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Living with TM

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Pictured here: Austin, mother of Owen, living with Dravet syndrome, and daughter, Dylan





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AT OUR CORE

We are excited to share the fifth 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 of 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 self-care, an important but often overlooked act for caregivers to loved ones living with rare epilepsy. While taking time for yourself may feel like a luxury, it's really a necessity that benefits more than just the caregiver. We hope the experiences and advice from families who have come to embrace self-care will encourage you to do the same.

In *Self-Care Is Not Selfish*, a mother and caregiver shares her journey to realizing that self-care is one of the most unselfish things a person can do.

Words of Advice focuses on 3 caregivers whose paths to self-care were unique but whose appreciation for the value of self-care is common. Learn about their

challenges, what self-care provides for them, and advice for other caregivers.

In *Sibling Self-Care*, we meet Mikenna, a sister to 2 siblings living with TSC. Discover why sharing her feelings with others who understand her situation is a form of self-care for her.

I Can and I Will is the story of Phil Haydon's history of epilepsy and how 5 important words helped him sail forward in life. Learn about how giving back and sailing both play vital roles in his life.

We hope this issue of *Living With* helps you see self-care as a valuable aspect of being a caregiver and prompts you to look for opportunities to add self-care to your daily routine.



To download previous issues or select future topics, visit LivingWithMag.com



WORDS OF ADVICE

Self-care conversations from caregivers of those living with rare forms of epilepsy

When caring for someone with a rare form of epilepsy, self-care is often pushed aside as “a luxury” or even “selfish.” However, it is a vital part of being a caregiver because you need to tend to yourself to be able to help others. Here, we share conversations with 3 caregivers about the value self-care provides for not just them but those around them as well. We hope their stories inspire you to also seek out those important moments of self-care.



Ben D.

Father of Addie, living with LGS

My family includes my wife, Jackie, my daughter, Addie, 27, who was diagnosed with LGS at 4 years old, and my son, Leo, 25.

How did you come to understand the importance of self-care?

After our daughter was diagnosed, it was crucial that my wife and I took time for ourselves, both as a couple and as individuals. However, it took quite a while (and a nudge from my parents) to act on that knowledge. My dad said, “Make sure you and Jackie take some time for yourself. Go out to dinner,” and it seemed so ridiculous. Who can go out to dinner at a time like this? But we would do it, and then we made a habit of doing things like taking long walks around our neighborhood together.

All of this really helped with the anger I was experiencing. Jackie and I would talk, and she said, “This sort of anger and frustration isn’t helpful to Addie.” We realized we needed to be the best version of ourselves that we could be. Additionally, as part of the therapeutic preschool that Addie attended, we were required to go to couples therapy. I think that’s one of

the reasons why all of these couples, many of whom we still know, are together 20 years later.

What are some ways you practice self-care individually?

I find great joy and satisfaction in doing things I have never done and, in fact, have never dreamed of doing, like writing a musical, painting, and boxing. I am one of the last people I would imagine who would find comfort in a boxing gym, but it was a productive place for the anger I felt.

I eventually brought Addie to the gym with me, and she took to it like a fish to water. I think she saw the example of us taking care of ourselves and taking care of her. She’s 27 now and trains daily in martial arts and hasn’t had a seizure in 17 years. I add this to my long list of “things I never expected.” For her to find strength, literally physical strength and emotional strength, through fighting is great. It’s everything.



What does self-care mean to you?

Getting myself in a good place so that I can be my best for those I love.



who see my commitment to the gym and say, "I should go," and they start going. I would've never gone to a boxing gym. It just happened that a guy I knew was involved with it.

Is there anything that you would tell new caregivers that may help them meet their challenges?

Never lose hope. Addie learned to read at 13. She also lives on her own. These are 2 things I never expected. Everyone's experience will be different, but I have been struck by the life course of all of the little kids who struggled along with Addie growing up. They are all, each and every one of them, doing things nobody would have imagined possible back then.

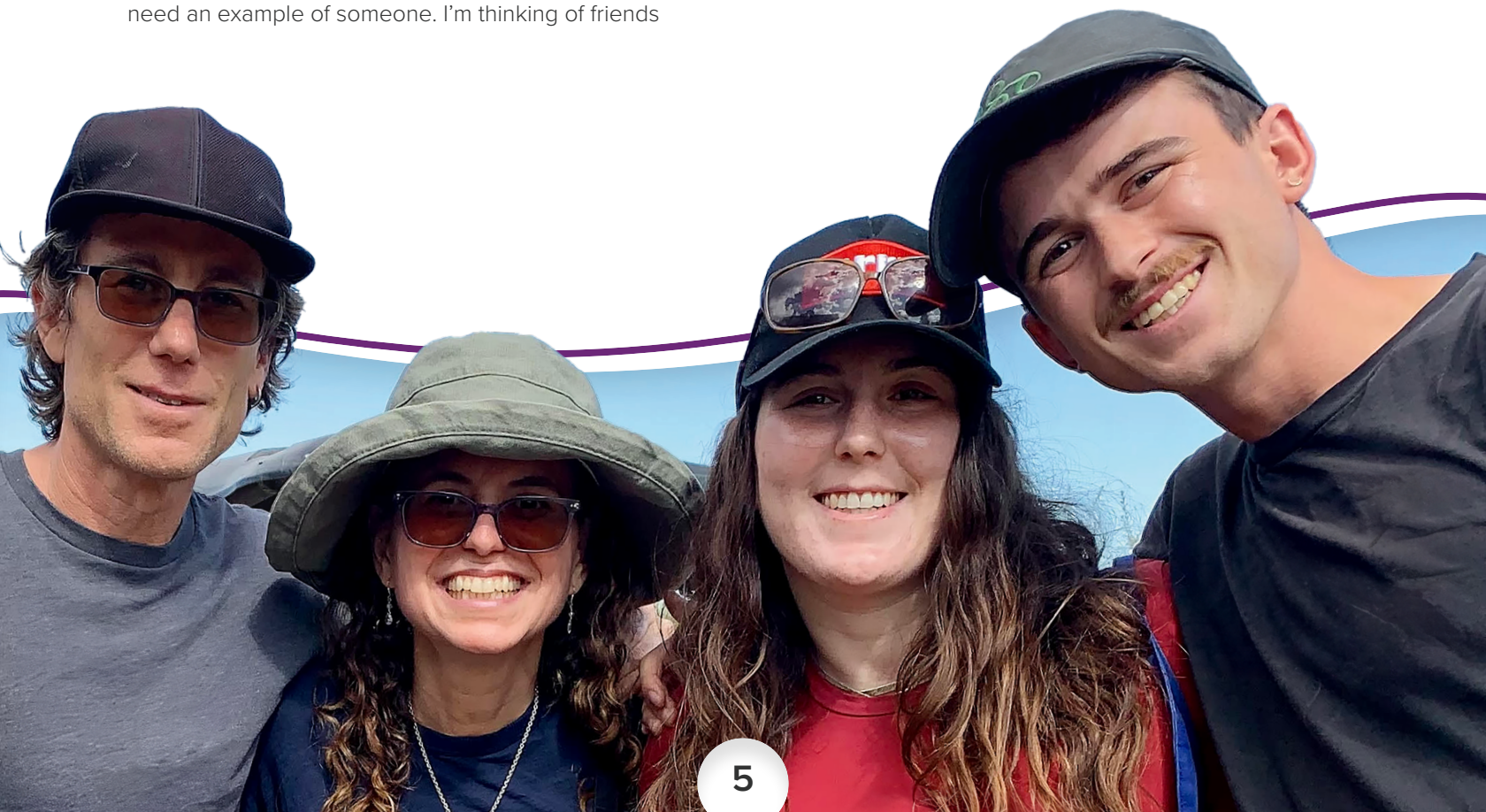
Have you found a way to pay it forward?

Writing has been helpful because when people read it, they reach out to me about their experiences, which I really like. I've been through a lot, so I do things like go to Epilepsy Awareness Day at Disneyland® and talk to people. I got a text this morning from someone who said their friend has something going on with their kid and asked if they can reach out to me. That kind of connection means a lot.

There's also something about doing things that are seemingly for yourself, but by doing those caretaking things, you are providing a service for the community, your family, and maybe your kids. Sometimes, you just need an example of someone. I'm thinking of friends

Do you have a mantra?

Just remember that everyone is doing their best, and people are imperfect. I hate to admit it, but I probably am, too. And this is all okay.





Lilian A.

Mother of Atrina, living with TSC

My family includes my husband, Saied, my son, Ardalon, 19, who lives with autism, and my daughter, Atrina, 15, who lives with TSC.

How does your epilepsy community play a role in self-care?

Although I am very connected now, I didn't connect with TSC families when Atrina was first diagnosed. I connected with other families that had medically fragile children or kids with autism. You meet people in the waiting room. You start talking to each other, and you develop a radar for other kids with disabilities when you're out and about in the community.

Everybody's stories are different, but we developed instant connections and built a community because we all were dealing with grief, uncertainty, fear, and exhaustion. That was about 14 years ago, and we held on to each other for dear life. A small group of us ended up really sticking together, and we still see each

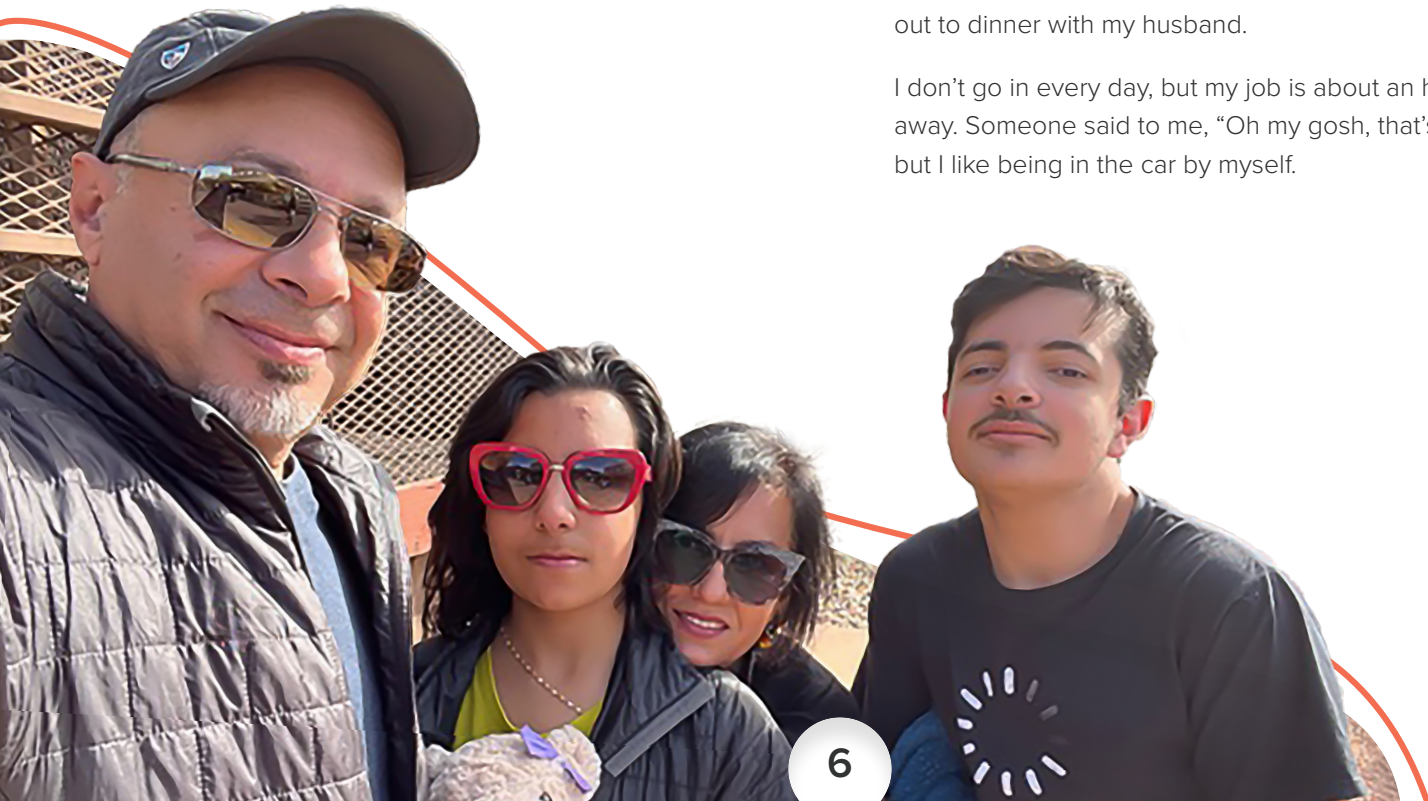
other regularly. It's the center of our survival. We have dinner together on Friday nights, and the kids hang out together.

I would not have been able to survive without having a community. I was a first-generation immigrant, put myself through college, cared for my only sibling with a disability, and then had a child with a disability.

What other ways do you find opportunities for self-care?

I realized if I wait for things to slow down or calm down, I will never get to do the things I want to do, so I look for pockets of joy and relaxation. I aim for simple things, like taking a watercolor class, meeting with a friend while the kids are at school, taking a walk with the dog, and occasionally, with lots and lots of planning, going out to dinner with my husband.

I don't go in every day, but my job is about an hour away. Someone said to me, "Oh my gosh, that's so far," but I like being in the car by myself.





That's my "me" time. I listen to music or audiobooks, make calls, or just sit quietly. And sometimes, it feels really nice to just be quiet. My nervous system feels fried every now and then, so I don't want any music or noise.

Give yourself grace.

Taking care of our kids is really as hard as it looks. Don't try to white-knuckle your way through this or you will not survive. Find pockets of joy now. Don't wait for things to change or slow down.



clean and I can shower, put lipstick on, and leave the house does not mean I'm okay. So, I've gotten a lot better at asking for help.

As an advocate for both Atrina and your son, Ardalon, what advice do you have?

Trust your gut. I help support other families, and many times, the caregiver comes to me and says, "Something's up with my kid. This is not feeling right." You are the expert on your kid, but if you don't speak up, you might be dismissed over and over again. I've heard a lot of dismissive thoughts about my children. "Your kid is bilingual. That's why." "Boys eventually catch up." "I had a cousin who had this, and he was fine by the time he was 6." But my gut was screaming to me that this was different. Trust that gut.

What advice do you have for new caregivers who may be unfamiliar with self-care?

I was super independent and wanted to do things on my own. That had to change for me to survive. I had to ask for help and not try to keep it together all the time. I need to remind people that just because my house is

Do you have a mantra or words that you live by?

I have been working on saying "no," not overcommitting myself, and simplifying life when I can, which is why my current mantra is "just because you can, doesn't mean you should!"





Melanee S.

Mother of Daijah, living with a rare form of epilepsy

My family includes my daughter, Daijah, 21, who lives with a rare form of epilepsy, and our 2 fur babies, Princess and Cutie Pie. My mom, Melody, my sister, Tamara, and some close friends also play a large role in our lives. Our home life is small, but our extended family is large.

What was your approach to self-care while also caring for Daijah during those early years?

I was a full-time employee and full-time student at the start of this journey with my daughter. Self-care was not on my list of things to do. It was initially challenging to consider self-care when my daughter was in so much pain and dealing with so much. Feelings of guilt for wanting to have fun or do something for myself when she is not feeling well would surface.

I have a lot of friends who are quite social, and I turned down many invites to meet up. I felt a sense of losing myself and falling into depression. But I hid it very well. I wore this mask. Nobody knew that I was crumbling on the inside. What I found solace in was reaching out to others near and dear to talk about their lives and coordinate a day and time for us to get together for lunch or dinner.

I understood that I needed to get together with others for me, but I made it more about them. It was a little trickery, if you will, to create the space I desperately needed.

What shifted that made you embrace self-care more fully?

I realized I had to make a change because I'd be no good at caring for my daughter if I was not in the shape to do so. An "aha" moment for me was my physical limitations. Daijah is now non-ambulatory, so I have to transfer her repeatedly throughout the day. This has caused a lot of wear and tear on my body and now my back, shoulder, and arm have issues. One morning, I woke up and couldn't move, and it scared me. I thought, "What if I can't get up and take care of my daughter? If I can't move, she can't move." Now, I take my physical health seriously and go to the doctor to get checked out. The thought of not being capable of caring for my daughter sparked a deep commitment to prioritize my self-care. This led me to adopt a dedicated stretch routine and commit to taking daily vitamins.

I also realized that I needed to create a routine around self-care if I was really going to make it a priority. I had to be intentional with my time and self-care schedule. I wanted to make it a priority rather than an afterthought.



Self-care to me means recharging my battery so that I am ready to operate at my highest potential.





What is included in your self-care routine?

I schedule monthly outings—lunches or dinners with my mentors and close friends, massages, or other activities that allow me time to carve out moments for relaxation and enjoyment. I also try to sit down for at least 15 minutes every afternoon to have a snack, play with the fur babies, journal, look at social media, play a game on my phone, or read a couple of pages of a good book. After all the craziness of the day, I need a moment to breathe and reset.

I try to also include activities that my daughter and I can do together, such as binge-watching our favorite shows or movies, singing karaoke, practicing cheer routines, doing a puzzle, or playing an interactive game.

This provides a relaxing self-care moment for me while I also spend time with her. I also have written a book, which was therapeutic for me and became my outlet. It allowed me to express my frustrations, anger, sadness, and other emotions without regard for how others felt about it. I now feel like I have a voice.

Do you have a mantra that you live by?

“Laughter is the best medicine.” My daughter and I find that music and laughter have been a great outlet for us. Life is short, and we must take lemons and turn them into lemonade so that we do not get swallowed up by the difficulties of the journey.





What's new with patient advocacy

Photo provided by Sofie's Journey, founder of Epilepsy Awareness Day at Disneyland.



Brad Levy, father of Sofie and co-founder of Sofie's Journey, and Gabi Conecker, MPH, Executive Director and co-founder of DEE-P Connections, share their stories and how their foundations can help support you and your family.

Sofie's Journey presents:

Epilepsy Awareness and Education Expo & Epilepsy Awareness Day at Disneyland®

Our world changed when Sofie was 5-and-a-half and we were rocked by her first seizure. We're not sure how many went previously undetected, as they were pretty mild staring spells in the beginning. Sofie's first identified seizure was on Friday, May 20, 2005, just before 6 AM, a day we will never forget. Sofie woke up and tried to talk, but her speech was "stuck" (for lack of a better word). At first, we thought she was playing around, but then we panicked.

By the time the paramedics arrived, 3 of the longest minutes later, she was yapping up a storm and questioning why there were paramedics in the house!

Sofie continued to have seizures despite many medication changes due to several (mis)diagnoses. We sought several opinions and consulted many neurologists, epileptologists, and neurosurgeons nationwide.

When Sofie continued to have seizures, 3-and-a-half years later, the opportunity was presented for Sofie to have a neurosurgical evaluation to see if she was truly a surgical candidate.





We were fortunate enough to find Sofie’s cure at the pediatric epilepsy surgery program at UCLA Mattel Children’s Hospital with our hero, pediatric neurosurgeon Dr. Gary Mathern, Dr. Raman Sankar, and their team.

Shortly after her successful surgery, the doctors encouraged us to create a community awareness day, as at that time, there was nowhere for families with epilepsy to connect.

In 2013, we had our first Epilepsy Awareness Day at Disneyland. We used social media and gathered 972 people (all in purple shirts) at the park, and in 2014, we debuted our first Epilepsy Awareness and Education Expo with the help of Dr. Deborah Holder.

Skip ahead to November 2023, and we just wrapped up our 11th annual event. We had a 2-day expo featuring 35 epilepsy centers bringing more than 150 epilepsy providers, 5 rooms with presentations running all day,

and 100 exhibit booths bringing everything epilepsy under one roof. On the third day, we shot our largest group photo to date, with more than 900 people making it into the picture.

February 27, 2024 marked Sofie’s 15th year of seizure freedom. Our family is committed to making the epilepsy journey easier for others. We had so much misdirection when Sofie was first diagnosed, and that was just time lost. Now, every time that we introduce a patient to a nationally known epileptologist or surgeon, we know that we just fast-tracked the pathway to success. That’s why we work so hard on bringing the best doctors in to speak and meet families.

We have already started planning for 2024, with a new website launch. As always, the expo will be free! Just come on out to the Disneyland Resort in Anaheim, California to be part of the largest gathering for epilepsy patients and professionals on earth.



Visit [epilepsyawarenessday.org](https://www.epilepsyawarenessday.org) for more info



Building **Community** and **Collaboration** across the DEEs

As caregivers to a loved one who struggles with difficult-to-treat epilepsy and its profound impacts including developmental delays, we have had nowhere to turn in the past for information that helps us manage care for our medically complex children. DEE-P Connections, run by DEE (developmental and/or epileptic encephalopathies) caregivers who know how complicated and challenging this life can be, is working to fill the gap in support and resources for our families. Our goal is to ensure that caregivers have the resources they need to feel supported and empowered to advocate and care for their loved one with a DEE.

Over the past three years, DEE-P Connections has grown to be an increasingly full-service resource for families whose children are impacted by the relentless

seizures and associated challenges that define DEEs. Our 45+ partners have a shared vision for DEE-P as a one-stop hub for DEE families to access high-quality resources and services.

Our webinars and ever-growing Resource Center offer families a single place to find reliable, vetted resources tailored to the DEE experience. Our webinars are developed and led in coordination with leading experts on topics critical to families, such as autonomic dysfunction, brain surgery, rescue medications, and therapies. These webinars are paired with a range





of resources from our partners in our Resource Center. These resources are helping caregivers navigate the many challenges they face with their loved ones who have DEEs—improving their knowledge about how to address medical and care challenges, aiding them in advocating for and finding better care, and ultimately improving quality of life for their families.

DEE-P is also a highly effective research partner working to fill the gaps in the understanding of DEEs. Among other efforts, in 2021, we started The Inchstone Project, a rigorous clinical research project aiming to tackle the challenges associated with measuring progress in the most severely affected populations and improve the efficacy of clinical trials to measure this population.

In 2023, DEE-P expanded beyond educational and research efforts to also provide critical support and community for DEE families. We are providing caregivers with opportunities to connect via DEE-P Discussions—panels of caregivers dialoguing on critical issues—as well as DEE-P Chats, which are unrecorded

open sessions for families to be in community with one another to listen, learn, ask, and talk with others who truly understand.

We hope you will take a look and see if our resources might be of help to you on your journey caring for a loved one with a DEE. If you don't see any resources on the issues that you need help navigating, please reach out to us and let us know so we can explore adding those to our Resource Center. And if you like what you see, please share our resources with your community and other families who you think may benefit from them.

We welcome hearing from families, clinicians and researchers who have ideas or may want to work together. You can reach us at info@deepconnections.net.



For webinars, resources, and additional support, visit deepconnections.net/care-and-family/caregiver-support

Watch *the* CAREGIVER video series

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.



For stories of strength, hope, and connection, visit TheCareGiverSeries.com





Seizure First Aid

How to help someone having a seizure

1

STAY with the person until they are awake and alert after the seizure.

- ✓ **Time** the seizure
- ✓ Remain **calm**
- ✓ Check for **medical ID**



2

Keep the person **SAFE**.

- ✓ Move or guide away from **harm**



3

Turn the person onto their **SIDE** if they are not awake and aware.

- ✓ Keep **airway clear**
- ✓ **Loosen tight clothes** around neck
- ✓ Put **something small and soft** under the head



Call **911** if...

- ▶ Seizure lasts longer than 5 minutes
- ▶ Person does not return to their usual state
- ▶ Person is injured, pregnant, or sick
- ▶ Repeated seizures
- ▶ First time seizure
- ▶ Difficulty breathing
- ▶ Seizure occurs in water

Do **NOT**

- ✗ Do **NOT** restrain.
- ✗ Do **NOT** put any objects in their mouth.
- ✓ **Rescue medicines can be given** if prescribed by a health care professional

Learn More: epilepsy.com/firstaid



In Partnership With



24/7 Helpline: 1-800-332-1000 | 1-866-748-8008 (en español)



Primeros Auxilios de Crisis Epilépticas

Cómo ayudar a alguien que está teniendo una crisis epiléptica

1

PERMANEZCA con la persona hasta que esté despierta y alerta después de la crisis epiléptica.

- ✓ **Registre** el tiempo.
- ✓ Mantenga **la calma**.
- ✓ Revise si lleva alguna **identificación de alerta médica**.



2

Mantenga a la persona **SEGURA**.

- ✓ Aleje o guíe a la persona de **objetos peligrosos**.



3

Acueste a la persona de **LADO** si no está despierta y consciente.

- ✓ Mantenga **las vías respiratorias** despejadas.
- ✓ **Afloje cualquier ropa ajustada** alrededor del cuello.
- ✓ Ponga **algo pequeño y suave** debajo de la cabeza.



Llame al 911

- ▶ Si la crisis epiléptica dura más de 5 minutos.
- ▶ La persona no vuelve a su estado habitual.
- ▶ La persona está lesionada, embarazada o enferma.
- ▶ La persona tiene una convulsión tras otra.
- ▶ Es primera vez que presenta una crisis epiléptica.
- ▶ Hay dificultad para respirar.
- ▶ La crisis epiléptica ocurre en el agua.

NO

- ✗ **NO** le sujete.
- ✗ **NO** le ponga ningún objeto en la boca.
- ✓ Se pueden administrar **medicamentos de rescate** si los receta un profesional de la salud.

Para más información: epilepsy.com/espanol



epilepsy.com

Línea de Ayuda 24/7: 1-866-748-8008 | 1-800-332-1000 (en Inglés)



Lili, living with LGS

SEIZURES™ ARE SIGNS

A general epilepsy diagnosis may not be telling the whole story

Noticing these signs may be clues that a more specific diagnosis like Lennox-Gastaut syndrome could be behind uncontrolled seizures.

- Persistent seizures
- Impaired motor function and difficulty walking without assistance
- Trouble concentrating and learning new things, or not engaging with others
- Hyperactivity, autistic traits, or even aggression

Visit Seizures Are Signs for these resources created in partnership with patient advocacy groups, epilepsy experts, and other families living with epilepsy:



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



Stories from other families who received a more specific diagnosis



Information about other rare forms of epilepsy and their signs

To take an assessment that could lead to a more specific diagnosis, visit SeizuresAreSigns.com/Assessment



Self-Care IS NOT SELFISH

| A musing on the most selfless act you can do for your family

What do belly dancing, a “Wall of Bad-Assery,” therapy, and moving to Idaho have in common?

They were essential in my realization that self-care is not selfish. Let's start from the beginning.

Austin W is the Family Network Coordinator for the Dravet Syndrome Foundation who enjoys backpacking, reading, and writing. She has also become an avid belly dancer within the last several years. She and her husband, Stewart, live in Idaho with their children Owen, 10, who lives with Dravet syndrome, and Dylan, 7.



My husband, Stewart, and our children, Owen and Dylan, have lived in Idaho for more than a decade. Stewart and I moved here right after our wedding in Portland, Oregon. We started to lay roots, and in the fall of 2013, we welcomed our first child, Owen. We watched him grow and change. He had his first seizure at three-and-a-half months old. At 13 months old, we got the diagnosis of Dravet syndrome. As you can imagine, we were devastated when the doctor called us in on his day off, thus changing the trajectory of our family.

After watching our son seize with no answers from doctors, I needed a way to try and relieve stress, anxiety, and depression. The only self-care I allowed myself was to exercise one hour per week, so I turned to a local studio. The woman who owned the studio has a daughter with Down syndrome. I asked her, “How do you deal with having a child who needs extra help?” Her reply, “Self-care is NOT selfish.” This proved to be the catalyst in my search for community and self in a profound way.

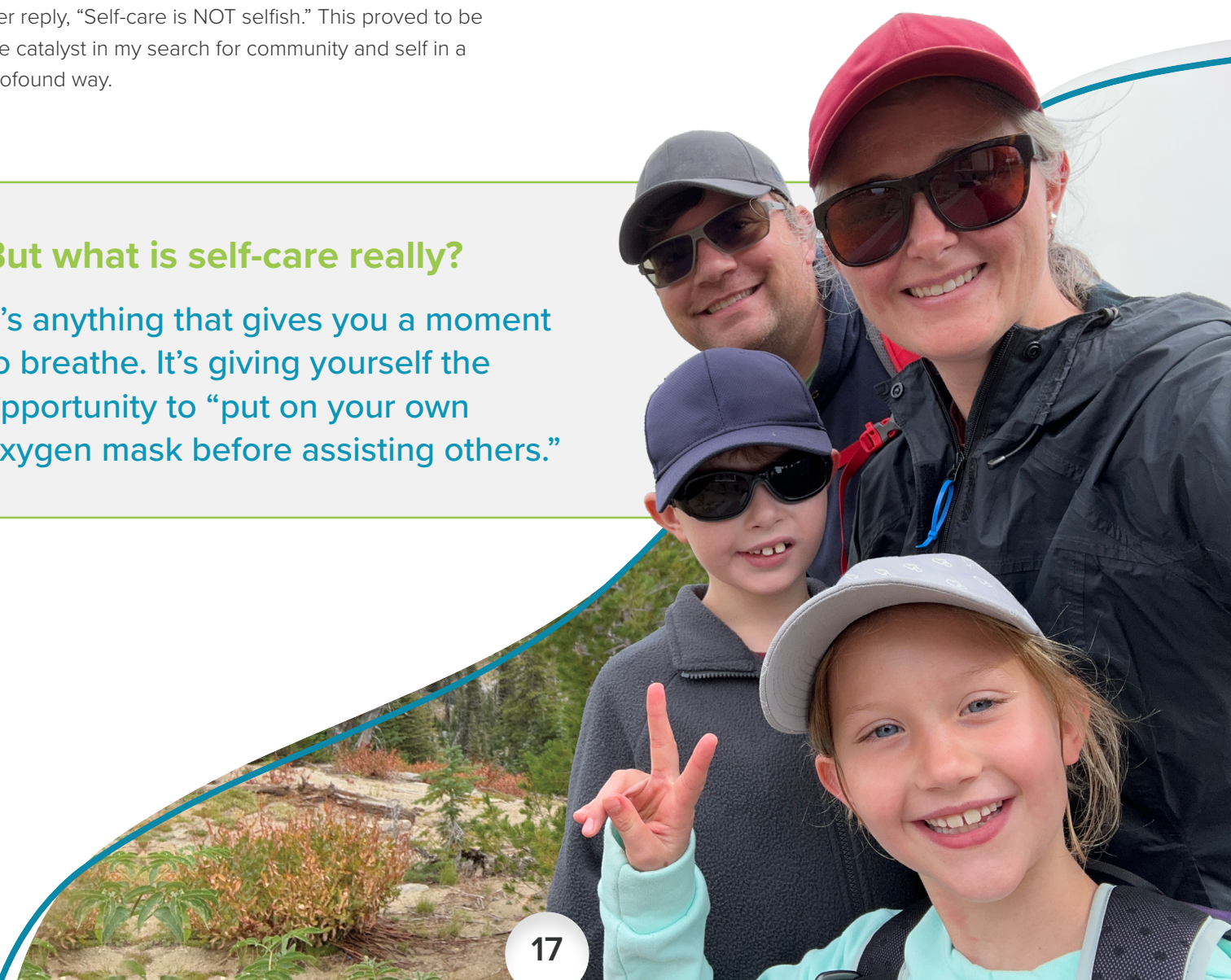
Over the last decade, I have worked to create self-care moments and experiences for myself. It’s taking 5 minutes to do a guided meditation with an app. It’s creating a “Wall of Bad-Assery” in my bedroom that is full of images, art, and memorabilia to remind me I’m powerful and strong. I sang in a local choir and joined a rock band. Three years ago, I became a belly dancer. In the last year, I began backpacking. In the last 6 months, I got a therapist. And at least once a year, I leave my family for at least 3 nights to be alone.

“The size of the self-care event is irrelevant. The important part is that it actually occurs.”

“

But what is self-care really?

It’s anything that gives you a moment to breathe. It’s giving yourself the opportunity to “put on your own oxygen mask before assisting others.”





But how do I find the time for self-care? How does it happen? I'll tell you one thing; it doesn't happen alone. I cannot care for myself without others caring for me. It can only happen with the help of a community we lovingly call "fram-ly." Our fram-ly consists of a collection of family and friends who we can call or text and say, "HELP" and they respond with, "I'm on my way!" Owen quickly taught us the need to cultivate and grow our community.

We found these people through our church, through the studio I worked out in, through a meet-up group we joined, neighbors, therapists, the Dravet Syndrome Foundation and its Facebook support group, and in my belly dance troupe.

You have to find the community that holds you together while allowing you the safety to completely fall apart. I found people, or perhaps they found me, when I needed them the most. People who literally held me in their arms as I collapsed. If you have to mask or temper yourself around someone or a group of people, they are not your community; find someone else.

Our fram-ly is there for us in every way possible. They give me the safety to be vulnerable, to be a mess, and help to remind me I am strong even when I feel weak. And they help to ensure that I have time to breathe and take care of myself.

It is not lost on me how lucky and fortunate I am. I am blessed with a mother-in-law who is very involved in the care of our family. I have a partner who will do anything for our children and affords me the opportunity to follow my dreams. I've spoken to many and have been asked, "How do you do it?" well, I "Just do." But that isn't the whole answer.

“ I am able to care for myself entirely because of my community.”





But why do self-care? Why does it matter? Simply stated, I'm a better version of myself. I'm more alive, more able to face the next thing.

“When I take care of me, I'm much better equipped to take care of others.”

And those others notice. My daughter knows that when Mommy goes to therapy or goes on her trips, she comes home with more energy to play and be silly and be the best mommy she can be. Plus, my daughter is learning something that took me decades to learn—I am worthy of self-love.

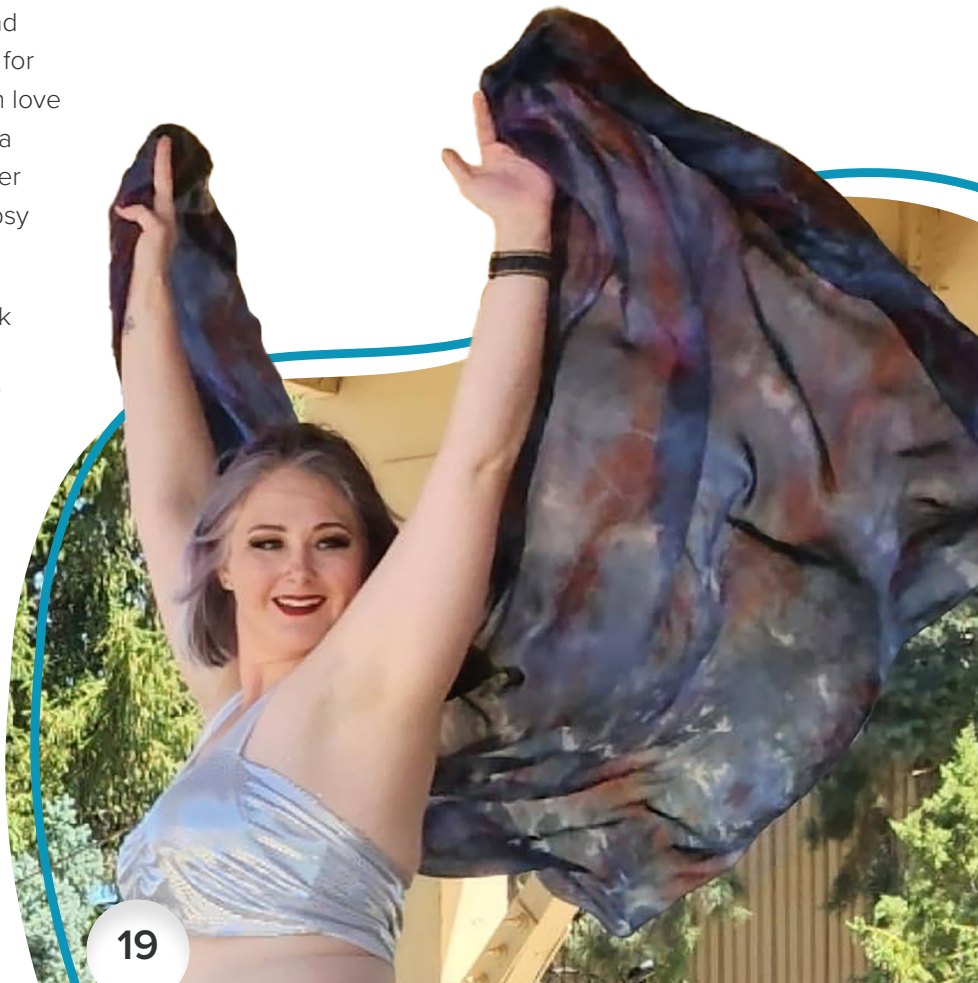
So, where do you start? Start by downloading a meditation app and spend 5 minutes meditating before bed every day. Go for a 30-minute walk, even if that means pushing your child in their wheelchair. Ask a friend to go to coffee or brunch on a Saturday morning. But my best recommendation is to get a therapist well-versed in complex PTSD, prolonged grief and trauma, and/or chronic illness. It took a long time for me to finally get a therapist. But after some tough love from my sister, I set a deadline that I would have a therapist by a specific date. And I did. So, consider this some tough love from your intractable epilepsy sister, and get a therapist.

It is a great act of courage and vulnerability to ask for help. But if you don't ask, you're only hurting yourself. There is a beautiful exchange of energy that happens with self-care. I cannot achieve self-care without the help of others and they cannot care for themselves without my help. What better way to be selfless than to ensure that self-care is happening for someone else? I'm beginning to realize that not asking for help and not giving



yourself some love is, perhaps, one of the most selfish things a person can do.

Our family has a lot of little mottoes by which we live. But the most important is “self-care is not selfish.” It is necessary. It is vital. It is hard. But it is worth it. My family is worth it. I am worth it. And so are you. Take care of yourself, and everything else will be easier to take care of.





Sibling Self-Care

Siblings are often unsung heroes for families living with rare forms of epilepsy.

We talked with Mikenna, sister to Ashlin and Mason, about her relationship with them, how she now shares her feelings without guilt, and what she wants other siblings in similar situations to know.

Mikenna, 19, is a freshman in college, and when she's not studying, she can be found writing articles for her campus club or listening to Taylor Swift while taking a walk. Mikenna loves playing softball, reading fantasy and romance books, and is always up for a movie (just no horror, please!). Her sister, Ashlin, 22, was diagnosed with TSC at 5 months old, and her brother, Mason, 10, was diagnosed 4 days shy of 7 months.

How is your relationship with your older sister, Ashlin, and younger brother, Mason?

I think it's a pretty standard relationship with Ashlin where we get along, but we also get into disagreements like siblings do. She is highly affected by TSC, so we don't have full conversations like sisters typically would.

My relationship with Mason is different because he isn't as affected by TSC. He and I go at it sometimes, but we also get along really well. We're pretty close. We talk about his interests most of the time. He doesn't really relate to my interests, except that I've gotten him into Taylor Swift a little bit.





What do you do to make sure that you can recharge with some “Mikenna” time?

Before college, when I was living at home, I tried to take my dogs for a walk every day. I put my earbuds in and either listened to music or a podcast and just got out of the house for a while.

I also typically had softball practice, so I was out of the house for a couple of hours after everyone was getting home from school. When I would come home, I would kind of decompress and relax in my room. I'd do my homework, listen to some music, and then read at night when everyone was going to bed and it was quiet.

Do you have someone you can share your experiences with?

My best friend, Taylor. We have been friends basically since the moment we were born, and her mom is also really good friends with my mom. They know everything that goes on, and every time something happens, I always text Taylor about it. She understands everything from my perspective versus other people who might not fully grasp what I'm feeling at that moment. I was hesitant to talk to other friends about it just because it's always so much to explain.

But talking about it is important. I participated in a video that focused on other siblings in similar situations. Seeing their stories was helpful because it validated what I was feeling. I feel like, sometimes, when I talk about my siblings, it comes across as though I don't like them or I hate my situation, and that's not true at all. So, it was really validating to understand that other people were going through the same thing, that my feelings were valid, and I was understood by other people.

“I hesitated to talk with my parents because I knew that they were always stressed. But now I'm able to do that. I appreciate it because they understand that I'm not trying to complain.”

I also started seeing a therapist pretty early on, so I always had her to talk to. I initially hesitated to talk with my parents because I knew that they were always stressed about everything. But now I'm able to do that, and I really appreciate it because they understand that I'm not trying to complain. I'm just trying to express what I'm feeling. I'm glad that I can go to them now. I think I could have in the past, but I didn't.

What advice would you give to other siblings of people living with rare forms of epilepsy?

I would say that whatever you're feeling about the situation, your feelings are valid, and there are people out there who might not be in the same circumstance but can understand what you're feeling and relate to it. And definitely try to find someone, like a friend, a parent, or a therapist, to talk about your feelings with and process them. It's more helpful than you would think, and it's very beneficial to understand that what you're feeling is okay.

“Whatever you're feeling is valid, and there are people out there who can understand what you're feeling. Try to find someone, like a friend, a parent, or a therapist, to talk about your feelings.”





“I Can and I Will”

Five words to live by

By Phil Haydon, PhD, President of Sail For Epilepsy, and a person living with epilepsy

On July 6, 1973, my life changed forever.

That day, I was hit in the forehead by a brick. It fractured my skull and started my journey with epilepsy. Over the next 4 years, I went through 2 skull surgeries, various medications, and numerous absence and tonic-clonic seizures.

I was fortunate enough to eventually gain seizure control. With hard work and a little motivation from my grandmother (I'll explain in a second), I built and advanced my career to become Chair of Neuroscience at Tufts University School of Medicine. But it wasn't an easy path.

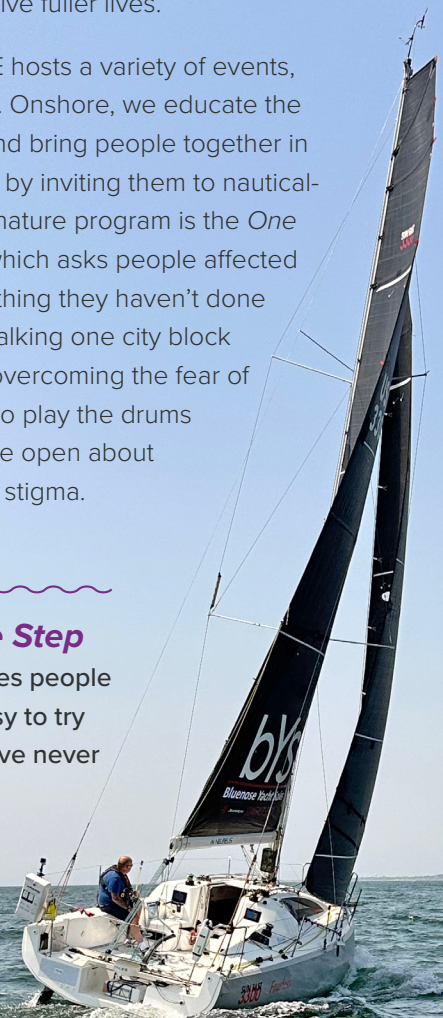
In those early years, I lived with fear of the unknown, a fear with which I suspect many of you are familiar. During that time, my grandmother, Grandma Lil, would cut phrases out of self-help books and magazines to inspire the family. One day, she hung a magazine clipping on the refrigerator door with the 5 words that I've learned to live by: *I can and I will*. When the going got tough, she would say, "Phil, I can and I will!" It's been my motto ever since. Though I didn't realize it at the time, she was the inspiration that has helped me get to where I am today. Thanks, Grandma Lil.

“My family lived by one statement in my early years of dealing with epilepsy: **‘I can and I will.’**”

After remaining silent about epilepsy for decades, I realized I wanted to help other members of the epilepsy community. So, I made a big decision in 2019. I established a non-profit with a friend of mine who was passionate about sailing. We named it Sail For Epilepsy (S4E). Our goal for S4E is to use sailing as a unique platform to raise awareness of epilepsy, to educate the public about the condition, and to inspire people affected by epilepsy to live fuller lives.

How do we do this? S4E hosts a variety of events, both on land and at sea. Onshore, we educate the public about epilepsy and bring people together in the epilepsy community by inviting them to nautical-themed events. Our signature program is the *One More Step Challenge*, which asks people affected by epilepsy to do something they haven't done before. This could be walking one city block alone, riding a tricycle, overcoming the fear of doctors' visits, learning to play the drums or guitar, and being more open about epilepsy to help reduce stigma.

“**The One More Step Challenge** invites people affected by epilepsy to try something they have never done before.”





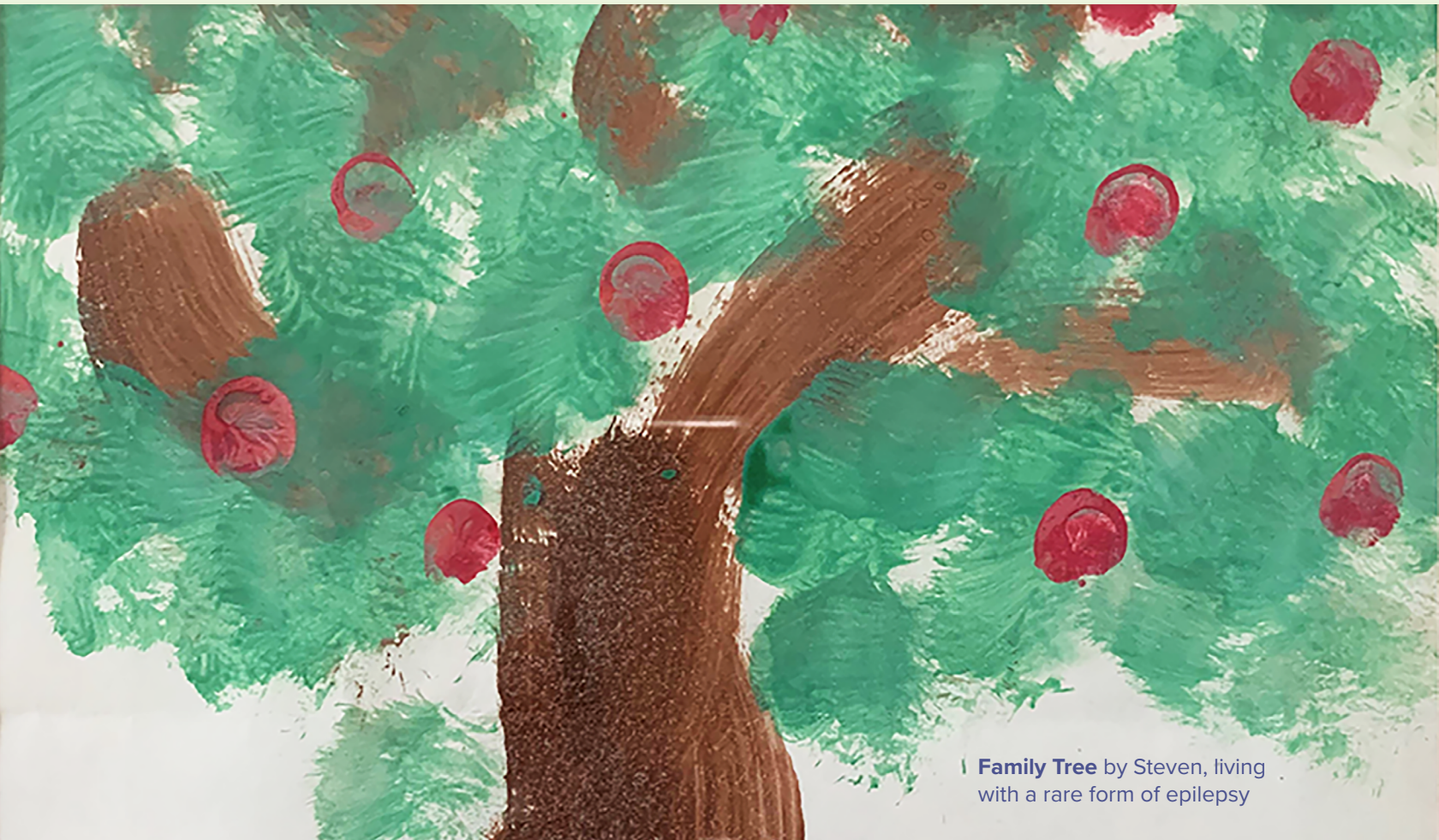
Participants in the *One More Step Challenge* become Virtual Shipmates. We add their names to the hull of the boat, and we sail for them. This serves as a reminder to keep moving forward even through choppy water and is a way for us to carry the epilepsy community with us on our trips. S4E works to support the community in other ways, too. During our sailing adventures, we transmit live video broadcasts to our epilepsy community. We also share real stories of ways others are living their life despite epilepsy.

Getting into sailing was my personal *One More Step Challenge*, and that one step has taken me farther than I ever expected, crossing the Atlantic Ocean and sailing solo to Bermuda multiple times. Whether you participate through S4E or on your own, I urge you to push yourself safely into new territory. You may be surprised at how far you can go. People in the epilepsy community are proving every day that they can and they will, and I believe “you can and you will”, too.



Would you like to go further with the *One More Step Challenge*? Visit sailforepilepsy.org/oms to learn how to get involved.

Philip Haydon is an internationally recognized neuroscientist and former Chair of the Department of Neuroscience at Tufts University School of Medicine. He runs an active laboratory researching a multitude of neurological disorders, including epilepsy. As president of Sail For Epilepsy, Phil is on a mission to inspire people with epilepsy, their families, and their caregivers to take *One More Step* toward living a fuller life, with the necessary safety measures in place.



Family Tree by Steven, living with a rare form of epilepsy



WHERE ART TURNS TO MUSIC RIGHT BEFORE YOUR EYES

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