

Supporting Rare Epilepsy VIP Siblings

A Guide for Parents & Caregivers



Parents & Caregivers,

Many deeply dedicated patient organizations and members collaborated on this guide and the VIP Sibling Project as a whole. The rare epilepsy community benefits every day from its members' advocacy, caring, and expertise.

Supporting Rare Epilepsy VIP Siblings is based on research and inspiration from the rare epilepsy community. It offers information and resources to help you care for your child without a rare epilepsy—your VIP sibling. Use this guide to help identify specific signs that could mean your VIP sibling is going through a challenging time. It will also help you learn different ways to show your concern and support.

— *VIP Sibling Collaboration Team*

MORE RESOURCES ONLINE: VIPSIBLING.COM

Your Family and Rare Epilepsy

All rare epilepsy families face challenges—it's a reality of living with a rare seizure disorder. You know better than anyone that caring for a child with a rare epilepsy, while also managing your family's schedule, takes enormous energy. It can feel impossible to get everything done.

Having a child with a rare epilepsy can make family bonds stronger. It's not uncommon to have everyone in your family pitch in to help. That's why your child without a rare epilepsy—your VIP sibling—may “grow up” faster than other children their age and take on more responsibilities around the house.

While every family does their best to take care of each other, it's important to remember that the major impact a rare epilepsy has on the whole family, including siblings, is the norm—not the exception.

What Is a VIP Sibling?

Having a child with a rare epilepsy can bring out some amazing qualities in your other children. VIP siblings are often unselfish and dedicated. They show grace, patience, and are very important people in their circle of friends and loved ones. They often demonstrate an amazing ability to see beyond the challenges, exhibiting understanding and compassion beyond their years.

“More compassionate, good perspective, loyalty and commitment to family...”

“She is a more kind and patient teen.
Especially to the special needs kids she meets.”

“He has the biggest heart and I know he will have a future
in helping children. He loves his sister so very much.”

*“She wants to become a neurologist.
She’s become mature beyond her years.”*

“He has done so well with other kids who have differences in school,
and he is recognized for his loving, caring, and accepting ways.”

“SHE IS VERY EMPATHIC AND IS TOUGH PHYSICALLY BECAUSE
HIS IMPULSIVE BEHAVIOR SOMETIMES IS AIMED AT HER.”

“My kids truly
developed a close
bond and love each
other deeply.”

Research

How Rare Epilepsy Impacts Siblings

A recent study called the *Siblings Voices Survey* looked at the emotional impact of growing up with a brother or sister with severe epilepsy. For example, many siblings say they have learned to feel compassion and are more understanding of others who are disabled. Other findings showed that siblings can often feel stressed, anxious, or fearful. They report experiencing:



Unhappiness

47% of siblings reported being unhappy sometimes or a lot of the time.



Depression

35% of adult siblings reported a history of treatment for clinical depression.



Anxiety

79% of young siblings expressed fear that their sibling might die.



Irritability

54% of young siblings reported feeling irritable or grumpy sometimes or a lot of the time.

Siblings also reported emotional challenges and concerns

YOUNGER SIBLINGS:

- Feeling worried or scared
- Wanting more attention from their parents
- Having their activities disrupted

OLDER SIBLINGS:

- Worrying about their parents being stressed
- Feeling worried or scared
- Having more responsibilities at home
- Being embarrassed

Knowledge is power for siblings

The findings of the *Siblings Voices Survey* suggest that focusing on the sibling's emotional health can help improve sibling well-being. When your child without a rare epilepsy has knowledge about their sibling's condition, it can have a positive impact. The survey found that:

52–76% of siblings who felt knowledgeable about their sibling's condition or helped during a seizure reported **lower depressed mood and anxiety symptoms**.

38–86% of siblings who felt knowledgeable about their sibling's condition **felt comfortable talking with others** about their sibling's diagnosis.

Staying in tune with your children

Having an open line of communication is important for any family. But it can be especially helpful for a family with a child who has a rare epilepsy. Checking in regularly and having conversations with your children without a rare epilepsy can help to create an environment for continued sharing of thoughts and feelings. This is important because the *Siblings Voices Survey* showed that:

24–58% of siblings experienced symptoms of anxiety, yet only **14–38% of parents** noticed their children's anxiety symptoms.

42% of siblings from ages 9 to 12 expressed feeling sad often, while only **20% of parents** reported noticing this.

These findings show that the parent's perception of how their child is feeling can sometimes differ from how the child actually feels. This is why ongoing and open communication in families can be helpful. It's also important to remember these are common challenges many families living with a rare epilepsy face.

Support

Being There for Your VIP Sibling

There are actions you can take to reassure and support your child. Some involve building and encouraging communication; others are creative expressions of pride and love.

Give your child some extra attention. Specifically try to do this when the family is not in crisis mode, even if your VIP sibling isn't asking for it.

Make time to talk. Be the one who starts the conversation. Your child may be hesitant to talk about themselves because they may feel guilty or fear being a burden. Reassure them that you do not expect them to be perfect—no one is! Let your child know it's okay to talk about how they are feeling. Having a heart-to-heart with a focus on listening, not problem solving, may help your VIP sibling process their emotions.

Plan one-on-one time. Try to find some time each week (or whenever you can) to spend quality alone time with your child, doing something you both love, or focusing on their special interests. Help your VIP sibling embrace who they are—including the positive qualities they may have developed from having a sibling with a rare epilepsy. Research has shown that siblings of children with special needs often learn skills that help them take on the role of a leader or teacher. Because of their unique family experiences, these children often display good social behavior.

Show praise. A rare epilepsy sibling may have to take on many roles and responsibilities, so it's helpful to express your gratitude and acknowledge their contributions and strengths. Tell them how and why they are important to the whole family.

Spread the love. Pop an encouraging or loving note into your child's lunch box so they have a midday reminder. For older siblings, slip a note into their textbook or backpack pocket.

TIP: Download our Love Notes from the Tools & Resources section of the VIPsibling.com website to get you started!

Focus on special events. Schedules in a rare epilepsy family are always subject to unpredictable change! Sometimes it's difficult to attend your child's sports games or school activities. One way to show your support is to be there for their milestone events. If possible, try not to let the needs of your child with a rare epilepsy overshadow these milestones. Give your VIP sibling a little extra attention and tell them how awesome they are!

TIP: When you can't make it to an event, ask another parent or friend to take a picture or video and send it to you, to keep you in the loop. Show it to your child later and recap together.

Explain rare epilepsy on their terms. Most VIP siblings can detect when parents withhold information. Try not to keep your child "in the dark" to protect them—this can increase their anxiety as they try to imagine what you're not saying. Educating your child about the specific rare epilepsy that impacts your family can help them manage their emotions and feel connected to the family. Make sure the information you're sharing is age-appropriate, so your child can easily understand it. Remember: older children can access information from the internet, but the better source of information is you!

TIP: Have several "mini conversations" with your child over a period of time. Offering information in stages like this will help you avoid overwhelming them.

Develop a support system for your child. It's important that your child feels supported in other parts of their life. Identify those individuals your child feels most connected to—such as a teacher, family friend, neighbor, coach, or a relative. Choose people who can be available for your child when you may not be. As the saying goes, "It takes a village!"

TIP: Try out the My Family Is Living with a Rare Epilepsy downloadable form in the Tools & Resources section of the VIPsibling.com website. This form is intended to be shared with the essential people who spend time with your VIP sibling, such as school counselors and extracurricular group and team leaders. The form explains what rare epilepsy is and the kinds of support that may be helpful when your VIP sibling is not in your care.

Create a VIP Sibling Seizure Plan. Your VIP sibling may want to be involved and help out, or may prefer to stay busy in a different room, when their brother or sister has a seizure or medical crisis. Talk to them in advance about their role. It's important to figure out what works best for your VIP sibling to make sure they're comfortable. Take a look at the sample VIP Sibling Seizure Plan in the Tools & Resources section of the VIPsibling.com website.



Your VIP Sibling: Is Everything Okay?

As a parent or caregiver, you have a special ability to understand your children and how they may be feeling. But when life gets busy, it's not always easy to recognize that your child could be struggling or experiencing symptoms of anxiety or depressed mood. It may appear that your child is doing well, but deep down they may be having a hard time. It's also important to note that if you are stressed or anxious, your child may pick up on those emotions.

When it comes to your child without a rare epilepsy, it may be helpful to make a note of their typical behaviors or patterns. That way, it will be easier to notice shifts in their mood or behaviors. Continue checking in with your child to stay in tune with what they are thinking and how they are feeling.

It's Okay to Ask for Help

Sometimes, talking on your own to your VIP sibling may not be enough to ease your concerns. If you observe signs your sibling may be struggling, don't hesitate to reach out: talk with your child's doctor, school counselor, or a licensed child or family therapist for additional screening and support. It's also a good idea to have regular check-ins with teachers and other adults in your child's life to hear their perspective on how your VIP sibling is doing.

Practice self-care for you!

It's important to make time for yourself. Your children will notice when you do! As Mary Anne Meskis, Executive Director of the Dravet Syndrome Foundation, writes in the *Decoding Dravet* blog:

"The extremes in your day-to-day lives as a caregiver for someone with any rare epilepsy can and will wear you down. It is important to remember to take care of yourself. You need to focus on eating well, moving your body, and taking time for things that bring you joy. Caregivers typically don't get to just 'turn off,' so it is important to realize when you're overwhelmed and to establish coping mechanisms and a plan. Whatever you need to do, prioritize yourself and make it happen. Let go of the idea that good caregivers don't need breaks. It is regular breaks that will keep you from breaking."

SIGNS THAT YOUR CHILD MAY BE STRUGGLING

Sleep

Does your child seem tired during the day? Are they having trouble sleeping or sleeping too much? Are they having bad dreams or nightmares?

Appetite

Has your child's appetite increased or decreased? Are they still craving the foods they once loved?

Engagement

Does your child still enjoy being around family and friends? Do you find that they are spending more time alone or in their room?

Activities

Is your child still participating in activities? Do they make excuses to not join in? Do you find that they are losing interest in things they once enjoyed?

School

Have you noticed a decline in your child's grades? Is your child skipping assignments or consistently handing them in late?

Attendance

Is your child trying to avoid going to school? Are they trying to cancel plans with their friends?

Emotions

Does your child seem sad or more emotional than usual? Do they seem afraid? Is it easy for them to start crying?

Behavior

Is your child showing anger or short-tempered? Do they have tantrums or outbursts?

Health

Is your child having more stomachaches or headaches than usual?

Resources

VIP Sibling Kits

If you ordered a VIP Sibling Kit by mail, this information will explain each item's purpose. (If you haven't ordered a kit for your child and would like to, please contact your rare epilepsy organization.)

These kits were created with care to make your VIP sibling feel special and acknowledged. While the youngest VIP siblings may not fully understand the purpose of every item, they will appreciate being recognized. And children of all ages enjoy receiving a special package in the mail just for them.

What's Included:

Sibling Journal: Coloring and journaling are both calming, peaceful activities. The VIP Sibling Collaboration Team has created two journals, one for ages 4–10 and one for ages 11–18. Positive messaging and thought-provoking prompts encourage siblings to express themselves. Every time your VIP sibling colors or writes in their journal, they'll be reminded of how important they are. Don't be surprised if your VIP sibling uses one of the tear-out pages to write you a letter or draw a special picture for you to share how they're feeling.

Family Journal: This journal is designed to be a communication tool that parents and their VIP Siblings can use to express their feelings, including hopes, fears, and of course, their love and care for each other. Use the journal to share what's on your mind or to let your family member know you're thinking of them. Write a short note or long letter—it's up to you! Take space and privacy to write on your own time, in your own words. Then leave the journal where your family member (grownup or sibling, depending on who is doing the writing) can find it and read it on their own time and in their own space. Maybe you can even have a designated spot where you "pass" the journal back and forth to each other. You can discuss it together and make a plan. This is your Family Journal so you decide what works best!

Rockin' It / Rough Day reversible wristband: We all have good days and bad days! With a quick flip of their wristband, VIP siblings communicate how they feel. Colorful side out—your child is Rockin' It. Blue side out—your child is having a Rough Day. Make sure you discuss the wristbands with your child (or children, individually) to decide how you will respond if your VIP sibling is having a rough day: they may need a hug, extra attention, or some space to process how they're feeling. If you have multiple VIP siblings in your family, you may have a different plan for each.

JUST FOR VIP SIBLINGS AGES 4–10:

Fun, expressive mood stickers for younger siblings will encourage them to give themselves a boost or show what they're feeling in the moment.

A plush star for your star! Attaching this to your VIP sibling's backpack is the perfect reminder that your child is a very important member of the family.

The *My Sibling Is Special* book is a comforting story you can read with your young VIP sibling to help them understand and cope with living with a brother or sister who has a rare epilepsy. *My Sibling Is Special* assures children that it's okay to have different feelings and emotions—positive and negative—and to talk about them. Some VIP siblings may want to read the book on their own. *My Sibling Is Special* also provides information for parents to help guide conversations about its contents with your VIP sibling.

JUST FOR VIP SIBLINGS AGES 11–18:

A letter sharing insight and support—written by an adult rare epilepsy sibling—is featured in the journal for older siblings.

Door hanger: Older VIP siblings tend to spend a lot of time hanging out in their bedrooms, door shut, making it hard for parents and caregivers to know how they're feeling. The VIP sibling door hanger lets you know when VIP siblings need space and when they want to talk—a simple way to keep a line of communication open.

VIP Sibling Kit (Ages 4-10)



My Sibling Is Special Book

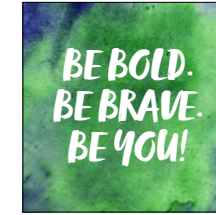
VIP Sibling Kit (Ages 11-18)



An Insightful Letter from a Sibling

Parents & Caregivers Kit

In addition to this guide, the Parents & Caregivers Kit includes two useful tools shown here, as well as the popular Love Notes (examples on the right). Download and share the My Family Is Living with a Rare Epilepsy form with your VIP sibling's support circle. Also available via download is the VIP Sibling Seizure Plan, which can be used to guide conversations and establish the role your VIP sibling will play during a seizure or other medical emergency.



My Family Is Living with a Rare Epilepsy

_____ **has a sibling with a rare epilepsy.**

What are rare epilepsies?
Rare epilepsies are severe forms of epilepsy that cause frequent seizures or seizures that happen for a long time as well as many other complex health conditions. Rare epilepsy can begin as early as the first year of a child's life and lasts throughout their entire life.

Rare epilepsies can have a huge impact on a family's quality of life. The extra care that a child with a rare epilepsy needs and the unpredictable nature of seizures can disrupt family life. For this reason, siblings are at a greater risk for

anxiety and depression. They can also experience feelings of sadness, stress, isolation, fear, worry, and fatigue.

Why rare epilepsies make life unpredictable
Seizures can happen at any time. Emergencies at any time of day or night are a "normal" part of life. Because of this unpredictability, siblings may:

- Feel emotionally "off" or distracted
- Arrive late to school or other events or cancel last minute
- Be tired from lack of sleep
- Fall behind on assignments or projects

How you can help
My child is doing their best to navigate an extremely difficult situation—but your support can make a big difference.

- If you notice any changes in my child's mood or behavior, please feel free to reach out anytime.
- If my child is late, unprepared, or distracted, it would be helpful if you could share that with me.
- If you sense my child is struggling or falling behind, some words of encouragement can go a long way.
- If possible, please provide feedback on how my child is doing, including how well they're able to connect with you.

Thank you for everything you do to help support and encourage my child.

Our family's emergency plan Here is our plan for when their sibling has a medical emergency:

During school or practice: _____

In the evening: _____

During the weekend: _____

In the middle of the night: _____

My contact info

Name: _____ Phone: _____

In case you can't reach me, please call:

Name: _____ Phone: _____ Relationship to child: _____

Local hospital information: _____

Inspired by patients. Driven by science.

Visit VIPsibling.com to download this form.

VIP Sibling Seizure Plan

When your child with a rare epilepsy has a seizure, your VIP sibling may want to be involved and help out, or may prefer to stay busy in a different room. It's important to figure out what works best for your VIP sibling to make sure they're comfortable. Talk to them in advance about their role, when the family is not in crisis. This may help them feel more prepared and better able to cope when emergencies arise. This is also the perfect opportunity to review your family's emergency plan.*

You can use this worksheet to help create your VIP sibling's plan. Making decisions together can be reassuring!

Ask your VIP sibling:

- How do you feel when your brother/sister has a seizure?
- When your brother/sister has a seizure, would you like to help? Or would you rather do something else? Either choice is okay!
- What would you like to do when your brother/sister is having a seizure? For example, you could grab the medicine, watch for the ambulance, read a book in another room, or go to your "safe place."
- Do you have any questions or suggestions about how you can help when your brother/sister has a seizure? Or is there anything else you want to talk about?

TIP: If your VIP sibling has a hard time discussing what kind of VIP Sibling Seizure Plan they want, think about who else could help start or join this conversation.

Our seizure plan

Using the space below, write down the VIP sibling role that you decided together:

Discussing who will provide care during a medical crisis for your VIP sibling when you are unable to is another way to reassure your child. Using the space below, write down who will provide this care and any contact information:

Name:	Phone:	Relationship to child:
_____	_____	_____
_____	_____	_____
_____	_____	_____

Talk about who else in your VIP sibling's support circle might benefit from knowing your child's plan.

From time to time, review and update your VIP sibling's plan if their feelings change. Once you've completed the plan, put it where it can be easily retrieved.

*From the My Family Is Living with a Rare Epilepsy form.

Inspired by patients. Driven by science.

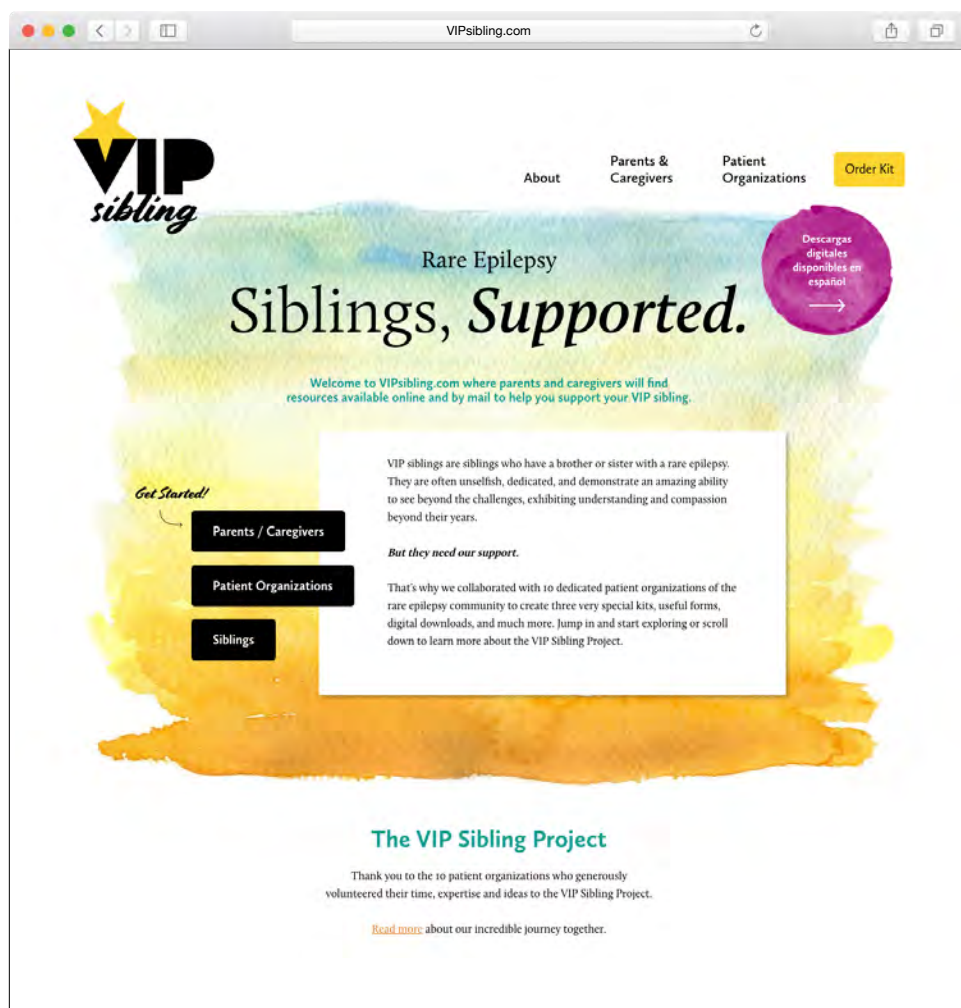
Visit VIPsibling.com to download this form.

VIPsibling.com Website

Siblings, Supported.

“The materials are convenient, easy to use, and easy to fit into the hectic life of living with a rare epilepsy. When children are young it is easy for siblings to get lost in the shuffle and these materials help us slow down and balance the needs of all of our children.”

—Rare epilepsy parent



Connect with Other Rare Epilepsy Families

Nobody understands what you and your family are going through better than other rare epilepsy families. To connect with other families and receive helpful resources and tools, join the community that supports your rare epilepsy.

Learn about opportunities to meet other families like yours by going to conferences and events for families with rare epilepsies. This will help your VIP sibling find others they can relate to, which may make them feel less alone. Get involved in rare epilepsy events like regional workshops or local fundraising and awareness walks. Being active in the rare disease community can make a positive impact on the entire family.

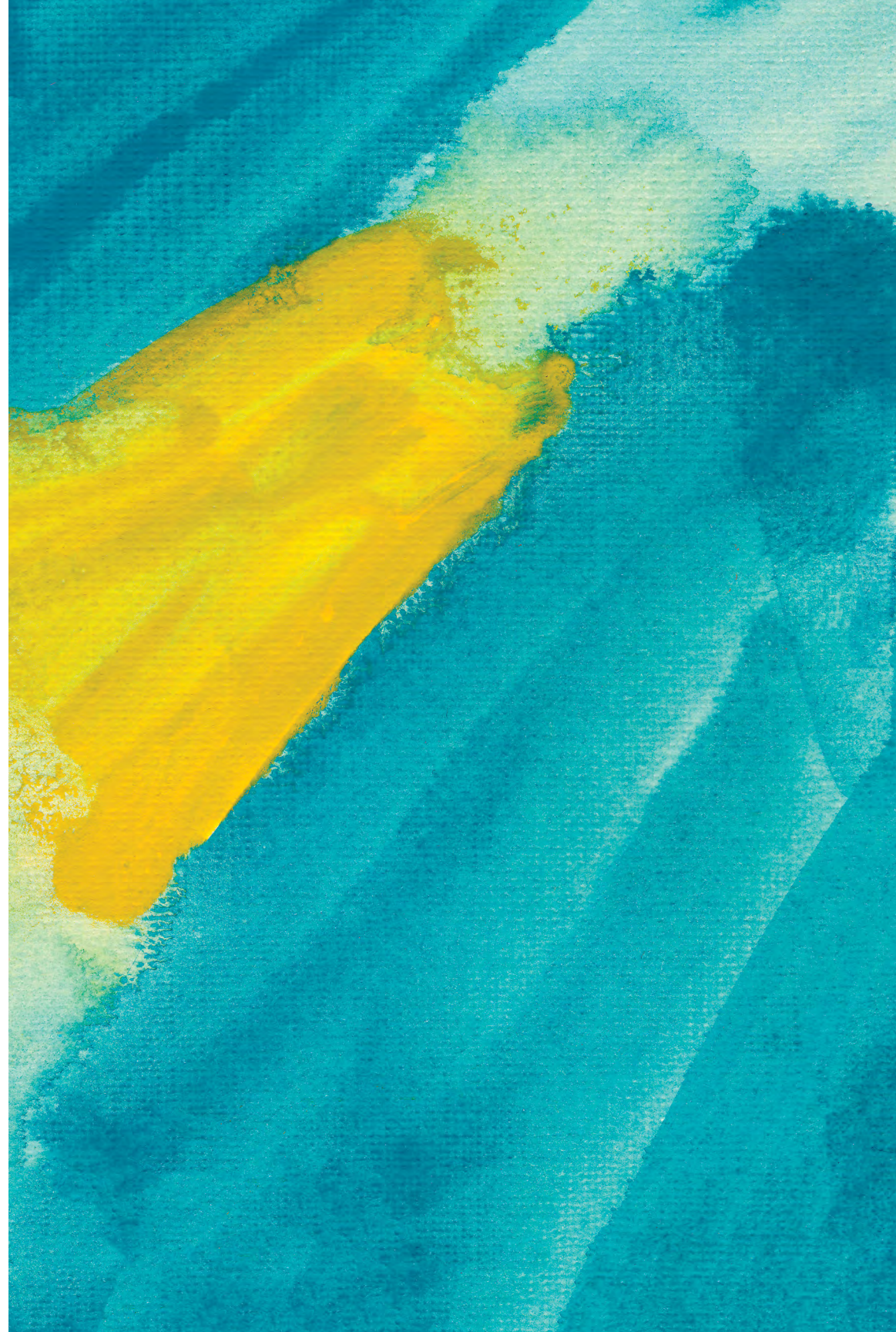
Visit your rare epilepsy
community patient organization
or the VIPsibling.com website
for additional information,
resources, and tools.





Always remember:

You are not alone. A strong, supportive community is ready to share information, experiences, and support for you and your children, including your VIP siblings.



Collaborating Patient Organizations

For more information on these ten organizations and the VIP Sibling Project, please visit VIPsibling.com.



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