

AWARENESS... OF SELF *by Jen Wong*

In all the past years of working to raise awareness for Cri du Chat within the medical and neighborhood community, I forgot to include one of the most important people in my awareness campaign, Emma. This year is Emma's transition IEP into High School (yikes, time flies!). While looking at a transition curriculum, one section was to have Emma develop a paper on "Who Am I?" The first step of the project was to answer personal questions. The first statement she had to complete was "My disability is.." This statement made me realize I had never discussed Emma's diagnosis with her. It never crossed my mind and I'm not sure why. Obviously, early on, she was too young to understand, but through 4th-8th grade, she would be able to understand some basics. If able, having a basic understanding of yourself, and diagnosis, gives one a better sense of self. If someone is able to understand that their struggles or inability to do something is not a shortcoming of them but a result of their diagnosis, they are able to have a greater confidence. In a sense it is, "it's not my fault, it's my CdCs". It's not that I'm trying to shift responsibility but rather remove the negative feeling of "I'm bad" or "I'm dumb". Emma's teacher told me about a student that was getting frustrated at task and when asked if he was okay said, "Yes, it's just my Autism getting in the way". I thought this child's self-awareness was probably better than some of his "typical" peers or even some adults.

This year, my first priority for Awareness Week is to educate Emma on her disability and help her understand that it isn't that it makes you less, just different and unique. Hopefully, Emma will be able to learn to better advocate for herself as well as join me in raising awareness of Cri du Chat.

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Conference Update: Hotel is sold out of rooms. There are hotels around the area, but not in walking distance. If you are not going and have a room **do not cancel**. Let Laura take over your room and reassign it to someone in need.

LIGHTS CAMERA ACTION—#TAKETHATCRIDUCHAT
<http://5pminus2016conference.blogspot.com/>

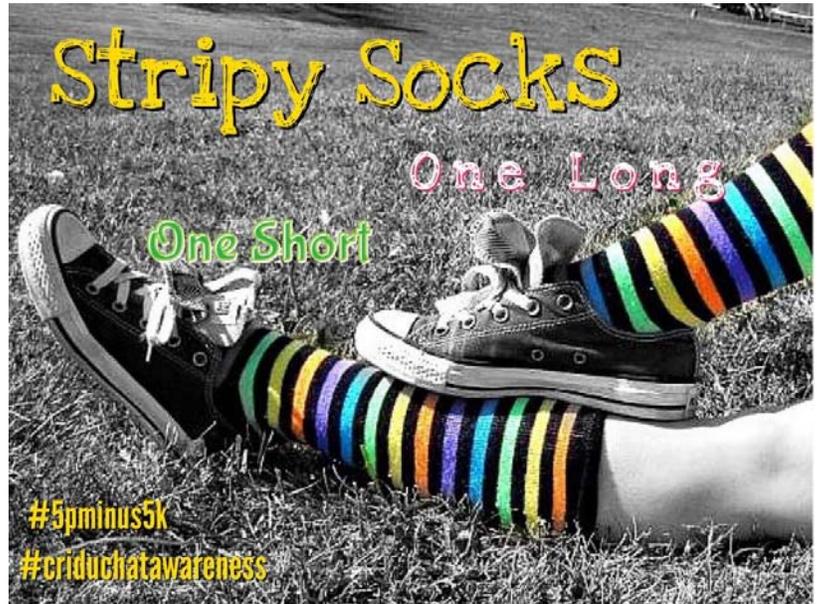
The 2016 conference will be held on July 28-31 at the Hilton Costa Mesa, in Costa Mesa, California. Room rates have been locked in at \$139.00 per night plus tax. The California Conference Committee is busy working behind the scenes on the different events of the conference.

Southern California is a perfect destination for a conference. So much to see and do within a two hour drive. Costa Mesa borders two world renown beaches along the Pacific Coast, Newport Beach and Huntington Beach. Of course there is Disneyland, California Adventure, Knotts Berry Farm, Universal Studios, Beverly Hills, Rodeo Drive, Sea World and several Zoos and Aquariums while you are visiting.

The conference brochure is ready and was sent out last month. If you did not receive it, please let us know.

STRIPY SOCKS CAMPAIGN

Awareness Week is also Stripy Sock Campaign Week. It is so much fun to see all the pictures. Remember to wear one long and one short to show the two 5th chromosomes. Also, don't forget to #stripysocks #criduchatawareness #CdCS #5pminus5k. Tweet your pictures @5pminus, or upload to Instagram @5pminus



LEARN SHARE CONNECT

Blogs to follow:

- * <http://livingwithcriduchat.blogspot.com/>
- * <http://elastamom.com>
- * [All Things Beautiful 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>

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/>
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.

WHERE IN THE WORLD IS C5? BY NICK WALLACE

Some of you may have heard about the book Flat Stanley. The premise of the project is that kids send a printed version of Flat Stanley to a school, a celebrity, a family member, a politician or anyone of interest and the recipient returns the little flat guy along with a completed journal and perhaps some souvenirs such as post cards, photos, or special items.

C5 is the mascot of the International Cri du Chat Awareness week. We have made a version available to print and send like the Flat Stanley project. Also, being in the digital world, we can send C5 via email or social media. We will be posting a downloadable version of C5 on our website and on our social media outlets. We have two versions of the C5 printout. One version is a color version and the other is black and white. We figured that the black and white version would allow for creativity and would also make a great project for anyone that may be presenting, about Cri du Chat Syndrome, during awareness week. We have also adapted our CdCS fact cards to help raise awareness but to also give instructions on how to share C5 with the world, on social media.

Our goal is to get as many photos, from across the globe, of people posing with C5 during awareness week. We will use the hashtag #SeeC5 and #criduchatawareness to help spread the awareness on Instagram, Facebook and Twitter. Our hope is that we can get as many people involved in this project as possible, and by starting early, we might be able to get some big names to help us raise awareness by posing with C5 and posting the photo on their various social media pages.

Please take a moment to stop by our Facebook fan page www.fivepminus.org/CriDuChatSociety and the closed group www.facebook.com/groups/385907554759706/ for more information on this project. We will also be posting details on our website www.fivepminus.org and on the international awareness website www.criduchat.org. The files will be posted there for you to download your copy of C5.

I am excited to see how far we can get C5 to travel and to see if he can meet up with any famous people along the way. I am also excited to see how creative you can be with your C5.

Happy Travels!



Do you like to shop at Amazon.com? Do you have AmazonPrime? Help the 5p– Society raise some easy money by shopping through AmazonSmile. 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 AmazonPrime too!! Thanks for your continued support!!!



The 5p– Society will get \$10 for each Bravelet ordered. Several colors and styles are now available. Two different sites to order from - check out the new styles

<https://bravelets.com/bravepage/cri-du-chat-syndrome-support>
and <https://www.bravelets.com/bravepage/virtual-5k-for-5p>

5p– Society client Margaret Hood, has create vinyl decals that you can put on your vehicle (in the window) or in the home. Our own C5 can be proudly displayed or our 5p– logo. Cost for each is \$10.00 with a portion of the funds going to the 5p - Society. Colors available will be black, white, grey and blue.



To order these, please go to this link. <http://mkt.com/5p-society/car-decals>

See C5



C5 Coloring Page



THANK YOU TO OUR 2015 DONORS

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All efforts were made to make sure we list everyone who has donated \$100 or over. If you feel this is in error, please contact Laura at the 5p- Society office or send an email to Laura – director@fivepminus.org. Conference registrations are not included in this list.

MY STORY BY DARIEL JAMES



My name is Darriel James I'm from Greenville, North Carolina. I'm 34 years old and was born with Cri du chat syndrome. My grandma raised me, I have no brothers or sisters and I'm the only child when I was Diagnosed with Cri du chat syndrome. The doctors did not know anything about of what I was born with up to one doctor came in and notice of what I have so from that day on I been diagnosed with Cri du chat syndrome. My language is good. I been seeing a therapist because I do think it would help with communication with people who has Cri du chat syndrome. Half of children with this syndrome learn enough verbal skills to communicate. The cat-like cry becomes less noticeable over time. I have something called gastroesophageal reflux which means food and drinks comes back up but I'm getting help with that. I went to the doctors and they said that gastroesophageal reflux is related to what I was born with. I am now on medication and it has helped keep the food and drinks down. I would like to communicate with

others who are like me and I hope this helps some of you. Thanks for listening, Darriel.



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Email: director@fivepminus.org

RETURN SERVICE REQUESTED



Meet C5

The Mascot of the International
 Cri du Chat Awareness Week

May 1-7, 2016

Tweet with Us
[@5pminus](https://twitter.com/5pminus)

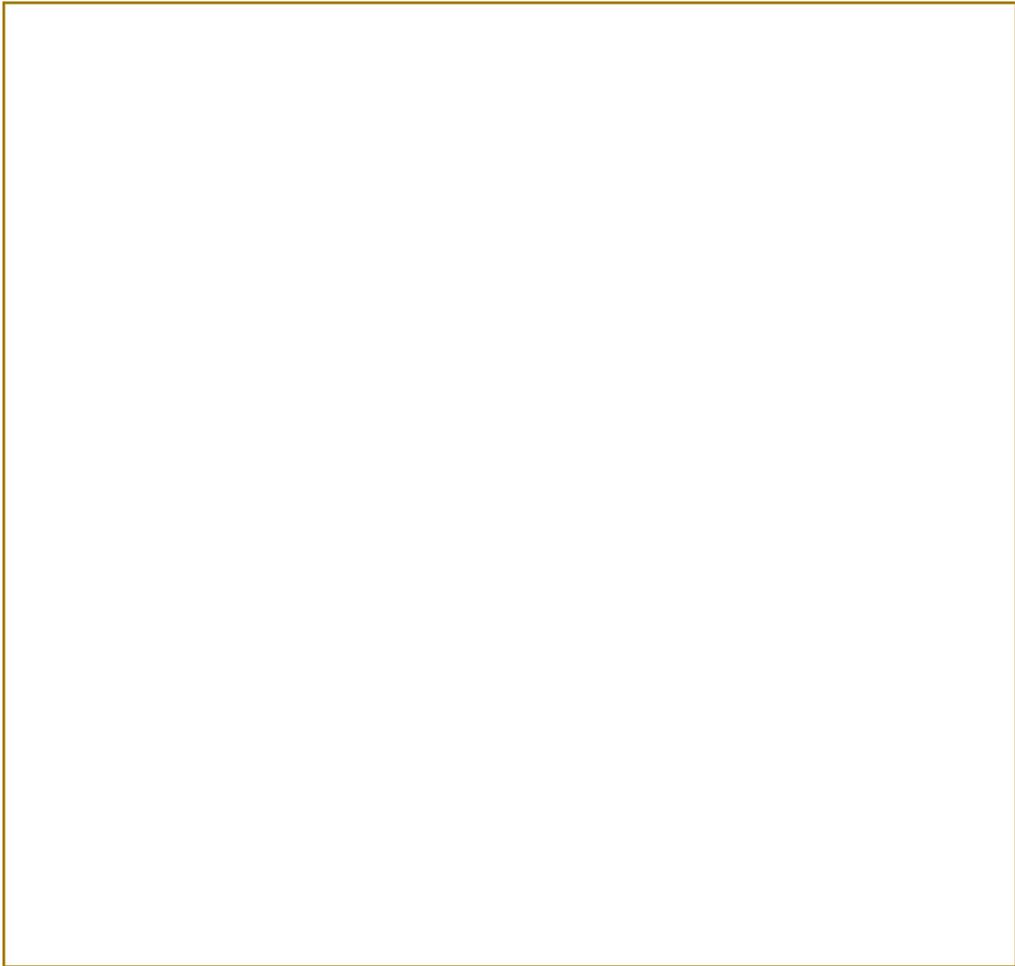
We're on the Web
www.fivepminus.org

Find us on FaceBook at <http://www.facebook.com/CriDuChatSociety>

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>



EVENTS & ITEMS

Arizona Get-Together

April 30 - 5-8 PM
 Contact Sam Brown at (480)710-8022
sandsrfer@q.com or on FaceBook

SoCal Get-Together and 5k Walk

May 1 - 1:30-4:30 PM
 Rynerson Park, Lakewood, California
 Contact Laura Castillo at (562) 804-4506;
lc5pminusociety@aol.com or on FaceBook

NorCal - Mya's 2nd Annual Walk

May 1 - 9 AM to 12 Noon
 San Ramon Valley High School
 Contact Robert Fernandes at rrfern@yahoo.com
 Register at: <https://www.crowdrise.com/myas2ndannual5kwalkfor5p/fundraiser/robertfernandes>

Wisconsin-5p Awareness Walk

May 1- 2 PM
 Contact Jannie at 920-837-7638. Visit the Face-Book Event page at: <https://www.facebook.com/5p-AwarnessWalk-336327666561966/>

New York - Team Sara Borrello #SaraRocks

May 1 - 10 AM
 Veterans Memorial Park, Crystal St, Harrison, New York
 Contact Rosanna Borello at rosaborrello@aol.com
 Register at: www.5psociety.redpodium.com/virtual5kfor5pminus

Northeast United States

Contact Holly Gattone for up-to-date info at holly22@pa.net or on FaceBook

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www.cafepress.com/5pshop or
[www.fivepminus.org/5p- Logo'd_Items](http://www.fivepminus.org/5p-Logo'd_Items)