

President's Message

Nick Wallace

Just recently Nate and I had the chance to see the musical Dear Evan Hansen. The show revolves around high school senior Evan Hansen and a letter he wrote as a therapy exercise. This letter was written as an exercise to help his confidence and to help his social anxiety. The letter was never meant to be read, but ends up in the hands of a family who is grieving the loss of their son. This leads to Evan telling a lie to help ease the pain the family is experiencing, but it also gives Evan the chance to belong.

There were so many things that spoke to me in this show and I would like to share a few of those things with you.

"So where's the map? I need a clue 'Cause the scary truth is I'm flying blind and I'm making this up as I go."

This is a lyric from one of the songs at the beginning of the show and it really hits the nail on the head. I know all of us have wished for a map or a guide to help us parent our children, both typical and special needs. I know this is exactly how I felt when Allie, our first child, was born, but I really felt it when we received her diagnosis. Man, I really felt like I was flying blind, and I knew that Angie, my co-pilot, was flying blind as well. I am thankful that we were able to get our radio working and have had people like you to help us navigate some of the rough patches and to celebrate during the smooth patches.

"No one should stick it out or have any doubt that it matters that they are here."

In this song the lyric discusses something that I find hard to do at times and that is to be open with my feelings and when I am having a hard time to ask for help and not just "stick it out". While social media can be a wonderful thing, it can also be deceiving and difficult. When a person looks at whatever social media platform they choose to look at, it often appears that everyone is living their best life ever. The family photos look amazing because everyone is so happy. Their kids aren't struggling with bad grades or behavior issues. They are happy, so there is no way they

would be struggling with depression or addiction. People are always jet setting off to different places, and no one is struggling to make ends meet or to keep up with medical bills. (Sidebar note here ... this doesn't mean that I am a fan of everyone airing their drama on social media. Moderation is the key!)

Social media can be deceiving to anyone, but I think that social media can be an especially difficult place for special needs parents. Don't get me wrong, it can also be a place of comfort and guidance, but it can be difficult to navigate sometimes. I know for myself I don't post in our Facebook group often, because I often feel that the issues we face with Allie are not as significant as those others in the group are experiencing. I sometimes feel the same way about achievements that Allie accomplishes, because I don't want other families to be discouraged that their child isn't able to do the things that Allie is able to do.

So, when I thought about this lyric, it made me realize that

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no one should have to stick it out, but that we should feel free to ask for advice as we all go through things at times. We need to feel free to reach out for advice or support and to feel free to share our joys as well. So remember you matter, and you should feel free to ask for advice even if you think it is something insignificant compared to the problems others face. We are all here to support you.

"It takes a little patience, takes a little time. A little perseverance and a little uphill climb."

This song lyric was sung by the grieving father. It is about breaking in a baseball glove, but the meaning behind the lyric can mean different things to different people. I really felt the lyric was about parenting, in general, but also parenting a child with special needs. Most of us are familiar with how much patience and perseverance it takes to raise a typical child, but that is often doubled with a child with special needs. Yes, the patience, time, and perseverance is sometimes frustrating, but when they hit those milestones, the feeling you get seeing your child succeed is indescribable. I can remember the feeling of elation when Allie started to walk on her own. All of the therapy sessions, the gait trainers, the AFO's, and the time spent encouraging her to walk, and then it finally happened. It is so hard to describe how that makes you feel, as it is such a mixed bag of emotions. I know we have all had, or will have, these moments, be they walking, talking, or even just getting a smile. These are the moments that make the extra patience, time, and perseverance worth it.

"When you're falling in a forest and there's nobody around do you ever really crash or even make a sound?"

"Even when the dark comes crashing through, and when you need a friend to carry you, when you're broken on the ground you will be found."

I am combining the two lyrics above because when I started thinking about the lyrics, even though they are from different songs, I felt the two went together. Being a parent to a child with special needs can sometimes be a very lonely place. Often we start comparing our kids with CdC to other typical kids. Sometimes we have good friends who desert us in our time of need. There are times when we feel like no one understands what we are going through. We are the

only ones that are going through these issues, and we have reached our wits end.

I know that when Allie was diagnosed, we had friends who came to visit us in the hospital. I happened to hear them say that they hoped that their child didn't get what Allie had, and after they left the hospital they never contacted us again. These were friends that we were really close to and in our time of need they chose ignorance over educating themselves and choosing to support us. Looking back, it is probably best that they chose the path they chose. We really didn't need that negativity in our lives, but at the time it was difficult to see people fleeing from us.

Now here is why I think that the two lyrics go together. During this time, when the dark came crashing through, when we needed a friend to carry us, we were found. At this time of darkness, we had the support of our church family, who pulled together a fundraiser to help us during the time we spent in the hospital. We found support from our amazing family. We found friends in Tiffany Townsend and Laura Castillo, who were a couple of our first contacts after Allie was diagnosed. These two people I still consider wonderful friends. I can't count the number of times that Laura has been there for our family when we have needed her support. We found the 5p- Society and have attended several conferences. The conferences have provided us with so much information to help us when the dark is threatening to crash in. I know that I mentioned the Facebook group earlier, and although I don't post often, I find that when I need to post about something I can always post and know that someone will be there to help! So even when I feel I am broken on the ground ... I know I will be found!

So, remember that no matter what you believe about yourself or even what someone tells you, in life we will have successes and we will have failures. We will go through the highs and we will go through the lows, but just remember that no matter what you are going through, you are worth more than you believe, and there is always someone who will be there for you. So, I will leave you with one final quote. This is a quote I have on my desk at work.

"Today is going to be a great day and here's why: because today at least you're you and, well, that's enough."

CDC Moms: *Welcome To Your Tribe*

Natalia Rodriguez



Mothers are natural nurturers. We love hard, we sacrifice, we do anything and everything for everyone else; we are Mother Hustlers. Add on extra brownie points if you are a CDC (Cri du Chat) Mom. I know because I am one, I was raised by one, influenced by lots of them around me; whether they were moms or grandmas, mothers of boyfriends while I was growing up and even my own mom in law. I was directly influenced by all of them, and they are all powerful.

I admire their ambition, their unconditional love, their determination and tenacity to get sh** done. What's not to love? I admire their resourcefulness, their grit, how they continued to do what needed to be done long after they were tired, fed up, burnt out and even emotionally spent. And even then they still had more to give.

I watched these women ultimately sacrifice themselves for others.

When NeeSee, my CDC daughter (now 12 years old) came along, I naturally did the same as I had watched all these other women in my life do. After all, who else was going to do it if I didn't?

Any of this sound familiar yet?

So slowly by slowly my entire life became about her and this syndrome. It can happen to any of us, if not all of us. Life became about surviving, and I was no longer thriving. I also stopped taking care of me because I thought that is what needed to be done.

This is what mom's do, right?

I continued like this until it didn't work anymore. And side note: it never worked from the beginning either. One day I found myself depressed, unmotivated, passionless, 40lbs overweight and to top it off, angry and resentful.

I looked back at that time and thought:

"How did I get here?"

"Who am I?"

"What about *ME*?"

"Does anyone even care?"

"*Can* I keep doing this?"

I'm happy to report that after some soulful exploration my answer to that last question was a total Heck YES!

I write this article as both a caution and also an inspiration.

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The CDC Journey is filled with challenges, and it is also filled with tons of joy. CDC at times can feel like it has taken over our lives. So I invite all moms and also yes the Dad Dudes to learn a different way. I am here to spread the knowledge that there are tools and resources we can learn to better manage our lives and this journey. I invite you to acknowledge that CDC is a *part* of your life but NOT your ENTIRE life.

As CDC moms or parents we do not have to turn our lives over completely to this syndrome or anything for that matter. I'm inviting you to put yourself first again. It may feel impossible at the moment, and that's okay. I mean I understand, we all have so much going on. And all I ask is for you to try and see what happens.

To get you started I will share a few methods below that helped me gain my life back after it was touched by Cri du Chat. Use the acronym **SMILE** to help put you back on track in an instant. You can reach for any of these in any moment.



Step 1

Surrender—Stop the need to control. This was a huge step in not allowing the syndrome to overpower my life. Stop fighting or trying to control everything or every situation. *Easier said than done I know.*

Step 2

Make Yourself a Priority—Always. Exercise, Exercise, Exercise! Find hobbies. Eat well. Hydrate. Sleep... (Please sleep more often). Learn how to relax and have a toolbox of things and people you can turn to.

Step 3

Influence Others To Be a Part of Your Journey—Stop the isolation. Ask for help. Recruit and Pay someone to do your laundry (Lifechanger!). Have lunch with Friends. Get Out More Often.

Step 4

Listen to Your Needs—(and all the family's needs—not just your CDC child). You need to be loved and cared for as well. I'll say this loud and clear: YOUR PARTNER IS A PRIORITY! This includes Sex. Can you hear the husbands cheering? Date nights. Communication. Think Mind/Body/Soul.

Step 5

Encourage Your Children's Growth—Keep doing what you've been doing. Continue to be their best advocate and also learn to advocate for *you* as well. Do this at the pace that's most sustainable for you and your family.

Remember: What brings you happiness is sustainable! The goal is to make sure you show up energized: physically, emotionally and mentally.

For more support and tips like these, please join us on Facebook by searching CDC Mom Tribe.



We encourage all CDC moms to join the community to help one another make self-care a priority in this journey. You don't have to do this journey alone.

Self-care is self-love. XoXo.

Natalia Rodriguez

Natalia Rodriguez—Certified High Performance Coach™, Cri du Chat Mom
fb.com/NataliaRodriguezOnline

Natalia has announced that there is talk about a CDC Mom Tribe Mastermind launching soon!
Details will be posted in the CDC Mom Tribe Private Facebook Group as information becomes available.

Cheers to Your Journey!

How many of you have played or heard of the Oregon Trail game? It was one of the first computer games that was developed in the 90's. We had it, and the kids love to play it, traveling from the Mississippi River to Oregon by covered wagon. Only so much can be carried in those covered wagons, too much and your wagon would tip, or the horses wouldn't be able to pull them. But the funniest part of the game is not getting dysentery, sick and dying on the trip. Your host families wanted to make sure that we were all very much aware of the history of Oregon via the Oregon Trail. The decorations were absolutely superb! Thanks to the talents of Becky Owens and Angela Borek and friends for the many covered wagons and pioneer life ambiance that they set for the weekend. Becky even wore a different "Oregon Trail" shirt throughout the conference. The Family Outing was on a real farm that was instrumental during the pioneer days and on the Oregon Trail. There was a lot of simplicity to the conference. There was also a lot of really great planning by Becky, who used her past experience as an event planner to take the conference up a notch (we had walkie-talkies with ear plugs – I felt like I was super important!). Many, many thanks to Becky & Rob and Angela & Roger along with family members and friends who made this happen. The Ron & Paula Johnson family rounded out the host families and assisted where needed with hospitality and welcoming. Of course the Board (skeleton crew) stepped in to assist where needed.

Some of the highlights of the conference were the many great speakers that came and presented, including former Governor of Oregon, Barbara Roberts, who is also a parent of a child with special needs. She pioneered several programs in the State of Oregon that are still in effect today that assist the children and adults with special needs. On Sunday, we were able to listen to Dr. Andras Spaan talk about an exciting future research opportunity for members of the 5p- Society. The research has to do with the identification of multiple otherwise healthy patients with heterozygous deleterious mutations in a gene named *OTULIN*. These patients suffer from life-threatening inflammation in response to bacterial infections of the lungs (pneumonia) or skin (necrosis). *OTULIN* is located on the short arm of chromosome 5. More information on this research coming soon.

We also had some awesome presentations by Dr. Dennis Campbell on Cri du Chat 101; Dr. AmySue Reilly on Effective Positive Behavior Strategies; Mary Anne Elhert on the ABLE Act and Planning for the Future; Leisha Vogl on Speech and Language strategies for different levels of speech development; Sherry Manion from the Love & Logic Institute telling us about their program and philosophy; Patrick Tomblin on IEP's and How to Craft Strong Goals; Dr. Dréa

Petersen on the Genetics of 5p- and how a Genetic Doctor can Help.

This year we had our Fathers' Seminar, brought back by popular demand, facilitated by 5p- Society president Nick Wallace; and new this year Moms' Support Circle, Energy & Self Help by parent and life coach, Natalia Rodriguez. Both of these have been highly sought out by our parents for years and very successful. Founder of the 5p- Society, Kent Nicholls, held his New Family Orientation on Thursday night, welcoming all the first time conference families. The Welcome Reception has some really yummy food, entertainment and great conversations.

Siblings enjoyed a well-run sibling mixer on Thursday night with games and a large space for running around. On Friday, Stephanie Gorman, founder of Socialkraft, a unique support service for individuals with special socialization needs, and Dr. Marie McMahon, a licensed psychologist who is associated with Children's Development Institute, facilitated the Sibling Workshop. On Saturday, the kiddos hopped on a bus to the Oaks Park Amusement Park, one of the oldest amusement parks in the Pacific Northwest, for a hot dog lunch and fun, rides and games.

The Saturday banquet and family dance was super fun with the kiddos and adults enjoying themselves tremendously. Patrick Frank (a 37 year old adult with 5p- Syndrome) of Moscow, Idaho had the winning ticket for the 80/20 raffle. He graciously donated his winnings back to the 5p- Society. Thank you to everyone who participated in the 80/20 raffle. The total raised was \$9,900.00.

Of course a conference cannot be substantiated without sponsors and volunteers, especially the Anderson and Pretty families and Becky's tribe of awesome mom friends. Many thanks to the financial sponsors and rewards recipients of the Portland Conference: Lee & Katherine Lenker and Family, Tim & Dawn Turner and Family, William & Christy Blount and Family, Cedar Sinai Park, Jill Rinaldi, KeyBanc Capital Markets, Robert Glimcher Family Foundation, Ripple Coworking, Inc., Dale Huffman Trust, Be A Voice and the Grasso Family, Pam and Bonnie Wald, Pat Strong, William & Rita Bourne, Matthew & Ashley Summers, Barbara Jo Gray - Gray Matter Career Coaching, Life to the Max Foundation.

Many thanks to everyone who donated items to be raffled off at the conference. We had several quilts, a signed Trailblazer's basketball, jewelry items, Beats Headphones, an iPad tablet, clothes, hand painted items, and various other items that were graciously donated.

Oh and to top it all off, the weather was absolutely beautiful! Thanks Portland for a great conference. I don't think anyone got sick or had any dysentery; that's a big Game Over Win!



2019 Regional Family Get-Togethers

Southwest Regional Get Together ————— Kathryn Gladden

The sense of belonging and connections that last a life time always happen when 5P Minus families come together, and the SW regional get together was no exception. For those that have been unable to attend an annual conference, the addition of the regional get togethers offers the opportunity to meet families in an affordable, less overwhelming environment. And for those of us that have, as in my case, I now have connected with local families that I don't have to wait until the next conference to see again!

The Nevada families were well represented at the get together held in Las Vegas on April 27, 2019. Las Vegas locals included Samantha Fusco, Gracie and siblings Ella and Lukas; Christine Blake and Kendall; Holli Hudman and Sarah and the grandparents, Ed and Diane; and the host family Kathryn, Chuck, Alyssa, and grandpa Ron. Leo and Marlene Obando came in from California with their son Derek and his brother Eddie.

This was the first time the Fuscos and the Hudmans had the experience of meeting other individuals with Cri du Chat. As the host, I was hoping for more families, but when I discovered that they had never met other families, I realized size doesn't matter! While it seems like the discussions typically focused on their similar features, their unique personalities did not go unnoticed!

The adaptive merry-go-round was a big hit with the kids which also served as a great work out for the parents! For me, the biggest hit is the freedom of being amongst people that, with no judgement, understand the of challenges we face and the joy that comes with every accomplishment that is reached – Priceless!

Thanks to the 5P Minus Society for funding and facilitating the families to get together. Now let's keep it going...

“When I’m awake, I dream” ————— Heather Meza

“I’m angry,” she said. “I’m angry” and I hear her clear as day. It’s 2 a.m. and I hear my 3, almost 4 year old tell me “I’m angry.”

But she isn’t angry now, she isn’t even awake. I hear her tiny voice, her broken articulation, and see her gestures just as clearly as I did several hours ago when she tried desperately to tell me “I’m angry!”

I couldn’t decode it in her waking hours, and I told her I was sorry that I didn’t understand. She told me “ok” and went about her business. She carried on with dinner and playing and bedtime, just happy to be heard, even if she wasn’t understood.

I, on the other hand, didn’t move on. My brain worked to the point of obsession trying to match syllabic patterns and decode her limited sound repertoire.

And at 2 a.m., laying awake, I heard her clear as day. “I’m angry!” And she was. Her tv time was over, and she didn’t want the show to change. Why, Lord, WHY, couldn’t that dawn on me hours before. I wanted to wake her and tell her “I hear you, and I UNDERSTAND you.” I wanted her to know that it was important to me, that I felt defeated because I didn’t know what she was working so hard to tell me.

I let her sleep. She is far more forgiving of me, than I am of myself. In the end, she didn’t care that I didn’t understand. She cared that I tried. I asked her over and over, we went where it was calm and quiet, and I made a million guesses. In my failure, she still knew she was heard.

Everyday I admit my defeat to her. And 2 am revelations don’t always come. Honestly, I’m not sure I like when they do because it makes it hurt all over again. Everyday I will be honest with her, to appreciate her work and let her know I am sorry. For now, that’s what we do, but I often, especially at 2 a.m., lay awake dreaming of the day that her sweet, tiny voice is heard and UNDERSTOOD.



The Meza Family consists of Jason, Heather, Kateri, Alix, and Cinna (CdC). Cinna currently attends an inclusive PPCD program, receives Speech, OT, and PT at school and privately, and will be celebrating her 4th birthday near the end of October. Our favorite family activities include visits to the zoo, parks, and just hanging out!

Hi there. My name is Michelle Sandbulte, and I am Mia's mom. Mia is 12-years-old and has 5p-. I have 3 other children (one being a twin [typical] to Mia), and we live in Bondurant, IA.

I was privileged to co-plan the Midwest Regional Gathering. I, along with Taylor VanBruggen, was blessed with beautiful weather (in the midst of a super raining spring) and lots of connections and smiles.

On May 5, we celebrated 14 families and nearly 50 people. Families came from 5 different states: Iowa, Illinois, Wisconsin, Minnesota and Missouri.

We gathered at the beautiful Village Park in Altoona, IA. Altoona is nestled just East of Des Moines and conveniently 5 minutes from my house. This is one of my children's favorite parks, with a huge slide and a beautiful gazebo.

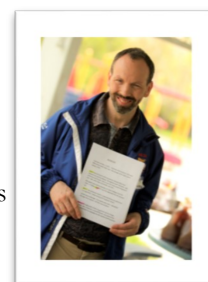
Families enjoyed fellowship and conversation throughout the day; the kiddos (and adults) with 5p- were all different ages, from babies to adults.



We started the day with activities from Courage League Sports. Courage League Sports is a non-profit adaptive sports and recreational facility that offers year-round programming for children and adults who aren't able to go full speed due to a physical, cognitive or emotional disability. By adapting the pace, equipment, or nature of an activity, Courage League can provide a safe and accessible environment where participants can go at their own speed. Read their story on the [website](#).

Lunch was yummy and was coordinated by Taylor and myself. Families were able to connect with each other and talk amongst each other.

After lunch, James Chalmers gave his speech, which he titles "My Birth Gift". Many had not heard James speak before, myself included, and others have known James a long time. After his speech, there was not a dry eye in the house (or gazebo in our case). As a mom to a 12-year-old daughter, I often wonder what her future will look like. I know I'll never know, but James gives so much hope that whatever it looks like, it will be fantastic. James talked about how important Special Olympics has been to his life, saying, "because of Special Olympics, I can meet the world head on!!!" James is a true blessing to all of us, and I know we all are blessings to him, because he ends his speech by saying, "if God did not make me this way, I would not be in Special Olympics, have a Positive Life, and I would not be here with you today."



Following the speech, which is hard, because his speech was so great, two balloon artists joined us to round out the day. They crafted ninjas and crowns and mermaids and many other things.

I truly enjoyed this opportunity to meet other folks and re-connect with others I hadn't seen in years. It's such a neat experience to be surrounded by families who "get you." My other children cannot stop talking about the exposure and how so many kids "looked like Mia."

Books to read

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

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.

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



Parent of the Year 2019

Jolene Towers

I was 21 years old when we had our first child. I knew nothing about Cri du Chat syndrome or how the diagnosis would change our life. We joined the Society when Taylor was just a few weeks old. Luckily we made it to our first conference when she was 17 months old. We made life-long friendships that weekend where I think I felt every emotion imaginable. I was happy to see that we were not alone in this journey. I was overwhelmed with what the future held, but at the same time felt joy at seeing how happy the adults with the syndrome were. The first conference was the beginning of a whole new journey for me.

In 2002 I helped with the conference in Salt Lake City, and at the end of the conference I joined the 5p- Society Board of Directors. This was my first time serving on a non-profit board and I had a lot to learn. Some of my very best friends I have made both on the board and in the Society. I went on to be Secretary, Vice President, and President of the Society. I hosted the Ohio conference and helped with the Indianapolis conference. This has been a wonderful experience of growth and friendship.

Outside of the Society stuff, I am mom to 4 kids. Taylor is our oldest and only girl. I coach girls lacrosse at the high school and I coach my youngest son's U14 club soccer team. I run a local special needs mom's group that has grown to over 1100 members. I am also about to launch a 501c3 to help needy families in our local area. In my "free time," I enjoy family time, usually playing games and eating; traveling, date nights, and girl's night out with my friends.

Superhero of the Year 2019

Jorica Veres



My name is Jorica Veres and I was honored to be chosen as superhero of the year by the 5P- Society. I first heard of Cri du Chat syndrome when I started working with Kerri. She was 14 at the time. Kerri lived with me until she turned 18. The day she turned 18 we lost more than half of her funding. She moved into a group home with 24/7 care. When Kerri first moved in with me Cri du Chat was very new to me! I learned more about it through the Facebook group and also through attending conferences with her. The conferences are the highlight of my year! I loved going with Kerri because that was, and still is, the only place where I felt that people understood what she was doing and what I was going through. I am no longer working with her but am a friend of her family and may pick her up and have fun whenever it works for me. A few years ago at a conference,

the 5P- society was looking for someone to take over making the children's quilt. I thought to myself that my mom and I love quilting together, so why not? It's a fun and super easy way to raise funds for the 5P- Society. I also have organized the 5k for 5P- in our local city for several years now. I love raising awareness about Cri du Chat syndrome and am very thankful for all the help and support I received while Kerri lived with me!



Grandparents of the Year 2019

William and Rita Bourne



Aloha 5P- Ohana (family in Hawaiian). The Carty family is very thankful for being the recipients of your scholarship and for the great experience we had at the 2019 conference. Our daughter Makani'olu is 2.5 years old and has 5P-. Her sibling is Wailani who is 5.5 years old. Along with my wife Josephine, myself & our girls flew into Portland from Maui for our first conference. We were scared to face the music, as we had never met another person who has 5P-. We wanted to learn all we could to help our daughter to thrive & live her best life, & we were hopeful that we would meet other families who could relate to us in a way that those not touched by 5P- cannot. We were blessed to be joined by my sister Kim and her husband Larry who came down from Canada to help us take care of the kids.

Our first experience was meeting Molly and her sisters at breakfast the day before the start of the conference. It was such a sweet encounter and an encouraging look at what the future could be for us. Hearing other people making similar sounds to the sounds that we have only heard come from Makani'olu's lips was mildly disorientating. It was not only our first glimpse into what Makani'olu might be like in a few years, it was also our first look at just how amazing the siblings are. It quickly became clear that one of the great benefits of our time at the conference was to have Wailani plug into a powerful network of amazing siblings.

Josephine and I attended as many classes as we could. Our plan was to divide and conquer to take in as much information as possible and then share in our findings. My personal favorite was the "Protected Tomorrows" meeting with Mary Anne Ehlert. Josephine's favorite was not one class, but rather hearing others share so many day to day experiences, thoughts & feelings that she too had lived through over the last 2.5 years while mothering a child who has 5P-.

Even though we were tired from the busy days soaking in valuable information, at least one of us made it to each of the social events because we were most interested in making connections with parents that had more experience than us and establishing relationships that could help support us through the years to come. We are very isolated out here in Maui and do not know anyone in the state of Hawaii who has 5P-. We felt very blessed to make some special connections. It's heart-warming to have families with more experience than us reach out and go out of their way to include us and really want to know what is going on. Special thanks to these families.

It was extremely meaningful to witness this community engage with our daughter Makani'olu in ways that she enjoyed, that honored her for who she is & did not require explanations or smoothing out others discomfort.

To feel her being so accepted was a gift & a sort of prayer in action that she will always find herself in the company of others who engage her with love & acceptance, & celebrate who she is.

One of the things that I am most grateful for is the support that Wailani received. Even though we had discussed it with her before, while at the conference it was really the first time that she realized what having 5P- meant for her baby sister. She had a good cry about it and we could tell that it affected her. But the joy of making new friends who showed genuine interest in her & who modeled supportive behavior towards their sibling who has 5P- made it an empowering experience for Wailani. Having fun events like the amusement park and the Lewis & Clark farm outing made it a much nicer transition for her as well.

Of course the journey parenting a child who has 5P- is difficult and a conference can't fix that. But having plugged into your community, receiving knowledge that is the result of years of research & experience largely gathered by parents gone before us & witnessing our two daughters embraced with support, we walked away with the feeling that we are no longer alone & a greater sense of "we can do this".

Our thanks to the organizers and leadership of the 5P- Society. See you in Chicago 2020,
John, Josephine, Wailani & Makani'olu Joy Carty





We arrived at the hotel on Wednesday, July 17. The few days before the conference we had been staying at a house at the beach and enjoying the nice weather and the beach.

I want to begin to tell you a little bit about Emma, our daughter with 5p-. She is 8 years old and super high functioning. Her best quality is how open and outgoing she is. She has the easiest time getting to know new people. So, we knew that she would have the best time at the conference and we were not mistaken.

At the first get together she ran from people to people to talk to the kids and of course check out their rides, because Emma loves wheelchairs and bog strollers. And especially g-tubes and all that comes with them. She actually loves watching instruction videos about g-tubes.

Therefore, at times she can be a little much to handle, haha. But it was so incredible how understanding and nice everyone was with her.

She began to say hello to people she met and ask their names. She had learned to say what's your name in English and was really good at making herself understandable in her little English.

Then it was time to go with her siblings to the sibling mixer. Sara, her 13 year old sister was very excited to go and meet the kids. Her younger brother Viktor who is 4 years old was a little nervous but had the best time ever, and we had a hard time getting him out.

When the kids were at the mixer we went up to AmySue's Place and Emma had a blast with some girls.

The next day we went to a meeting and we all shared our concerns and what was most troubling in their behavior. Most of the things parents were saying was spot on. But most of the time what works for one child will not work for the other one. Most of the time, at least with Emma, we just have to work it day to day. We have noticed that now that she is getting older

her behavior is getting better, but often has bad days and they may come in piles. The meeting was great and so wonderful to hear from other parents that you are not alone in this.

Next up was a meeting with all the mommies and grannies. I think that meeting got my mom to understand a little more about what we all go through, or at least I hope so. And most definitely helps her to understand why I need and love CrossFit.

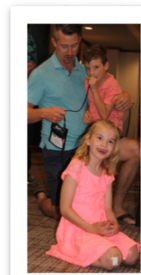
While we were at the meetings our kids were at the fun camp with other kids. They absolutely loved their time there and Emma just wanted to stay.

The family outing was great, the bus ride not so much, but the kids had a great time playing and singing. Emma and Viktor played a lot with two girls that had a sibling with 5p-.

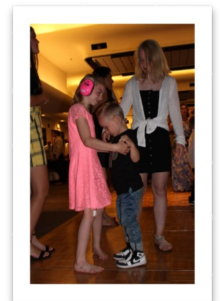
When we got back everyone was so hot and almost everyone had the same idea to go to the pool. So, when we got to the pool it was crammed. And our kids are used to warm pools and the sun was not shining at the pool. So, we didn't spend a lot of time there.

On Saturday it was time for the sibling outing. We wanted Viktor to go with them, but at the last minute he got a little scared and his father ended up going with them. They had a really good time and Viktor tried out all that he could.

On Saturday night it was the banquet. We all got dressed up and went downstairs. Well in Iceland people often come a little late to these kinds of things so we thought we were coming pretty early being almost on time. But everyone was already there! We will try to remember that for next time.



At the banquet Viktor played with his new friends and had such a great time. Sara danced with her friends and Emma played in the halls. She didn't like the loud music. Pictures say more than words so here are some good ones.



On Sunday it was time to say our good byes. We had the best time at the conference and so grateful of all the great welcomes. We can't wait to attend another conference although it will be a couple of years until next time.

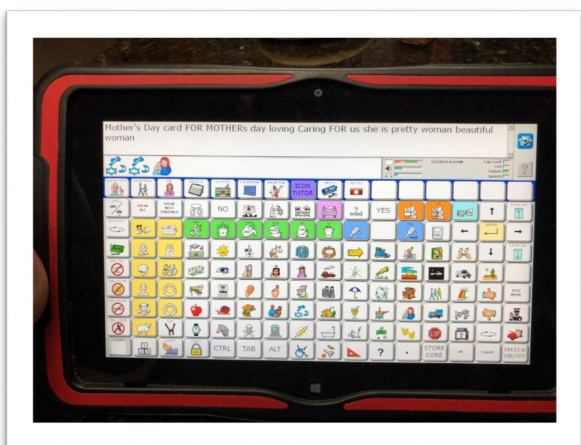
Our son Tyler was 2 ½ years old when his speech therapist at Easter Seals told us that she thought he would benefit from using an augmentative communication device. We decided to pursue getting him one, and it ended up being one of the best decisions we ever made for him. He was given an Augmentative Communication Evaluation by a team of therapists at Easter Seals, and they recommended a device called the Delta Talker by Prentke Romich. We submitted a large packet of paperwork to Tyler's primary insurance and then to Arkansas Medicaid, and both paid for the device. We were thrilled! Tyler got his device when he was three years old and has never looked back.



The Delta Talker was big, bulky, and heavy, so we carried it for him initially, as he was still working on ambulating long distances and up and down stairs with his physical therapist. As he grew and ambulating became easier for him, he began to carry his device around his neck and shoulder with a strap like a trooper. The device used a language called Unity, which is an icon-based system. At the time, Unity had as few as 8 locations and up to as many as 128 from which to choose. We chose to start Tyler out on the highest level of 128 locations so that he wouldn't have to relearn icon sequences as we added locations. The user typically selects two to three icons in a specific sequence to speak one word or phrase. For example, the word football is spoken by selecting "shoe + shoe + shoe." The word golf is spoken by selecting "shoe + shoe + music." The word baseball would be spoken by selecting "shoe + shoe," and then the final icon would represent the word baseball. Tyler quickly learned what each icon represented by repetition.

The more Tyler used his device, the easier it was for him to learn the vocabulary. This was accomplished in part by letting him have access to his device at all times. He also received two to three hours of speech therapy per week initially, then less as he grew older. His speech therapy was not focused so much on teaching Tyler how to use the device as it was on helping him incorporate using it, along with sign language, low tech boards, and verbal communication to communicate his wants and needs to those around him. He progressed rapidly from saying single words on his device to forming phrases and sentences. The sentences might not have always been grammatically correct, but a speech therapist once told us that it didn't matter if he used the words "A" or "the," it just mattered that he got his point across quickly. By getting Tyler a communication device at such a young age, he was able to grow up with Unity as one of his languages, just as English and American Sign Language are also his languages.

Tyler used his device at school, which enabled him to participate in class and communicate with his peers. For instance, his kindergarten teacher would send home the week's vocabulary words the week before they were to be used in class. I would then program the words into the device that were not already in it, as Unity allows the user to customize the vocabulary specific to the user. I would then spend a little time showing Tyler where the new words were located so that he could answer questions in class. I also programmed friends and family members' names, pet names, favorite athletes, places he liked to visit, etc. into his device so that he could talk about them. Tyler had a one-on-one aide through elementary and middle school, and the aide would write down Tyler's answers from his device onto his paper for him. In addition to selecting icons to speak words, Tyler was able to spell words on his device making it an easy way for him to take spelling tests or say words that weren't stored in his device.



After nine years of wear and tear on the Delta Talker, we were able to upgrade Tyler to the latest Prentke Romich device at the time, the Pathfinder. This device was also paid for by his primary insurance and Arkansas Medicaid. The best part about the Pathfinder was that it also used Unity. Tyler was able to pick up where he left off with his Delta Talker. He used his Pathfinder for another nine years, which leads us to his current device, the Accent 1000 by Prentke Romich. It also uses Unity, and this time it was paid for only by Tyler's Medicaid. This device is the size of a tablet thus making it easier for him to carry. It has 144 locations as opposed to the 128 on his two previous devices. Changing devices was a little traumatic this last time, as he was so attached to his Pathfinder. We started calling his Pathfinder

Continued on page 12

“Grandpa.” We told him that Grandpa was ready to retire and was going to live on the beach in the Bahamas. We named his new device “Junior.” Every once in awhile Tyler will talk about Grandpa being on the beach and we’ll all get a good laugh out of it.

Besides using his device, Tyler is able to say some words verbally and also signs many words. If we don’t understand him, we always tell him to get his “talker” and tell us. This can be frustrating at times when he wants to say something that’s not already stored in his device or he’s unable to spell it. He keeps trying to get his point across though, and we are usually able to figure it out, although there might be a few tears shed before we get there. As Tyler has matured, he has taken over programming new words into his device, which is a favorite pastime of his. Having a communication device has helped Tyler learn to read and spell, as he is constantly seeing the words displayed on his device. Being able to read and spell has allowed him the ability to email and text friends and family members on his iPad and computer. It has also caused us to make sure we don’t leave any paperwork lying around or any texts visible to him that he might read and get a little overly excited about!

Tyler is now 26 years old and lives at home with us. His brother, Seth, is away at college. Tyler often texts Seth to tell him he loves him and that he should come home for a visit. Tyler attends a day program four days a week for four hours a day. He also has an aide that takes him out into the community a few hours during the week. Our family of four has definitely been blessed by Tyler’s desire and ability to use his communication device. He is able to tell me what he wants me to cook for dinner or which restaurant he wants to eat at, where he wants to go for vacation and which airline he wants to fly on, or even which football teams are playing each other, when, and where. Being able to hear Tyler speak whatever is on his mind whenever he wants is a gift that we do not take for granted.



The Piepergerdes family, Todd, Lora, Tyler 26, and brother Seth.

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YouTube Videos to watch

5p- Society “I Can” video
<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>
 Adam & Tyler Buckner on KASA morning news! 5/30/2014
<http://kasa.com/2014/05/29/cru-du-chat/>
 Cri du Chat Awareness US
<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> Australia Support Group awareness video for 2012 Awareness Week.
 International Cri du Chat Syndrome Awareness— Meet Nellie
<https://www.youtube.com/watch?v=zw2joxiYjR4>
 Emma’s “Steps of Faith”
https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player
 Documentary by Maria Ripoli
<http://www.cromosomacinc.com/>
 Meet James Chalmers
<https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- www.kathymcclelland.com by Kathy McClelland
- <http://livingwithcriduchatmosaicism.blogspot.co.nz/>
- <http://mikeandbrittanycrickson.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://praiseyouinthe storm.com>
- www.prayforellee.org
- <http://notquiteearthmother.wordpress.com>
- <http://tricia-themama.blogspot.com>
- www.angelarichey.blogspot.com/
- <http://lessonsfrommydaughter.me>
- <http://martianmommy.blogspot.com>
- <http://www.specialneedsdadchronicles.space>
- stripesforeliana.com
- <https://www.grengenetics.com/a-window-into-cri-du-chat/>
- <https://lovingyoubig.com>
- <http://lifesunexpectedblessings.wordpress.com>



Time to gear up for the 34th Annual 5p- Society conference. We are heading back to where it all began in 1985 — Chicago, Illinois. This will be our fourth Chicago conference. To keep updated on the conference, make sure that you check our dedicated webpage at <https://fivepminus.org/event/2020-5p-society-conference-chicago-illinois/>. Here we will update and provide you with information about the venue, the cost, the speakers, scholarship info, and registration info. Registration will open in February 2020.

Currently, hotel bookings with the Eaglewood Resort and Spa are now available to make. Hotel group rate is \$149.00 per night. The online booking link can be found on the conference page listed above, or you can call the hotel directly (630) 773-1400.

We are looking forward to having 5p- parents and friends from around the globe for an International meeting. If you are a member or organizer for one of the International 5p- or Cri du Chat Organizations please contact Laura Castillo at director@fivepminus.org.



PO Box 268, Lakewood, CA 90714-0268
Toll: (888)970-0777; Phone: (562)804-4506
Fax: (562)920-5240
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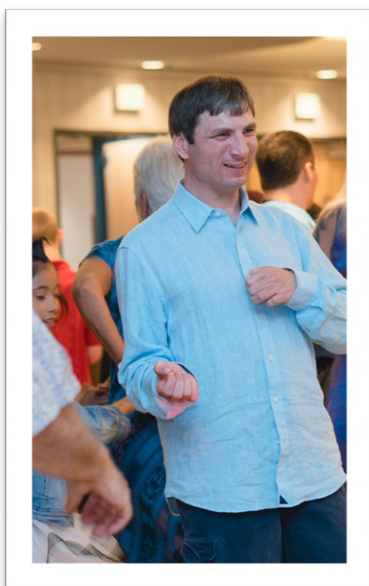
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Meet C5

The Mascot of the International
Cri du Chat Awareness Week
May 1—10, 2020



Patrick strumming that guitar



Siblings enjoying the SibOuting in Portland



Homecoming Queen Emma

Ways to Help the 5p- Society

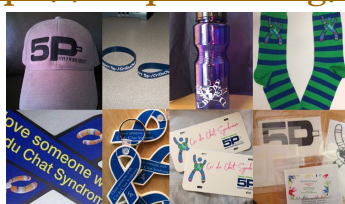
When SEARCHING the internet, don't forget to use GOODSEARCH – sign up and put in 5p- Society as your Cause. The 5p- Society gets a penny for every search. www.goodsearch.com.



When purchasing items on Amazon, make sure you go to AmazonSmile at <https://smile.amazon.com/> and choose to support 5p- Society (Lakewood). The 5p- Society gets a small % of what you purchase. Every little bit counts and we are grateful to you for your participation.

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