

NATIONAL SUPPORT GROUP FOR FAMILIES WITH CRI DU CHAT SYNDROME

Volume 32 Issue 4

BC ______ by Nick Wallace

Well, the 2017 conference has come to an end, and I would first like to say a special thank you to those who had a hand it making this a great conference. As I attend the conferences and as Allie starts to get older, I can't help but think of some of those pioneer families, and how life was BC ... Before Conferences.

When Allie was first diagnosed with Cri Du Chat, we were in shock for a little bit, but then we turned to the internet for help. We quickly found the 5p- Society and a few other families that helped us to get back on our feet and provided a light that would help guide us down this new path we were going to be traveling. I stop and think about those families who didn't have the internet or the 5p- Society. They had to take this new path without a light to guide their steps.

Take a moment to reflect on that for a moment. Think about not being able to go online and Goodsearch (shameless plug of a site that helps easily make money for the 5p- Society by searching and shopping) for Cri Du Chat Syndrome and pull up endless amounts of information and contacts to help you through this journey, especially the 5p-Society.

Thanks to the efforts of some of these pioneers the 5p- Society came into being. It was their way of providing a map, of this path that they traveled down, for the rest of us. A way to connect us with other families and with information to help us navigate this path together.

I am sure you are probably wondering where I am going with this article, besides just asking us to reflect upon how things were for families before the 5p- Society and the conference. During the conference and after the conference I heard a few comments about how people were bummed they couldn't make it to the conference or how seeing the photos made them feel depressed. I truly understand those feelings, because I have been there and I have experienced those feelings before. I even heard some families stating that they had never met another family or child/adult with Cri Du Chat before.

So, the purpose of this article is to challenge all of our families to use the tools you have access to, by being members of the 5p- Society, and to find families in your area who would be willing to get together. The get together doesn't have to be an extravagant event like the annual conference. It could just be a meeting at a local park on a Saturday afternoon. Just think what the BC families would have given to have a meet up with another family. We have so many tools that they didn't have, but often we choose not to use them.

Being a parent of a special needs individual can be lonely sometimes, but it doesn't have to be. Reach out and see if there is a family near you. If you are having a small gathering, post it on the Facebook group because we have had gatherings in Ohio that have pulled people in from Michigan, Indiana, Kentucky, West Virginia, Pennsylvania, and even Canada because we posted it there. I know I look for any opportunity to get together with my 5p- Family. Just like in the movie "Field of Dreams" they say, "Build it and they will come." I say, "Plan it and we will come, and we might not leave."

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Letters from Scholarship Recipients

5P-Society,

We had the pleasure of being a scholarship recipient and able to attend the 5P- Society Annual Conference in Wisconsin. This scholarship was greatly appreciated. We are so grateful that we were given this opportunity and able to attend the conference.



Being at this conference was a genuinely one of a kind, extraordinary experience. We saw some familiar faces from previous conferences and met some wonderful new families. It was

awesome to see past families and amazing to meet new ones. Everyone accompanies their own particular uniqueness that they can convey to the conference. In addition, this takes into account new ideas and more learning open doors.

I truly like how the hospitality suite is open to converse with families from the conference that you might not have room schedule-wise for the duration of the day. I acquired pertinent information from different families that help me help my daughter progress in various aspects whereas they have firsthand knowledge. The family outing provides more opportunity to see and address different families. I additionally like how there is the "New Family Orientation" for those that are attending the conference surprisingly for the first time and to help ease them into the gathering

I delighted in a wide range of workshops that were offered. The Lineagen workshop really sparked an interest in my eye. I enjoyed how they incorporated their audience in effectively taking part with their cell phones to lead overviews progressively. This allowed for continuous active participation which allowed us to see the surveys in real time. The workshop addressed different parts including the distinctive genetic testing that is possible and how certain tests can prompt clinical research to enhance results. I am anticipating checking whether an investigation and future research will be led by the 5P- Society. I observed it to be positive for the future of cri-du-chat. In

this workshop, I discovered that there are at present mouse models for CTNND2 (delta catenin) and also SEMA5A. I'm sure that it might require some investment to idealize this with the mouse models yet when they do, it appears to be hopeful that conceivably a portion of the genes lost in the deletion might be made to supplant what is lost.

Another beneficial workshop was the one on "Management of Spinal Deformities/Orthotic Intervention for the Low Tones Child." Amid this workshop, they filled in the gaps to answers that I had been tending to before seeking after the subsequent stage for my little girls' spine surgery. Numerous perspectives were elucidated for me and decided the future decisions that I will have to make. Notwithstanding this workshop, I found the service dog program to be something to ponder about. Moreover, AmySue Reilly's "Behavior Modification" workshops were exceptionally useful and supportive in dealing with some conduct.

In particular I want to specify that the host families and the greater part of the volunteers were totally exceptional and genuinely went well beyond. This conference was a success in light of the volunteers, host families, and every one of the individuals that are part of the 5P-Society. The 5P-Society truly connected with new and past families to answer any inquiries and enable them to feel calm. It is great to the point that we have such an astounding gathering to come to. I am grateful that they provide the chance to meet each year at various parts of the world by holding this conference for those that have a child or family member with cri-du-chat.

My family and I are to a great degree thankful and extremely appreciative that we were given this opportunity to attend the 5P- Conference. We have gained vital and valuable information. This conference has given us deep rooted data and furnished us with crucial and valuable resources. These resources give direction to enhance my daughters overall development. Thus, as a family we intend to utilize all that we learned and employ this knowledge in our advocacy in helping Arizona to optimize her fullest potential.

Sincerely,

Arizona and Family

Letters from Scholarship Recipients

Hello from the Meza Family!

March 2017 was a big month in our home. Cinnia finally received a diagnosis to help tie together lots of medical issues. Cri Du Chat made perfect sense, but was completely terrifying. Thankfully we were able to find support in the 5P- Society through the website and Facebook page.



Being given the opportunity to attend the annual conference this year was a blessing.

Our family traveled together, Mom, Dad, and 3 girls aged 14

to 21 months. I was worried about the girls enjoying their time since we counted this as our vacation. To my relief, they all had fun and made connections. Cinnia's sisters enjoyed the sibling workshop, childcare (even the teen because...video games) and the family picnic! Cinnia was happy to go play each time and was always happy when picked up! I cannot say enough about how much this quality care from the volunteers helped my husband and I be able to fully participate in the workshop sessions.

The variety of sessions was good. Many important topics like research, future planning, discussion panels, and professionally led topics like feeding and speech (and tons more).

The family picnic was absolutely amazing, the host families really did wonderfully. Our girls loved the venue and entertainment provided, so much so that they didn't even mind the funky weather!!

I don't know that I can fully put into words how much the weekend meant to me and my family. My husband, an introvert, spoke with people openly. We met families at many points along their journey and saw first hand how varied and wonderful CDC can be. We learned techniques and affirmed some things we were already doing. This conference experience was invaluable and we are already planning for 2018!



5p- Society 2018 Annual Conference "Conference of Champions"

The 5p- Society is in the planning stages of the 2018 annual conference. The conference committee, consisting of the Derek & Marie Corrado-Stevens, the mother-daughter duo of Johnna & Raeann Sleith, Patti Fowler, the Grasso clan and John & Christina Yauch (with help from Holly Gattone) have already made some concrete plans for the conference, including the Friday family event on the Gateway Clipper for lunch and a riverboat tour on the beautiful Three Rivers.

The conference will be held on July 26-29 at the Pittsburgh Marriott City Center, 112 Washington Place, Pittsburgh, PA 15219. Room rate will be \$142.00 per night (plus tax and service charge).

Make your hotel reservations by calling (412) 471-4000 or online at the following link: Marriott City Center 5p- Society Online Booking Link If you make your reservations online, on the REVIEW RESERVATIONS DETAIL PAGE please check the "Make Request" button on the right hand side to choose your room type (king or double) and any other amenities you may need (roll-a-way or crib), or you anticipated check in time. Please note that the hotel will do its best to accommodate your requests.

More information will be coming soon. Please also keep checking on our website for additional information at https://fivepminus.org/event/2018-5p-society-conference/?event_date=2018-07-26.

Registration will begin in March. If you need any additional information, please contact Laura at director@fivepminus.org.



Milwaukee Conference 2017 – the FESTIVAL of the YEAR!

By Laura Castillo, Executive Director

The 2017 5p- Society Annual conference was FUN, FANTASTIC, FABULOUS, FESTIVE and FULL of 5p- FAMILIES and FRIENDS. Ninety-seven families, 400 people (adults and children), 68 volunteers, over 150 donors, 5 scholarship recipients and three INCREDIBLE Host Families. Thank you so much to Alan and Maria Isberner, Jason & Hillary Losen and Hutch & Brenda Renk for rising to the challenge, hosting several fundraisers, impeccable planning, keeping everything well organized and working tirelessly the entire week-

end so visiting families could enjoy all aspects of the conference. We had a record breaking 21 first time conference attending families. It was so exciting to see two 47 (Peter & Jim) and one 45 (James) year old men with Cri du Chat Syndrome attend the conference, and our youngest attendee was 3-month-old Colton.

Highlights of the conference:

• The Family Outing at Malone Park. Face painting, slime, cotton candy, snow cones and an out-of-this world adaptive playground. Burgers, hot dogs, and the fixins' from Mr. Picnic were just what were needed. The rain stayed away so the families could have fun!

• The Hospitality Suite. Thanks to the Cutrara, Boulanger, Paplham, Ladwig, Brinkman and Isberner families for creating a warm ambiance for families to relax and chat in

the evenings with a drink (lots of wine was distributed) and snacks.

• The well organized and staffed child care rooms. Thank you to the Losen family for organizing child care this year and for all the awesome volunteers who kept our children entertained. They

even had service dogs come and visit and a musical entertainer.

• Our siblings were able to meet and have some fun on Thursday night with the help of Jannie Boulanger-Hanna and Travis Boulanger; attend a sibling workshop on Friday to learn skills on how to cope with having a brother or sister with a disability, and have some fun on Saturday at the Country Springs Water park.

The Family Dance!! Keeping with the Festival Theme, there were jugglers, magi-



Milwaukee Conference 2017—the FESTIVAL of the YEAR

cians and fun props for the photo booth as well as a super great DJ who really kept everyone on their feet dancing.

• The slate of speakers and topics were educational for all ages. All the speakers volunteered their time to provide the attendees with the best information to absorb and bring back to their teachers, therapists, physicians and facilities. Presentations included new family orientation, planning for the future, the

ABLEact, raising an adult with Cri du Chat Syndrome, behavior modification, Cri du

Chat 101, future research, respiratory support for sound production, managing spinal deformities and orthotic intervention for low toned children, feeding and swallowing challenges,

sensory integration therapy, understanding special education and your rights and learning more about service dogs.





• For the first time we had a Father's seminar, led by Nick Wallace, that was well received by the dads in the group (they would like it to be repeated).

• A very emotional and inspirational speech by James Chalmers, a 45 year old adult male with Cri du Chat Syndrome, ended the conference on Sunday.

Many thanks to the families and friends who donated items for the raffle and silent auction. Ray & Christine Lowe from San Gabriel, California were the big 80/20 winners and won \$2220.00. Thank you to everyone who participated.

I would also like to take this opportunity to thank the 5p- Society board of directors who make my job a lot easier at the conferences by taking over the registration table; my parents who transport items from California to the conference destination, help out tremendously



with organization, work the raffles and facilitate the grandparent's workshop; my husband Mike for accompanying us this year, assisting where needed and overseeing the sibling outing to the water park; and of course, my daughter Katie. My life was changed in an instant the day she was born (almost 30 years ago), but without her, I would have never met my best friends and extended 5p- family members.

As we end the 32rd conference in Milwaukee, we are already planning the 33rd conference in Pittsburgh. Hope to see you there!!

Sensory Processing

Being the parent of a child with Cri du Chat Syndrome (CdCS) brings many unique challenges! As both an occupational therapist for 32 years, and the mother of Hannah, a 23 year old with CdCS, I have experienced sensory processing difficulties at their finest! Being a professional and living with a daughter with this has opened my eyes even more to the challenges we face with the complications of poor sensory processing. So, what do we do? There are many books, blogs and other information sources out there and one could write volumes on this subject. In an effort to simplify the information, I will address the basics in this article.

What is sensory processing? It is a neurological process where our brain takes in sensory information from our bodies and the environment then organizes or processes this information to make sense out of it. This sounds simple enough yet is extremely complex.

Most are aware of the five senses – sight, hearing, smell, taste and touch. However, there are two more that are not as well known – proprioception and vestibular. Proprioception is sensory information that we receive from our muscles, joints and ligaments about our body's position in space. Vestibular is related to sensory information that we receive from our middle ear that is related to movement and balance.

When our sensory systems are not working properly, it causes our brains to misinterpret the sensory information that we receive from our body and the environment. This is then often manifested in unique behaviors which are the result of poor sensory modulation.

Let's look at 2 categories of sensory modulation difficulties which can affect children or adults: being over responsive and being under responsive. Keep in mind that understanding sensory processing becomes even more confusing as the same person can experience symptoms of over responsiveness and under responsiveness at the same time.

People with over responsivity to sensory stimuli show signs such as:

avoidance of grooming, including having hair,	visual distraction
teeth or face cleaned	super sensitivity to smell
limited clothing choices	gagging or vomiting at certain smells
resistance to getting dirty	oral defensiveness
overreactions to loud noises	narrow food range due to avoidance of eating cer
excess attention to sounds	tain textures
covering of their ears	dislike of food on lips
aversion to noisy events	fear of movement which can result in leaning on
intolerance of bright lights	adults
covering of their eyes	avoidance of running or climbing even though they have the motor ability

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Those with under responsivity to sensory stimuli may:

- be unaware of temperature
- not notice when they are dirty
- ♦ head bang
- ♦ have a high pain tolerance
- not orient to sound
- ♦ have poor voice modulation
- wants the TV loud
- ♦ lack visual interest
- ♦ stare
- hesitates on escalators

- have trouble with coloring and writing
- ♦ loves strong smells
- may smell people or objects
- crave oral input and put everything in their mouths
- seeks certain textures
- be a messy eater
- seek movement
- ♦ know no fear
- not appear to get dizzy
- like to be upside down

Looking at these, I can identify my daughter, Hannah. At several stages of her life she has experienced sensory processing difficulties and still has quite a few. Hannah was difficult to get and keep asleep as a baby and toddler. She required more swaddling and rocking than most children. To this day, Hannah is not as aware of hot temperature as she is of cold, and I have had to adapt by keeping my water heater less hot to avoid burns. She keeps the TV or her tablet on very loud and has adapted with this by going to her room if she wants it loud. She still doesn't like brushing teeth or washing her face, yet, constant work and consistent routines in this area have helped. Hannah will still gag at certain smells. She has gravitational insecurity (fear of her feet coming off the ground) and has a very difficult time crossing over from one color or texture of flooring to the next, requiring lots of coaxing to get her to cross the floor. As she has grown, her ability to tolerate changes in auditory and visual stimuli has greatly improved. When she was young, in order to go to the grocery store or movies, she would have a piece of cloth that I draped over her stroller and we would enter the store this way. She eventually was able to peek under the cloth and then remove the cloth as her sensory system adapted to the environment.

So what else can we do to assist our children with their difficulties in sensory processing?

Proprioceptive activities (deep pressure/heavy work) almost always assist in organizing the senses. The following are some activities that are proprioceptive in nature:

- deep pressure hugs
- "sandwich games"
- * wheelbarrow walks
- play on all fours
- pushing/pulling a heavy cart or suitcase
- playing in w
- et sand
- playing with playdoh or Thera putty
- chewing hard/crunchy foods,
- for older children, vacuuming, sweeping, mopping, or raking

Sensory Processing-

Vestibular activities can also help, and can include:

- smooth, linear movements such as swinging
- playing on playground equipment
- 💥 jumping on a trampoline

What are some strategies to help over responders?

- * allow them to wear familiar clothing
- ★ create low sensation get away spots
- ★ allow use of sunglasses or hearing protectors (or in Hannah's case, a piece of cloth)
- * decrease visual distractions
- * establish routines
- ★ for smooth transitions use visual schedules and talk about changes and expectations
- ★ use a weighted blanket at bedtime
- * use a weighted lap pad or weighted stuffed animal
- * use footie pajamas with spandex

What strategies can help under responders?

- ♦ allow use of fidget tools
- ♦ allow the child to stand rather than sit for tasks
- have contrasting colors on activity sheets
- ♦ provide activities that are high in sensory input such as finger painting, playing in shaving cream, eating varied food tastes and textures, or chewing gum

Yes, life with sensory processing difficulties can be challenging and confusing! To experience success, meet your child where they are – meaning start making changes slowly and consistently to their environment and be consistent in a routine to assist them in processing the sensory experiences in their life. Ask your occupational therapist to establish a sensory diet for you to follow with your child. Embrace the uniqueness of their abilities and never stop looking for adaptations to meet their challenges!

Sandra (Sandy) Cooley is an occupational therapist who is a self employed contractor, working for Therapeutic Rehab Services, serving Lee County Schools in Alabama. She has been practicing for 32 years, with the last 15 in the local school systems. Sandy was widowed 18 years ago and has been in a long term relationship with her boyfriend, Jerry Lang, for 7 years. They live in Smiths Station, Alabama with his son Joel (age 25 with Downs Syndrome) and her daughter, Hannah (age 23 who has CdCS). In addition to Joel, Jerry has two grown daughters and 2 beautiful granddaughters, who are actively involved in their lives. Needless to say, life is never dull at her place!



2017 Hall of Fame Recipients.

Parent of the Year: HILLARY LOSEN



Congratulations to Hillary Losen as the 2017 Parent of the Year. Hillary is a 5p- Society Ambassador who does several tabling events throughout the year (her last one was one week before the conference). She was also one of the hosts for this year's conference in Milwaukee. Hillary and her husband Jason ran the child care and coordinated the volunteers for the event. Hillary was able to obtain the Wisconsin Proclamation for Cri du Chat Syndrome Day as May 5 and had a meet and greet with her family and the Governor of Wisconsin. Hillary, married to Jason Losen, has three children. Jacob (9 year old with Cri du Chat Syndrome), Evelyn and Marian. A nurse by trade, she has a very nurturing way about her and you instantly feel at ease in her presence. Thank you Hillary for your dedication to the 5p-Society.

Grandparent of the Year: SUSAN LOSEN

Susan Losen is the grandmother of Jacob Losen, 9-year-old with Cri du Chat Syndrome. According to her daughter-in-law Hillary, Susan is a selfless, caring, helpful individual crucial to the success of raising Jacob. She has spent countless days/nights driving after work and from afar, almost 218 miles daily (4 hours if coming from northern WI) to help our family with bath/bedtime routine. Jacob requires constant supervision and many times full assistance with activities of daily living, and she allows Hillary the time and ability to provide care to Jacob. She helps watch Jacob's siblings frequently, especially in the times when Jacob had surgery, or 1 of his 11 specialist appointments at Children's Hospital of WI. Sue is always willing to help, provide guidance/opinions, and is a very involved grandparent. Susan also brings awareness of Cri du Chat Syndrome by providing



pamphlets, fact cards and short awareness educational sessions prior to work functions. Sue has made frequent, substantial monetary donations to the 5p- Society and especially during awareness week and for the 2017 Milwaukee Conference. Sue has assisted with providing raffles/donations/Badger Football tickets/and gift baskets to multiple fundraisers including 2 pig roasts, and encourages her friends to help out as well.

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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.

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





Siblings of the Year: JANNIE BOULANGER-HANNA and TRAVIS BOULANGER

Jannie and Travis are the younger siblings of Matthew (25 years). Both Jannie and Travis have been instrumental in spreading awareness of 5p—Syndrome through fundraisers, classroom assignments and presentations, educational events and participating in leading the sibling mixer for the 5p- Society conferences in 2015 and 2017. Travis even brought C5 to life this year by creating a costume and appearing as C5 at the Welcome Reception at the Milwaukee Conference. They both participate in planning the Awareness Walk for

5p- in their communities with other 5p- families. Congratulations and thank you for your continued support.

Superhero Volunteer of the Year: JASON JONES

Jason Jones is the uncle of Wade Jones of Monticello, Illinois. Jason, nominated by his sister-in-law Megan, has been instrumental in raising over \$18,000 for the 5p- Society and the Jones family by organizing Wade's 5k for 5p- for the past two years. He also educates the community about the syndrome by appearing in TV and radio interviews. Because of these interviews several families who thought they were alone in their community have been able to reach out to the Jones family and get connected with the 5p- Society. Jason is currently planning the 3rd annual race scheduled for October 7th. For more info on the race go to



www.wades5kfor5p.com. Thank you Jason for your continued support and dedication!



How would you like your child to receive a personalized letter from Santa for a small donation to the 5p-Society? The 5p-Society is helping out Santa again this year. All we ask is for a small donation and some information that we can personalize the letter with and send to your child. Campaign dates November 15 to December 15. The link to participate is https://5psociety-regfox.com/5p-society-letter-from-santa-campaign. Thank you for your continued support.

5p- T-shirts

Bi-annual 5p- logo t-shirt sale. Starts October 15 and will run until November 1st. T-shirts, sweatshirts, jackets, and knit hats with the 5p- logo on it will be available. Please go to www.cmsportinggoods.net and click on the "spiritwear" tab. Look for the 5p- Society to see the items with the 5p- logo on it. We will repeat the fundraiser in the spring.



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.cromosomacinco.com/

Meet James Chalmers

https://www.facebook.com/james.chalmers.3994/

videos/10207221038346912/

Blogs to follow _____

- http://livingwithcriduchat.blogspot.com/http:// elastamom.com
- All Things Beautiful by Kathy McClelland
- 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://crazvincognito.blogspot.com http://myriversride.wordpress.com
- http://allaboutvayla.blogspot.com
- http://brennanandcalebsmom.blogspot.com
- http://praisevouinthestorm.com
- www.prayforellee.org
- http://notquiteearthmother.wordpress.com
- http://tricia-themama.blogspot.com
- www.angelarichev.blogspot.com/
- http://lessonsfrommydaughter.me
- http://martianmommy.blogspot.com
- http://www.specialneedsdadchronicles.space
- www.mydanceintherain.org

Books to read _____

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

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.

5p- Gear Items ____

There are several places that you can get your 5p-Gear. Many items can be found at www.cafepress.come/5pshop

There are also several items at the 5p-Society Square Market store. You can shop at https://squareup.com/store/5p-society

Items available:

- **♦** Hats—\$20.00 each
- ❖ Waterbottles—\$10.00
- **♦** Decals—\$10.00
- **♦** Magnets—\$8.00
- ❖ Coffee Tumblers—\$10.00
- ❖ Wristbands—\$5.00
- **♦** Keychains—\$5.00
- Calendars—Early Bird \$15.00, After December 1st \$20.00







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

RETURN MAIL REQUESTED

Email: director@fivepminus.org



■Meet C5■

The Mascot of the International

Cri du Chat Awareness Week

May 5-12, 2018

WE'RE ON THE WEB

WWW.FIVEPMINUS.ORG

TWEET WITH US

@5PMINUS

FIND US ON FACEBOOK AT http:// www.facebook.com/CriDuChatSociety

YAHOO GROUP PAGE: 5PMINUS

HTTP://HEALTH.GROUPS.YAHOO.COM/
GROUP/5PMINUS/JOIN/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

2018 Faces of Grace Cri du Chat Syndrome Calendar

The 2018 Faces of Grace Calendar is anticipated to be available by mid-November. The calendar features twelve **beautiful** individuals with Cri du Chat Syndrome. Pre-order your copy now at the pre-sale rate of \$15.00 per calendar (includes shipping) until December 1st. After December 1st they will be \$20.00 each (including shipping). For more information on how to order, please contact Laura at director@fivepminus.org. Thank you to Cordelia for once again putting the calendar together.

