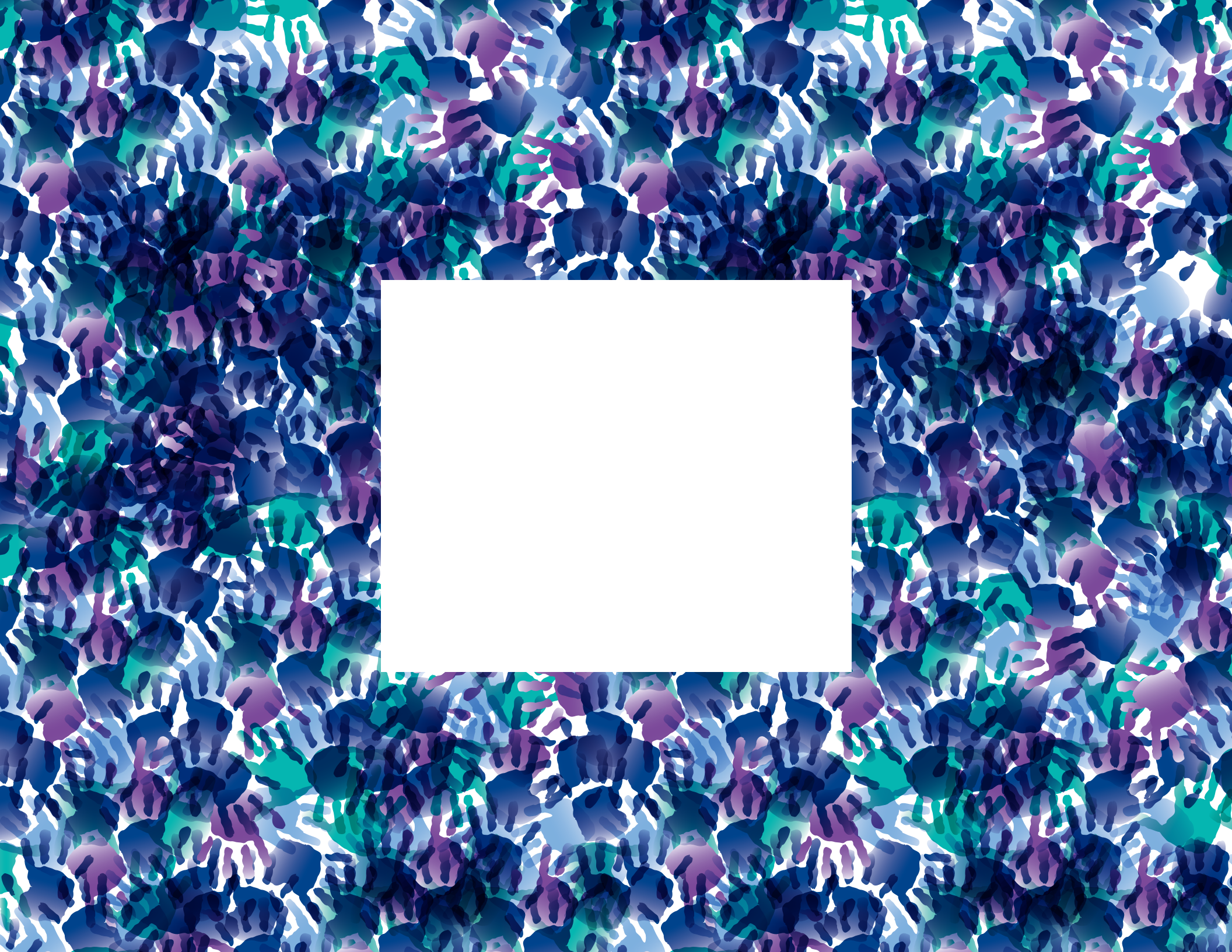




The Journey of
Lennox-Gastaut Syndrome (LGS)
in art and words



A Heartfelt Welcome

Managing the day-to-day needs of Lennox-Gastaut syndrome (LGS) can be overwhelming. But with the support of the LGS community, you can learn how to navigate the challenges, stay hopeful about the future, and move forward through the harder times.



From our families to yours, we hope this book comforts and inspires you at every stage of the journey.





Sharing Experiences Across the Journey

At the 6th International Family and Professional Conference in Seattle Washington, Aquestive® Therapeutics and the LGS Foundation joined forces to host a community project called the Art of Living with LGS. Through this project, families and friends affected by LGS were able to share their experiences, advice, and encouragement through art and words.

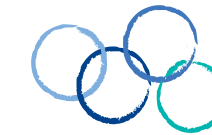
The art activities focused on 4 key points in the LGS journey:



Early Symptoms
and Diagnosis



Managing the Disease
and Treatment



Community
Connections



Future Hopes
and Dreams

Together, they created not just art, but the picture of strength, hope, and support for all those living with LGS. We hope their work and stories inspire you, wherever you are in your journey. They have inspired us as we continue our quest to advance medicine, solve problems, and improve the lives of those living with LGS.





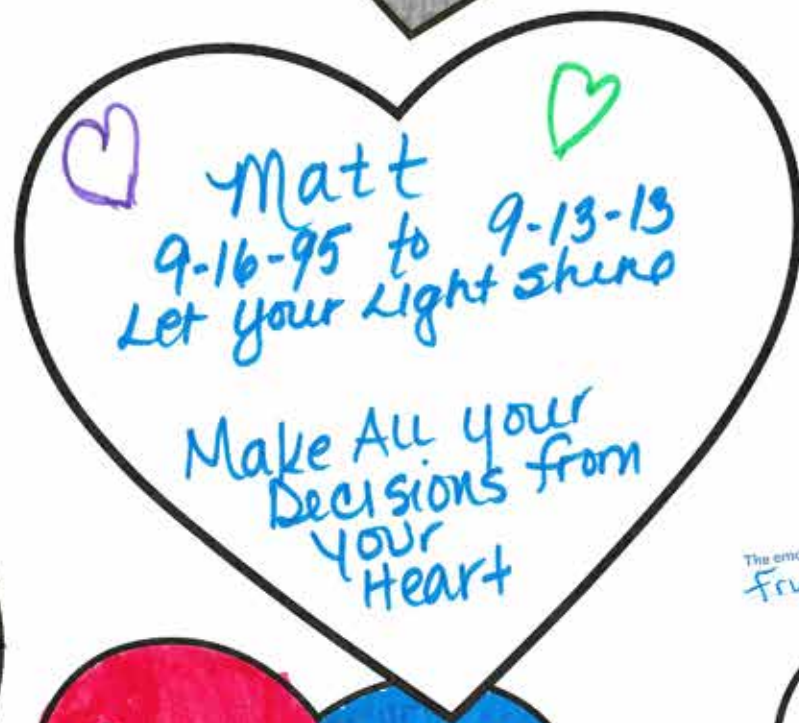
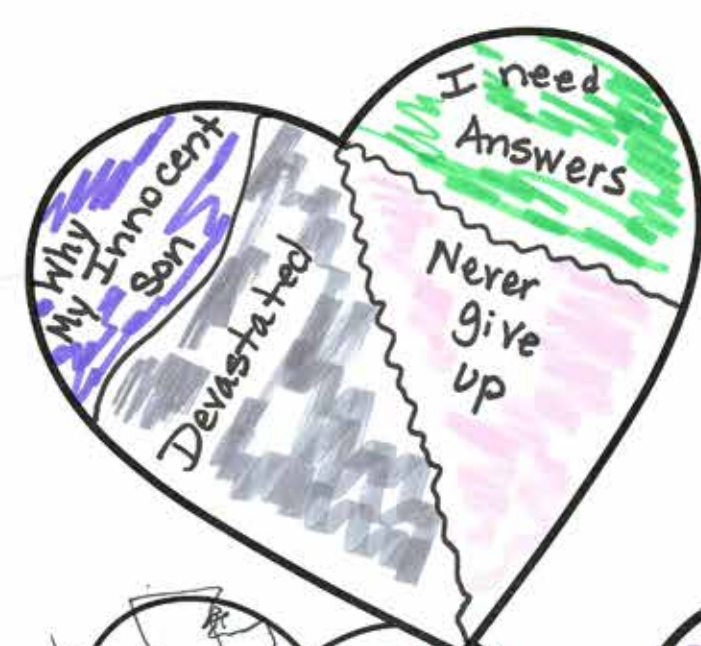
EARLY SYMPTOMS AND DIAGNOSIS

Heart Maps

The time from the very first seizure to getting a diagnosis is a rollercoaster of emotions. For this activity, families and friends created Heart Maps to show the collection of emotions they experienced at this early point in the journey. Others used the Heart Maps to express how they were feeling at that moment.

Though each person's experience with LGS is different, these Heart Maps show how much there is in common—and how getting a diagnosis is the first step to finding the right treatments and connecting to a community of support.





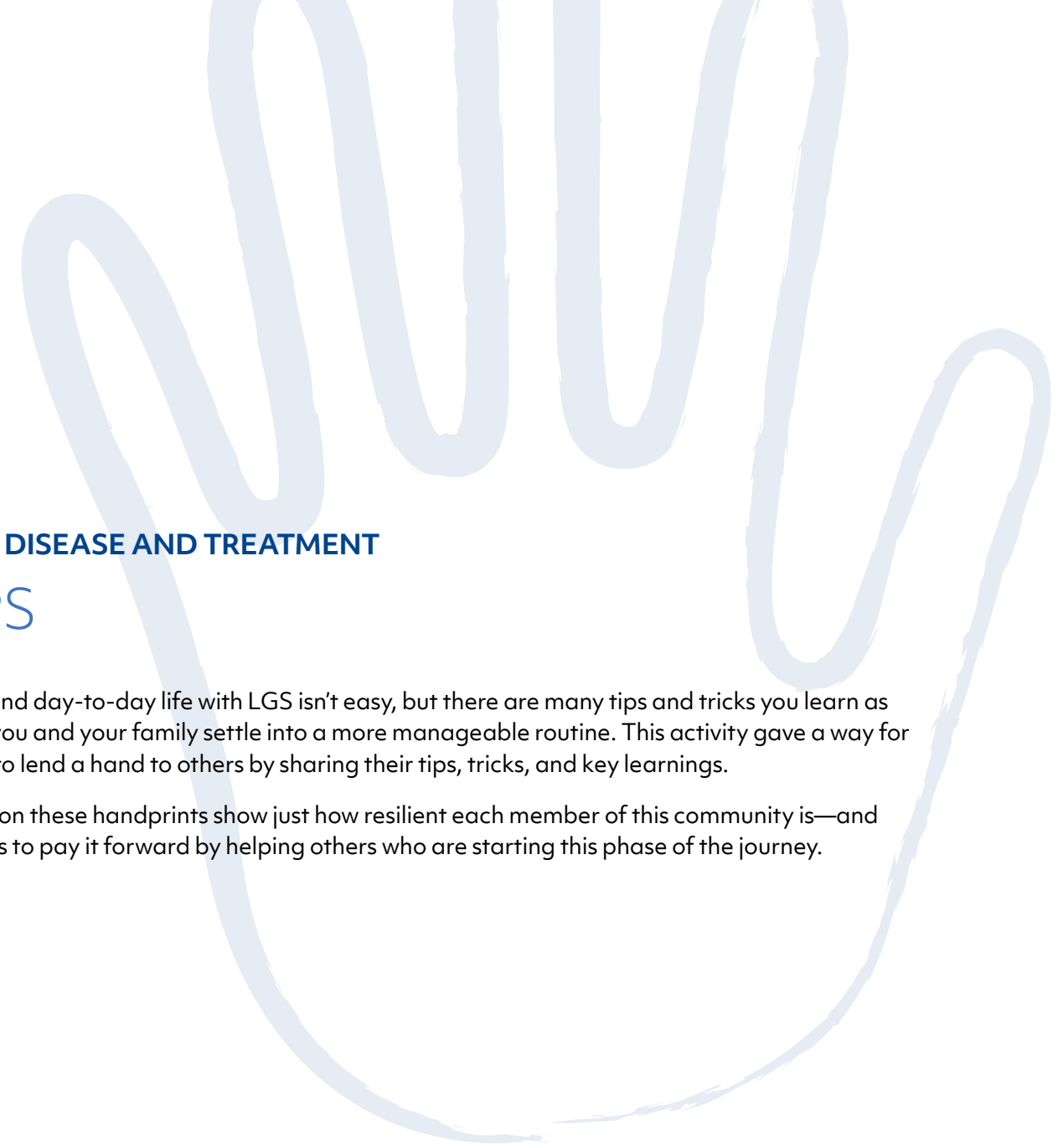


MANAGING THE DISEASE AND TREATMENT

FingerTIPS

Handling treatment and day-to-day life with LGS isn't easy, but there are many tips and tricks you learn as you go that can help you and your family settle into a more manageable routine. This activity gave a way for those living with LGS to lend a hand to others by sharing their tips, tricks, and key learnings.

The words of wisdom on these handprints show just how resilient each member of this community is—and just how important it is to pay it forward by helping others who are starting this phase of the journey.





What is NORMAL?



- Make time for YOU!
- Education breeds understanding
- We are not ALONE!
- The only opinion that matters is yours!



brother
I Love you brother
you are sweet
#JJSTRONG Faith

I MY LGS FAMILY!



Ask for help

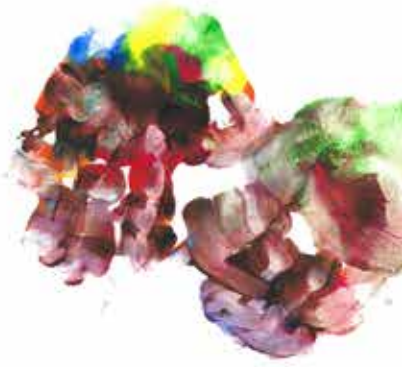
Think Positive

laugh

remember to breathe

Advocate!
speak up!
You know your child best!
One day at a time

#JJSTRONG



- Build relationships
- Find Positive People

- Live in the moment

Did I already say "Live in the moment"?

- Never give up



Sometimes I cannot shake your hand but a pound of the fist still says hello



hello

Make time for yourself



Be patient

Don't get upset

Be calm

Be soft

Be Patient

Be nice

Be happy

Have Fun

acceptance



My hand is not perfect, and I am not either but that's what makes me different and stand out. Be different is the best option.

Be Patient



GO HAWKS!

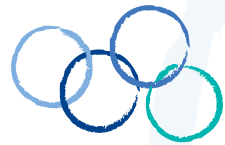
- Breath

- Dance

- Laugh!

- Church every week

- Go the little things



COMMUNITY CONNECTIONS

Links to the Lennox-Gastaut Syndrome Foundation (LGSF)

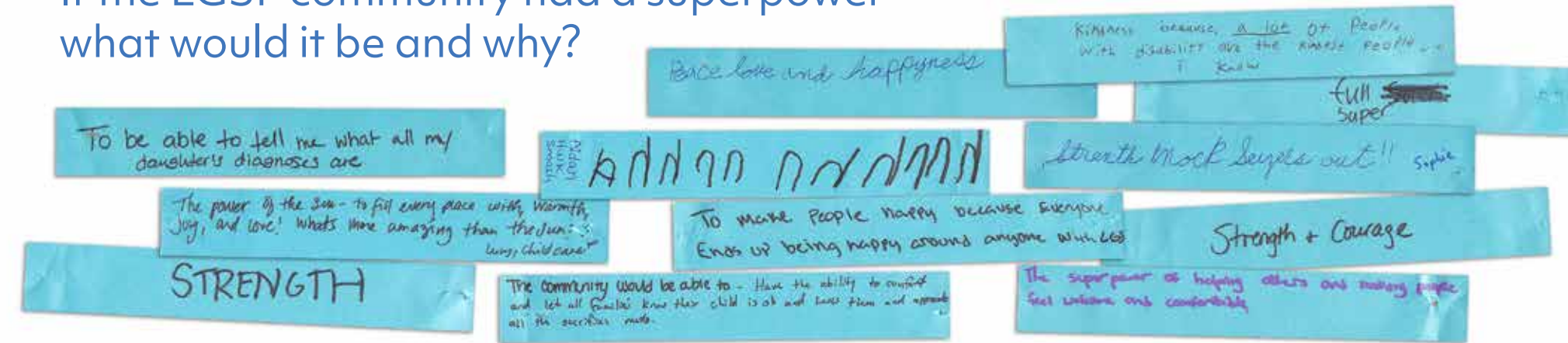
Connecting with the LGS Foundation has been life changing for many. Through these links, families and friends shared what the community means to them and what they value most about being a part of it.

The links in this chain show the strength of the LGS community—and like any strong bond, it cannot be broken. It truly takes a village of support and members of the community are a very strong tribe. Don't be afraid to reach out when you need help or just need to talk. The LGSF community is here for you. Visit www.lgsfoundation.org to learn more about the foundation and connect to the support you may need.

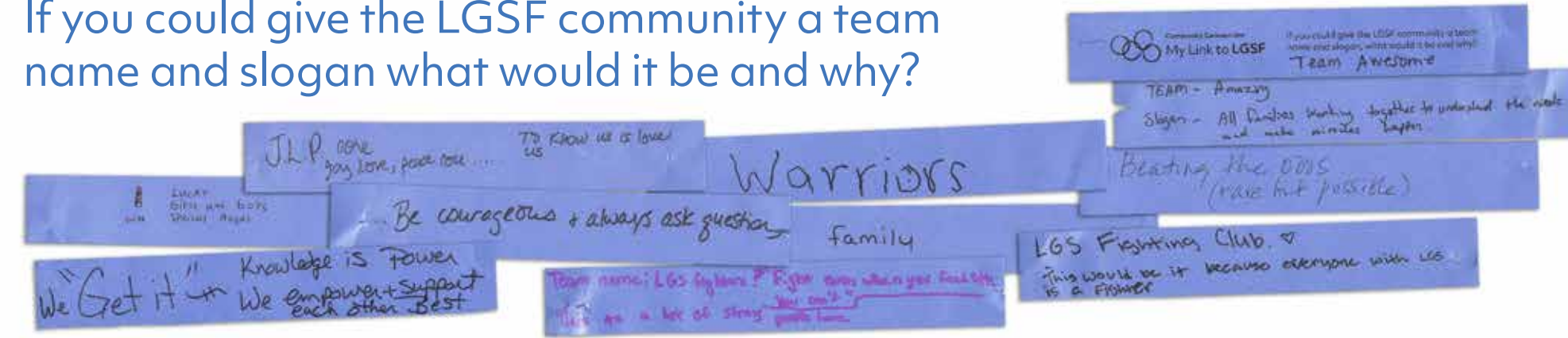
What 3 words best describe what the LGSF community means to you?



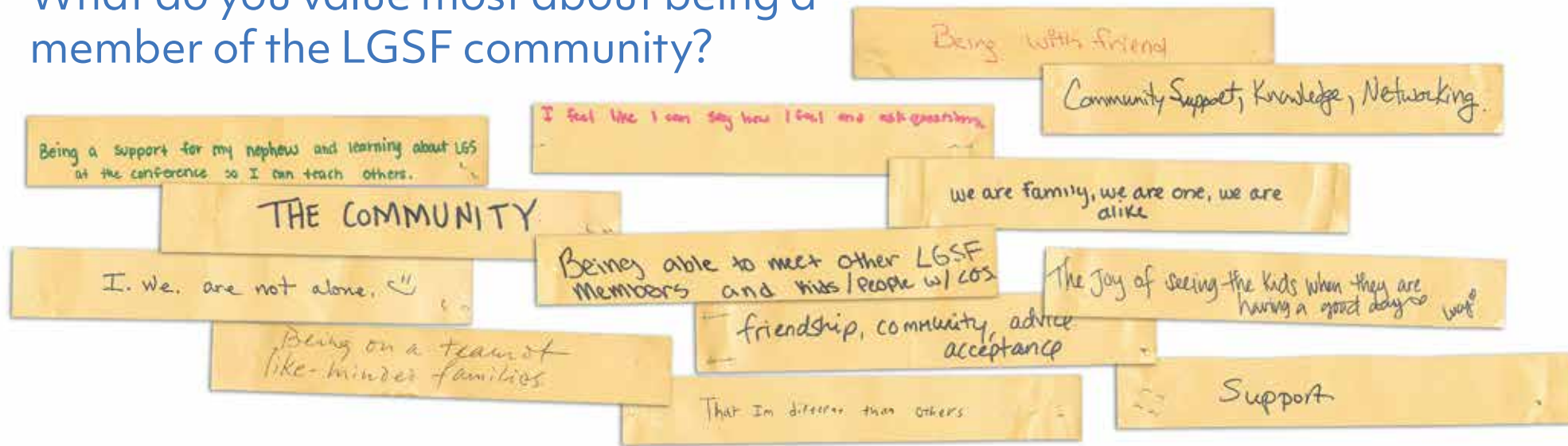
If the LGSF community had a superpower what would it be and why?



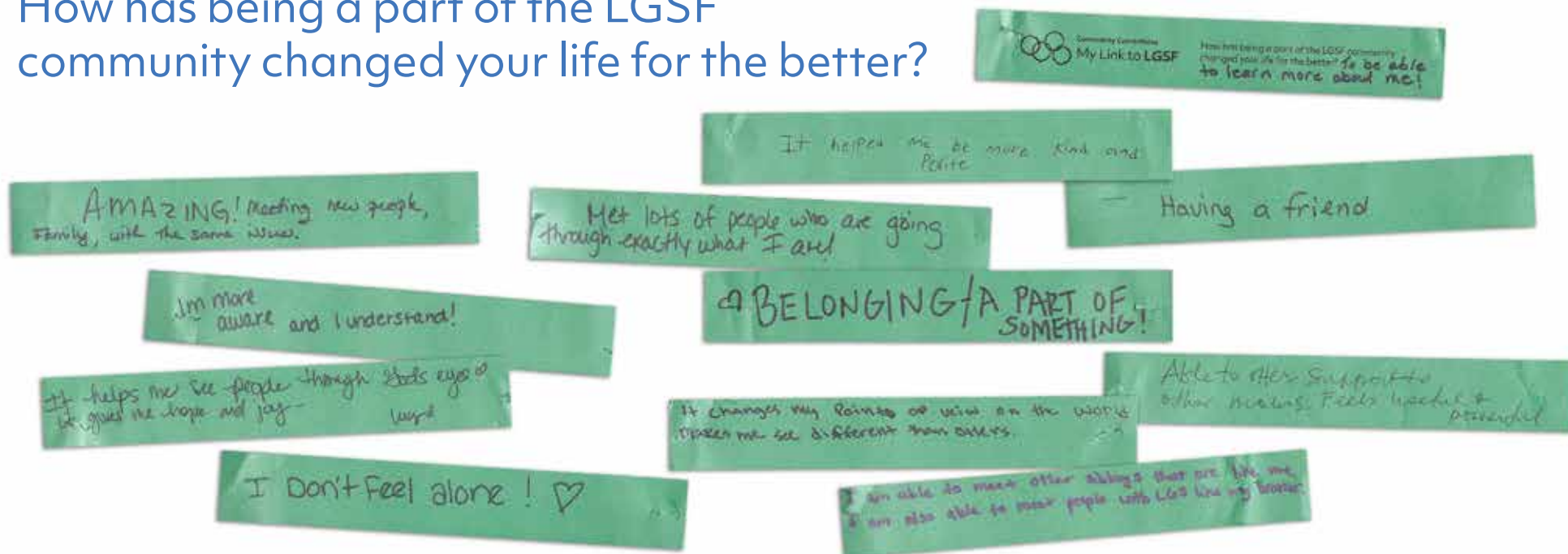
If you could give the LGSF community a team name and slogan what would it be and why?



What do you value most about being a member of the LGSF community?



How has being a part of the LGSF community changed your life for the better?



EPILEPSY CAREGIVER SURVEY

Common Challenges With Medication Routines

In a survey, 50 parents and caregivers of young children with epilepsy were asked about the challenges of giving their child medicine. Almost half said their child resists taking medicine at least once a day. We also learned that:

46%

of caregivers mixed a crushed pill with food to give their child the medicine

53%

of children didn't finish the food that was mixed with their medicine

70%

of children have refused to take their medicine at some point

72%

of children have spit out their medicine

74% of caregivers are concerned that their children aren't getting their full dose of medicine

If you face challenges like these, you may want to talk to your doctor about other forms of medication that may be simpler to administer.

Aquestive Therapeutics. Data on File. 2019.



FUTURE HOPES Dreams

The days with LGS can seem long, but looking forward can keep you moving in the right direction. With these mobiles, the community expressed the hopes, dreams, and wishes they have for their loved one with LGS, their families, and themselves.

With the support of the community, you can turn dreams into reality—and create a future with hope and new possibilities for all those affected by LGS.

My Dream
Name: *Maria*



I Dream of My mom to not have as much stress on her

I Hope That my family can all get together more

I Wish for My family to get custody of my nephew

My Dream
Name: *Julie*



I Dream of more research trials to help the LGS community find the best treatment regimen for those kids

I Hope that my nephew to be able to express his needs through some form of autism catlin

I Wish for more acceptance from the community for people who are different than us

My Dream
Name: *Cheri*



I Hope that my daughter always knows & feels love

I Wish for a life full of happiness & love for Jolie

I Dream of fewer limitations & seizures for Jolie

My Dream
Name: *Jess*



I Hope that My brother will have more good days

I Wish for My brother with less to stop having seizures

I Dream of My brother being by my side for future

My Dream
Name: *Prachel*



I Wish SEIZURE FREE DAYS

I Dream of A CONTRIBUTING HAPPY LIFE!

I Hope that MY KIDS KNOW HOW SPECIAL AND LOVED THEY ARE

My Dream
Name: *Sophie*



I Hope That I can have more seizures

I Wish for Jimmy (brother) to be able to get some justice

I Dream of Diving a Car meeting my love one. (Michael)

My Dream
Name: *Amarce*



I Dream of less seizures and more giggles!

I Hope that I can giggle more and stay up longer till I'm more open eyes!

I Wish for No seizures & always be happy!!

My Dream
Name: *Leah*



I Hope that my son does know how much I love him

I Dream of hearing my son talk to me about anything

I Wish for a future with healthy happy son

My Dream
Name: *Rachel*



I Hope that more treatment options will become available

I Wish for more nights of restful sleep for my nephew Jackson

I Dream of a world where more people are aware of LGS

My Dream
Name: *William*



I Wish for Jump High

I Dream of Straight Hair

I Hope that I'll be a big boy

My Dream
Name: *Laurenz Daniera*



I Dream of a seizure free life!!

I Hope that a cure for LGS will come soon

I Wish for the strength and energy to cope daily

My Dream
Name: *Dylan*



I Dream of being stronger

I Hope that that I'm the strongest blazer

I Wish for like the strongest blazer

My Dream



I Dream of being a super hero

I Dream of no more seizures

I Wish for to be strong like hulk

My Dream
Name: *Miranda*



I Wish for Pillows, tooth balls, and hair brushes to play with

I Dream of warm sunny days sitting on the grass

I Hope that They will find a cure to stop seizures



LIVING WITH LGS

In Your Words

The stories shared during the Art of Living event were so touching, we followed up with members of the community after the event to learn more.

These are just a few of the stories we heard—each of them tells of the heartbreak, perseverance, and altruism common to all of those living with LGS. Your stories matter. To share your experiences with us and the LGS community, LGSart@aqestive.com.

A different perspective

Why does it seem that every seizure hurts like it's the first?

I've thought that many times over the years. When I look back, I see two grinning children and a young and darling little family. There is joy, happiness, and perhaps even a scoop of perfection. **It seems inconceivable that a dark ominous cloud called LGS was hanging over this family—my family.**

What at first felt like a dark and dangerous diagnosis became a platform for possibilities. We created hope and witnessed many miracles once we learned how to view this new world of LGS through the lens of possibilities.

We call "milestones" "miraclestones" instead. Another birthday? A miraclestone for sure! Walking, talking, self-feeding—all miracle stones. And at the end of a long day, after brain surgery, and decades since my boy could tell me he loves me, he looks into my eyes and says, "I 'wub' (love) you, Mama." That is a miraclestone that melts my heart to this day!

We figured out how to be proactive, rather than reactive. We learned to laugh again. We now know that we are not alone. As the parent of an adult with LGS, I work as a volunteer with the LGSF to show those with younger children that it can be okay. It can get better. So, while I am tired sometimes, I work to create hope. **There is hope through research and knowledge. There are opportunities to gather with others who understand.**

– Mother to an adult son with LGS

Knowing what you don't know

We remember his first seizure very clearly. **When we got the initial diagnosis and began medications, we felt uncertain, panicked, and a loss of control.** It seemed that his diagnosis changed on a regular basis as his testing and seizures progressed. We knew nothing about seizure management, and we did not know enough to ask for the information we needed. Each neurology appointment was eye-opening and, at times, frustrating.

We were entering a field where knowledge is assumed and questions often go unasked and therefore, unanswered. **It would have been helpful to have someone with us who would answer our questions and give us tips as we went along.**

That is what we found in the LGS community. **The LGS community provides information, experience, and some answers to questions we never thought to ask.** We can also reach out with our experiences and insight and help others. We have learned that a cure is not necessarily our goal; control and quality of life is the true goal. Simply put, I want my son to have the best life he possibly can.

– Father of son living with LGS

By emailing your stories, artwork, and photographs to us, you are confirming that Aquestive Therapeutics, Inc. and the LGS Foundation have your permission to reproduce your materials, in whole or in part, for publication on their social media, websites, printed publications, and/or promotion of events intended for the epilepsy and LGS communities.

Finding light in the darkness

When my son had his first seizure episode, I thought he had fainted. I was terrified because I knew he wasn't okay. I was afraid I had done something wrong. Between that time and when we actually received a diagnosis, I was stripped of all my security and rest. **I was afraid for the future, and afraid of the present.** I felt like I wouldn't be enough for him, or for the rest of my family. What I didn't know during that time was that I would have the strength to get through it.

Eventually, LGS became a part of our lives, rather than consuming every waking moment of it. I still wish my son could speak so that he could ask for what he wanted, or so that I could hear him say, "Mommy." But with his medication now, he will occasionally look right into my eyes. It lets me know he's interested, that he's in there. Our son has become the brightest light, and his joy saturates our family.

With the LGS community, I have a place to celebrate those joys, and to find comfort when life gets hard. I will never be a lone. **This community is an endless source of knowledge and experience that is always available.**

– Mother of son living with LGS

Through the years

My son was just 2 days old when his first seizure happened. I was just a new mom, trying to find my way. I can remember how helpless I felt as they took him away down the hall to the NICU and shut the curtain closed. The sadness, grief, and helplessness I felt on that day is still with me, even now, 19 years later.

We went through so much in those first few years of life—so many seizures, so many types of seizures, so many medications, so many diagnoses. We were already discouraged, scared, and heart broken. **What I didn't know early on was that I had a say. That I had a voice. I needed to help my son. That was my job.**

We've learned over the years that treatment does not mean stopping the seizures. Watching my son seize during the happy moments of his day is an extra punch to my system. But treatment can mean fewer seizures, fewer side effects, better quality of life for my son, and better overall well-being for our entire family.

You have to believe in yourself and your knowledge of your child; you know your child the best. That is one thing I try to tell families I meet in the LGS community. When my son was a baby, there was no social media and very little support for me. It is extremely important to make connections with other families so that you know you're not alone. Having this support has been a huge factor in my life.

– Mother of adult son living with LGS

“My anger and sadness weren't just about my daughter, it was also the loss of the motherhood I'd envisioned.”

“It's an ongoing journey finding the best treatment to enable seizure control and the quality of life balance.”

“I would not be where I am today without my LGS family. The friends I have made and the experiences I have had are invaluable.”

“My wish for my daughter is to live a life intentionally with her own wishes and dreams; not the ones we create for her.”



#TheArtofLivingWithLGS
Aquestive



To All Who Participated Thank you for making memories with us

Inspired. Determined. Resilient.

These are some of the ways to describe the LGS community. After seeing the artwork you created, we humbly add "Creative" to that list.

The work you created at the Art of Living event shows how strong the LGSF community is, and how much support surrounds you. Thank you for sharing your experiences, your emotions, and your words of wisdom, and for inspiring others who are on the journey with you.



#TheArtofLivingWithLGS
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Visit [Aquestive.com](https://www.aquestive.com) to find out more about Aquestive Therapeutics —
our products, our medicines, and our commitment to epilepsy.

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