5P- NEWS

5P- SOCIETY NATIONAL SUPPORT GROUP FOR FAMILIES WITH CRI DU CHAT SYNDROME

WHAT MAKES A HERO? *BY JEN WONG*

During our San Antonio conference, I was admiring all of our Superheroes, and there were A LOT!! But I'm not talking about all the Supermen, Wonder Women, or Batmen. I'm talking about all the parents that advocate in doctor's offices, schools, and their community to ensure the needs of their child are met. I'm talking about the siblings of our children with CdCs who are so kind, compassionate, and protective of their brothers or sisters. I'm talking about the siblings who have created and put into action ways to raise money to help fund awareness and research to help their brother or sister. I'm talking about extended family who give us respite, encouragement, and a shoulder to cry on when needed. I'm talking about our friends who have stuck with us through the diagnosis and beyond. I'm talking about strangers who give our children a kind word and smile instead of a silent stare. These are what Superheroes are to me. Who needs someone to leap over a tall building? Unless your leaping over that tall building to come do my laundry or help clean my house, don't waste you're energy. I think one of the things Emma has taught me is to focus on the small things people do just as much as the big. A small gesture, such as an encouraging smile, can completely erase the horrible day you were having.

I don't think actions have to be grandiose to be heroic or have big impacts. I loved hearing McKenna Myatt's story of deciding to collect enough recyclables to raise money for the sibling outing in Indy next year. This is a very simple plan but it will make a big impact on the conference. It has also inspired me to donate our recycling money to the 5P- Society. I wonder how many others will hear her story and think "I CAN" do that!! Think how much money we could raise, if all of our families donated money from collecting cans/plastic from their schools or offices! Look at how many times someone reaches out on Facebook for an encouraging word or advice and in less than 24 hours, if that, has 50+ responses! It's that encouragement of knowing people have your back, even if they live in another state or country, that help us get through the tough days.

I think the same holds true when looking at your own accomplishments. Some days some of the smallest tasks make the biggest impact. Taking time to sit with your child and ask about their day or play a game when you have a to-do list a mile long. Your children will not remember or really care if they lived in an immaculately clean home but they will remember the time they spent with

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FALL 2014

In this issue:

30 YEARS RACING TO AWARENESS

http://5pminus2015conference.blogspot.com/

The 2015 conference will be held at the Sheraton at Keystone Crossing in Indianapolis, Indiana. The dates will be July 30 to August 2. The host families are meeting, sharing, planning and preparing for the event. As soon as more information is available we will share it on our dedicated webpage (url listed above).

RACE TO REWARDS

Earn rewards as you raise money for the 2015 conference. Raise $1500.00 and your registration fee will be covered for up to two adults and two children; Raise $3000.00 and your registration fee for up to two adults and two children and one night at the hotel will be covered; Raise $5000.00 and your registration fee for up to two adults and two children as well as three nights at the hotel will be covered. See https://adobeformscentral.com/?f=70tEq6U9rETr9wx3Qe9tnA

I RUN FOR MICHAEL. . . .BY MICHELLE GILBERT

At the San Antonio conference this year we met up with an Army buddy of mine. This girl has always loved to do 5ks, triathlons and most other races short of a full 26.2 miles. Now that she has a niece with Spina Bifida she often runs races to raise awareness. Through all of this she found a program called "I Run for Michael". She suggested we sign Jacob up for a runner. At first I didn't really understand the function of this group, but she insisted it was great. We joined the Facebook group, signed Jacob up on Wednesday night. Thursday he was paired with a runner!

This woman he was paired with had been waiting six months to be paired with a buddy. There are so many wonderful people waiting for a buddy the wait list is SIX months long. I was SO shocked. We didn't know this woman, she had never heard of Cri du Chat but she was elated to be dedicating her runs, workouts, and races to Jacob. The group is really great. It's a fantastic support group, everyone in the group, but especially your runner, will share all of your child's milestones with you, give your child another supportive, loving person in their lives and remind you how incredible you are for doing things that, for you, have become second nature.

There are hundreds of people on the wait list, patiently waiting for us to sign our kids up so they can have a buddy. There is also an I Run for Siblings group, so our 4 year old has a runner, too. It makes her feel really special when she gets Facebook messages from her friend.

Both programs are really wonderful.

If you want to sign your child up for a new friend, just go to www.whoirun4.com/match-me/

LEARN SHARE CONNECT

Blogs to follow:

- http://livingwithcriduchat.blogspot.com/
- http://elastamom.com
- http://livingwithcriduchatmosaicism.blogspot.co.nz/
- http://mikeandbrittanyerickson.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://myriversride.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
- https://www.facebook.com/sophieourgift
- http://mydanceintherain.org

YouTube Videos to Watch

5p– Society “I Can” video
https://www.youtube.com/watch?v=2AEvN0-6M6I

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.

Cody promotes the 2012 Denver Conference
https://www.youtube.com/watch?v=A47tRTi8YPw

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.cromosomacinco.com/

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.

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you making cookies or snuggling while watching a movie or reading a book. Everybody's journey is different so you cannot use anyone else's standards to judge yours. I think many people are their own worst critics. They would never judge others to the impossible standards they hold for themselves. Just as you celebrate each milestone of your child's life, no matter how small, celebrate your own accomplishments with the same enthusiasm. Accomplishments build on themselves. Smaller ones give you the confidence to tackle bigger ones. Think back before your child was diagnosed and look at how much you have grown. Who would have thought you could know more about a genetic syndrome than some doctors? Who would have thought you could make MacGyver look like a Boy Scout with all the contraptions you've created to keep your child out of trouble/harm? Who would have thought you could change the way an entire school district does something because you advocated tirelessly for your child? Who would have thought you could positively affect the lives of people around the world with one post? Don't underestimate the heroic nature of a small action whether you are the giver or receiver. I don't know how many times people didn't realize the huge impact, what seemed to them an insignificant gesture, had on me. Just because you're not wearing tights and a cape and leaping over tall buildings, doesn't mean you're not a hero. It does mean you will get a lot less people staring at you though! But when have we ever been worried about people staring at us?!

FACES OF GRACE—2015 CALENDAR *BY CORDELIA BRAXTON*

Parents and Loved Ones of those that are connected to CDC. I'd like to let you know the first Faces of Grace Calendar is ready for purchase. It has been my vision and passion to create a product that would raise awareness for children with Cri Du Chat, and provide a vehicle that would assist with their overall well-being.

I first learned of CDC when I met my step-son, Tre' Braxton over four years ago. Since that time, I have researched and done everything I can to challenge him. Yes, our children are challenged because we as parents and caretakers choose to challenge them.

I've also learned that there's limited information and resources to help children and adults that carry this condition. It is to that end that I am hoping this project will make a difference with education and perhaps a small contribution to the society and the many households that are doing their very best to provide quality of life.

In this calendar, ten beautiful children have been featured providing a few facts about them as well as where they reside. If you are interested in contributing to this worthy cause, please visit https://mkt.com/faces-of-com. The price of the calendars is $15.00 and an additional $2.00 for shipping in handling within the United States. A portion of the proceeds will go directly to the 5p– Society and the households of the children who are featured. For more information please contact Cordelia Braxton at cordelia.kirkland@yahoo.com.

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amazonsmile
You shop. Amazon gives.

Do you like to shop at Amazon.com? Do you have Amazon*Prime?* Help the 5p– Society raise some *easy* money by shopping through Amazon*Smile*. When you go to http://smile.amazon.com/ch/48-1022202 and register the 5p– Society (Lakewood) as your charity of choice, the 5p– Society will receive a percentage of your purchase. It works with Amazon*Prime* too!! Thanks for your continued support!!!

The 5p- Society now has its own page for "Bravelets" -- please use the link to order your brave bracelets. $10 of each purchase will go to the 5p- Society. Thanks Donna Folino-Grasso for the great fundraising idea.

There are different colors to choose from. I specified the dark blue, light blue and light green to match the International Cri du Chat logo.

https://bravelets.com/bravepage/cri-du-chat-syndrome-support

- Thank you to the McSeed family for their fundraising event at Underground Fitness that raised over $2500.00
- Thank you to all families and friends who participated in the 80/20 raffle. The winning ticket was won by Lisa Juliar of Shoreview, Minnesota.

THE SUPERHEROES OF 5P- - SAN ANTONIO TEXAS

Two weeks prior to the San Antonio conference, the 5p– Society received a phone call from the director of sales from the host hotel. It's not unusual for this type of phone call, as a check up to make sure everything is okay, and that they are looking forward to seeing us soon. Unfortunately, that is not the phone call that we received. Instead the host hotel basically told us that they could not host us anymore because they ran out of sleeping rooms and could not guarantee any of our members a room when they went to check in (there was another group starting one day before us and was taking over the hotel). WHAT!!! You would think that booking with the hotel 2 1/2 years prior to the event, and being in constant contact with hotel personnel for several months prior, they would have said something. The host hotel offered to move the conference (sleeping rooms, meeting rooms, concessions and food and beverage) to the Hyatt Resort and Spa 20 minute away. The Board of Directors had to make a choice and there were basically two choices, move the conference or not have a conference. With only two weeks away the only logical decision was to move the conference. So the Board of Directors and the Host Families put on their SUPERHERO CAPES and contacted all the families, all the vendors, buses, and volunteers and miraculously turned what could have been a disastrous situation into a fantastic SUPERHERO conference. The only hiccup was one of the buses didn't get the memo and went to the previous hotel. It turned around and made it though, and got the siblings to their event. The Hyatt Resort and Spa was just that, it had a lazy river, water park, flow rider, several pools, a golf course and a spa. It was very close to Sea World San Antonio and several families took advantage of this and spent a day at Sea World. The move ended up being a blessing in disguise. Families were happy with the new venue, the staff at the hotel was more than accommodating.

The highlight of the conference was the family outing at Morgan's Wonderland. Morgan's Wonderland is a special needs amusement park that had rides perfect for our kiddos. An awesome barbeque lunch was served by Bill Miller's BBQ. The siblings had a fantastic mixer on Thursday evening and outing to the Roller Rink. There were 92 families in attendance, 22 of them, first time attendees. Presentations on Self Care, Genetics 101, Unbalanced Translocation and Mosaic Occurrences, Communication Devices, IEP's, Health & Wellness, Hippotherapy, CdCS 101, Effective Behavior Therapy, Guardianships & Conservatorships, were all well received and attended.

The host families worked tirelessly throughout the conference making sure that all the families were being cared for and fed!! They also did a FANTASTIC job raising money for the conference to pay for all the extra amenities for the families. There is a new found love for Breakfast Tacos!! The conference t-shirt design was so well received that it was the largest pre-order that the 5p– Society has had and the left over shirts (50) were sold rather quickly, with families wanting more (note to families of future conferences: always best to pre-order your shirts!!) The Banquet and Family Dance was enjoyed by all, but how could it not when Magic Mike was the DJ!! The kiddos were dressed as their favorite SUPERHERO and the decorations were fun!!

Many thanks to RANDY & MARI ROWE, AMY & DAVID RATLIFF, CLIF & ROBERTA LOTSPEICH, MATT & RACHEL STANFORD, JIM & SHARON DEMCZAK, and PETE & PATRICIA LONGORIA, and to all their VOLUNTEERS (friends and families) who helped in childcare, hospitality suite and sibling events. Thank you also to Jessica Diaz for her behind the scenes assistance.

On page 9 you can see a montage of pictures of some of the families in their SUPERHERO costumes.

HONORING DR. AMYSUE REILLY

For those of you who have attended any of the past 11 conferences you have had the honor of meeting Dr. AmySue Reilly. AmySue has brought energy, knowledge and compassion to the members of the 5p– Society. She and Dr. Dennis Campbell initiated research and have keep records on approximately 100 kiddos with Cri du Chat Syndrome and their development. She has presented on Effective Behavioral Therapy and has provided families with a wealth of information and tips on how to handle their behavior. AmySue, Associate Professor Department of Special Education, Rehabilitation & Counseling at Auburn University in Alabama, is a member of our Professional Advisory Board, assisting with the review of research requests and assisting families when needed. She can be found at the Hospitality Suite in the evening during the conferences giving families one-on-one time. She does this all, happily and voluntarily.

The Board of Directors wanted to honor AmySue for her dedication to the 5p– Society. They decided to honor her in two ways. The first honor is renaming of the Hospitality Suite. It will now be known as "***AmySue's Place***", True Southern Hospitality. The second honor is naming AmySue the Superhero of the Decade. Thank you AmySue for your dedication, time and friendship to the 5p– Society.

CALL FOR CRI DU CHAT SYNDROME RESEARCH

BY MEGAN LESTON

It was in 1963 when Dr. Jerome Lejeune became the first to research and describe the syndrome that eventually became known as Cri Du Chat. There was much to be learned about this syndrome. However, the technology of that generation would limit his findings and those of future researchers, while only scratching the surface of a syndrome that affects approximately 1 out of 50,000 live births a year. In the United States alone, over the 51 years since Dr. Lejeune's uncovering of this rare genetic disorder, it is estimated that nearly 4,000 babies have been born with this syndrome. And that is where my family's story of Cri Du Chat syndrome begins.

In October 2013, my son, Liam Joseph, was born with this rare genetic syndrome, which is now commonly referred to as "5p minus." I had what most would have considered a typical, complication-free pregnancy, which included regular visits to our obstetrician. However, three weeks into my newborn son's life, we were given the diagnosis of Cri Du Chat syndrome.

Like many families who have walked this path before us, the medical professionals provided us with a relatively simplistic prognosis characterized by an enormity of physical and cognitive challenges. These challenges and the severity of the situation were labeled for all those affected by the syndrome. We were given little hope that there may be a brighter future for Liam, other than the impossibly challenging path described on the 8" by 10" piece of paper that was handed to us.

Over the past 9 months, my husband and I have contacted many of the known experts on this syndrome in order to find answers and gain a deeper understanding. But we quickly realized that we were facing a daunting task due to the lack of more complex research. The majority of information presently available focuses on diagnostics, identifiable physical features, the type and location of the chromosomal deletion, and descriptions of symptoms. Only very recently has there been published research that begins to identify specific gene and protein insufficiencies due to the 5p deletion, establishing it as a causative factor for the clinical features that occur. The sad fact remains, though, that the syndrome is still relatively poorly researched in comparison to other more common genetic syndromes.

Unfortunately, as genetic technologies continue to advance the world of medical science, there remains scarce funding and a lack of a centralized cohort of Cri Du Chat specimens for scientists to utilize. This has limited the extent and quality of research that can be conducted on a cellular level to gain a more comprehensive understanding of the specific chemistry that actually causes the symptoms and challenges of this syndrome.

We believe, that this information is essential if we are ever to make progress in understanding this diagnosis and finding other ways to help the ones we love. Currently, there is little understanding of the insufficient proteins or enzymes causing interrupted message pathways in the bodies of those affected. Or, the potential of a natural body substance that could be acting as a toxin if over-expressed. Furthermore, it is unknown if there are even vitamin deficiencies as a result of the specific chromosomal deletion.

These uncertainties represent extraordinary opportunities for further research into Cri Du Chat syndrome. We have found many examples of other genetic diagnoses (i.e. Down Syndrome and Cystic Fibrosis) that have benefited from increased knowledge of the pathophysiology, which can be gained through enhanced research. This information has led to treatments that utilize nutrition or diet, drugs or preventative medicine to improve the quality of life of those affected. We have been encouraged, by our team of professionals to explore the use of organic molecules, nutritional supplements and medications to support the pathways interrupted by the 5p deletion. These are just some questions to which we are unable to receive any definitive answers as of today.

In July 2014, with the support of family, friends and other Cri Du Chat advocates, we started the Cri Du Chat Research Foundation, which is specifically intended to advocate for and facilitate research. During our fact-finding work into the activities taken on behalf of other genetic disorders, we were enlightened to the importance of the use of biobanking along with genetic registries. These crucial pieces function as central repositories for well-described genetic samples to facilitate biomolecular research. To that end, we have partnered with the Genetic Alliance Registry and Biobank (GARB) to share in their infrastructure and help guide us through the process of facilitating this type of research.

We recognize that this research will not necessarily "find a cure" for those affected by Cri Du Chat syndrome. However, we remain hopeful that it will lead to translational research and, ultimately, improve the quality of life of those dealing with the daily challenges caused by this rare disorder. We, like you, want our loved ones to reach their absolute fullest potential.

You can help. We cannot do this alone. We will need the support of families like you – families who can provide the genetic samples and registry data required to begin this important research. Both GARB and our Foundation understand the sensitivity of the information gathered from those who are interested in participating. Policies are in place to maintain the privacy of all participants. For more information, please visit us at CriDuChatResearch.org

Megan Leston, Parent & Certified Pediatric Nurse Practitioner

* References furnished upon request.

THE END OF CRI DU CHAT? *BY KENT NICHOLLS*

We have noticed a significant trend over the last several years as we meet families and children at our annual 5p- Society conferences. We are drawing a broader variety of families and children with a broader range of intellectual disabilities (ID) and developmental disabilities (DD). It is becoming apparent that cri du chat syndrome, as was classically defined by Dr. Jérôme Lejeune in 1963, cannot encompass or describe what our families are experiencing in the real world.

What is happening here?

Better genetic testing. A part of the change can be attributed to the advances in genetic testing and the resulting ability to identify smaller deletions, translocations, and other rarer genetic variations such as mosaicism and ring. Geneticists and genetic counselors are labeling any 5p deletion as "cri du chat syndrome".

Better survival rates. Children with medical complexity are benefiting from increases in neonatal care and intensive medical technology use.

Better early intervention. We are seeing the results of more and better early intervention with higher expectations for our children. Not an insignificant factor!

Better communication. More families are finding out about our society and conferences because of the internet and, more recently, our Facebook page. This has helped families with a broader range of capabilities to communicate with each other and subsequently attend our conferences.

By definition, a syndrome is a group of symptoms that together are characteristic of a specific disorder. But what happens when those symptoms are so broad or variable that they do not effectively characterize the same disorder. This is the case with autism and that is why autism is more commonly referred to as ASD (autism spectrum disorder). A spectrum disorder is a range of closely-related disorders with a shared core of symptoms. As you can see, this more correctly describes what we are seeing with 5p deletions: a set of closely-related disorders, all centrally related to the 5p deletion.

A great example of the broad spectrum we are seeing is 5p Unbalanced Translocations (UBT). 5p unbalanced translocations are very special cases that deserve a lot more attention. That is why I hosted our first UBT break-out at our annual conference in San Antonio this year. Rather than just being a simple deletion (terminal or interstitial), UBT associated with 5p can come in two variations:

1. UBT with 5p- and trisomy of some portion of another chromosome. So these kids are dealing with not only a deletion of genetic material from 5p, they are also dealing with a surplus of gene material from another chromosome (like kids with Trisomy 21 aka Down Syndrome).

2. UBT with 5p+ (trisomy of 5p) and deletion of some portion of another chromosome. While rarer, these kids are also dealing with both a deletion and a surplus of genetic material.

So children with UBT have to take on all of the issues associated with a deletion and the somewhat unknown (and perhaps unknowable) issues associated with having extra copies of other genetic material. This makes them, in some respects, distinct and different than the kids with a simple deletion. And anecdotal evidence suggests that their level of milestone achievement as a group is overall lower than kids with simple deletions as a group and somewhat more medically complex.

Now contrast this with a child with 5p- mosaicism. In mosaicism, the 5p deletion does not occur at conception but rather at a subsequent cell division, so that some cells have no 5p deletion and some do. Depending on when this occurs and the resulting percentage of cells with a deletion, a child can have very minor ID & DD, or be more similar to a child with a simple deletion.

This inevitably leads to the conclusion that 5p- is not clarified or well described by "cri du chat syndrome". It is my considered recommendation that we move past this label and think of 5p- as a spectrum disorder (5PSD) and start tracking the primary groups as identified by the genetic commonalities:

Deletion with critical region missing (CRM)
Deletion with critical region intact (CRI)
Unbalanced Translocation (UBT)
Mosaicism (M)
Ring (R)
Other (O)

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Why not term it "cri du chat spectrum disorder" (CDCSD) or in English, "cat cry spectrum disorder" (CCSD)? What other conditions are named after animal sounds (or would be today): growl of the bear, squeak of the mouse, or snort of the pig? And perhaps more importantly, some of the children in the spectrum do not have a "high pitched cry".

So you may ask, "Kent, how does knowing all this and calling it 5PSD help anyone? My child did not suddenly start walking and talking!!"

Well, it has always been our goal to help families prepare for the future, by giving a realistic assessment of both the challenges they face and the achievements that are possible. We know we cannot predict the future. But if we can identify groups within 5p- and do a better job of relating that group to more specific outcomes (and perhaps mitigating therapies), then I believe we have helped and made an impact.

I suggest the following:

Understand the groups and which one your child's genetics identifies you with.
As you talk with other families and message on Facebook, identify your group so we can start seeing better trends and group issues. Let's be very careful here not to exclude some of the rarer groups and remember the shared core of symptoms.
Complete the Family History Registry that our Executive Director, Laura Castillo, has posted on Facebook. We already do a great job of connecting families geographically, but now let's expand on that and connect families by group.
Let's build a comprehensive list of research topics that are meaningful to each group. For example, if your child has 5PSD UBT, you may be interested in medical fragility and what early medical intervention is helpful for your child.
Raise the money to collect information on each group and do the research to improve our efforts at mitigating the effects of 5PSD.

Please note these are my personal suggestions. The 5p- Society Board of Directors has not yet taken a position on this. By the way, my 30 year old daughter has 5PSD (CRM).

Thank you!

FUNDRAISING EVENTS

Helena's Hundo
Dad, Derek Stevens participated in The Pine Creek Challenge 100 mile Ultra Marathon on September 6 to raise money and awareness for Five P –.

To celebrate his 40th birthday, Derek decided to take this occasion of extreme personal challenge and to raise money for a charity very dear to his heart. Derek says that it is difficult to express how this diagnosis has changed his life and has taught him more about love, compassion, and understanding then he could ever imagine. He is very lucky to have a great pediatrician who direct him and his partner Marie Corrado to better resources, including the 5p– Society. His daughter, Helena started kindergarten this year!! Derek raised over $8,000 through a GoFundMe/Razoo fundraising site. Thank you to Derek and congratulations on challenging yourself and spreading awareness of Cri du Chat Syndrome.

5p- Society SoCal families and friends. We will be participating in this 2 mile fun run, walk, dance or swag on October 4 . . . mark your calendars!! Tickets will be available soon - $35 per adult, $10 children 8 and up; free for kids 7 and under. This will be a fundraiser for the 2016 SoCal conference. If interested, please let me know so I can order the tickets. It's gonna be fun!!! www.colorrainglow.org

5P– Pie Challenge - want something fun to do and to raise some money for the 5p– Society? It requires a pie, a face, a camera, social network and calling out friends and family to repeat the challenge!! Take a pie, cut it into 5ths, eat one of the pieces (yum), put a lot of whipped cream on it and put it in your face!! A $25 donation is suggested to put a Pie in your or your friend's face, challenge as many people as you would like and suggest that they too donate $25 to put a pie in each of their faces, or an amount (say $100) if they do not. You can set your own donation amounts. Make sure you video it happening and post it on our FaceBook page!! *Let's get it going!!!* To date, the 5P– Society has raised over $1000 in the 5P– Pie Challenge!!! Thanks to everyone who has already participated!!!

"SUPER HERO" HALL OF FAME AWARDS 2014

SUPER HERO OF THE YEAR AWARD: RACHEL DEMPSEY - I come from a small city in New Zealand called Wanganui and I went to the Cri Du Chat conference in San Antonito with my Mum and it was the greatest two weeks of my life so far. I got to hang out with my Mum for two weeks and we had loads of fun like going to the wax museum in LA, seeing Bradley Cooper and Vin Diesel at a movie premier and going for a tour seeing all of the celebrities and where they live like Leonardo Di Caprio's house and Orlando Bloom's and Lady Gaga's gargoyles and Katy Perry's two houses as well. Then Mum and I flew to San Antonito for the Cri Du Chat conference it was amazing because I had the best time meeting everyone off from FaceBook. I enjoyed going down the lazy river swimming and pushing my Mum along in a rubber ring and going down the waterslide as well. I learned so much about Cri Du Chat and the genetics side of it all. On Saturday night Mum and I got dressed up in our superheroes costumes and went down to the dinner in a big tent. I had so much fun seeing everyone dress up in their costumes. Guess what I won Cri Du Chat superhero of the year and I won a trophy which is proudly displayed on my shelf in my living room. The first thing that I did when I got back to Mum and I's room I made a video message for my boyfriend and showed him my trophy. The next morning Mum and I flew to Santa Fe where the airline lost my luggage for a day and I went hot air ballooning which I didn't enjoy but another day we went for a walk with my brother up to Tent Rocks which is a walk in one of Santa Fe's national parks and I enjoyed that apart from going slowly back down the track to the car and I had fun hanging out with my family for the five days that I was in Santa Fe. (Rachel has a form of Cri du Chat Syndrome that is a Mosaic occurrence).

PARENTS OF THE YEAR: DENNIS & SHARI CAMPBELL - Congratulations to Dennis & Shari Campbell for parents of the year. Dennis & Shari have been attending 5p– Society conferences since 1992 about 10 months after their daughter Amy was born with Cri du Chat Syndrome. They have become a pair of the biggest advocates for the syndrome and the 5p– Society. They co-hosted the 2003 5p– Society conference in Memphis, Tennessee; they serve on the Conference Committee as members of our Welcome Committee. Dennis has been the Chairperson of the Professional Advisory Committee for the past 11 years. Dennis is aa Associate Professor of Education in the Leadership and Teacher Education Department at University of Southern Alabama. Shari shares her passion for art with many and has designed some pretty cool 5p– items that were sold at the 2011 conference in Ohio. Shari also assists in welcoming parents of newly diagnosed parents. It has been an honor knowing the two of them!!

GRANDPARENT OF THE YEAR: ROBERTA LOTSPEICH - Roberta is the grandparent to 6-year-old Benjamin Ratliff. Roberta and her husband Clif joined the 5p– Society shortly after his birth. They have been big supporters of the organization. When the conference was announced to be in San Antonio, Texas, Roberta called and said that she lived pretty close and that she would be willing to help out. Roberta, along with several other conference families, coordinated the Morgan's Wonderland outing, helped find some of the local speakers and along with her daughter Amy Ratliff , coordinated the child care for the conference.

SIBLING OF THE YEAR: MIRA CUTRARA - Awareness week was approaching and 14-year-old Mira decided that she wanted to do something to raise awareness for her 4-year-old sister Kaya, and Cri du Chat Syndrome. Being a competitive swimmer, Mira decided she wanted to host a swim-a-thon. Mira contacted the swim board of her team, Tinley Park Thunder Swimming, and they were happy to support her in any way. Soon she had over 40 swimmers signed up, collecting donations and spreading awareness for the first annual "Kickin' it for Kaya" swim-a-thon held on May 5th 2014. Together Mira and Tinley Park Thunder Swim raised over $3300 and had more than 900 hits on her GOFUND Me web site.

THE SUPER HEROES OF 5P-

WHO'S YOUR SUPER HERO?

2014 ANNUAL CONFERENCE

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Fax: (562)920-5240

Email: director@fivepminus.org

RETURN SERVICE REQUESTED

Meet C5
The Mascot of the International
Cri du Chat Awareness Week

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We're on the Web
www.fivepminus.org

Find us on FaceBook at http://www.facebook.com/groups/385907554759706/

Yahoo Group Page: 5pminus
http://health.groups.yahoo.com/group/5pminus/join/

HAVE YOU SEEN IT?

Thanks to Adam Greenberg and his team the "I Can" video production is complete. You can see it at https://www.youtube.com/watch?v=2AEvN0-6M6I

SUPPORT AND REPRESENT—WEAR YOUR GEAR

Once again we will be selling 5p– shirts in an array of colors as a fundraiser. The website to order will open on October 15, and will close on November 15. You should expect to receive your shirts two to three weeks after the close of the orders on November 15.

How to order go to the website: http://cmsportinggoods.net

1) Go to the link 2) Click on Promotions 3) Go to the 5p- promotion and type in promo code 5p 4) Click on CHECKOUT 5) Choose SIZE, COLOR, and QUANTITY 6) Click ADD TO CART 7) Click on CHECK OUT at the bottom of the screen, 8) Complete billing information 9) Complete Shipping Information

The t-shirts will cost $10.00 with $3.00 going to the 5p– Society. Infant sizes have been added as well as new colors. (shirts larger than XL will have an additional cost)

NEW ITEMS: Long sleeve t-shirts, sweatshirts also available—check website for prices and colors.

Any questions, please contact the 5p– Society office at 888-970-0777 or director@fivepminus.org.

Hats, wristbands, magnets, keychains and tumblers with the 5p– logo can be purchased through the 5p – Society. Other Clothing, drinkware and logoed items through www.cafepress.com/5pshop.