & COMMITMENT

Working Toward Better Communication

By Bobby, father of Haley, living with Dravet syndrome

Lisa and I have been married for 26 years and counting, and we have a strong bond. But like all marriages, it has not been without its challenges—for one, our daughter, Haley, has Dravet syndrome. Our relationship is a constant work in progress, but we have always been committed to each other, our family, and our faith. No matter how difficult things get, we never give up on each other. We are a steady ship, riding the waves of life together.

Our journey with epilepsy began when Haley had her first seizure at just 5 months old. We didn't know what was causing her seizures for some time. A few years later, when we were still searching for a diagnosis, our twin boys, Peyton and Parker, were born prematurely. These were very challenging times for us. To care for our family, we had to make some major changes. At the time, we both had careers, but Lisa selflessly put hers on hold to

take care of Haley and the boys. I am so thankful to have Lisa as my wife and the mother of my children—I honestly don't know what I would do without her. With Lisa becoming the full-time caretaker of the children, I stepped into the role of sole financial provider. The way Lisa and I see it, we each have multiple roles to play to make our family function.

**“Neither of us would be able to do it alone, and that’s what you need to remember in a marriage.”**





When raising a child with disabilities, you can't throw yourself a pity party about the life you thought you were going to have. You have to work together to embrace the life that you've been given. We know we're exactly where we're meant to be, and we wouldn't want it any other way.

While I work out of the house, I also understand I have a role to play at home. I try to leave my work at the office and not bother Lisa with information she doesn't need to know. Upon arriving home, I do my best to remember to ask Lisa how she is. Sometimes, I can pick up on how she's doing just by her demeanor, and I try to offer her extra support if she's had a tough day. Then, I turn my focus to Haley and taking care of her. The thought of having to respond to Haley's seizures when they first started used to fill me with fear. But now, I've gotten used to it and learned what to do. I sleep in Haley's bedroom at night so that I can respond quickly in case she has a seizure. We could rely on monitors or cameras, but I fear the power going out and not being alerted to Haley's seizure activity. So, this is something I do for both my own peace of mind and to allow Lisa to rest.

It's so important for caregivers to have that time to rest and take a break from caregiving. Lisa is passionate about health and fitness, and she works out every morning. I make sure to support her however she needs before I go to work so she gets that time to herself to exercise and recharge. It's something every caregiver deserves. My outlet is fishing and, believe it or not, sappy feel-good movies. Even just having a space to retreat to can be helpful. I am a general contractor, and a few years ago, I remodeled my and Lisa's bedroom so that it could be her sanctuary at home.

Taking care of your spouse's needs is just part of being married. But it can definitely be harder to keep in mind when you're raising a child with disabilities.

Lisa and I are deeply committed to each other. But communication is an ongoing work in progress. Some days, Lisa and I frankly don't get the emotional support we need from each other because we are both exhausted. We try to remember how important we are to each other and give each other grace when we feel upset. On tough days, our love for each other is what gets us through. Lisa and I married each other for a reason.

“

**Our marriage is not perfect, but one thing we know for sure is that **we love each other until the end.****

”

“

**As a married couple, you need to remember to put your spouse first.**

”





“

If you and your spouse are struggling, you need to **remember what brought you together in the first place.**

”

Try to make time for date nights. Ask for help from others when you need it. If that's not possible, try to just get out of the house together for a bit, with your children in tow. A change of scenery can be good for everyone.

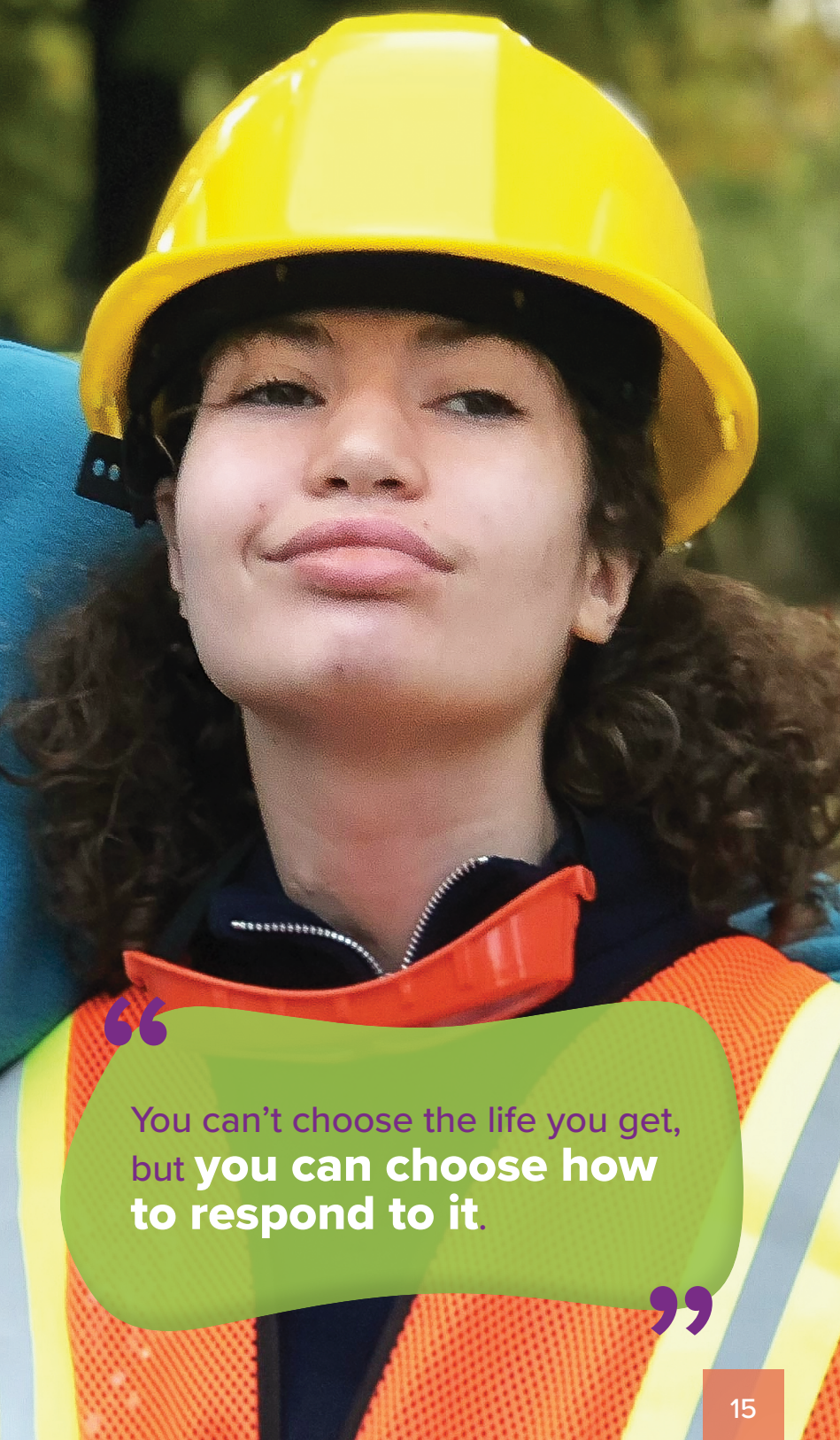
We've always tried our best to keep a sense of normalcy in our home, especially for Peyton and Parker. That has been easier lately, as Haley's seizures have been more stable, and we have had some breathing room to work on active communication. Our boys have individual emotional needs, so we always try to make one-on-one time for them and support them in all their separate interests and activities. It isn't always easy, but we never give up because our family is so important to us.

Haley has changed our lives, and raising her has given Lisa and me a different perspective on what "real" problems are. The things we have had to handle at home have helped us more easily handle things in the outside world, and I firmly believe we are stronger for it.





Because who wins if we give up? Hearing Haley say, "I love you Daddy," when I'm running on empty means the world to me and reminds me of how blessed I am to have found a partner like Lisa.



“

You can't choose the life you get, but you can choose how to respond to it.

”

# The CAREGIVER



SCAN THE QR CODE for stories of strength, hope, and connection, or visit [TheCareGiverSeries.com](https://TheCareGiverSeries.com)

## It's not easy for caregivers to take time for themselves.

That's where Greg Grunberg comes in! As a caregiver himself, **Greg understands the power of the caregiver-to-caregiver connection.**

He's ready to give other caregivers of loved ones living with epilepsy a day to remember and learn all about their journeys along the way.





Fighting for Change:

# How PARENTS Can Make a Difference






One mom's mission for seizure safe schools



Advocating for a loved one living with epilepsy can mean working with other caregivers or epilepsy organizations to change the laws in your state. There is power in the epilepsy community, and amazing things can happen when people band together. This is the story of how the Seizure Safe Schools initiative got its start and how parents and caregivers can make a difference.

Seizure Safe Schools is a nationwide initiative to support the safety and continuity of care of children and youth in the event of a seizure while they are at school. It is led by passionate grassroots advocates and the Epilepsy Foundation. Lyndsey Crunk is an Epilepsy Foundation Teens Speak Up! Ambassador who led the initiative for the first Seizure Safe Schools law. When the law was passed in Kentucky, it was named after her.

While every state will have its own specifics, the 5 key components of every Seizure Safe Schools bill are:

-  Requiring school personnel to complete seizure recognition and first-aid response training
-  Mandating that the Seizure Action Plan is made part of the student's file and made available for school personnel and volunteers responsible for the student
-  Ensuring that any medication approved by the Food & Drug Administration and prescribed by the treating physician is administered to the student living with epilepsy
-  Educating and training students about epilepsy and first-aid response
-  A Good Samaritan clause

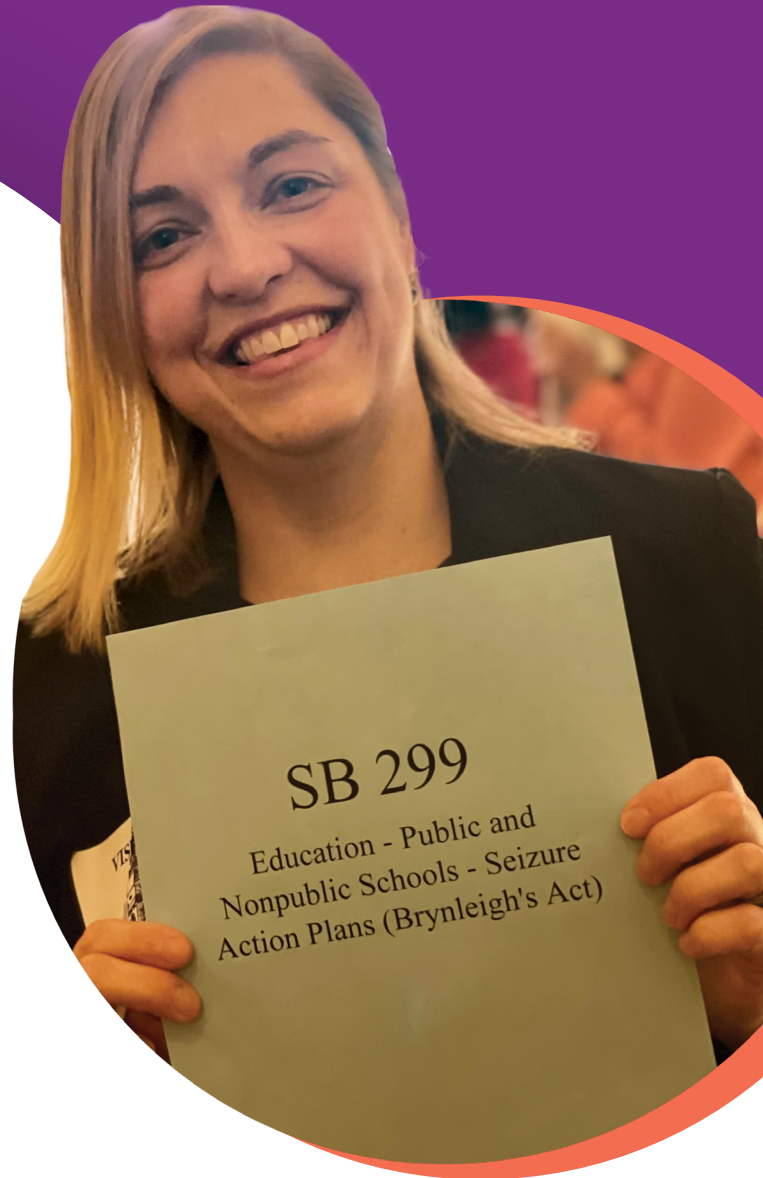






Without these laws being passed, the critical safeguards and protections in schools for children with epilepsy would not be mandatory and, in some cases, may not even exist. That was what drove Lauren, whose daughter, Brynleigh, lives with tuberous sclerosis complex. “We’ve always had concerns about her transition to school. At school, who would be trained to respond to her seizures?” At first, Lauren and her husband were the ones educating potential responders. They met with school teachers, administrators, and staff themselves in order to ensure that the adults in charge of Brynleigh at school were adequately trained.

However, Lauren knew it wasn’t a permanent or even a good solution. No one was under any sort of obligation to attend Lauren’s training. In certain cases, staff who wanted to attend the training were unable to due to their workload or other obligations. Lauren also worried about and became a voice for other parents and children, “What about parents who can’t take time off to train teachers themselves? What about the children who didn’t have a Seizure Action Plan on file?”



“

**I knew** this was something that **needed to be done** through official channels.

”



When Lauren found out about the Seizure Safe Schools initiative, she contacted the Epilepsy Foundation for guidance and support on how to get started in her state.

The Epilepsy Foundation (EF) supports families living with epilepsy. One way the EF helps the community is by connecting advocates and consolidating efforts to change state laws. The EF supported Lauren in what would eventually become Brynleigh’s Act, or the Maryland Seizure Safe School Act. The EF provided the draft language for Brynleigh’s Act and showed solidarity when Lauren went to meet with state legislators. They also provided language for supporters of the bill to use when calling or writing their legislators. “It was very much a joint effort,” Lauren says. “They put me in contact with large hospitals and medical institutions as well to gather support for the bill.”

The process of getting a new law passed can take some time and energy. Caregivers can also be involved in a simpler way by joining forces with other caregivers

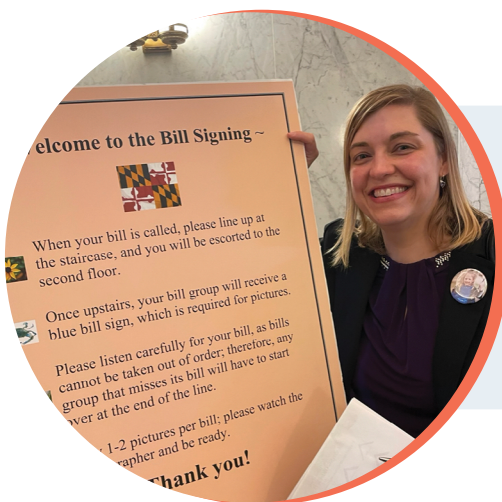
to make a difference. Legislators consider many factors when deciding on a bill, and hearing from the families directly impacted is always important. Caregivers who want to be involved can help out by writing testimonial letters or contacting their representatives to show support for a particular bill. They can rally support on social media or even testify in committee hearings. If you are interested, the first step is to reach out to your local EF organization in order to identify what the needs are.

Legislation is one way to make the world a safer and more accessible place for those living with epilepsy. There are bills that have become laws addressing Medicaid expansion, rights for those with disabilities, seizure first aid, and more. If a cause moves you, don’t be afraid to jump in. Support is available, and any of your efforts, big or small, is changing the lives of your loved one and those in the epilepsy community. For Lauren, advocacy has become her passion. “It feels like something tangible that I could do.”

“

It’s a way I can fight for Brynleigh until she can fight for herself.

”



**Download Seizure Safe Schools key information:**

[https://www.epilepsy.com/sites/default/files/2022-10/Seizure\\_Safe\\_Schools\\_Position\\_Statement\\_October2022.pdf](https://www.epilepsy.com/sites/default/files/2022-10/Seizure_Safe_Schools_Position_Statement_October2022.pdf)



Visit the Epilepsy Foundation to learn more about Seizure Safe Schools:

<https://www.epilepsy.com/advocacy/priorities/seizure-safe-schools>



To **GET INVOLVED**, visit [epilepsy.com/local](https://www.epilepsy.com/local) to find your local Epilepsy Foundation organization.



## Sibling

# REFLECTIONS

For families living with epilepsy, there's a lot that parents and their children need to talk about, like planning for the future, setting boundaries, and individual needs. In this article, 2 sisters—Christina, 30, and Grace, 26—reflect on how they communicated with their parents over the years and how their lives have been shaped by their brother Theo, who lives with LGS.





# CHRISTINA

**Age: 30 | Older sister of Theo, 20**

Christina is the oldest child in her family, and she’s absolutely obsessed with her siblings. “They’re my most favorite people in the world.” She remembers being so excited when her parents told her she would first be an older sister to Grace, and a few years later, to Theo. Her siblings both faced different health conditions early in life—Grace had a case of meningitis, and Theo was diagnosed with LGS. Both had a great impact on Christina and it made her deeply protective of them. “Anytime they’re sick or in pain, it’s been really hard. I’m not the one going through it, but it’s really difficult to be witness to that.”

While Christina loved spending time with her siblings growing up, playing music became her “thing.”

“**I’m a sensitive and creative person and music became a really natural outlet for all the things that were happening in my life.**”

It took her years to realize that having that time and space to herself make her a better sibling, and she’s so thankful to have that outlet. As a sibling, Christina believes you should never feel guilty taking time for yourself.

Today, Christina still lives close to home and talks to her family every day. Her parents have always been there to support her, so she tries to give them back as much support as she can. Now that she’s older and more involved in Theo’s care, the conversations about her brother have gotten a little heavier. “There are times

when I don’t want to talk about it because there’s so much emotion. But it is important to talk to your parents about reality, it’s just that there’s a time and place.”

Christina’s advice for siblings like her is to keep open communication with the people who mean the most to you. That includes family, friends, and partners.

“**Any partner I’m really serious about has to learn to love my brother and be open and understand that my future includes him and caring for him.**”

She believes that it’s important to find the right people to confide in about the hard stuff—whether that’s a therapist or just someone close to you. For her, she’s lucky to have her sister, Grace. They talk about planning, finances, and the future when it comes to Theo.

Christina’s advice to parents is to be open and honest with your kids, while still allowing them to be kids. “It’s a constant balancing act. The kids are going to have to help out, but it’s not their responsibility to raise their sibling. It’s the parents’ responsibility.” And that responsibility extends to planning for the future as well—reassure your kids that you have a plan (even if you’re still figuring it out). As a sibling, it’s stressful to think any responsibility is on you.





In Christina's family, responsibility never falls on one person—they take turns so that everyone can have time to do their own thing. As a musician who travels for work, her family has always supported her career—and they all supported her sister Grace when she moved across the country a few years ago. Their mom also recently took a once-in-a-lifetime trip to Paris. These are all things that require a lot of planning and sacrifice but are so worth it, in Christina's opinion.

Christina's last piece of advice would be to try to live in the moment as much as possible—and don't let fears of the future weigh you down. Life as a sibling of someone with special needs can be difficult at times, but she wouldn't have it any other way.

“

There's no way I would be the person I am today without having Theo in my life. **Anytime I'm doing something difficult or challenging, I think about the strength my brother has.**

”

## GRACE

**Age: 26 | Older sister of Theo, 20**

Grace is the middle child in her family, 4 years younger than her older sister Christina and 6 years older than her brother Theo. She loves her family with all her heart, but it's always been important to her to have her own life. Her family is in California, but she moved away a few years ago. This was a tough decision to make, but she's so glad she did. She's always had a tentative timeline in her head—that she'll take the time for herself to explore the world until she's 30—and then move back closer to home, so she can provide more support for her brother as her parents get older. It's important to her to have this time now so that she doesn't hold any resentment in the future.

As a sibling of someone with special needs, Grace believes that having that time to be “young” is critical, and she's glad her parents have always supported that and encouraged her to have her own social life. Her advice for parents would be to do whatever you can to maximize your other children's time as “kids.” Let them know that their teen years are theirs, and that they don't need to skip social events in order to care for their sibling.





Another piece of advice Grace has for parents is to try to be mindful of “the pieces of caregiving you choose to give to the siblings so that they can still have a normal sibling relationship.” As Theo’s sister, there were some tasks she helped him with that weren’t the most comfortable for her—and for all she knows, weren’t comfortable for Theo either! Feeding Theo was fine, but changing or bathing him, especially as they both got older, made Grace feel less like his sister and more like a caregiver. She encourages parents to try to preserve that sibling dynamic when they can.

Grace’s advice for other siblings is “to be really clear about what they want for their life, separate from their sibling. And then figure out how their sibling fits into that.”

“

You might not get what you want, but you need to be open. **If your parents don’t know what you want, they can’t help.**

”

Grace’s ideal future life would be owning a house back in California where Theo could have his own space and trusted professionals to take care of him. She realizes this is very dependent on her financial situation, which has guided her career decisions and influenced her saving habits. It’s a goal she actively works toward.

Grace is grateful to have Theo as a brother. “I don’t view Theo’s situation with a lot of resentment because I’ve always been reminded of the fact that there’s so much good that he brings. Theo needs us all, but we need Theo, too.”

Now that Grace is older, her parents will sometimes admit that they wish Theo didn’t have LGS for his sake, but never for their family’s sake—because they are all luckier for knowing him.

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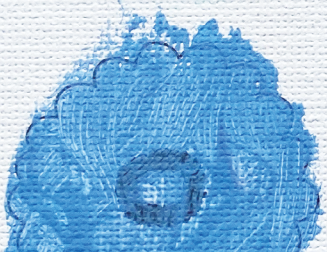
I’ve gotten more out of this than I’ve given **because it’s really changed who I am as a person.**

”





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