

HAPPY BIRTHDAY TO YOU! *BY JEN WONG*

Happy Birthday to you, Happy Birthday to you, Happy Birthday Cri du Chat Syndrome, Happy Birthday to you. 2013 is the 50th Anniversary of Jerome Lejeune first describing CdCS.

One fact some of you might not know about CdCS is it's one of the most common syndromes caused by a chromosomal deletion. "Most common chromosomal deletion" is not the phrase any of us think of when we think of CdCS. If it weren't for our conferences many of us would go our family member's whole life without meeting another person with CdCS. We have come a long way in 50 years, but we have an even longer way to go in spreading awareness and encouraging research, especially in the medical community. In general, we could all probably write similar stories on our journey with Cri du Chat Syndrome. Most of our stories contain information given to us such as "Children with CdCS die before their 1st birthday". I think that is the main statement that everyone can recount the exact moment when they heard it. I had "googled" CdCS the evening after receiving Emma's diagnosis, alone, because my husband was deployed and due back the next day. I remember sitting in our basement in Alaska and thinking "Emma is 4 months old that only gives me 8 more months with her." After reading the rest of the very grim information, my coping mechanism went into overdrive and told me "It's okay if she dies in a year, it will be too hard taking care of her for more than that. I can handle 8 more months." After I joined the 5p-Society and was given the correct information regarding the syndrome, I felt horrible and guilty for thinking that I was okay with my child dying at a year. What mother thinks like that?! Luckily, during one of my many late night parent sessions at a conference, this topic came up. I was so embarrassed to admit I had such horrible thoughts for my daughter. A few parents mentioned they had similar thoughts. After a heart felt discussion, we all came to realize, these thoughts did not come from our heart, but from a self-preservation area in our brain, because the information we received was just too painful to handle. I was so grateful for the mom, who was brave enough that night to take our discussion to such a raw and vulnerable place. Even greater, no one judged. Everyone, even if they didn't have these thoughts, understood. The guilt I had for those thoughts was erased that night. I realized how we all cope in different ways and some of these ways may not be easily understood, even by ourselves.

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2013 Conference Info

The New York conference will be held July 25-28, at the Hilton Long Island Huntington in Melville, NY. Room reservations at the Hilton are now being accepted. Cost per night is \$159.00. Please call 1-800-HILTONS and tell them you are with the 5p- Society.

Registration fee is \$150.00 US for up to two adults and two children. Extra children are \$25; and Extra adults are \$50. Registration form will be available in March 2013.

We are happy to announce that Rachel Coleman of Signing Times will be performing at the 2013 Conference. Thank you to the host families for making this happen!!

One of the reasons, I joined the 5P- Board of Directors is to help prevent other families from having to go through this pain. Getting the initial CdCS diagnosis is difficult enough without being given outdated incorrect information. My goal to honor the 50th Anniversary is to educate 50 people about CdCS this year. Whether it's a pediatrician, a therapist, or the person staring at my daughter, I'm going to get the word out about CdCS. Even if it's a simple "My daughter has CdCS" or providing 5P- Society pamphlets to NICUs and doctors' offices. I ask that everyone please join me in educating the world on CdCS and how wonderful our family members are.



LEARN SHARE CONNECT

Blogs to follow:

- * <http://mydanceintherain.org>
- * www.sophieourgift.wordpress.com
- * <http://livingwithcriduchat.blogspot.com/>
- * <http://elastamom.com>
- * <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>

YouTube Videos to Watch

[5p- Society 2012 Conference Pictures](https://www.youtube.com/watch?v=D16fsTN9I7g)

<https://www.youtube.com/watch?v=D16fsTN9I7g>

Pictures from the 2012 Conference

[Cri du Chat Awareness US](https://www.youtube.com/watch?v=GbWDG3JXFL4)

<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)

<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)

<https://www.youtube.com/watch?v=A47tRTi8YPw>

[International Cri du Chat Syndrome Awareness— Meet Nellie](https://www.youtube.com/watch?v=zw2joxiYjR4)

<https://www.youtube.com/watch?v=zw2joxiYjR4>

[Isaac at Inspire](https://www.youtube.com/watch?v=kafOs4dOrYE)

<https://www.youtube.com/watch?v=kafOs4dOrYE>

[Taelor's Big Justin Bieber Surprise](https://www.youtube.com/watch?v=6vQeNtmzuW8)

<https://www.youtube.com/watch?v=6vQeNtmzuW8>

[Happy Baby Ellee](https://www.youtube.com/watch?v=a1PEK7pIWgE)

<https://www.youtube.com/watch?v=a1PEK7pIWgE>

[Janine Can Read](https://www.youtube.com/watch?v=Fb-EnS3Xvy8)

<https://www.youtube.com/watch?v=Fb-EnS3Xvy8>

Have a video to share? Send the link to 5p- Society office at director@fivepminus.org



5P- SOCIETY

IDENTIFICATION DOG TAGS

National Family Support Group for Individuals with Cri du Chat Syndrome

Tear-off Order Form

Method of Payment

- Credit Card PayPal
 Check www.fivepminus.org/donate.htm

Dog Tag Information

Butterfly Monster Logo Y N Necklace
 Birthstone Y N Month _____ Key Chain
 Name(s) on Front (optional): _____
 Information on Back: Line 1: _____
 Line 2: _____
 Line 3: _____
 Line 4: _____



PO Box 268
Lakewood, CA 90714-0268

Butterfly Monster Logo Y N Necklace
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 Name(s) on Front (optional): _____
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Phone: (888)970-0777
 (562) 804-4506
 Fax: (562) 920-5240
 E-mail: director@fivepminus.org

Name _____
 Address _____

 Phone _____
 Credit Card # _____ Exp. date _____
 Signature _____

For more than 2 please put information on separate piece of paper.

Total ordered _____ x \$15.00 each, plus \$2.00 shipping (up to 3 tags, add .50 for each additional tag ordered)

JEWELRY FUNDRAISER

My name is Linda Reed and I have a daughter who has 5p-. I have come up with a bracelet design that I am calling 5 p minus Awareness bracelet. I just posted it on my Etsy website, I have spoken with Jolene about it a couple of times and now I finally made the bracelet a reality. I am going to donate \$5.00 from each sale of the bracelet to the Five P Minus Society. Jolene wanted me to contact you in hopes that you could put it in the upcoming newsletter. Please feel free to contact me if you have any questions or concerns. Thanks!

The website is www.simplyyoursbylin.etsy.com, the bracelets are listed under the Cri Du Chat section in my shop. There are a few for \$18.00 and a few for \$20.00.



DIFFERENT . . . BY LAUREN BROUSSARD



Dear Ava,

You have felt my tears, falling on your face. Someone else might think they are tears of sadness because of what you can't do. I know DIFFERENT. I know those tears pour from my heart out of gratitude for you, because of what you can do: you can love everyone in the purest form possible. unconditionally. You can be judged, but will never judge in return. I know DIFFERENT. Because I let you know in my hugs and kisses that you are perfect just the way you are. You have seen me hang my head down in shame when we go places.

Someone else might think I am ashamed of having a child like you. I know DIFFERENT. I know that I am ashamed of the grown-ups who ignore you, yet talk happily to all the other children. The grown-ups who won't look me in the eye, but stare at you when they think I can't see. I know DIFFERENT because there have been many, many more times I have raised my head up high because you are mine! You have heard me whispering desperate prayers at night. Someone else may think I am asking God to make you a typical kid. I know DIFFERENT. I know that I am thanking him that you got to be here with me, for another day exactly how you are. I know DIFFERENT because I have asked for you never to leave me. You have heard me cheer for you every single day of your life so far, I have told you, you don't need to be typical to be amazing, you just need to be here. I know I have



a big job taking care of you. I know that more than anything I want to hear you say my name & I worry that I'm not good enough, and that I will fail you. But I know and I know you know DIFFERENT!! I know that even on my worst days, I will always be good enough for you and you will always love me more than I know. I love you Ava Girl :)

- Mama



“No one is ever quite ready; everyone is always caught off guard. Parenthood chooses you. And you open your eyes, look at what you've got, say "Oh, my gosh," and recognize that of all the balls there ever were, this is the one you should not drop. It's not a question of choice.”

— [Marisa de los Santos](#), [Love Walked In](#)

A MAJOR INTERNATIONAL CRI DU CHAT AWARENESS ANNOUNCEMENT *BY NICK WALLACE*

Ok, I have a major announcement to make. In recognition of the 50th anniversary of the discovery of Cri Du Chat Syndrome, by Dr. Jerome Lejeune, we are preparing an educational video that will focus, not on what our kids can't do, but on what our kids can do.

Recently I posed the question, to our Facebook group, about their diagnosis experiences. What I found interesting about the responses were that a good majority of them were the same. The responses usually said this, "My doctor/geneticist told me that my child would never ...". Then the response followed up with, "but he/she can do those things." Some of the major points that I read were that our children will never walk, never talk/communicate, never live past the age of 1, they should be institutionalized, never learn, essentially never touch anyone's life.

So, here is the exciting part ... we are going to create this video based on videos submitted by you. We want to have videos that include children/adults, that may be very severely affected by they syndrome, to those who are not as affected by it. We want videos showing your kids saying, signing, or using a communication board/device to say, "I Can!" We want to see your kids at work, school, or play. Send us videos of people surrounding your child and saying how much your child has touched their life. We will not be able to use all of the videos submitted, but we plan to use as many as we can.

Now to take this project one step further, we are compiling these videos from 5p-/Cri Du Chat Support Organizations across the globe. This is going to be a major focus for this year's International Awareness Week. We hope to get this video to go viral and to get this video in the hands of our health care professionals, to help them better understand what our kids can do, but to also be able to show other families what their child may be able to do. We also hope to get this video in the hands of the media. It would be great if it could go in one of their Public Service slots. *****VIDEOS MUST BE RECEIVED BY MARCH 31 TO BE CONSIDERED*****

Now, to answer the questions:

How do I submit a video?

To submit a video, you will need to use <https://dropbox.yousendit.com/Awareness2013>. If you have any questions, please send an email to videos@criduchat.org.

Do I have to fill out a release to use my video?

Yes, you will need to fill out a release. You can request a release form at videos@criduchat.org. A release form will need to be on file prior to the release of the main Awareness Video.

What type of videos do you want us to submit?

We really don't want to limit the videos that are submitted. We want to make sure that every level of severity is included in this video. Also, your video may spawn another topic that we want to cover in this video. So, submit your videos showing us what your child can do.

Can I submit multiple videos?

Yes, feel free to submit multiple videos. We will not be able to use all of the videos that are submitted, but we plan to use as many as possible.

Is there a certain way I should shoot the video, if I use my phone?

The best way to shoot video, if shooting from your phone is to shoot horizontally. It helps to fill up the entire frame when it is converted. If it is shot vertically, it will show black boxes on the side and the video will look small.

If you have other questions, please feel free to post them in our FaceBook group:

<https://www.facebook.com/#!/groups/385907554759706/>

I can't wait to start looking at some of your videos. With your help, this project will put accurate information in the hands of our medical professionals, newly diagnosed parents, and people around the globe.

THANK YOU FOR THE DONATIONS — 2012 SPONSORSHIP LEVELS

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**All efforts have been made to include all individuals that have made a contribution of \$100 or more during the 2012 calendar year. Please accept our apologies if we are in error and your name is not listed. If you are in need of a receipt for taxes (one should have already been sent), please contact the 5p- Society office at director@fivepminus.org. Conference Registration fees are not included in this list.

GROWING PAINS *in a good way!!*

2012 was the year of growth for the 5p- Society. We would like to welcome all our new families from around the globe . . . Last names and location are listed below: (this list almost doubles a typical year — and there are families who are referrals, but whose information is not complete) Please keep in mind this is 2012 info (we've had several adds so far for 2013).

Beckham Morrison, Colorado
 Bennette New Orleans, Louisiana
 Bentley Goderich, Ontario, Canada
 Brentano Sublimity, Oregon
 Broussard Youngsville, Louisiana
 Buckner Albuquerque, New Mexico
 Castillow Semmes, Alabama
 Castro-Castillo Bogota, Colombia
 Coles Springtown, Texas
 Dalzell Abington, Pennsylvania
 De La Garza Laredo, Texas
 Diss Lake Mary, Florida
 El Trabulsi Baytown, Texas
 Garcia Louisville, Alabama
 Garcia San Jose, California
 Gillespie Brookfield, Missouri
 Grasso Haverton, Pennsylvania
 Green Fairview, Illinois
 Isberner St. Francis, Wisconsin
 Jones Monticello, Illinois
 Karosas Lithuania
 Klemp Aurora, Colorado
 Lozano Northridge, California
 Manteiga Fall River, Massachusetts

Moore Eastchester, New York
 Neil Layton, Utah
 Nikitina Kemerovo, Kuzbass, Russian Federation
 Peters Atlantic City, New Jersey
 Rankin Woodward, Oklahoma
 Rimachi Doha, Doha, Qatar
 Rocha Windsor, California
 Ryan Hilliard, Ohio
 Scollon Thornton, Colorado
 Soderberg Minneapolis, Minnesota
 Strozier Pikeville, North Carolina
 Taylor Nampa, Idaho
 Turner Tooele, Utah
 Walton Baytown, Texas
 Washington Independence, Louisiana
 Whitlow Salem, Indiana
 Wiecek Abington, Pennsylvania
 Wizner Clifton, New Jersey
 Woodley Sublimity, Oregon

Our FaceBook group page began in March 2012 and by the end of the year had over 600 members, many new to the 5p- Society and many from countries around the world!!



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

Email: director@fivepminus.org

RETURN SERVICE REQUESTED

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/>

Interested in having a gathering in your area? Contact the 5p- Society for information and how to get in touch with families from your state or province.

Coming up:

Ohio—6/21-6/23 Columbus, Ohio
 FMI: Tammy Boring
tboring@advocate4buyers.com

Arizona/California-4/20 Chandler, Arizona
<http://www.facebook.com/events/150287855129537/>

FMI: Sam Brown
sandsrfer@q.com

GET YOUR GEAR ON!!



Car Magnets are available. \$8 US each

Limited # of hats available \$20 US each (black with white, white with black or tan with blue)

Bracelet (\$2 US) and Keychains (\$4 US)



Cri of the Cat DVD by Helen McGrath \$15 US (order the above by contacting director@fivepminus.org)

You can also order 5p- /Cri du Chat logo'd gear at www.cafepress.com/5pshop

New Holiday Items are available, including items that can be personalized.

WINE TASTING EVENT

BENEFITING THE 5P MINUS SOCIETY, a non-profit organization dedicated to supporting families of children with Cri du Chat Syndrome

SUNDAY, APRIL 14
 2:00 – 5:00 PM

ARCHWAY GALLERY
 2305 Dunlavy
 Houston, TX 77006
 (713) 522-2409

Minimum tax deductible donation to the 5p Minus Society: \$35/person

All proceeds from the event go to the 5p Minus Society for the 2014 Conference

FMI & RSVP: rachel.stanford@gmail.com

If interested in wine sponsorship or donating a silent auction item for the event, please contact rachel.stanford@gmail.com