

Living with TM

LGS • DRAVET • TSC

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SIBLING SUCCESS STORIES

Pictured here: Ronan on Capitol Hill after advocating for funding tuberous sclerosis complex (TSC) research. His brother, Trent, is living with TSC.



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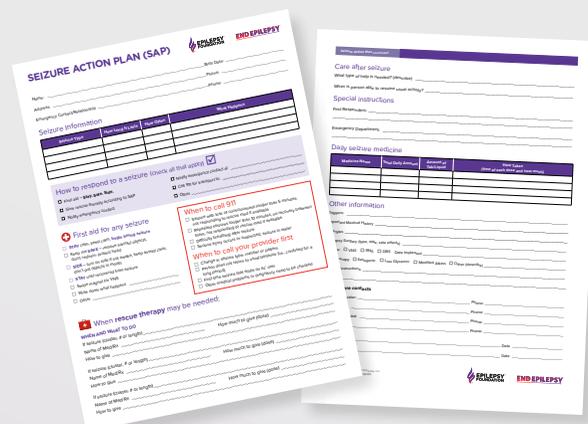
AT OUR **C** **RE** LGS DS TSC

It gives us great pride to bring you the second issue of *Living With* Magazine. At Greenwich Biosciences, families living with rare neurological diseases are at the center of everything we do. We're honored to work with parents, caregivers, and siblings to help create resources for families living with Lennox-Gastaut syndrome (LGS), Dravet syndrome, or tuberous sclerosis complex (TSC).

This magazine contains your words, your success stories, and your thoughtful advice. We've simply gathered it together to help support you on your journey.

In this issue, we're excited to share more stories of success from siblings, like Ronan, who made it all the way to Capitol Hill to advocate for his brother, Trent, living with TSC.

Ronan's success is remarkable, and he's not alone! Our sibling article shares more success stories from siblings to get inspired by.



You'll also find a copy of a Seizure Action Plan (SAP) that you can tear out and fill out to share with healthcare professionals or teachers. The accompanying article was written by the Seizure Action Plan Coalition. The Seizure Action Plan Coalition was founded by the LGS Foundation, Dravet Syndrome Foundation, and TSC Alliance to help educate families on the importance of personalized seizure action plans. Thank you to the Seizure Action Plan Coalition for contributing this important resource!

In addition, the pages of this magazine feature support for you! As Jen, an adult living with TSC, said, "It's always nice to know you're not alone—whether you just received a new diagnosis, or haven't had a seizure, but you're experiencing a new symptom with epilepsy—it's beneficial for our community to know there are other people out there, and we have an outlet to share." From advice on respite care, to tips on making the most of a telehealth appointment and easy ways to connect with patient advocacy groups, this issue is all about support and togetherness whether we're close together or miles apart.

As always, thank you for reading *Living With* Magazine. We hope you enjoy it as much as we enjoy learning from all of you! To download previous issues of *Living With* Magazine, go to LivingWithMag.com.

How to Make the Most of Your Telehealth Appointment

Telehealth has been a life-saving resource this past year for many families living with LGS, Dravet syndrome, or TSC. For example, many caregivers have noted how convenient it is to spend less time on the road yet still have access to healthcare providers. As Jen, an adult living with TSC, said about the benefits of telehealth, “The driving there, the waiting to be seen... it just saves so much time to be able to do an appointment virtually.” Hopefully, for families in the epilepsy community, telehealth may still be an option. To help you make the most of it, here are some tips we’ve picked up from parents, caregivers, and even some patients that can help make telehealth work for you.



Give yourself time to test the tech

Treat it like any other appointment. Schedule it on your calendar, give yourself time to test out the tech, and make sure to show up on time. Whether you’re dialing in, or logging on via an app, it’s important to leave time to troubleshoot. For a telehealth appointment, caregivers have advised checking your provider’s link when they send it prior to your appointment—this way you’re ready to go. One caregiver also noted that she found it helpful to ask the doctor at the beginning of the call how she could reach them if they are disconnected. Having these answers will help you feel at ease if you need to disconnect for any reason.



Decide which device you’re using

Whether it’s a desktop computer, laptop, tablet, or your cell phone, pick which option works best for you. Make sure it’s plugged in and/or fully charged and, if possible, place it on a desk or sturdy surface so your hands are free and the video isn’t wobbly. Some caregivers found a mobile or tablet device worked better because it’s portable and can provide the doctor an easier way to virtually conduct a physical exam. A mobile device also offers you the flexibility to be where your loved one is most comfortable.

shhh

If possible, find a quiet room

While it's great to be at home, that may also mean certain distractions like siblings and other family members, a TV in the background, or even pets may interrupt the visit. If possible, find a quiet room. And don't forget to turn off any background noise like TVs or music, and silence your phone. If you need to show the doctor a video of a seizure or want them to see something specific, try to find a well-lit room, if possible. For example, your doctor may need to examine your child's body language or other physical symptoms. While a quiet, well-lit room is ideal, don't stress if you can't find one—do the best you can to make sure the doctor can hear and see you.



Have reference materials ready

Have paper and a pen ready for easy note-taking. If you have a notebook, or file with videos, seizure diary, medication logs, and other notes, keep these items close by to share with your doctor, if needed.

“**Take notes and keep them at your fingertips. It also helps to have any tools you might need readily available, like blood pressure cuffs,**” said Darla, mother of Aaron, living with LGS.

It's important to know that you can ask for help. For example, ask a family member or friend to be with you during the appointment in case you need help, or if you need someone to take notes while you focus on the call.



Send key information ahead of time

Communicating with your doctor prior to the appointment is an important tip we heard from caregivers and patients. If you are seeing a new doctor, it will help to send an updated list of medicines, videos of seizures, or any other important information related to your visit before the appointment. Planning for blood tests in advance will also allow enough time for results to be completed before your appointment.

“**Send an email or message to your doctor before your appointment of things you'd like to discuss. You may also want to send your seizure log or diary. This helps your doctor be better prepared as well,**” said Darla.



Give yourself some grace

This might be the most important tip of all. Things don't always go smoothly—technology may glitch, pets might pop into the frame, children may not cooperate—and that's okay. Your doctor will understand if things don't go according to plan. Telehealth is not always perfect, but we hope these tips help you to have more successful telehealth visits from here on out.

Patient Advocacy Group News

In the first issue of *Living With Magazine*, we introduced you to five patient advocacy groups and the work they do to support families living with LGS, Dravet syndrome, or TSC and other types of epilepsy. From helping families with epilepsy connect to raising awareness, funding research for new therapies, fighting for a cure, and everything in between, patient advocacy groups are here to support you as you navigate your epilepsy journey. Whether it's meeting other children and adults living with LGS, Dravet syndrome, or TSC and other types of epilepsy, or finding specific support services, like ambassador programs and events in your area, these organizations have you covered. Here are some ways to stay connected.

EPILEPSY FOUNDATION

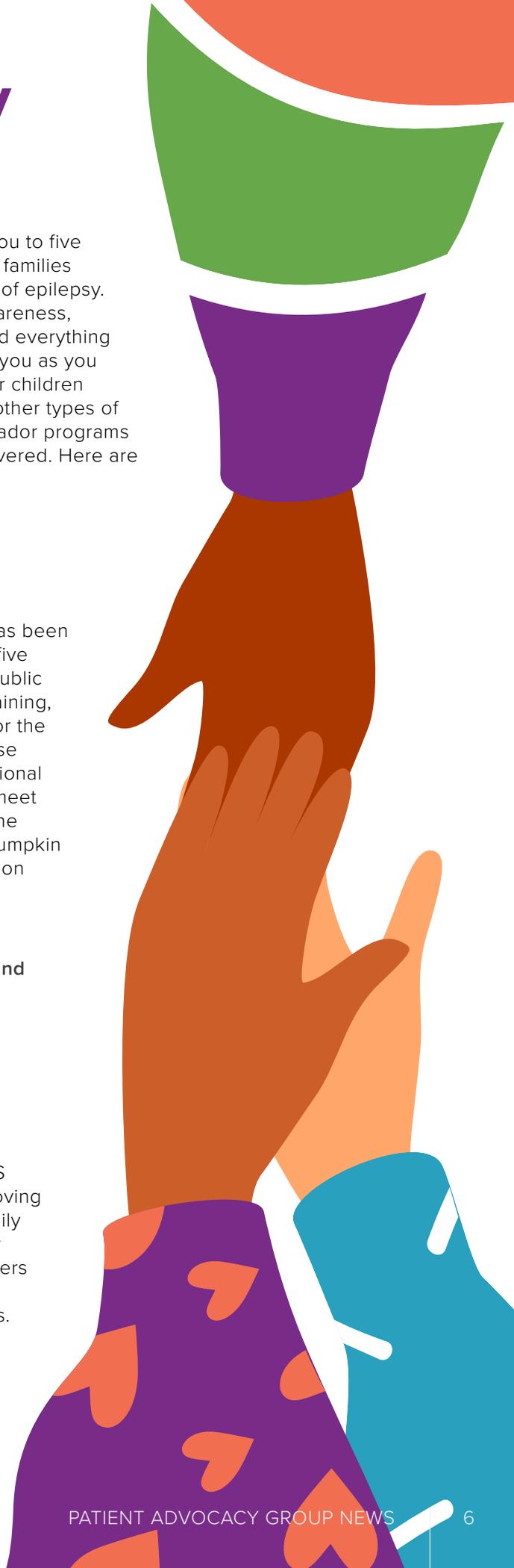
The Epilepsy Foundation is a national organization that has been placing a spotlight on epilepsy awareness for more than five decades. The foundation provides community services, public education, federal and local advocacy, seizure first aid training, and research funding for treatments and new therapies for the epilepsy community. If you're looking for ways to help raise awareness and fundraise, consider joining the annual national spring and fall Walk to End Epilepsy®. It's a great way to meet others in your community and get a few steps in! Or, for the artsy spirits, you might enjoy participating in the Purple Pumpkin Project campaign that takes place every fall. The foundation also hosts empowerment programs for kids and teens, as well as ambassador programs the whole family will love.

 Connect with your local Epilepsy Foundation and find regional events near you at [epilepsy.com/affiliates](https://www.epilepsy.com/affiliates)

 [@EpilepsyFoundationofAmerica](https://www.facebook.com/EpilepsyFoundationofAmerica)

LGS FOUNDATION

Founded by a sibling of someone living with LGS, the LGS Foundation is a nonprofit organization dedicated to improving the lives of those impacted by LGS through research, family support programs, and education. They also host a family Ambassador Program, which is made up of family caregivers who are there to listen and support others living with LGS while providing a wealth of resources, tips, and ideas. In honor of LGS Awareness Day, recognized worldwide every year on November 1, the LGS Foundation invites



everyone to celebrate in their annual Illuminate for LGS campaign, as well as participate in other activities in their communities.

Past events have included a silent auction, virtual benefit concert, and inspirational videos of stories from the LGS community. It's a day where families from around the world can celebrate the LGS community and raise awareness together every year. Another way to get involved and meet others is to participate in the annual Walk 'n' Wheel that takes place every spring. At this fun global event, the LGS community unites while raising funds for research and programs that support those impacted by LGS.

 Check out the latest global LGS community events at lgsfoundation.org/category/events

 [@LGSfoundation1](https://www.facebook.com/LGSfoundation1)

DRAVET SYNDROME FOUNDATION

The Dravet Syndrome Foundation (DSF) was founded by a group of parents whose mission is to aggressively raise funds for Dravet syndrome and related epilepsies, support and fund research, increase awareness, and provide support to affected individuals and families. Keep an eye out for events, like the DSF Family & Professional Conference occurring during Dravet Syndrome Awareness Month in June each year, Day of Dravet family workshops each fall, and the annual Steps Toward a Cure walk each September. Events like these not only provide a wealth of information and resources for families, but also bring the community together to help raise funds for research and patient assistance grants. DSF also hosts regular evening events for parents looking for a night out, with themes like Casino Night and Dance for Dravet. Keep up with the latest DSF news by signing up to receive the weekly newsletter, magazine, or email communications.

 Read how the DSF provided support and acceptance for Zora, Steve, and their family on page 10!

 Explore and learn more about DSF events at dravetfoundation.org/events

 [@DravetSyndromeFoundation](https://www.facebook.com/DravetSyndromeFoundation)

TSC ALLIANCE

The TSC Alliance is an internationally recognized nonprofit dedicated to finding a cure for TSC, while improving the lives of those affected. For educational resources, consider attending the International TSC & lymphangioleiomyomatosis (LAM) Research Conference every October, or listen in on their TSC Now podcast series. To kick off TSC Awareness Month every May, the TSC Alliance holds an annual walk-run-ride event called Step Forward to Cure TSC® as a way to meet others living with TSC while increasing awareness and raising funds for research and support programs. The TSC Alliance also offers an evening of laughter, hope, and awareness about TSC with their Comedy for a Cure® event. Find out about the latest news, events, webinars, and more by subscribing to receive the monthly magazine, bi-monthly newsletter, or email communications.

 Stay up to date on the latest TSC Alliance events by visiting tscalliance.org/events

 [@TSCalliance](https://www.facebook.com/TSCalliance)

CURE EPILEPSY

Over two decades ago, a small group of parents of children with epilepsy joined forces to launch CURE Epilepsy. Driven by their frustration with their inability to protect their children from seizures and the side effects of medications, they began a relentless search for a cure. CURE Epilepsy is laser-focused on funding research to find a cure for epilepsy, awarding grants for novel research projects to both young and established researchers. In addition to funding critical epilepsy research, the organization serves as a comprehensive resource for all the latest epilepsy news, webinars, town halls, conferences, and events, like the Team CURE Epilepsy Run for Research. CURE Epilepsy also hosts the Seizing Life® podcast featuring personal anecdotes and stories from the community, which is a great way to connect with families and get inspired no matter where you are.

 Discover events hosted by CURE Epilepsy at CUREepilepsy.org/events

 [@CUREforEpilepsy](https://www.facebook.com/CUREforEpilepsy)

Learn more about the patient advocacy groups who joined forces to create the Seizure Action Plan Coalition and how you can build your own plan on page 20.

FINDING INSPIRATION TOGETHER

WORDS OF ADVICE FROM FAMILIES LIVING WITH LGS, DRAVET SYNDROME, OR TSC

Living with LGS, Dravet syndrome, or TSC has its ups and downs, but when you find a community that you can connect with and learn from, you can get through the challenges and celebrate the wins together. That's why it's so important to share your story and connect with others. Here, you'll read a collection of everyday tips and emotional support from caregivers and

patients. Turn to these tips for inspiration to help you find balance in your day. While reading through their words, know that you are not alone. As one mother, Tara, said, "Finding the right support for your loved one can feel like you're spinning in circles. Trust your intuition." Or as another mother, Peg, told us, "A key part of being a caregiver is also to take time for yourself. Give yourself a break. We are all human." Thank you to all the families who shared their advice for this article. We hope you will find inspiration in the collection of tips on the following page.



It's never too late to join or get involved with patient advocacy groups like the TSC Alliance. I actually met some of my best friends through support groups. It's amazing to know you're not alone and you can connect with people who understand.

–Tara

Getting enough sleep and staying hydrated is really difficult for me. **I started using a phone reminder to drink water throughout the day, and used my phone to track my sleep.** What a difference that has made for me!

–Jen

Be prepared! **Take some time to prep a few days before traveling to an appointment.** Trust me, it will take a huge weight off your shoulders. I also learned to keep a to-go emergency bag packed and ready, so if I ever need to run, I can grab it and hit the road.

–Ronda

I figured out a clever way to keep my daughter's straws from being damaged and getting dirty by storing them in a toothbrush holder.

My husband and I also worked out a system and have each other's back to avoid mistakes.

We prep medicine weekly and double check each other to ensure it's correct ahead of time.

–Lisa

Find a few things they love, like food, toys, videos, and use those for positive reinforcement.

For example, my son loves to go to gas stations. So, if he doesn't want to go to school, I'll say to first go to school, and if I get a good report, we can go to the gas station afterwards. This tactic works well for us.

–Peg

Ask for help! Often times, friends and family are willing and able to help. They just aren't sure when to offer it or what type of help is needed. All it takes is a little communication. Like asking for help with babysitting, picking up something at the store, or making a meal.

–Lauren

Try to schedule a romantic date or a respite getaway weekend to relax and rejuvenate with your partner.

–Lauren

We celebrate as much, and as often, as we can.

Everybody and anybody can identify something achieved each day, no matter how big or how small it is.

–Carly

Support Spotlight:

Finding Acceptance and Freedom

By Steve, father of Zora, living with Dravet syndrome





Steve and his wife, Dawn, live in North Carolina with their two daughters, Eva and Zora. Zora was diagnosed with Dravet syndrome when she was 4 years old.



All of a sudden, she started regressing. She struggled with simple things, like grabbing onto a bottle, or reaching for things. She wasn't crawling, walking, or talking the way she was supposed to. And of course, the seizures continued.

Zora has an open personality—she loves people, is very friendly, and also very demanding. She wants what she wants and she's going to get it. She doesn't have great communication skills, so it's hard for her to tell us what she wants, but she'll be pretty forceful to ensure she gets it. She's just a very determined and happy kid. She's like any other kid, and we don't let Dravet syndrome define us, or her.

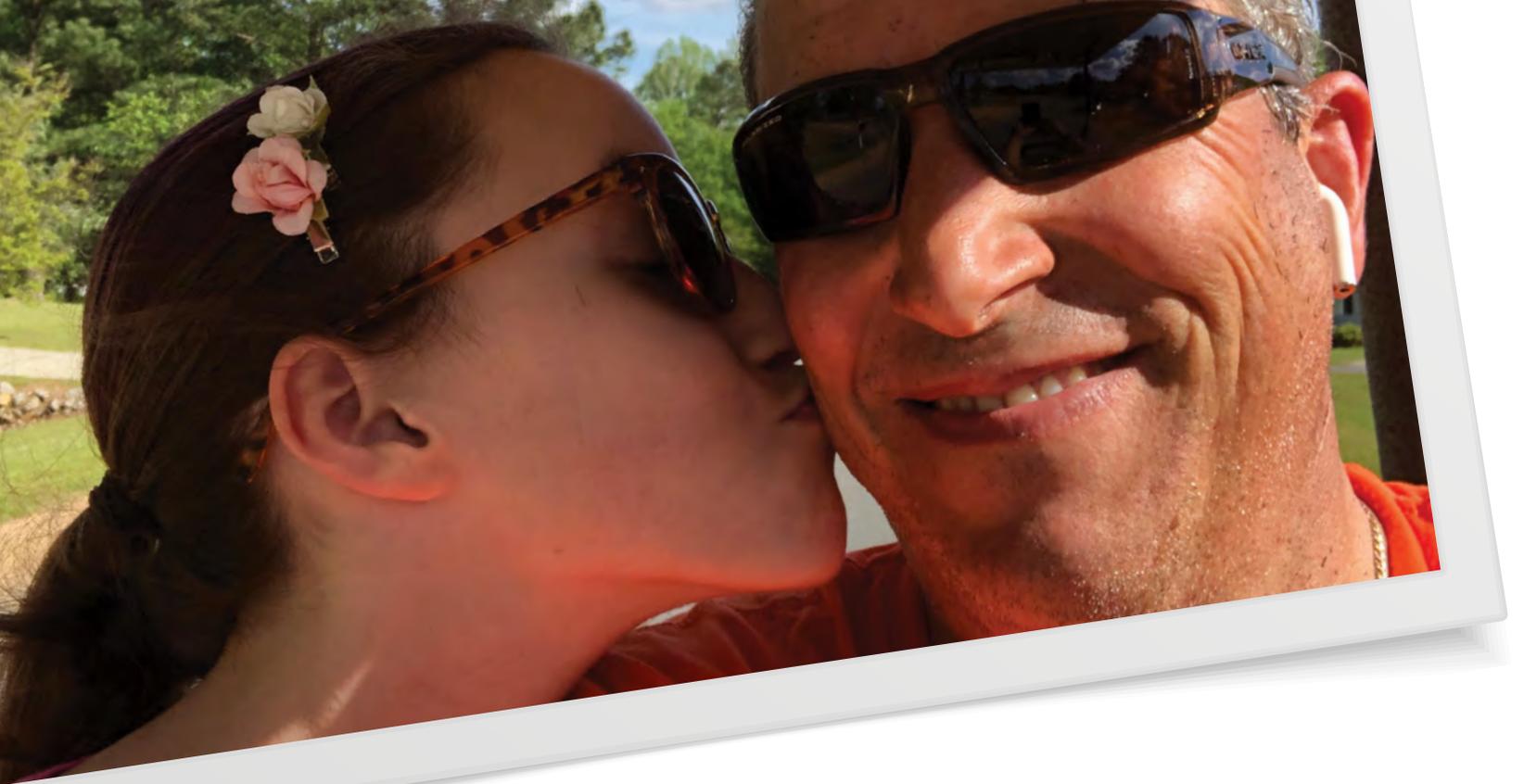
When Zora was born, 11 years ago, everything was normal. My wife, Dawn, had a normal pregnancy—happy, healthy, and everyone was fine. We were home and out of the hospital by

the next day. Zora was hitting all of her milestones quickly and seemed to be doing great.

At 6 months of age, Zora had her first seizure. I got a call from a neighbor at around 6PM at night, and he said, "Your wife's in an ambulance and on the way to the hospital with Zora. It seems like she had a seizure and you need to get here." At that point, they didn't know what it was. Maybe it was a fluke? A fever? She was fine by the time she got to the hospital. We just went home and monitored her from there. Within a few days, we started seeing what we now realize was one seizure after another—it was surreal.

Doctors labeled it as generalized epilepsy without giving us much more explanation. We later learned that it may have been labeled that because the seizures were occurring throughout the brain. At the time, they said it may be something she'll grow out of, but when the seizures didn't stop, we had to seek more answers. All of a sudden, she started regressing. She struggled with simple things, like grabbing onto a bottle, or reaching for things. She wasn't crawling, walking, or talking the way she was supposed to. And of course, the seizures continued.

Looking back at all the seizures she was having, my wife and I



Normally, when we're with Zora in public, it's like trying to control a greased octopus. But at the conference, within minutes of stepping onto the floor, Zora invaded another girl's personal space. Instead of being put off or unnerved, or looking at her funny, this girl just understood.

wondered: could there be a more specific diagnosis other than just generalized epilepsy? Fortunately, my wife is a nurse and she's amazing at it. She had heard of LGS, but we didn't know if there were other types of epilepsy, until we learned about Dravet syndrome.

Kids with Dravet syndrome have seizures that start in one or both sides of the brain. Some seizures can start on one side and spread across the brain. That's basically what was happening with Zora.

After the doctor reviewed the genetic test and Zora's symptoms, they diagnosed her with Dravet syndrome. She was 4 years old at the time. We wish she would have been tested sooner. A lot changed after we received her diagnosis.

At first, our doctors told us to check out the Epilepsy Foundation, a resource to find help. But it was shortly after her diagnosis that we discovered the Dravet Syndrome Foundation (DSF).

We learned so much through the DSF. There was a lot of information there, and a lot of people who were all going through the same exact thing. We heard about the DSF conferences and attended our first one as a family a few years back. Nothing could have prepared us for the overwhelming feeling of acceptance we felt at that conference.

We had attended epilepsy conferences in the past, but we never really felt like we belonged because Dravet syndrome is just so different. Normally, when we're

with Zora in public, it's like trying to control a greased octopus. But at the conference, within minutes of stepping onto the floor, Zora invaded another girl's personal space. Instead of being put off or unnerved, or looking at her funny, this girl just understood. She took her hand and away they went. Right away, it was like they were best friends. We didn't have to explain why Zora doesn't talk—she understood. It was so heartwarming, and it didn't stop there.

Over the next few days, we were so taken by the sheer number of people involved, especially those with no personal ties to Dravet. These were advocates who didn't have to be.

Yet there they were, working with us to make our children's lives better. It really blew us away.

There was the unrestricted access to all that invaluable information: an education in Dravet syndrome more specific than any we'd ever received before; information on new therapies that might be coming down the pike; different points of view from parents in the same situation who maybe thought of things that we'd never thought of. We even got answers to questions we would have never thought to ask. We drew so much from the life experiences of family and friends, but with Dravet, there aren't a lot of people to draw from. To be surrounded by people we could feed off of was nothing short of amazing.

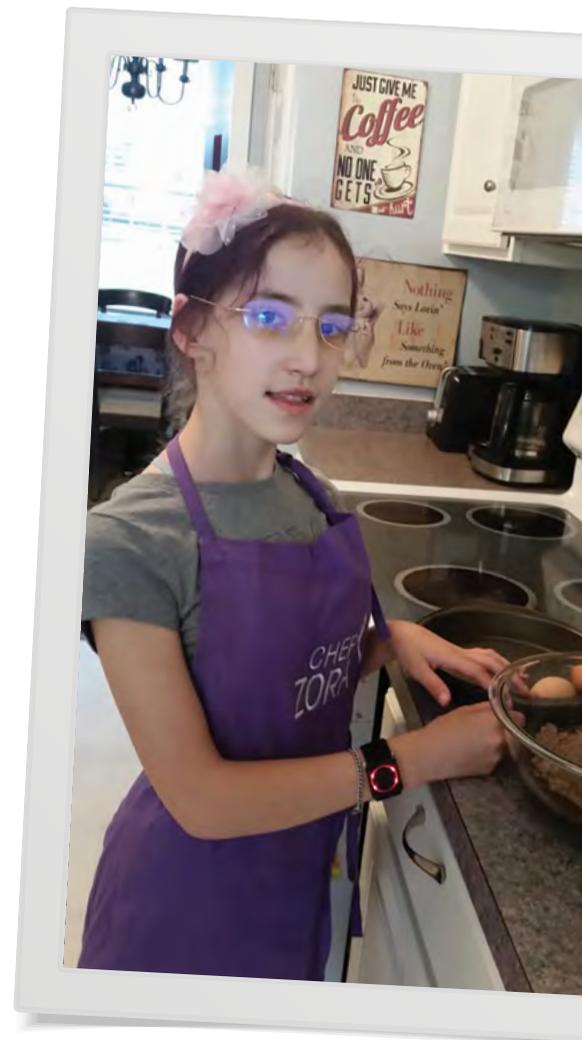
As for Zora? She received life experiences that she just wouldn't be able to get anywhere else. She got a week of play with open-minded kids who would actually play back. No judgment or questions asked. One of my fondest memories of the conference was seeing Zora gather for a group photo with all the other kids. One child was climbing on top of her, another had his finger up his nose, but they were all in their element, smiling ear to ear, not caring what anyone around them was doing, and feeling accepted.

The DSF was a big help to us then and still is today. Whether it's discovering valuable resources through the foundation or through their support groups, or being connected to new families who are in need of a little bit of advice, it has been a continual source of much-needed support. The best part is meeting other families and seeing the similarities between our children.

It's a big deal. You start to realize this is kind of normal, and very normal for Dravet syndrome.

My biggest advice would be to seek out the foundations that support your own family's journey. Finding the DSF made a huge difference for us. When you find the right foundation, you truly do feel like you're at home. But don't make it all about Dravet syndrome. For a long time, my life was Dravet, Dravet, Dravet. But there is so much more to life, other than the syndrome, that you and your family deserve to experience.

Zora is who she is because she has Dravet syndrome, and I wouldn't change that. She's awesome. She's very fun. She's happy. She likes people. She has a great personality, and she will make you fall in love with her.



Zora is who she is because she has Dravet syndrome, and I wouldn't change that. She's awesome. She's very fun. She's happy. She likes people. She has a great personality, and she will make you fall in love with her.

5

It could take nearly YEARS

of uncontrolled seizures before an accurate diagnosis is made

Not knowing your specific diagnosis could mean years of searching for answers, but a specific diagnosis could mean all the difference—it can open a door to treatment options, provide access to foundations and grants or financial assistance, connect you with a supportive community of others who can share their experience, and much more.

If you or someone you know is still seeking a specific diagnosis, don't wait. Take the assessment today at SeizuresAreSigns.com to receive a customized response summary to share with your doctor.

SeizuresAreSigns.com also has tools and resources for families living with LGS, Dravet syndrome, or TSC.

Start the conversation and find support at SeizuresAreSigns.com



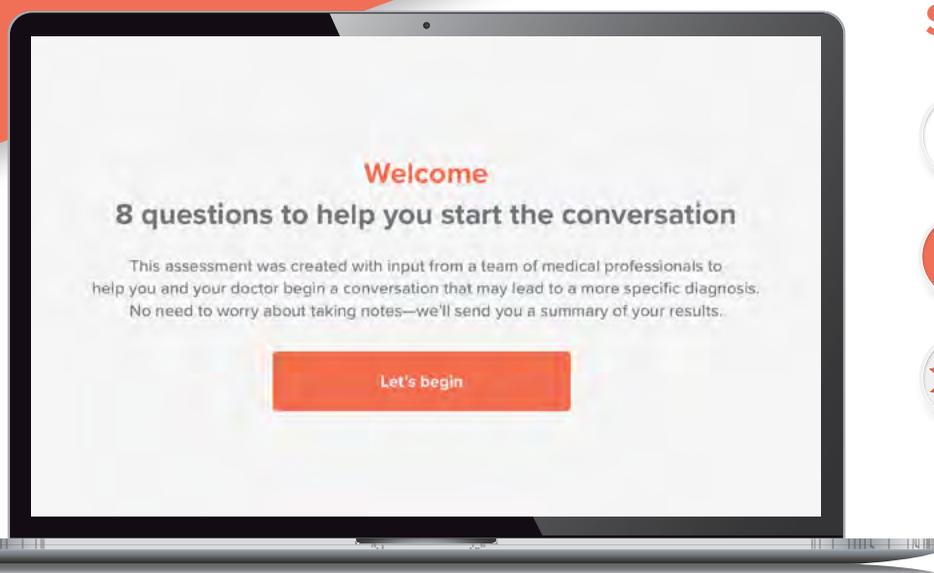
How to identify seizure types



Information on LGS, Dravet syndrome, or TSC



Links to find doctors, specialists, and advocacy groups



SEIZURES[™]
ARE SIGNS



How One Family Shared

unspoken symphony and How You Can, Too

Transforming art into music with an award-winning technology made especially for families living with LGS, Dravet syndrome, and TSC.

Brynleigh, a 6-year-old child with TSC, handed her grandfather a gift. It was a framed printout of the melody she created on unspokensymphony.com, an original melody that was created from her artwork, which is pictured here.

“I was moved to tears by *unspoken symphony*,” said Lauren, Brynleigh’s mom, the first time they tried it.

“Seeing the look on my dad’s face when she gave it to him was priceless,” Lauren said. Lauren went on to text all her friends about it, sharing the experience with others in the community and with friends from the TSC Alliance.

“We have so many teachers, specialists, and therapists that our kids see, and to be able to give them something that your child created—no one’s ever done anything like this for our community

Brynleigh gave her grandfather the gift of a symphony she created from her own artwork on unspokensymphony.com



before, whether it’s the TSC community, or LGS, or Dravet—this is something so unique,” said Lauren.

To be able to have or give the gift of a piece of art your child created is already magical. With *unspoken symphony*, families can now turn a keepsake into something more by hearing the music behind it—essentially turning one form of expression into another. It can be given as a gift or simply be an experience to try together as a family. And it only takes a few minutes to create your very own symphony from artwork.

Simply visit unspokensymphony.com to upload a picture of your loved one’s artwork—any type of art will work, even computer-generated art, or artwork made with the help of a caregiver (just like Riley’s watercolor artwork on the site). Take a picture of the artwork with a cell phone or scan it to your computer, then press “make a melody” on the homepage of unspokensymphony.com and follow the steps to upload your artwork to the site.

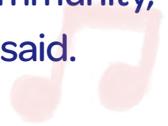
Once uploaded, the software will work its magic to analyze your artwork, and you’ll immediately get to hear a preview of your original melody. Every brushstroke and line put to paper becomes a note you can hear. The software picks up on colors, line density, shapes, composition, and translates them

into music notes. Next, you'll get to select different instruments to create your own unique melody that's music to your ears.

Once you are happy with the melody you've created from your artwork, you can submit it to the gallery and instantly download your files to keep and share in all sorts of ways, such as through email, social media, printing your artwork, and more. The files include an MP4 video file of your melody playing as the music notes animate over the artwork, and a printable PDF of the sheet music that's personalized with your name and the title and picture of your masterpiece—just like the one Brynleigh gave to her grandfather!



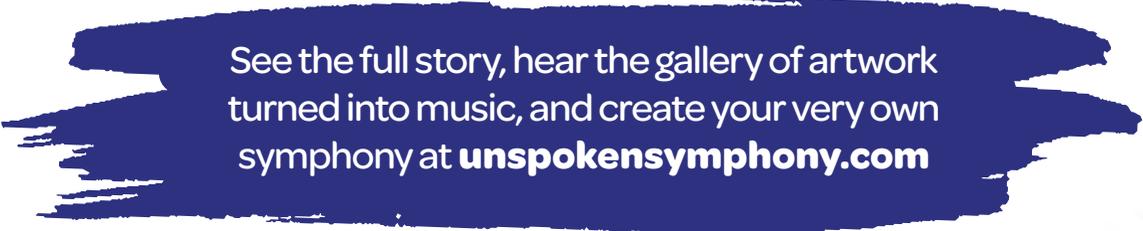
"It was created especially for families living with LGS, Dravet, or TSC. The best part is anyone in the community can try it, and it's free. I love that the idea was inspired by a little girl from the epilepsy community, too. You have to try it," Lauren said.



What is *unspoken symphony*?

unspokensymphony.com is a website that transforms artwork into original melodies, and was inspired by a girl named Riley who is living with LGS and TSC. To see the full story and watch what happens when Riley and her family hear Riley's art come to life as music for the first time, visit the website at unspokensymphony.com—and try it out with your own family!

To date, over 8,000 unspoken symphonies have been created on the website, a free service available to the LGS, Dravet syndrome, and TSC communities, and to all who struggle to express themselves. It's a wonderful experience for siblings, too—some families even tried it during music therapy sessions. For Lauren, it was one of the first times her daughter, Brynleigh, got to give her grandparents a gift she made all by herself.



See the full story, hear the gallery of artwork turned into music, and create your very own symphony at unspokensymphony.com



Reset With **RESPITE CARE**



“Caregiving requires taking breaks. I used to see taking a break as a weakness, or not a valuable use of my time. I started off small with walks around the block, moments of deep breathing, prayer, and meditation. It seemed so simple, but these acts reset my mind and recharged my batteries.”

**—Ronda, mother of Marissa,
living with LGS**

Caregivers share the importance of respite care and how to get started

WHAT IS RESPITE CARE?

Respite care is short-term care of children and adults living with rare diseases, like LGS, Dravet syndrome, or TSC, and a chance for parents and/or caregivers to take a moment for themselves. It’s vital for families to consider respite care and to know what options are available to them—even if it’s just for a few hours on occasion. Tara told us, “It’s hard to get a break, but I’ve learned it’s so important—and as a caregiver, it’s hard for me to admit that.”

It’s important to remember that respite care benefits both caregivers and their loved ones by providing a bit of independence, a change in routine, and a new perspective. Peg, mother of Tommy, living with TSC, reminds us, “It can be overwhelming at times, but talking to friends and family members, or just taking a walk or a ride to get coffee will give you that time you may need to reset.” The truth is, to care for others, we must take the time to care for ourselves. Since respite care support varies widely from state to state, this article covers some resources to assist you as you look into the process and benefits of respite care in your area.

HOW TO GET STARTED

A great way to begin your search for local programs is by going to archrespite.org/respitelocator, where you can search for care by city and state. The “search for respite funding” feature also provides key information on how to pay for respite care, including possible funding resources that may be available in your state—like Medicaid waivers, other state agency funding sources, eligibility criteria, and even how to apply for funding.

Finding care that meets your loved one's specific social and medical needs may take some time. To help you get started, we spoke with caregivers who shared advice on how to navigate the types of questions you should ask while looking for care.

CHECK CREDENTIALS, MEET IN PERSON, AND ASK QUESTIONS

First, it's recommended to check credentials, background information, or references, if available. Ask the person you are interviewing to demonstrate that they have skills to care for your loved one, like experience with providing seizure first aid or having cared for someone with seizures in the past, especially if they will need to handle a G-tube, PICC line, or advanced equipment. Walk them through what a typical day of care looks like and ask the caregiver what they might do in certain situations they could encounter while caring for your loved one. Even if they come highly recommended, it's important for them to meet your child or adult with you there. Peg explains, "After I interview someone and decide that they may be a good fit, I have them spend time with my son while I am present. I never leave him alone with a new person, even if they have the best references. It's important that the worker and the person who needs the respite care click with each other and that you feel comfortable with your child's caregiver."

PROVIDE A SEIZURE ACTION PLAN AND ASK ABOUT AVAILABILITY

It's also important to include examples of medical situations or emergencies that could come up and see how the caregiver/nurse would respond. Discuss an emergency plan. As Lisa said, "Talk about what center/hospital is the closest in case of an emergency." The Seizure Action Plan (SAP) template, which can be found on page 23 of this issue, is a helpful resource to provide. Finally, caregivers suggested asking up front for a list of hours and days of the week that the caregiver/nurse is available to work.

ADVOCATING FOR RESPITE CARE LOCALLY

If respite care is not available in your area, there are ways to advocate for the care you need similar to the way Ronda, mother of Marissa, living with LGS, did. She recommends checking out local organizations such as the county board of developmental disabilities. Some states offer respite care programs or have plans where you can hire your own providers, which can include family members, friends, or nurses you may know. Posting "help wanted" ads in local nursing school bulletin boards and websites is helpful, too.

WHY RESPITE CARE MATTERS

Ronda shared an important reminder, too: "Caregiving requires taking breaks. I used to see taking a break as a weakness, or not a valuable use of my time. On the advice of my family doctor, I started to explore activities that made me happy. I started off small with walks around the block, moments of deep breathing, prayer, and meditation. It seemed so simple, but these acts reset my mind and recharged my batteries. I then started to plan longer trips away, a day with a friend, lunch, or dinner out, a trip to the park, or even driving around country roads listening to my favorite music. These pre-planned, longer breaks gave me something to look forward to, especially on those not-so-great days. Now, I am actively seeking out new experiences and try to plan at least three days away a month. It clears my mind, brings me happiness, and makes me a better caregiver."

Peg echoed this same sentiment when she said, "A key part of being a caregiver is also to take time for yourself. Give yourself a break. We are all human and sometimes we need a minute so we don't burn out. We must remember what an important role we have in life and the reward is the successes we see—whether big or small—and the unconditional love our special people have for us. I feel lucky I was chosen; however, we do often need help."

It's important to take care of your personal health, take some me-time, or even simply run an errand. Taking the time to research respite care now can pay off greatly later when you need a break. As Ronda suggested, scheduling that time for yourself a few times a month is important. Whether you are new to respite care or looking for additional options, we hope these suggestions will help you know where to turn. Remember that respite care resources and information change often. If you have any questions about services offered, call your state agency directly, or look for resources available through the Epilepsy Foundation, local patient advocacy groups, or others highlighted on pages 6 and 7 of this issue. If you have difficulty finding care, don't give up. It's okay to ask for help from family and friends to take a moment to yourself—even if it's only for an hour.



PATIENT ADVOCACY GROUPS JOIN FORCES TO CREATE THE SEIZURE ACTION PLAN COALITION AND EDUCATE ABOUT THE IMPORTANCE OF HAVING A SEIZURE ACTION PLAN (SAP)

By the Seizure Action Plan Coalition

In November of 2020, the LGS Foundation, Dravet Syndrome Foundation, and TSC Alliance worked together to form the Seizure Action Plan Coalition to fill an unmet need in the epilepsy community. This collaborative effort was designed to raise awareness of what SAPs are, the importance of SAPs in the health management of those with epilepsy, and the resources available to develop an individualized SAP, including SAP Awareness Week.

As many of you know, a seizure is a medical emergency. And according to the Centers for Disease Control and Prevention, it's an emergency that affects approximately 3.5 million Americans—roughly 3 million adults and 470,000 children and teens. About one-third of those people with epilepsy will eventually develop refractory (drug-resistant) epilepsy, which includes LGS, Dravet syndrome, and TSC.

Patients with Dravet syndrome may experience frequent, often

prolonged seizures, which can be life-threatening. For children living with LGS and experiencing seizures, attending school on a regular basis may be difficult.

In fact, a 2009 survey conducted by the LGS Foundation found nearly 50% of school-age children with LGS no longer attend school due to uncontrolled seizures or behavior problems, and 21% of those surveyed miss school 50% or more of the time.

For individuals with TSC, seizures remain one of the most common neurological symptoms, occurring in 85% of patients.

For all individuals who are prone to experience seizures—especially those for whom medicine is not completely effective—developing a seizure action plan provides an important management tool to discuss with their doctors, caregivers, family, and friends and help to ensure their safety during a seizure.

WHAT IS A SEIZURE ACTION PLAN (SAP) AND WHO NEEDS ONE?

A SAP is essentially a set of tailored guidelines on how to respond during a seizure. It includes health and medical information specific to the patient and aims to help others around the patient recognize seizures and then take the appropriate steps to keep them safe from injury during the seizure or damage caused by prolonged or clusters of seizures. This tool provides more support to patients by generating awareness about their personal medical needs for those who spend time around them.

SAPs can be useful for educating patients and their caregivers about seizure medications and the status of their epilepsy. The SAP format should allow for modification at future office visits based on the current health status of both the patient and the caregiver, any lifestyle changes, or if a treatment change occurs. It should be reviewed by the patient and healthcare providers regularly to ensure it is understood and to determine whether it needs to be updated.

Seizures have the potential to be life-threatening, but creating and maintaining an updated SAP can help in those dire situations by letting other people know how to provide immediate support to the patient.

SAPs can reduce the time to act during a seizure, which is significant as it can reduce the risk of prolonged seizures, the risk of mortality, and the need for additional rescue medications. Despite the positive impact that SAPs can have on a patient's health and quality of life, a recent survey conducted by the SAP Coalition found more than 60% of respondents did not have an individualized SAP or had an outdated plan.

"We need to continually be talking about and raising awareness of SAPs," said Mary Anne Meskis, Executive Director, Dravet Syndrome Foundation. "In speaking with our caregiver community, we have learned that many of our newly diagnosed parents are not aware of this important healthcare tool. For our patients who have an individualized SAP, if they have remained relatively stable or seizure-free for a period of time, sometimes the caregiver becomes lax in reviewing and updating the SAP. We need to continue to educate and stress the importance and value of an updated SAP to the health and safety of the patient."

"A seizure action plan developed by the patient, caregiver, and patient's primary neurologist is imperative in ensuring appropriate care in a medical setting with healthcare professionals who are not familiar with the patient's disease and medical history. The Seizure Action Plan Coalition will work to increase awareness of

these issues," said Kari Luther Rosbeck, TSC Alliance President & CEO.



SEIZURE ACTION PLAN COALITION

"The Dravet Syndrome Foundation felt strongly that partnering to start the Seizure Action Plan (SAP) Coalition would make certain caregivers have the information and resources they need to keep their loved ones safe. Patients with Dravet syndrome may experience frequent, often prolonged seizures, which can be life-threatening. A SAP assures the patient's health and medical information are all in one place, including an emergency protocol that has been developed with their healthcare provider," explained Meskis.

SEIZURE ACTION PLAN AWARENESS WEEK

To educate patients, caregivers, and healthcare providers on the importance of maintaining an up-to-date SAP, the SAP Coalition recently launched the inaugural Seizure Action Plan Awareness Week to be held annually beginning the second Monday each February to coincide with International Epilepsy Awareness Day.

"SAP Awareness Week will highlight the need for people with epilepsy to have a conversation with their healthcare providers, especially if they are in a key subgroup who would benefit from a seizure action plan, like those who have intractable epilepsy syndromes who are at high risk for seizure clusters, status epilepticus, or have frequent nocturnal generalized tonic-clonic seizures," said Dr. Tracy Dixon-Salazar, LGS Foundation Executive Director.



Seizure Action Plan (SAP) template from the Child Neurology Foundation

All adults and children with epilepsy need a SAP—especially those with new-onset epilepsy and those with ongoing frequent convulsive seizures who had more than one seizure in the previous year.

Seizure-free patients who have risk factors for breakthrough seizures, those who need help in identifying their individual seizure patterns, do not have a plan, or live far from medical facilities are also key subgroups who would benefit from a SAP.

Developing a SAP is an opportunity to educate the patient and caregiver on the patient's specific seizure type(s) and which situations call for emergency action—and should involve and be shared with the patient, caregiver, and healthcare providers to create a customized plan tailored to the patient.

In addition to parents and caregivers, it's also helpful to share a SAP with school staff, coworkers, babysitters, medical personnel or emergency responders, or any other person who provides any type of care in

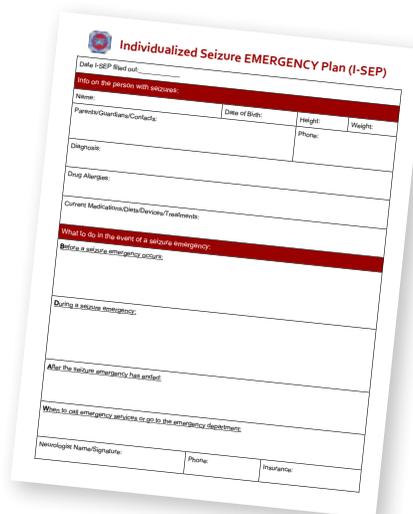
a patient's life. A SAP can also be helpful in guiding home management of seizures, which may reduce visits to the emergency department.

Promoting understanding and defining the use of rescue therapy within a SAP may reduce potentially unnecessary emergency healthcare needs, resulting in decreased direct and indirect costs.

RESOURCES AVAILABLE

The first step is to talk with the healthcare provider or neurologist and work with them to develop a personalized SAP. When creating the SAP, it is important to be clear and concise. Remember, the SAP may be utilized under situations of high stress and by individuals who may not know the patient.

For some patients, it is suggested the first page of a SAP includes their Seizure Emergency Plan (SEP), which contains all the information needed if a prolonged seizure or seizure cluster occurs. The SEP can be easily shared with other caregivers to prepare them for what to do in case of a seizure emergency and may also be shared with emergency personnel, if needed.



Seizure Emergency Plan template from the Seizure Action Plan Coalition

Once the SAP is complete, make sure it is readily available to those who know about the patient's seizures and who they are in regular contact with. A copy should be kept with the patient at all times, especially those who suffer from a severe form of epilepsy and may be nonverbal or have developmental delays.

More information, resources, and templates can be found on the Seizure Action Plan Coalition website at <https://seizureactionplans.org/sap-examples>. A ready-to-use SAP template is available just for you! See the next page.

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Individualized Seizure EMERGENCY Plan (I-SEP)

| | | | |
|---|----------------|------------|---------|
| Date I-SEP filled out: _____ | | | |
| Info on the person with seizures: | | | |
| Name: | Date of Birth: | Height: | Weight: |
| Parents/Guardians/Contacts: | | Phone: | |
| Diagnosis: | | | |
| Drug Allergies: | | | |
| Current Medications/Diets/Devices/Treatments: | | | |
| What to do in the event of a seizure emergency: | | | |
| <u>Before a seizure emergency occurs:</u> | | | |
| | | | |
| <u>During a seizure emergency:</u> | | | |
| | | | |
| <u>After the seizure emergency has ended:</u> | | | |
| | | | |
| <u>When to call emergency services or go to the emergency department:</u> | | | |
| | | | |
| Neurologist Name/Signature: | Phone: | Insurance: | |

SIBLING SUCCESS STORIES

Proud Stories of Positivity From Families Like Yours

If there's anything we've learned from getting to know families living with LGS, Dravet syndrome, or TSC, it's that each one of you has a remarkable story to share. The first time we spoke with siblings, we were inspired by their maturity, positivity, gratitude, and wisdom—even at a very young age! It's incredible to see how much siblings grow by supporting and learning from their brother or sister. Time and again, siblings prove that having a brother or sister with a rare disease can uplift and change their perspective on life in the best of ways. In this article, we are honored to spotlight the unique experiences and successes of four inspiring siblings from our community.



**Makayla, sister of Marissa,
living with LGS**

HOW CARING FOR HER SISTER SHAPED HER FUTURE CAREER

Having a sister with a chronic medical condition has given me an interest in the medical field from a very young age. Growing up, I would always accompany my mom and older sister, Marissa, to doctor appointments and visit them in the hospital when she was sick. I also loved incorporating Marissa's medical equipment into games I would play with my stuffed animals. I would often use some of her old feeding bags and oxygen masks on my stuffed animals to play doctor, which is now what I am working to become!

Being around medical professionals gave me such an appreciation for the work they do to keep kids like my sister healthy, and the hard work they put in to treat all kinds of illnesses. Marissa, and all the amazing healthcare workers that have taken care of her over the years, have truly inspired me to pursue a career in the medical field. I want to one day provide the same outstanding level of care for my patients like they did for my sister. I know that having those experiences of learning how to care for and communicate with Marissa will help me to succeed in my future career in healthcare.



**Abigaile, sister of Tommy,
living with TSC**

LIFE, LOVE, AND BASKETBALL

I always love seeing how happy Tommy is when he cheers me on at my basketball games. Just knowing he's there motivates me so much. Basketball is a big part of my life and being part of the basketball team is something I'm really proud of. It's important to me because it's taken me to so many places in my life. It's helped me travel to places I would've never thought of going to and make friends that I know I'll have forever. Playing a team sport like basketball also helps with life skills like responsibility, discipline, hard work, and how to work with others. I don't know where I'd be today if it weren't for basketball and having Tommy there by my side.

Tommy has impacted my life and helped me grow in so many ways. He's taught me patience and how to enjoy the little things in life. Tommy is one of the most genuine people I've ever met, whether he's sad or happy or just being silly. He has taught me how to never take life for granted and push through when things get difficult. Those lessons in perseverance and diligence have helped me succeed in basketball too, and I wouldn't trade them for anything.



**Natalie, sister of Marissa,
living with LGS**

FROM HELPING MOM TO BECOMING A MEDICAL PROFESSIONAL

Ever since I was little, I have been taking care of my older sister. I was fascinated with how my mom gave her medicines through her G-tube, even though I had no idea what it was or what it did back then. I'd always help my mom and dad prepare her medicines, or shake up her formula for her food because I loved doing it. I remember my grandma telling me once, "Natalie, you're going to make such a great nurse when you grow up." Of course, at the time, I didn't think much of that remark. But now that I've gotten older, I've grown more curious about my sister's condition, as well as many other things in the medical world.

I have the privilege to take the "Medical Pathway" classes at my high school, which have only furthered my interest in the medical field because I get to do fun and educational experiments that will help me later in my academic career. Next year, I will be taking a class where I'll be able to shadow doctors in a hospital and do fun projects—and I'm really looking forward to it. However, I never would've been on this path if my sister wasn't the person she is. She has inspired me to help people. I know she would do the same if she could, which makes me want to accomplish as much as I can throughout my journey to become a medical professional.

Thank you, **Makayla, Abigaile, Natalie,** and **Ronan,** for sharing your stories with us! We're inspired by your positivity and accomplishments and look forward to continuing to spotlight sibling stories like yours.

If you'd like to read more about families living with LGS, Dravet syndrome, or TSC, check out our other issues of *Living With Magazine* at LivingWithMag.com

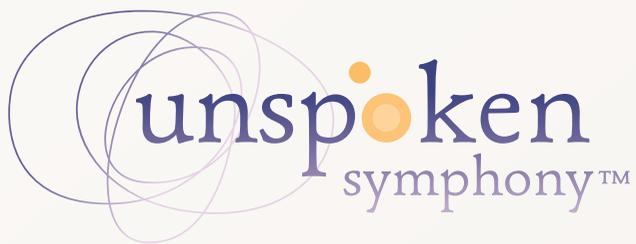


**Ronan, brother of Trent,
living with TSC**

FROM A TRIP TO D.C. TO MARCHING FOR TSC

My first trip to Washington, D.C. was in 2016 when I was nine years old. I also went in 2018 and 2020. My mom and I, along with many others from around the country, marched on Capitol Hill to advocate for funding TSC research. Finding a cure for TSC is vital for the health and quality of life of everyone affected by TSC, including family and loved ones, like my brother, Trent. I visited many state representatives/congressmen and the two Senate offices in California to represent siblings from across the country and tell my personal story of how TSC affects me as a brother to someone with the condition. I was only nine years old the first time I spoke in front of the members of Congress, and my story got them to approve the research funding that maybe wouldn't have otherwise been passed.

Talking about my personal experience is valid because everyone has their own story to tell. TSC affects me in ways that may be different than my brother, but that does not make it less important. Advocating on Capitol Hill made me feel empowered, emotional, connected, and part of a community who is advocating for a cause that is close to my heart. Speaking with staffers was very fun, because everyone I met had different backstories and they were all very educated. Learning what they did in high school and in college to get to where they are in their career was very interesting, too.

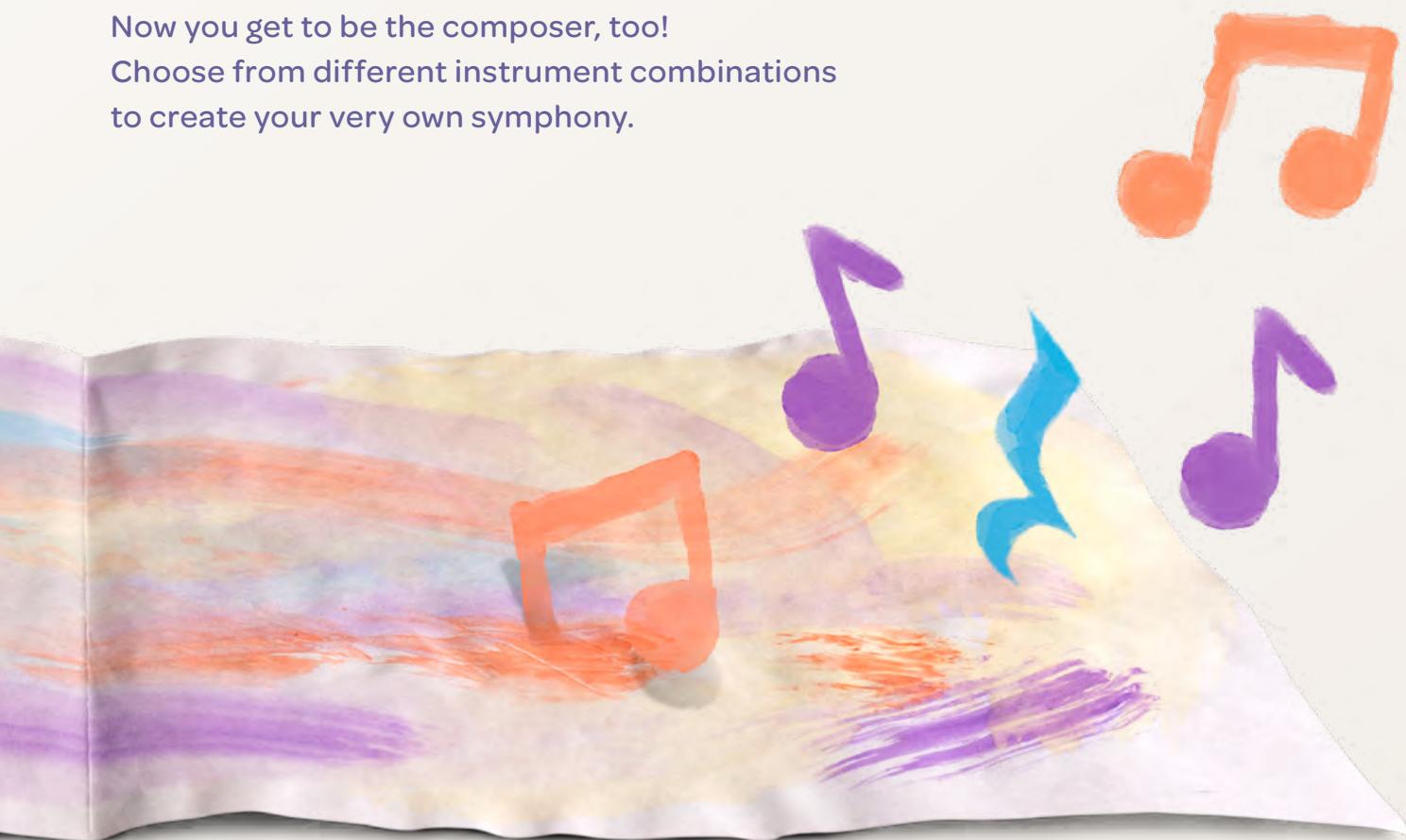


★ An award-winning program
A heartfelt story
How one family gave the gift
of unspoken symphony and
how you can, too! Read the
story on page 15.

where art turns to music before your eyes

Inspired by a girl who can't speak.

Now you get to be the composer, too!
Choose from different instrument combinations
to create your very own symphony.



Scan to start
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