

## President's Message

Nick Wallace



*Nick, Angie, Allie, Nate, and Laney; Nick's Mom, Cathy and great grandparents Fred and Ruth Meredith*

Hey there fellow hunker downers! (I had to steal this term from the one and only Leslie Jordan.) I hope this message finds you safe and healthy. These are unprecedented times we are living in right now. As the Covid-19/ Coronavirus pandemic looms over us, people are being uprooted from their normal routines, individuals are being furloughed from their jobs, teachers and students are having to ad-

just to distance learning, seniors are having to miss the final quarter of their final year of school, nursing homes are locked down, and major events are being cancelled or postponed.

Now before I get into my message, I want to take a moment to thank those people who are working on the front lines right now. Thank you to those essential workers who are out there working to keep us healthy, to help keep our hospitals clean and disinfected, the people who are keeping the supply chains running, keeping shelves stocked, and really anyone who is putting their self in harm's way so that we can stay healthy and obtain the essential goods we need to survive this pandemic. I know that I speak for everyone when I say, "Thank you for all that you do. We see the sacrifices you are making for us and we cannot say thank you enough."

What a crazy time we are living in right now. During this time it is so easy to get depressed, overwhelmed, and confused. We are constantly inundated with negative news,

mixtures of correct and incorrect information, and a deluge of people wanting us to agree with their opinions on the matter at hand. How does one find hope when we are constantly barraged by all of the false information, the negativity, and the hatred that this pandemic has brought us? I find hope in our kids/adults who have Cri du Chat.

I always love visiting our Facebook page, but during this time of confusion I have found myself going to our group page more often. I love Marcy posting about Dylan giving quarantine concerts on his piano, Brittani showing photos of Addyson smiling bright on her new bicycle, Leigh giving us an update on Madison who said her name for the first time. I could go on and on about all of the posts I have viewed and how much joy it has brought me during the times when I have needed it the most.

This pandemic has put a lot of stress on all of us. I know we have members who have lost their jobs and are struggling financially, we have members who have been uprooted from their homes due to natural disasters that hit during the pandemic, and we even have members who are fighting for their lives due to contracting the coronavirus. These are trying times for all of us and I know they affect our kids/adults as well, but I am so thankful for the moments of joy that they provide us with. I am thankful to all of you for continuing to post these moments for us all to enjoy and to find little glimmers of hope as we go through these uncertain days.

In thinking about moments of hope and joy, the place I tend to find the most hope and joy is at the 5p- Society's annual conference. Once again, this is another thing that the coronavirus has tried to take away from us this year. Yes, take note ... I did say that it "TRIED" to take the conference away from us. Yes, the conference in Chicago has been cancelled this year and moved to 2021, but the board of directors has been working to find a way to still host a con-

*Continued on page 2*

ference in 2020. While this conference will not be the same as our past conferences, we are working hard to come up with a way to have a virtual conference. How this will all work out, I am not certain yet, but make sure to keep an eye on our Facebook page and also your email as we will be distributing information about a virtual conference once we have all of the details nailed down. Hopefully this announcement will bring a little joy to your day and give you something to look forward to attending. Again, please make sure your contact information is up to date with the 5p-Society and if you aren't a member, or you are a member

and let your membership lapse, please consider becoming one or renewing.

Please know that although I cannot be with you at this time, I am sending love and prayers for all of you. I hope you all stay safe. Keep sharing your moments of joy with us as it helps to keep our spirits up. Remember, we are all in this together and we will eventually get through this.

Hang in there fellow hunker downers!



### **New Dates—July 15-18, 2021**

I hope that this letter finds you all safe and healthy. The Covid-19 (Coronavirus) pandemic has been forcing people across the globe to change the way they live their daily lives. It has also been causing major disruptions to schools and several public events. A few of these events are the Tokyo Olympics, college and high school graduations, the St. Louis 4<sup>th</sup> of July Firework Celebration, and unfortunately now the 2020 5p- Society Annual Conference.

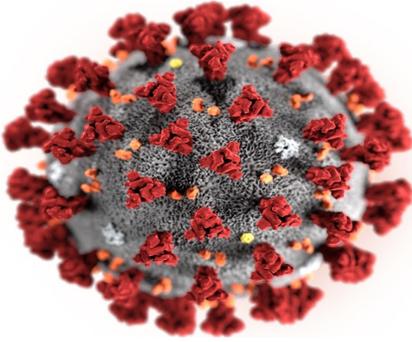
As most of you know, the Coronavirus is a respiratory virus and with several of our children/adults being immunocompromised, the host families along with the board of directors have made the decision to postpone the 2020 conference in Chicago and move it to the summer of 2021. This is the first time in 35 years that we will not have a conference.

We know that this will be a disappointment to so many of you, just as it is for those of us on the board and especially for the host families, who have been working hard to fundraise and prepare an amazing conference for our families. In the end we decided that the health and safety of our families is the most important thing.

Now having said all of this, the board has already started discussing how we may be able to have a virtual conference this summer. We may utilize video meeting technology to host seminars. One of the sessions we talked about having as an option would be one of our most popular sessions, the parent panels. Another thing that was discussed is increasing the number of regional gatherings; this would only be done once we can ensure the safety of our families though.

We will be making more announcements as we begin to shape what our virtual conference will look like. Please make sure that you have your contact information up to date with the society as we will be reaching out to our membership via email. We will also be reaching out via our Facebook group, but I know there are times that these posts can be missed, and having an updated email will help ensure that you are up to date on what is happening within the 5p- Society.

Finally, I would like to take a moment to say that I am sending out positive thoughts and prayers for you all. I am not sending this out just for your physical health but also for your mental health during this time of what some have deemed a time of isolation. This pandemic has uprooted our routines and often that is so hard for our kids/adults with Cri du Chat to understand. This can make it hard on the caregivers as well. Please, if you need to reach out and speak with people that understand, you can always visit our Facebook group for support. You are not alone in this even though it may feel that way during this crazy time. Hang in there everyone!!



# A Social Story About COVID-19

*By Michelle Myatt, MSW, M.Ed,  
Vice President of the 5p- Society*

The Corona virus, or COVID-19, is a germ that makes people sick. It causes a cough, fever, and other yucky symptoms. I don't like to be sick.

This Photo by Unknown Author is

But I can stay healthy by washing my hands often with soap and water. I can also stay home and away from others. When I go out to walk or play outside, I should stay two to three bubble spaces away from people who do not live in my home.

Although it is good manners to shake hands or give high fives, right now I need to keep my hands to myself so that everyone stays safe and healthy.

I feel sad to not be able to see my friends or hug my teachers. I wish I could go to school. But it is closed right now while the corona virus is in the air.

When I feel sad or nervous, I can ask those who live in my house for a hug. I can also squeeze my stuffed bear or love on my pet. I can go outside to play in my yard or go for a walk. I can even read a book.

I don't like being stuck at home so much. But I know it is important, so we all stay healthy. I do like being able to see my family more. My siblings are also out of school and my parents are working from home. I know this is hard right now, but it won't last forever. One day, I will be able to go back to school and see my friends and family that I miss. Then I will be so happy again.



## *2020 Regional Family Get-Togethers*

The 5p- Society is sad to say that all our Regional Family Get-Togethers are postponed due to the COVID-19 outbreak. Please know that we will reschedule as soon as it is possible. We wouldn't want to expose anyone to the illness, so it is best for everyone's safety. Look online and in newsletter for any updates.

### **Books to read**

*A Book to my son Nathan:* <http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=ywWDIdOAWC>.

*Raised by my Child* by Sally D. Yantis-Grube, 2011—Mom to Heidi, 18-year-old with Cri du Chat Syndrome.

*Her Name is Montel*, by Casey Evans, 2005—Dad to Montel, 20-year-old with Cri du Chat Syndrome.

*Beauty in Broken Dreams: A Hopeful Handbook for the Early Years as a Special Needs Parent*, by Kathy McClelland, 2017, Mom to Nathan, 4-year-old with Cri du Chat syndrome. [https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr\\_1\\_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams](https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr_1_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams).

*Confessions of a Special Needs Dad* by Mark Wallace Maguire, a book of hope, healing, and honesty that dads are not alone.

*Stripes for Eliana* by Ana Camelo Jackson

### **Coming Soon...**

*Love You Big* by Leah Witman Moore

*From a Cat-Like Cry at Birth to Essential Tremors Now: An Educational Health Memoir* by Debbie Small

# Give Me Five – Five Ways You Can Keep Your Sanity During Quarantine

*By Michelle Myatt, MSW, M.Ed, Vice President 5p- Society Board of Directors*



*Michelle, Jason, McKenna, (16) Delaney (14), Reagan (10), and Grace (2)*

1. Take time for yourself! Stay hydrated and eat well. Good nutrition is vital to keeping you on your toes. Make sure you are staying active. Take a walk, find an exercise routine online or make one up with items you have at home. Enjoy hobbies you normally don't have time for. Carve out 30 minutes a day that is just yours...this might mean getting up before your children or having older children watch younger siblings. This is your time to spend anyway you want. You will be better because of it. I promise.

2. Forget the housework and chores for a few minutes and find time to just play with your kids. As parents, we are always so wrapped up in doctor appointments, therapy, schoolwork and playing taxi for all the activities our kids are involved in. Play time is good therapy for adults and kids alike. Reconnect with your kids and learn something new about them. Build a fort out of blankets, play board games, make up a scavenger hunt (inside or outside), have a dance party in the living room or make a craft together. You might even make items to leave on the porch for loved ones you are missing.

3. Make a routine for yourself and stick to it. Pencil in the time for you, chores (let the kids help you) and time to help your kids get through their schoolwork. If you are working from home, add this time to your schedule as well. Make sure you are going to bed and waking up at the same time each day. Shower and dress just like you would if you had to leave your home for work or school. Routines are important and allow

us to feel as if we have some control over our day. We can look back at a checklist and see what we accomplished that day.

4. Limit your time watching and listening to COVID-19 updates. It's good to be aware of your surroundings, but it's also easy to become consumed by the sadness and anxiety that comes with inundating yourself with too much. Instead, reach out to friends and family. Call someone you haven't spoken to in a while. Don't forget those in nursing homes who are feeling very isolated right now. Did you meet someone at the last 5p- Society Conference? Contact them and see how they are doing.

5. Lastly, if you feel as if you are really struggling, reach out to self help groups in your community. Your child's school social worker or counselor would be a great place to start. They are well-aware of the resources in your area. If you need to chat with someone regarding concerns for your child with Cri du Chat, you can find contact information on the 5p- Society web page.

## About the Author

Michelle is the Vice President of the 5p- Society. She lives in the St. Louis area with her husband Jason and their four beautiful daughters. Delaney, her second oldest, is almost 15 and was diagnosed with 5p- when she was 8 months old. Michelle has worked as a School Social Worker for over 20 years. She has a Masters degree in Social Work from Southern Illinois University-Carbondale and a Masters in Education Administration from McKendree University.

# Five Ways to Help My Children Cope with Quarantine

*By Michelle Myatt, MSW, M.Ed, Vice President 5p– Society Board of Directors*



*Delaney Myatt*

1. Routine – stick to a schedule. Write it out, take pictures and make a visual schedule, or record it on your child’s device or tablet. Kids want to know what is expected of them and what they will be doing. This is a great time to remind kids to be flexible. Sometimes routines change. When they do, outline some ways you expect your child to cope with those changes (use their words, take a deep breath or two, or hug a teddy bear real tight).

2. Nutrition – make sure your kids are not snacking so much throughout the day that they do not eat the nutritious food you prepare for main meals. This only frustrates everyone. We all know how moody kids can be when they are hungry or thirsty. Their bodies are sensitive to big changes in blood sugar. If your child has a feeding tube...you might need to set a timer to remind yourself. You have a lot on your mind right now and we cannot always depend on our kids to tell us they are hungry.

3. Communication – talk to your kids at their level about Corona Virus and Quarantine. Give them facts that you feel they can handle without overwhelming them. Keep adult conversations away from little ears and limit their time in front of the television where updates seem to be constant. If you are having trouble

talking with your child about what is going on, try reading the social story I have included on page 3. I wrote this for my daughter Delaney (14) who is struggling with why we can’t see grandma and why we can’t go to school. You can have typical siblings illustrate the story which will also be good for their little minds as well.

4. Social – our kids are missing so many important people in their lives. Make video calls to friends and family regularly. Don’t underestimate how helpful it is even to toddlers to see and hear their favorite people, even if it is through a screen. My ten-year-old has started handwriting letters to friends and mailing them. These are kids who have grown up with technology. So, the idea of writing a letter, dropping it in the mail, and learning to be patient while you wait for a return letter, is relatively foreign to them. It helps to break up the monotony of life right now. This works for grandparents too. Remember how fun it was to have a pen pal when you were little?

5. Behavior – this is a crazy time for everyone with so many uncertainties. When kids feel stress, they communicate that through their behavior. You may see an increase in nightmares, whining, meltdowns and maybe even aggression. In addition to following the steps above, try teaching little ones to take deep breaths by blowing bubbles. You can make a spot in the house where your child or children can go if they are feeling overwhelmed. Give them pictures of family members and friends to look at, a stuffed animal, pillows and a soft blanket. Some kids may love to listen to music or even play an instrument. Big bear hugs or maybe a warm bath might be helpful. There are many scents that can be calming as well...lavender and eucalyptus are two of our favorites in my house. Lower your expectations a bit and give kids the benefit of the doubt when you can. They, too, are handling this the best way they can. They will be watching you for cues, so be sure to show them how you are taking care of yourself as well. Keep reminding them that this won’t last forever. We will get through this...together.

# Struggling Through Life with Amy \_\_\_\_\_ Kelly Campbell



Kelly (26) and Amy (28)

What is it like growing up with a sibling with special needs? Honestly, this was hard to write about because it is easy to talk about how wonderful it is being a sibling but no one talks about the struggles. I am going to talk about both.

My sister is 28 years old and has Cri du Chat Syndrome. She is 20 months older than me. I remember when I was young, I didn't think anything was wrong with her, she was just Amy. I have always been fluent in "her language," even at a really young age. I have always loved my sister. It wasn't until my early teen years that I started to "struggle being a sibling." My struggles I experienced in my early teen/teen years are what made me a strong, independent person but I didn't think so at the time.

**Feeling like I needed to be perfect all the time.** I knew how hard my parents worked to make sure all of Amy's needs were met. I often felt like if I made mistakes that it would add to my parents' stress.

**Feeling like I couldn't express my feelings.** Sometimes I felt as if my parents loved her more than me and sometimes, I was embarrassed by her behaviors or that she drooled all the time. When I expressed how I felt about her behaviors or drooling, my parents would get upset. I would try and express to my friends how I felt (you know just to get it off my chest, a little rant) but they would tell me I was being mean. Even though my friends always complained about their typically developing siblings, I often felt as if Amy were "in charge." For example, if Amy was ready to leave, then it was time to go. Even if I just started having fun.

**Feeling isolated.** Often times I felt isolated. None of my friends had a sibling with special needs. I usually told my friends about Amy before they met her because I never knew what to say when they asked, "what's wrong with your sister?" I often felt uncomfortable inviting friends over because I was unsure of how Amy or my friends would react. Would my friends treat her right? Would Amy mess up or rip up what we were doing? Would Amy have a meltdown?

**Feeling like I was asked to help with Amy too much.** I can remember being asked to help with Amy as early as 10-11 years old. I was asked to help shower her, dress her, brush her teeth and brush her hair. I started babysitting her for a couple hours at a time. Sometimes when I babysat her, she would have a meltdown and I didn't know what to do.

**Feeling like I had to grow up quickly.** Everything I had to do to help Amy and the pressure to be perfect made me grow up really fast. I learned at an early age how to care for someone.

Around my late teen years, 16-18 years old, I began to gain a new perspective about being Amy's sister. At age 15, my mom made me volunteer at this camp that Amy went to every summer. This camp was specifically for kids and adults with special needs. I was going to have to take care of someone else with special needs for a whole week. After working at this camp for a couple of summers, I realized how wonderful it was to be Amy's sister.

I learned all the things that she could do like swim, ride a horse, and go down a zip line. I saw that she liked to do art and that she was dedicated and passionate when she was working on something. I saw that she had so many friends and that she was very good at making friends. I realized how smart she was. She's nonverbal but she was able to communicate with so many people and I didn't even have to translate. I made friends at this camp who loved Amy and didn't freak out when she had a meltdown. I made friends who also had a sibling with special needs and this changed everything.

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Around age 18-19, I realized that Amy was my best friend. She was my biggest supporter and my biggest cheerleader. I learned that no matter what, she would always tell me the truth, even if I didn't like it. I learned that Amy is one of the funniest people I know and she has the biggest imagination. She always has a joke or prank up her sleeve. I learned that she understands way more than I ever thought. She may not know basic math or know how to read but she understands social cues and how to hold a conversation with someone.

Now that we are both adults, we are closer than ever. I treat her like I would treat anyone else. We fight, pick on each other, and she keeps me up to date on all things happening in her life. It might have taken us a while for our relationship to be this close, but I am so grateful it did, and I am beyond grateful to call her my sister.

### About the Author

Kelly Campbell lives in Mobile Alabama. She graduated in 2016 from the University of South Alabama with a bachelors degree in k-6 special education and general education. She is a certified Behavior Technician and is currently working as a Behavior Trainer. Kelly works with Dance without Limits, special needs dance classes for kids and adults. She is the adult dance class teacher and volunteers with five other classes. Kelly spends her summers at Camp Smile in Mobile AL. Camp Smile is a week long, over night summer camp for kids and adults of all ages having special needs.

## A Sibling's Journey

Nate Wallace

Being a sibling of someone with special needs has its ups and downs! I cannot imagine life without Allie. We are 16 months apart in age with Allie being older at 16 years old. For many years, we have been asked if we were twins!

She is so amazing, funny and smart! Sometimes people underestimate how smart she is, but I let them know there is so much going on in her head! She knows how to get what she wants!

Allie teaches me a lot! Every day she teaches me to be kind to everyone. She can be embarrassing in public sometimes. She likes to hug people and call people names of different characters. She does it to be kind and to connect with others. Not to be rude.

She also teaches me to be myself and always be unique. Everywhere she goes, she calls me her favorite characters. For instance, right now she is calling me Link Larkin from Hairspray. I guess there are worse things she could call me! Sometimes it can be annoying! But it teaches me to be my authentic self always.

So, if you are a sibling and are having issues with your brother/sister, just understand that they will love you unconditionally! That's all they want from you! In the end, they can be annoying at times but if you look down deep, they are always true to themselves and that is one thing we all can learn from them. I have really enjoyed getting to know other siblings through the 5p- Society and look forward to all their support as Allie and I continue our journey together!

### About the Author

Nate Wallace is finishing up his freshman year in high school. He loves acting and singing whenever he gets the chance to do it. Nate and his sister Allie (16), who has Cri du Chat, were born 16 months apart. Nate is one of his sister's biggest advocates. With Nate (15), along with his friend Corbin (15) who is an honorary member of the Wallace family, and her sister Laney (7) Allie is assured to be supplied with enough love and laughter to last several lifetimes.



Laney, Corbin, Allie and Nate

# She's a jerk sometimes, but we love her

*Katherine, with Emily and Chris Bruns*

When I was younger, I would think pretty often about what my sister would be like if she had been born without Cri du Chat Syndrome. I wondered what her voice would sound like, what her favorite subject would be in school, whether she would still be so annoying and in my space all the time. I had a hard time answering any of these questions, but I was sure that our family's life would clearly be improved if only she was normal. At the time, I told myself that I wanted this purely for her sake, so that her life wouldn't be so hard every day. I realize now that I was far more concerned with how much easier my own life would be.

I'm ashamed now of the selfishness of those thoughts. I think, however, that they're a pretty natural reaction to the difficulty of growing up with a sibling with special needs. We had to take on responsibility, for example, before we even realized that most kids didn't. It was our job to keep an eye on Beth out in public to make sure she didn't wander off if mom was busy, and we were always so jealous of friends in high school who could make plans without checking if their parents needed them to stay home with their sister. Not to mention, it was just maddening that we had to clean up all of the messes she made. We also had to be responsible for ourselves at a young age, keeping ourselves occupied and out of trouble while mom and dad were busy with Beth's appointments, therapies, and daily needs. Though that experience taught us independence, it could be difficult to overcome the feeling that our needs weren't as important because they weren't as severe.



*Katherine, Chris, Emily and Beth*

Now that we're adults, I don't wonder anymore about the ways that Beth could be different. It's still frustrating when we can't figure out what she's trying to tell us or when she starts throwing tantrums in public. But now, I appreciate that my sister, and everything about her, has always been just as normal and essential to our family as anyone else's siblings are to theirs. I have learned some wonderful things by growing up with her--compassion, patience, selflessness, humility--and I truly can't imagine any other way for our lives to be.

## About the Authors

This article was a collaboration of siblings; Chris is 30 and lives in Columbus, Katherine is 28 and also lives in Columbus. The twins, Emily and Beth are 26. Emily lives in Celina and Beth lives with mom (Laura Bruns former Society president) in Troy (all in Ohio). Beth attends a day program called Riverside Tech and loves to shoot hoops, go out to eat, and bowl. And she loves Kenny Chesney!

## LEARN SHARE CONNECT

### YouTube Videos to watch

[5p- Society "I Can" video](https://www.youtube.com/watch?v=2AEvN0-6M6I)  
<https://www.youtube.com/watch?v=2AEvN0-6M6I>  
[2015 Virtual 5k for 5p- video Recap](https://www.youtube.com/watch?v=EWX6NHj0nwY&feature=youtu.be)  
<https://www.youtube.com/watch?v=EWX6NHj0nwY&feature=youtu.be>  
[Adam & Tyler Buckner on KASA morning news! 5/30/2014](http://kasa.com/2014/05/29/cru-du-chat/)  
<http://kasa.com/2014/05/29/cru-du-chat/>  
[Cri du Chat Awareness US](https://www.youtube.com/watch?v=GbWDG3JXFL4) <https://www.youtube.com/watch?v=GbWDG3JXFL4>  
Video to increase awareness of Cri du Chat in the US and across the globe.  
By Larry McSeed  
[Cri du Chat Awareness Video—Australia Support Group](https://www.youtube.com/watch?v=V6wk4bFVz2g)  
<https://www.youtube.com/watch?v=V6wk4bFVz2g> Australia Support Group awareness video for 2012 Awareness Week.  
[International Cri du Chat Syndrome Awareness—Meet Nellie](https://www.youtube.com/watch?v=zw2joxiYjR4)  
<https://www.youtube.com/watch?v=zw2joxiYjR4>  
[Emma's "Steps of Faith"](https://www.youtube.com/watch?v=giW_ip5ibr8&feature=youtu.be) [https://www.youtube.com/watch?v=giW\\_ip5ibr8&feature=youtu.be](https://www.youtube.com/watch?v=giW_ip5ibr8&feature=youtu.be)  
[Documentary by Maria Ripoli](http://www.cromosomacinco.com/) <http://www.cromosomacinco.com/>  
[Meet James Chalmers](https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/) <https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

### Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- [www.kathymcclelland.com](http://www.kathymcclelland.com) by Kathy McClelland
- <http://livingwithcriduchatmosaicism.blogspot.co.nz/>
- <http://mikeandbrittanerickson.blogspot.com>
- <http://thissideofordinary.blogspot.com>
- <http://beautifulunexpectedjourney.blogspot.com>
- <http://www.cdcslovehope.com/blogspot.com>
- <http://clairematilda.wordpress.com>
- <http://crazyincognito.blogspot.com>
- <http://myriverside.wordpress.com>
- <http://allaboutvayla.blogspot.com>
- <http://brennanandcalebsmom.blogspot.com>
- <http://praiseyouinthestorm.com>
- [www.prayforellee.org](http://www.prayforellee.org)
- <http://notquiteearthmother.wordpress.com>
- <http://tricia-themama.blogspot.com>
- [www.angelarichey.blogspot.com/](http://www.angelarichey.blogspot.com/)
- <http://lessonsfrommydaughter.me>
- <http://martianmommy.blogspot.com>
- <http://www.specialneedsdadchronicles.space>
- [stripesforeliana.com](http://stripesforeliana.com)
- <https://www.greygenetics.com/a-window-into-cri-du-chat/>
- <https://lovingyoubig.com>
- <http://lifesunexpectedblessings.wordpress.com>

# Mother Knows Best

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It was supposed to be one of the happiest days of her life. Hairstylist Carrie Scanlan and her husband, Fred, were ecstatic at the birth of their new daughter. But from the baby's first wail, doctors knew something was wrong. Little Melanie's cry sounded like the meow of a cat, the first indication that she had Cri du Chat, also known as 5p Minus Syndrome, a genetic disorder that occurs when a piece of the fifth chromosome is missing. This abnormality is extremely rare, affecting only 1 in 50,000 newborns. "It was devastating," Scanlan recalls. "They said she would never walk, never talk. That she may be deaf, she may be blind. She was in the newborn intensive care unit for 76 days in total." Children afflicted with Cri du Chat can experience difficulty swallowing, severe cognitive, speech and motor disabilities, and many other developmental issues.

Scanlan's first instinct was to turn to the internet to find out as much as she could about the disorder. "They say don't go online because it's just going to upset you. But of course, I went home and immediately started searching, and then I just burst into tears. The pictures of all the kids, what they looked like. I just couldn't believe that my child was going to be like this."

But once the reality of the situation sank in, Scanlan shifted her energy to creating the best possible life for her daughter in such challenging circumstances.

Melanie was unable to swallow and had to use a feeding tube. She couldn't walk or speak and suffered from severe cognitive disabilities. Scanlan took her to many doctors, including neurologists, ear, nose and throat and gastrointestinal specialists, and geneticists. And while her focus was on improving Melanie's quality of life, she found that many physicians treated her as if she was a research project, collecting data but offering little in terms of advice and treatment.

## Discovering CBD

Scanlan returned to the internet, with the goal of finding hope and forward momentum. "I'd see other people's children and have hope. This child can walk. That kid is talking. This one's riding a bike. And they always said, don't give up. The more therapies you can provide for Melanie, the better. And that's what we did—look for new therapies that would help her."

She enrolled Melanie in a program at the Perkins School for the Blind in Watertown, Massachusetts, for children with severe disabilities, and later the Coting School for children with special needs in nearby Lexington. Early intervention therapists came to her house three times a week. And with specialized physical and occupational therapies and new methods for teaching communication skills, Melanie began to progress. But as she grew older and matured, new problems arose.

"Melanie has bouts of aggression and anxiety," says Scanlan. "A lot of it is still communication-based. She's trying to tell us something and we don't understand it. And she'll just lash out. She'll bite. Grab your hair, yell. And any change in her environment can cause major anxiety. She doesn't know if she should be happy or terrified."

*"It's almost as if someone has flipped on a switch in her brain, and she is now realizing, 'Oh, this is what I have to do!'"*

Scanlan brought her to a neurologist "to try to find something that would help calm her down. He put her on Risperidone, a very strong pharmaceutical commonly given

*Carrie, Melanie, Fred and Isabella*

to children with autism or bipolar disorder," Scanlan remembers. But it made her practically comatose. That was not living. Her neurologist lowered her dosage, but her behavior only improved slightly. She was having a lot of trouble focusing at the Coting School, and the doctor added another drug, Tenex, but he was concerned because the medications could have serious side effects.

That's when something miraculous happened. Scanlan was searching through Facebook groups for parents of children with Cri du Chat, looking for solutions that didn't involve heavy drugs, when another mother brought up the idea of using CBD. That mom's suggestion struck a chord in Scanlan, who purchased a tincture vial. She checked in with her daughter's doctor, who weaned her off of Risperidone.

## A Natural Solution

For a year, Melanie took Tenex and CBD, and exhibited marked improvements in her behavior. Suddenly, however, there was a shortage of Tenex and Scanlan was unable to procure it. With none available, she decided to keep Melanie on CBD and discontinued all prescriptions. To her surprise her daughter thrived! "Her attention level and communication skills are so much better. It's like her mind has aged three years in the past year." Scanlan is relieved that the CBD regimen has resulted in no negative side effects. "It's all natural. It's not a manufactured drug with side effects. I like that."

While Scanlan found it nerve wracking to challenge the treatments prescribed by the traditional medical community, she knew it was her responsibility to advocate and fight for her child. "Are you going to watch your child suffer or are you going to do everything in your power to help her?"

"I tell everybody about this, because I honestly can't believe how much progress Melanie's made," Scanlan says. "She's calm, focused and her personality has really shone through. It's done her a world of good."





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