

President's Message

Nick Wallace

The 2018 conference has come to a close and again, it was a wonderful experience. A special thank you to the host families and to Laura Castillo for using your talents to put together a very enjoyable and informational conference. For this conference, Laura created magazine covers that had a photo of our kiddos and what they are a champion of. We had a champion of compassion, a champion fashionista, a water sports champion, and several other champions in our midst. Often we get caught up in the things that our kids cannot do and sometimes we don't see the amazing things that our kids can do. I also feel that as parents we can often forget that we are champions also.

I don't know about the rest of you, but there are times I forget that there are things that I am a champion of. I know there are several of you who cannot believe that I would ever forget that I am a champion of being full of crap. Lol! Now, I do know that in the middle of a meltdown or in one of those moments when the struggle of being a special needs parent gets the best of me, I often think of the things I could do better or second guess myself as a parent. During these moments it is easy to get drawn into focusing on the negatives versus remembering that you are a champion at something.

This brings me back to the champion magazine cover project and the fact that we could probably name off several things that our kids are champions of, but may have trouble at times naming off the things that we are champions of. You do not have to be a champion of something that people would deem prestigious (i.e. athlete, actress/actor, musician). You could be a champion smiler, a champion friend, even a champion volunteer.



Entering a shameless plug here, but the society is always looking for people to volunteer their talents to the society. We are always looking for champion graphic designers, champion ambassadors, champion outside the box thinkers, and so many more champions. So, if you feel you are a champion who would like to help the society, please let us know.

Ok, we are returning to my original point now. Being the parent of a special needs child is not an easy thing to be, and it is often easy to forget how amazing you are. So, make sure you take time to reflect on what you are a champion of and try to find something positive about yourself. Also make sure you know that you are all champions in my book.

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Vice President's Message

Michelle Myatt

The 5p- Society Board of Directors is looking for a host city for the 2021 conference. Do you have what it takes to be a host family? If you want to give life to an annual conference, there are basically three main components the Board of Directors looks for. The first one is motivation. You know the old saying, "Where there is a will there is a way." It is imperative that a potential host family feels strongly about wanting to host. This is a big commitment that lasts about two years.

In addition to motivation, one must also have support. One person should not take this on alone. You need to have other families to help you plan and fundraise. When you divide the "to do" list among several families over the course of two years, it doesn't seem nearly as intimidating.

The final factor we look at is location. The Society attempts to move the conference strategically, so that it is closer to home for each family at least once every few years. We look for a large city with an airport in close proximity to a hotel large enough to fit our needs.

So basically, you and a few pals decide you want to give back to the 5p- Society. You have two years to fundraise and plan in a big city near you. Do you have what it takes? Are you ready for more details? Please follow along in the next few newsletters where you will find more specifics about the conference budget, fundraising and planning. Already think you have what it takes? Send us an email and we will be happy to chat with you.

2019 5p- Conference in Portland

Becky Owens, Conference Committee Host Family

The conference committee is very excited about hosting the 2019 conference in Portland next July! We have many great speaker ideas and will continue to work over the next several months to confirm those as well as other details for the conference, so stay tuned! What we CAN promise, is that you will have a great time in Portland and the Pacific Northwest. There is so much to see and do here!



Dates: July 18 – 21, 2019

Location: DoubleTree Hilton Hotel, 1000 NE Multnomah Street, Portland, Oregon

Room Rates: Between \$169 & \$189 depending on room type

Reservation Information: Room Block will go online very soon. We will put the information on the 2019 conference webpage as soon as it's live.

Family Event: Barbecue & Pioneer activities at the Oregon Trail Interpretive Center (<https://www.historicoregoncity.org/>)

Sibling Outing: Oaks Park: (<http://oakspark.com/builder/projects/template/>)

Other Helpful Links:

Hotel Homepage — <http://doubletree3.hilton.com/en/hotels/oregon/doubletree-by-hilton-hotel-portland-RLJC-DT/index.html>

Travel Portland Video (shown at 2018 conference) — https://www.youtube.com/watch?v=0fMJ_JwGc_g

TriMet MAX Homepage (our public light rail system) — <https://trimet.org/max/index.htm> <https://trimet.org/#/planner>

Travel Portland (our Visitor Center/Information Organization) — <https://www.travelportland.com/https://www.travelportland.com/article/portland-international-airport-pdx/>

See you next July!!

5p– Society Conference of Champions Wrap Up ——— *Laura Castillo, Executive Director*

WOW!! What an amazing conference. From the welcome reception with all the mascots from the local college and professional sports teams — and the cheerleaders . . .the fantastic family outing aboard the Gateway Clipper Riverboat Cruise . . . the sibling events. . . the wonderful speakers and topics . . . the awesome decorative flowers . . . the exciting banquet and family dance. . . to the closing speech by Justin Valenti (a shortened version reproduced for you all on pages 8-10), the host families played their best game and won the Championship!

Thank you to the Stevens-Corrado, Sleith, Grasso, Yauch, Fowler, Magulick and Gattone families for all the fundraising, planning, preparing, and executing of the 33rd 5p– Society conference. I know you worked really hard to bring the over 100 families who attended the conference a really great time. Thank you to all the families who donated items for the silent auction and raffle. Many thanks to Jorica Veres for creating the Kids Quilt from last year’s conference and again for this year’s conference. Your time and talent is greatly appreciated.

Many thanks to the board of directors for assisting with “running” the registration table, setting up, breaking down and overall support. Special thanks to Kristi Furnari for coordinating the Conference App. Feedback from conference goers on the use of the app is greatly appreciated for future conferences. Thanks also to Kent Nicholls for welcoming the 27 first time conference attendee families and Gloria Griffin for leading the grandparents in the Grandparent Workshop.

Speakers talked about planning for the future and the ABLE Act, toilet training, sleep training, Cri du Chat 101, ABA Therapy, Effective Positive Behavior Therapy, Anat Baniel Movement Therapy, IEP and Life After High School, Power of Genetics and Nutritional Deficiencies.

Looking forward to working with the Portland Oregon committee as we take the 34th conference to the end of the Oregon Trail!!

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.

Shop for your 5p– items below at

<https://fivepminus.org/shop/>



[Shop on CafePress](#)

[Shop on SquareUp](#)

[Shop on InkSoft](#)



C5's

Carousel of Possible Dreams

Regional Family Get-Togethers



On August 5, 2018 many CDC families gathered from Western Canada at the ACT centre in Edmonton, Alberta. It was a day of fun, friendship, and memories to last a lifetime. The gathering started with a swim, as our children all seem to love the water. Activities followed including: face-painting, jumping in the bounce house (or playing in the ball area), parachute games, sensory space and room to run around. A beautiful slideshow was shared, which captured the special moments in life of those attending with CDC. Special thanks to Breyanna Harper for compiling this. We had an amazing BBQ which included a Burger & Sundae Bar.

As we walked in the room of strangers, there were no walls; just love, acceptance, understanding, support and friendship. Tears were shed as our children connected amongst themselves. Stories were shared and connections were made. Since this gathering, a group of moms have already met up for a follow up dinner. Below are a few quotes from the event:

“What the day meant to me and my family:

A circle of friends, connected by hearts and souls.

Fulfillment through laughter, smiles and happiness.

It was the warmth that was felt, to see hands joining, feet following, arms reaching to hug and smiles that sparkled through beautiful eyes.

Enjoying the beautiful sound of hands clapping and hoorays that filled the pool. The pure joy to see confidence while swimming.

It was the understanding that happened without words being spoken and the warmth in the parents eyes that said ‘we get it and we are here for you.’

It was completely beautiful.”

Deanne Warren



“Just a few words: welcoming..... special.... inclusive.....incredible....it’s hard to put into words how we felt, the feeling was so unlike any of the conferences we’ve been to, this was way more intimate and special!”

Jorica Veres

“Our 5p- western Canada gathering meant so much to my family and I. It was a time to visit with other families and hearing about their Childs journey with Cri du chat and to feel relaxed in a loving environment where everyone gets it. No judgement.....just smiles and understanding. Bostons siblings described it as a sense of peace. My Dad and stepmom also enjoyed themselves and it was a time for them to talk to other families and their experiences. We are so thankful that we had the opportunity for all of us to be able to get together and we cannot wait for the next one.♥.”

Venitta Harper

Special thanks to Turner Smith for coordinating with your school (Spirit Of The North Community School) a fundraiser to help sponsor this event. We also appreciate the generous donation from the 5P- Society. Thanks to Venitta Harper in helping me plan this event and to all the family members that contributed in various ways (set up, clean up, hosting, BBQ’n). A great big “thank you” to Ryan Smith and family, for flying in from Manitoba for the weekend to join us. Seeing Ryan at age 49 enjoying life to the fullest has spread joy and hope to all 11 families in attendance. We are already planning a Christmas gathering for families to connect again.



We asked a few families to prepare a write up about their experience of attending the conference for the 1st time. Elaine Torre from Celaya, Guanajuato, Mexico wrote the following passage. It sums up what a conference means to most parents:

It was a great experience, since we got on the plane to Pittsburgh we were nervous, it was a new experience we were about to live!!! Meet families just like us having everything in common not feeling we were alone, it was sooo exciting, Carlos, Anna and I were very happy. It was a feeling that came from the heart, from the soul. In Mexico we don't have this so it was like we were going to meet our new family. A family that loved us even without saying a word, pure empathy and love. It was so wonderful to imagine getting together with human beings from the same species, it was the best feeling.

For the first time I wasn't sorry from the way Anna acted. I didn't have to explain to anybody how she was or why she was on the floor or acting up, everybody just helped. Anna was excited too, like she knew there were families just like hers. I can't explain in words all the good feelings we were experiencing. From the time we arrived at the hotel, different people came and talked to me, asking where we came from and how Anna was, this is where the story began, everybody was so nice, helpful and understanding. We got to walk about and know Pittsburgh until we had to get registered and get to know each other, hearing different stories and experiences that would show me lots of things. It was like a dream come true, like if we were picked from the complicated world we live in and were put there in Pittsburgh to learn from each other and give what we are surrounded with love.

It didn't matter what country, color, race, or religion, it was about other things that are really important like understanding, relying, having support, getting a hug, extending your hand to somebody that needs it. This is the importance of accepting life as it is, with difficulties and ups and downs, but together we strengthen this group, we are heard, helped and understood, that's life, that's everything.

The presentations were the most important topics that can help us raise a child with special needs. They were so well organized. We told each other without words, we are doing our best and yes we can do it!!!! We were given tips and different ways we can help our family stand up and give the best for our child. Hearing everybody's ways helped also because I learned everybody is different and has different ways to deal with their child. That was the most important part of the conference. Listening to each other. I also got to know where we are standing 7 years after the diagnosis in Mexico. Hearing genetics say the same information that I got in my country was very important also. Evaluating everything I got to see after therapies, behaviours, doctors, information the most important thing was going to Pittsburgh and just feeling what that hotel had for us a great or the best experience for our families. I thank each person that organized this and all the conferences. With all my heart, thank you. I came back home and realized what we had experienced.

Regional Family Get Togethers *Jolene Towers*

The 5p- Society sponsored five Regional Family Get-Togethers. Thanks to Clara Thomsen for organizing the North West gathering in Alberta Canada, andtThe Liberman and Watt family for sponsoring the gathering in the North East in Massachusetts. Thank you to the Vaden Family who hosted a gathering in the South East at Panama City, Florida; the Myatt family for hosting the Mid-West gathering in St. Louis, Missouri; and Sam Brown for hosting the South West gathering in the Phoenix, Arizona area.

Interested in hosting a Regional Family Get Together for 2019? Contact Jolene Towers at gnjtowers@aol.com.

2018 Hall of Fame Recipients

Congratulations to Matthew and Heather Grasso, 2018 Hall of Fame Parents of the Year. Matthew and Heather live in Havertown, Pennsylvania. They have four children, with their third child Matthew Jr. (8) with 5p- Syndrome. Matt & Heather host a major fundraising event called Be A Voice that has assisted the last three conferences. Matt & Heather were also one of the host families for this year's conference, assisting with child care and were the DJ's for the family dance! We absolutely love this family!!



Congratulations to Lyn Stephens, 2018 Hall of Fame Grandparent of the Year. When My husband Mike and I, along with our three children, came to the USA from England some 20 years ago. I was asked to join the Beta Sigma Phi sorority by my neighbor and now dear friend Nancy. This group of ladies have helped me to try so many new things.

For four years I chaired our sorority golf tournaments for Cystic Fibrosis and enjoyed it very much. But now with our 4-yr old granddaughter Claire, with CDC, fundraising has become so much more personal.

When I have time I love to quilt, read mysteries, play golf with my husband, and of course spend time with the family and three grand kids.

Congratulations to Sharon Demczak as the 2018 Hall of Fame Sibling of the Year. Sharon is the younger sister of Sandy Barnes (57 years old). Sharon and her family live in Montgomery, Texas. Sharon was one of the host families of the 2014 5p- Society conference in San Antonio, Texas. Sharon's family ran the sibling events at the conference. Sharon and her brothers and sisters share amazing stories of their big sister Sandy.



Congratulations to Cheryl Allison as the 2018 Hall of Fame Volunteer—Superhero of the Year. Cheryl Allison has over 30 years experience in Film/TV, Broadway and Regional Theatre as an actress, producer, director and filmmaker. She is best known for her starring role in the feature film *No Letting Go*. She is the founder of WOW FILMS, and has produced several award-winning films. Cheryl searches out projects that show her love of advocacy for marginalized communities. She most recently directed and produced the feature length documentary *'Shatter the Silence'* which will be released in 2019. Cheryl is most proud of producing and directing the 5P Minus Society PSA *'This is Cole'* which starred her cousin Cole Cargol. "I was honored to help raise awareness for such an important cause that is near and dear to my heart." The PSA has won several media awards including the prestigious Silver and Bronze Telly Award, the Gold Hermès Award and the Gold DotCOMM Award. The PSA is currently running on FOX Television Stations throughout Texas.

LEARN SHARE CONNECT

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/>

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 a four-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.

Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- www.kathymcclelland.com by Kathy McClelland
- <http://livingwithcriduchatmosaicism.blogspot.co.nz/>
- <http://mikeandbrittanierickson.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://notquiteearthmother.wordpress.com>
- <http://tricia-themama.blogspot.com>
- www.angelarichey.blogspot.com/
- <http://lessonsfrommydaughter.me>
- <http://martianmommy.blogspot.com>
- <http://www.specialneedsdadchronicles.space>
- <http://lifesunexpectedblessings.wordpress.com>
- www.specialneedsdadchronicles.com

Protected Tomorrows Hosts a Family and Professional Campowerment

Mary Anne will be joined by several professionals at a retreat specifically designed for you. These are professionals considered to be leaders in their field of expertise. They will work with you, one on one, for the needs of your loved one with a disability.

March 15-18, 2019, 50 financial professionals and 50 family members are heading west to Malibu, to **Campowerment**, a magical place where the Santa Monica Mountains overlook the Pacific Ocean. With Mary Anne and her team of pioneers, we'll get Protected Tomorrow's mission of *Helping Families Plan a Safe, Fulfilling Life for their Loved Ones with Special Needs* accomplished at Campowerment, the sleepaway-camp-inspired experience designed to equip grown-ups to live life better.

Learn more at: <https://protectedtomorrows.com/family-and-professional-retreats/>

Newsletter Articles Wanted

We welcome articles for the newsletter. Please submit articles to
Shari Campbell at
djcshe@mchsi.com

Learn more about the ABLE Act by watching a free Webinar by Protected Tomorrows at: <https://www.youtube.com/watch?v=agrFxKETPZU&feature=youtu.be>

Justin Valenti 21-year old with Cri du Chat Syndrome

5p- Society Conference Presentation

In the beginning, I wasn't diagnosed with Cri du Chat right after I was born. But, I had some of the features --

- I had a round face with wide-set eyes.
- I had folds on the inner corner of the eyes.
- Initially I was slow to grow and I met most of my early milestones on the later end of "normal."
- I had chronic reflux - many of my baby pictures show me with a bib on to protect my clothes.
- I had, and still have low muscle tone -- which is part of why I crawled and walked a little later than other kids. Low muscle tone caused me to have feeding difficulties when I was a baby. And I have poor posture because my core muscles are weak.
- I had a lot of ear and sinus infections - doctors took my adenoids and tonsils out and put 2 sets of tubes in my ears to minimize ear and sinus infections; and recently, nasal cavity surgery to help me breathe better.
- My speech and language were delayed -- I began working with a speech therapist when I was 15 months old.
- I have always had issues with constipation. A couple years ago, I started taking Linzess and it has really helped with this.

I was diagnosed with Cri du Chat Syndrome when I was 2½, and then was diagnosed with autism when I was 3 years old. My parents said that getting these diagnoses was a little overwhelming, but was also helpful -- it allowed them and professionals to narrow their focus for supports and services that could help me. And having the diagnoses has helped me qualify for services and funding that I have needed (and continue to need).

When it was time for me to go to preschool, we lived in Melbourne, FL and I went to Space Coast Early Intervention Center. Here, I got speech, occupational, and physical therapy. AND, other kids with disabilities and I played and learned with kids who didn't have disabilities. This school introduced my parents (and me) to the idea of inclusion, which has played an important role in my experience with living with a disability. Space Coast Early Intervention Center gave my family a solid foundation of inclusion and self-advocacy, which has allowed me to have many of the same opportunities as kids without disabilities. Right before I started kindergarten, I moved to Maryland. In Maryland, I was included in general education classes, with support from a para-educator from kindergarten through high school.

Most kids who had disabilities at my school were in special education classes, but I wasn't. I was included in "regular" classes (with kids who did not have disabilities) for most things and I received Special Ed services and support in

these classes.

I liked being included and it was good for me for a lot of reasons. I liked being able to make a lot of new friends each year and being able to learn about history (which was my favorite subject). And, I liked when my peers helped me instead of adults helping me all of the time. And there were also sometimes when it was difficult. One of the hardest things about being included was that many of my teachers in middle and high school didn't have (and sometimes didn't want) training that they needed to support me. So, me and my parents (and sometimes an attorney :)) advocated for and helped with training. I think that the best part of my experience with inclusion was that it has allowed me to participate in the same clubs and activities as kids without disabilities. Even though I am sometimes quiet, I have always liked being around people -- kids and adults.

Another thing that was not easy for me was when classmates were accomplishing things that I couldn't or hadn't yet accomplished. The hardest thing was when I turned 16 and everyone at school was learning how to drive. I would hear them talking about getting their learners' permits and driver's licenses AND of course they posted and tweeted about it too! I got really frustrated - especially when my younger sister got her license because everyone around could drive and I couldn't. I still don't know how to drive, but I learned how to get to where I want and need to go -- I use buses, the subway, taxis, and Uber. I still want to learn how to drive, but I know that may not happen for a while. For now, I'm going to focus on learning how to ride a bike!

I began working with a speech therapist when I was 15 months old and did not babble until I started saying "ma-ma" when I was 26 months old. My parents told me that I used to get really frustrated when I needed or wanted something and didn't know how to tell people what I needed or wanted.

When I began working with a speech therapist, she worked to teach me sign language and spoken language. She told my parents that when she taught the signs while developing



speech and language, many kids learned to sign before they learned how to talk. She said that as kids developed verbal language, they just stopped using the signs. And it worked -- I learned signs for the "important" words like "bathroom," "cookie," and "dog," so that I could better communicate what I wanted and needed.

You can imagine how excited I was when I learned to sign "more" and "cookies" and my parents gave me cookies!! They said that they were so excited that they knew what I wanted that they just kept giving me cookies every time I signed "cookie"! I continued to learn the signs for words and some phrases for about two years, until my speech and language development really took off. And now, I like to talk and when I get anxious, I will talk about whatever I am anxious about over and over again. My parents remember when they wished that I would talk...they should be careful what they wish for! As my language developed, I learned to ask for things that I needed or wanted, and eventually I learned how to tell people for example when things were too loud or scary for me. My parents said that as my language continued to develop, I didn't have as many behaviors. Finally, I had a better way to communicate than with my behavior.

In addition, I learned how to use the computer and an alpha-smart to type my thoughts. Even though I didn't use technology to talk, technology has been really helpful to me. The tool that I started using early in life and that I still use today was a laptop computer. I learned to type (not well, but effectively) and I've been able to compensate for low muscle tone and poor fine motor skills when I was younger by typing out my thoughts.

Today my iPhone is my "go to" device. I know there are a lot of apps to help with communication and these have been really helpful for a couple of my friends who are non-verbal. I see a lot of the kids and adults here have smartphones and tablets; that's encouraging.

In my experience, being able to communicate what I want has been important -- I still struggle with it at times, and sometimes it takes me a while to organize my thoughts and get them to come out the way I want to. But, whether I point, grunt, sign, type or use words to communicate - communicating with others is rewarding.

Up until about second grade, I met with speech and occupational therapists after school. My parents thought it might be good for me to participate in activities with other kids my age (with and without disabilities). So I stopped meeting with speech and occupational therapists after school and joined cub scouts. I liked going camping and doing other things with my friends in cub scouts. My parents helped me

find activities that I like by looking for activities and clubs that are related to my strengths and interests. This has worked out pretty well -- I liked everything I have tried except soccer.

My first year of high school, I was in Best Buddies and Cougar TV (student-run, weekly news broadcast). In 10th grade, I joined marching band because I loved music and I had been taking drum lessons since I was in 6th grade. In 11th grade, I began taking sign language class and I joined the sign language club and the anti-bullying club. In 12th grade, I had an internship as a student aide in the counseling office and I delivered passes to classrooms. I liked being an aide because I knew my way around the school and navigated the school independently. I worked at Best Friends Pet Care as a Pet Activities Associate -- I took dogs outside, on walks, played with them and read them bedtime stories. Since graduating in 2014, I have been taking credit and non-credit classes at the local community college. In January 2017, I joined an art program called VisAbility Art Lab, which has helped me grow as an artist.

As long as I can remember, I have known that I have Cri du Chat and autism. I learned about this from my parents, who have always talked openly to me and others about my diagnoses.

I remember my parents reading a book about what it means to have autism with me when I was younger. And they have always talked about how each of us has things that we are good at and may be easier for us than for others. And other things are more difficult for us.

*I'm glad that my
parents didn't keep
the knowledge of my
disability from me.
It's part of who I am
and I use it to help
people better under-
stand me.*

I used to ask why my sister was so good at riding a bike and why I hadn't learned how to do it yet. My parents explained that riding a bike was something that was easier for Jessica than it was for me. And they reminded me that Jessica was still working to learn how to read. Sometimes I still get frustrated and depressed when others make things look easy, but they're really difficult for me.

I'm glad that my parents didn't keep the knowledge of my disability from me. It's part of who I am and I use it to help people better understand me.

I have learned over the years what my strengths/interests and weaknesses are. I keep this list up-to-date so I can share it with people who are supporting me and others in my life, as I work towards greater independence as an adult.

Learning about my strengths and weaknesses has helped me a lot. One way that this has helped me is by figuring out what classes/activities that I would want to participate in

and what type of job that I want to have. Knowing what I am good at and what I like doing also helps me find things that I have in common with other people. For instance, I know that a couple of my friends like music so I use that to start conversations with them. Sharing my strengths and weaknesses also helps people better understand me as a person and how to support me.

My Strengths and Weaknesses

• Strengths/Interests

- Good memory
- Reading, history, art
- Taking care of myself (e.g. getting dressed, personal hygiene, feeding myself)
- Dogs
- Using public transportation independently
- Swimming (took years to learn!)
- Playing basketball (free throws)
- Responsible (e.g. chores)
- Public speaking

• Weaknesses

- Not the best when attention to detail is needed
- Easily distracted
- Cooking (can only prepare simple meals)
- Not too athletic
- Cleaning up after myself (all versions ;-))
- Social media – I am online too frequently
- Math

A couple of examples of my strengths are that I am good at reading, I am good at swimming, and I am good at public speaking. A couple of examples of my weaknesses are that I am not too athletic, I use social media too frequently, and I am easily distracted.

As a toddler, I also showed a lot of interest in computers and technology - I loved using the computer and watching VHS videos. I was really active when I was younger and often wore out my parents before I was done exploring and learning. So I ended up having some unsupervised time on the computer and in front of the television.

I learned how to change a game in the computer (they were on CDs then) and how to change the tape in the VCR. These skills didn't come without some pain - my parents say I wore out about three VCRs and countless VHS tapes of kid shows and educational videos before I mastered the task, but the key was once I mastered those tasks I could independently choose what I was doing.

As I got older my parents continued this thinking, and increased the variety and amount of options available to me when they presented me with choices. They were willing to let me fail from time to time by extending the boundaries outside of my comfort zone as I got older. My favorite example was when I went to a "Field of Screams" in the fall. My parents knew I'd hate it (which I did), but they let me go and discover that on my own. Over time I learned that I needed to speak up when engaging in social activities with friends (encouraged to speak up to get my ideas heard or needs met -- for example, where are we going to eat? Or, should we go to the movies or bowling?, etc.)

While at home I was involved in simple day-to-day decisions such as:

- Meals (amounts, selections, restaurant choices, etc.)
- Movie choices
- Social activities (with family and friends)
- Family vacations

I was also encouraged to help plan my future. This included participating in my IEP meetings and selecting my classes at school.

For kids with Cri du Chat, I think being offered the opportunity to choose should be encouraged where achievable - we're usually happy when we think we're in control :-).

Even though some things are difficult and frustrating for me, I'm learning to focus on moving forward. Some things I am focusing on include:

- Exploring my interests in art, animation, and graphic design (I am considering this as a career path).
- I am also interested in public speaking and training others. I have trained police officers how to interact with people who have disabilities, and I have also taught people with disabilities how to advocate for themselves and their needs.

Some of my other goals include:

Living independently or with a roommate • Finishing community college someday • Getting my driver's license • Maybe even getting married...

As a person with a disability I've found these ideas to be helpful:

Learn who you are • Look for opportunities to participate • Find way(s) to communicate and connect with others

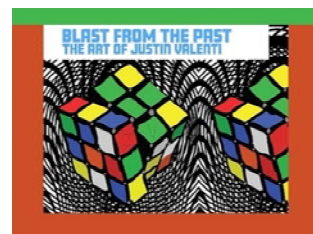
My parents would like to let you know these ideas have been helpful:

Explore age appropriate activities • Provide opportunities to choose • Help me set and support me in achieving my goals

That's my story as a person with Cri du Chat Syndrome. I hope you've learned something about what it's like to have a disability.



an internship job and published a book with his artwork. He has been very busy!!



As a side note, we are happy to let you know that Justin did go to a camp to learn how to ride a bike through icanshine.org and succeeded. He practices daily! He has also recently landed

Clinical Partnership Announcement



The Lineagen/5p- Society clinical partnership will launch at the July 2018 National Conference!



The 5p- Society's Board of Directors and Lineagen are excited to announce the launch of a two year clinical partnership! This relationship will include access to clinical resources and will also help promote awareness and recognition of the condition among healthcare providers.

Lineagen is a clinical testing laboratory located in Salt Lake City, UT. We perform CMA for individuals with developmental disabilities, and have presented posters about 5p- at several national genetics conferences.

Laila Andoni, one of Lineagen's licensed and certified genetic counselors, will be at the National Conference again this year. She will be on the professional panel, and will have a booth set up to say hello to families. If your child has never had a chromosomal microarray (as opposed to karyotype or FISH), you may wish to learn more, including asking for a kit to take back to your child's physician for testing.

For example, did you know that having a chromosomal microarray (CMA) can better characterize a person's 5p deletion? It may help determine which genes are involved, identify changes on other chromosomes, and may allow for participation in future research studies. Also, comparing CMA results from multiple people with the same condition can help to identify which genes cause which clinical features (such as seizures or heart defects). Lineagen and the 4p- Support Group have generated several publications about this topic, and it may be possible to do the same with the 5p- Society!

No more needles!

Lineagen's CMA can be done with a cheek swab.



Patients tested through Lineagen's CMA process will have the chance to opt-in or opt-out of automatic uploads into the 5p- Society's genetic registry!



To learn more about Lineagen's CMA service, please visit www.lineagen.com

If you and your child's physician believe testing is indicated, it would be billed through your insurance carrier. Your child's physician will be required to submit medical records about your child's clinical history in the test kit. Depending on your insurer, a formal genetic counseling appointment may also be required. Once we receive your swab, your family will be contacted by a Lineagen representative to discuss insurance coverage and the billing process.

Please note that Lineagen is unable to accept most state Medicaid/Medicare plans at this time. If you have questions about your insurance plan and your eligibility for testing, please call or email Laila Andoni (801-931-6213 or landoni@lineagen.com) who will direct your question to the right insurance expert at Lineagen. Lineagen is contracted with several insurers including BCBS-MA, Optima, United Healthcare, Tricare, & Colorado Medicaid among others.

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If you would like to request a collection kit for FirstStep^{Dx} PLUS (chromosome microarray analysis genetic testing) from Lineagen please contact Laila at landoni@lineagen.com. It is great that you are interested in further testing and learning more information for your loved one. The benefits of this testing include more accurately defining deletion break-points (the exact start and end of a deletion), identifying other chromosome changes, or additional opportunities to participate in research.

The collection kit contains all the material and paperwork needed to begin testing. This testing needs to be ordered by a medical provider, such as a physician, physician's assistant, or nurse practitioner. We also request a recent medical progress note and prior genetic test results if available. We encourage you to schedule an appointment with your loved one's physician now to complete the kit and obtain the paperwork. Here is a brief video about the swab DNA collection:

<https://www.youtube.com/watch?v=y6N0XB6XAW0>

Lineagen's team handles all the billing and insurance correspondence. If you have questions about testing or the process, you can contact the Lineagen genetic counselors at 801-931-6191.

If you already have a microarray testing result for your child and you would like it to be included for future research, please contact Laura at director@fivepminus.org for more information.

You will have the option to share the results of your child's testing through Lineagen with the 5p- Society to be attached to your 5p- Society profile and registry.

Vision Statement

Provide families having a child with 5p- a comprehensive resource to turn to for accurate up-to-date information, support, and acceptance.



CAREGIVER'S GUIDE
For Families of an Individual with
CRI DU CHAT SYNDROME

A publication of the 5p- Society



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RETURN MAIL REQUESTED



Meet C5

The Mascot of the International
Cri du Chat Awareness Week
May 1-10, 2019

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WWW.FACEBOOK.COM/CRIDUCHATSOCIETY

Mission Statement

To maximize the quality of life for an individual with 5p- and their families.

