

DO YOU HAVE TO BE AWARE OF YOUR AWARENESS TO BE AWARE? BY JEN WONG

Whew, say that three times fast. This question came to me after William, my 7 year old, read me the book "Don't call Me Special". It is about how children with disabilities do not like to be called special because it insinuates they are different, and like all children, they do not like to be looked at as different. It goes on to describe different disabilities, both physical and learning, and adult helpers children might have at school to help them. After he finished reading I asked him, "Do you know anyone with a disability?" He said, "No." I pressed further asking if he knew anyone who needed an adult to help them at school. Once again, he answered no (he knows and sees Emma's aide every day). Now William has been known to let the obvious escape him so I thought I would ask something more concrete. I explained how someone with a physical disability might not be able to use their legs to walk and if he knew anyone like that. Once again, he said no. William's best friend's sister has CP and is in a wheelchair. We see them every day at school and have play dates at each other's homes. At first, I was worried William has a real problem with recognizing the obvious. But then I remembered what my 9 year old Chris' Kindergarten teacher once told me. The sister with CP was in Chris' Kindergarten class. His teacher told me how when she first came in the class, all the children were scared of her wheelchair...all except Chris. She also mentioned how Chris would help her (e.g. if she dropped her pencil) without even giving it a thought, it just came naturally to him. To Chris, she was no different than the rest of his friends. They are now in 3rd grade together and he mentions how he hopes when they change desks, he gets to sit by her. This made me very proud, but back to William. I know William's youth has something to do with his answers. But I also prefer to look at it in a more positive light. Adult helpers, wheelchairs, therapy equipment are all a part of his "normal". Because he is growing up with Emma, disabilities aren't different, they're just part of his world. When most of us were growing up, children with disabilities were barely seen. They didn't attend school with us, didn't play sports with us; they were hidden away at "special" schools and institutions. Because of that, many adults in our generation

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FALL 2012

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 February/March 2013.

Conference committee has some awesome speakers and topics that will be announced in the next newsletter . . .

Big announcement coming in a few weeks!!!

80/20 RAFFLE WINNER

Thank you to everyone who participated in the 2012 80/20 cash raffle. Eighty tickets were sold this year and the winning ticket received \$1,600.00.

The winning ticket was pulled on July 15 by Christian Zepeda,

(a non-related individual to the 5p- Society.) The winner is Joan Demeike from St. Louis, Missouri.

The remaining 80% of the raffle monies will be used to cover expenses from the 2012

conference or will be carried over to the 2013 conference in New York.

**THANK YOU FOR YOUR
CONTINUED SUPPORT!!**

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are nervous and yes, even scared around people/children with disabilities. Many parents are learning a valuable lesson about accepting all differences from their children and I'm proud my children's friends are playing a part in teaching that lesson.

I have had many small talks with my boys about Emma's disability and why she sometimes acts the way she does. I've also talked to them about CDCS. Despite all this, their conclusion is she's just being "a sister". How I wish Emma had a sister to share girlie things with and not be the "odd girl out" all the time (she has **three** brothers). But she also has three brothers who will protect her, her own personal security team. I know as my boys get older, they will understand their sister better. When they are older, they will be more educated on CDCS and disabilities, but will they be more aware? Do you have to notice a disability to be aware of it? If you think of your friend in the wheelchair no differently than your able-bodied friend, does that mean you're not aware? If these things pertain to you, I would say you have reached the highest level of awareness, you are unaware. But as we all know, there are many Doctors, Therapists, Teachers, and Community Members who are not even aware CDCS exists. 2013 will be the 50th Anniversary of Dr. Jerome Lejeune first identifying Cri-du-Chat. Let's all take the challenge to make 50 Doctors, Therapists, Teachers, and Community members aware for the first time, that our children not only exist, but are happy, contributing members of our communities.

I would like to know what you think; I will be posting this question on our Facebook group site and would love to hear your thoughts.



LEARN SHARE CONNECT

Blogs to follow:

- * <http://lifesunexpectedblessings.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>

YouTube Videos to Watch

[Emma The Little Red Riding Hood](https://www.youtube.com/watch?v=x83wYXyNCg&feature=youtube_gdata_player)

https://www.youtube.com/watch?v=x83wYXyNCg&feature=youtube_gdata_player
Watch Emma the Little Red Riding Hood on her storybook Adventure . . . Will Ryan be able to save her???

[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.

[My Sweet Angel](https://www.youtube.com/watch?v=0ss-fwO2yz4&feature=g-upl) by Angela de la Garza

<https://www.youtube.com/watch?v=0ss-fwO2yz4&feature=g-upl>
A tribute to her son with Cri du Chat Syndrome

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

5p- Society

National Family Support Group for Individuals with Cri du Chat Syndrome

Identification Dog Tags



Many thanks to Dana Schellhase, Kendra's mom, for introducing the 5p- Society to Brenda Hull of *bjaw-elledparties* company. Brenda has designed, especially for the 5p- Society, identification dog tags for you to purchase for your child or adult.

There are several options to choose from. 1) You have the option of putting your child's name on the front, and identification information on the back (up to 4 lines); 2) leaving the name off the front and only putting identification information on the back; 3) only putting the name on the front. The

price is the same for any of these options.

Brenda can make your dog tag into a necklace or a key-chain. She can also add a birthstone charm to your dog tag (please indicate the month on your order form).

There are two original artwork designs by Brenda that you can choose from for the dog tag (pictured to the left).

Dog tags are \$15.00 each plus \$2.00 for shipping (up to 3 tags, add .50 for each additional tag). Please fill out the attached form, make your check payable to the 5p- Society, and send to PO

Box 268, Lakewood, CA 90714. Orders will be forwarded to Brenda weekly.

Payment can also be made by credit card or through PayPal (if making payment through PayPal, an order form will need to be faxed or emailed to:

director@fivepminus.org before order can be completed).

Dog tags can also be made without the 5p- Society logo for siblings, relatives or friends. Please note on order form.

Tear-off Order Form

Method of Payment

☐ Credit Card

☐ PayPal

☐ Check

www.fivepminus.org/donate.htm

Name _____

Address _____

Phone _____

Credit Card # _____

Exp. date _____

Signature _____

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: _____

____ 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: _____

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)



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IN THE EYES OF BY JANNIE BOULANGER, SIBLING

Hi, my name is well it doesn't really matter. People stare at me and I wonder how they have the nerve to. I can't do anything without somebody staring at me. It's frustrating when I have something I want and it's not on my communication system. When it's not on my communication system, I have to either try to sign it or go find it myself. Usually it's not something I can sign. If it is one of the few things I can sign, nobody is in the room and sometimes it's one of those times that nobody even knows I'm up. That's because I get up too early. In conclusion then, I must be independent and find whatever it is I need. When I look for what I need it usually ends up in a mess. I mean well, but I just don't have the coordination like everybody else to look for things any differently. By the time I find what I'm looking for, I just don't have the patience to clean up the mess I accidentally made. It's not any easy task to clean up a mess being uncoordinated and having no patience. I do end up forgetting about the mess. I'm only human, humans have the natural tendency to forget at least once in a while. When people remind me of the mess, I'm just angry that I left a mess for so long and I'm sorry. My anger usually comes out before my apology. I was born the way I am. If there were some magical way to change this I would. Sometimes I wonder why this happened. "Why can everyone else function normally and I can't?" Why am I different? Why can't somebody else be different? Sometimes I want to cry. When I have a dream I want to share, I can't. I can't communicate it to others. I can only communicate through a communication system and if I want to say something that isn't on there, then I can't tell my dream. There are so many other things that make my life ruff, but I won't bore you with those. I try being happy and not think of all of those things I can't do. All I want to say I guess is that maybe one should think before they say my life is easy and that maybe I may look and act different, but I'm human too, so don't laugh or stare at me. I can't help that I act younger than I am. I don't try to. It's just something I was born with. Like I said before, if I could change it I would. In conclusion one should think before they stare or make any harsh comments about me.

This was written through the eyes of a child with 5p- Syndrome.

CREATIONS BY RAEANN, SIBLING

The 5p- Society has been fortunate to have a very special sibling, Raeann Sleith. Raeann has been making bead bracelets to raise funds for not only the 5p- Society, but for several other organizations for the past 8 years. She has raised over \$33,000.00. She does this as her way to help spread awareness of Cri du Chat Syndrome and to teach friends and families about her brother, Derek's disability. Raeann has also helped purchase tracking devices for people with special needs, and PALS's Adaptive baseball program where she also coaches Derek at baseball. Raeann does not keep any of the moneys she raises; all of the profits are donated.

The bracelets are \$10.00 each. The 5p- Society has several bracelets that Raeann has donated to sell at the conferences and we will continue to do so. The little charm that comes on the bracelet says 5p-. If you would like to order a bracelet with color beads of your choice, an order form can be sent to you by contacting Raeann's mom, Johnna by email—sleith11227@msn.com, by phone (724)861-5655. The 5p- Society also has several order forms and you can also get one by emailing—director@fivepminus.org

RAEANN YOU ARE SUPER AWESOME!!!

THANK YOU SO MUCH!!!



IF I COULD TELL THE WHOLE WORLD

BY TEEN SIBLING GROUP—OHIO 2011

DELILAH'S STORY,

SIBLING

The thing about having a sibling with special needs . . .

.

- Hard Work
- Everything we do we have to base on them
- You have to be helpful
- Cheer you up
- Likable
- They make us mature faster
- Makes our family closer
- Don't Judge them until you know them
- You learn more about them & yourself
- We have to learn how to calm them down
- We have to give up things for them
- Everything take more time
- They are not gonna be quiet
- They like to give hugs
- Some times they get lonely-everyone needs friends
- They need us all the time
- Makes us grateful!
- They are smart!
- Sibs are proud of their families
- There is a reason why they act the way they do.

My little brother Angel has Cri Du Chat and sometime he is hard to understand. I can understand him. When he says something's he does the sign in sign language and that is how I know what he is saying. My brother likes some of the same things I like. He likes music, toys, movies, dancing, coloring and a lot of other things. It is difficult sometimes.

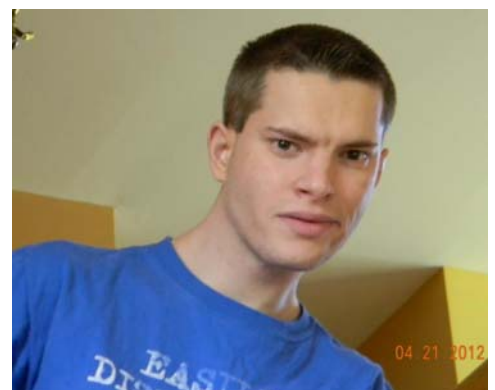


WE JUST WANT THEM TO BE ACCEPTED!!!

TIMMY-ISMS BY MELANIE DEL SOLE

Our son Timmy, who is 25-years-old with Cri du Chat syndrome, is a constant source of joy for all of us. He is quite verbal and has a wicked sense of humor. I often share his "Timmy-isms" with friends and family on FaceBook. I thought I'd share one of his most recent ones with all of you.

Tim decided to get a buzz cut today at the hairdressers. When she finished he looked at himself in the mirror and said "The chicks are gonna eat me up!" Then as I was waiting to pay he says to 2 women—"Hey you're chicks—what do you think of my hair? I should be in Sexy Hair magazine!" No lack of self-confidence in my son!!



SIBLING FUNDRAISING EVENT *BY HEATHER GRASSO*

The sky was blue and so were the balloons, tablecloths, and cookies. It was the day of our annual block party and we were raising money for the 5p- Society. What started out as a little girl's small idea, blossomed into a day of awareness and lots of money raised for a great cause.

Gianna Grasso is a very special 7-year-old girl. She loves to ride her bike, build Legos, and play with her 4-year-old sister, Nina. But what makes Gianna even more special is that she has a little brother who has 5p- Syndrome. Matthew was diagnosed in February 2011 when he was 8 months old. He receives Early Intervention therapies four times a week, has a G-tube, uses a walker, and wears Sure Step AFOs. However, Matthew is the happiest little boy you will ever meet! He never complains, is very affectionate, and especially loves his big sisters. They are always willing to help Matthew in any way they can. Gianna and Nina read him books, play ball with him, and even help him learn to walk.



While shopping in a store one day, Gianna noticed a box with a picture of a sick child on it. She asked me what it was. I explained that any money that gets put into the box would be used to help sick children. Gianna thought that was great and said "I think we should do that." So I gave her a dollar and she put it in the box. When we got home, Gianna took some money out of her piggy bank, \$6.35, and said, "I want to give this money to sick kids." I told her that was a great idea, but we should probably try to get more money and donate it to the 5p- Society.

Since our annual block party was coming up, we decided that would be a great day to raise money. Gianna suggested that we have a lemonade stand and we began planning. It soon grew into a lemonade stand/

bake sale/ fundraiser. We sold lemonade, cookies, cake-pops, rice krispie treats, popcorn, bracelets, and pins. On September 22, with the help of our family, friends, and neighbors, we raised more than \$500 for the 5p- Society. The continuous generosity and kind words from everyone were extremely touching. Gianna did a fantastic job running the stand and providing people with more information about 5p-. She had a wonderful time and is very excited to do it again!!



My husband and I could not be more proud of Gianna and her enthusiasm to help others. We are so thankful to be able to help such an amazing organization that has continued to provide us with support and education. We look forward to meeting everyone next year at the 2013 annual conference in New York.



THANKS GIANNA!!!

SOMETHING TO SAY BY KATE JENSEN

Imagine this: You can speak, but it takes extraordinary effort to form your words and utter them. Every day, people say hi and ask, “How are you?” It takes you about 8 seconds to answer (if you don’t get distracted along the way). Most of the time people cannot understand your words, and you stare at them when they ask you to repeat something, still frustrated from the initial effort. You use ASL signs to convey what you mean, but most people just stare back.

You can communicate with a computerized speech-generating device. It took hard work and years of practice, and you have learned to express your ideas in complete sentences. It is also much slower than typical speech, but at least the words are understandable to everyone. Often, however, before you can finish saying what’s on your mind with your Talker, you get distracted or tired from the effort involved. The people around you get impatient, interrupt you, finish your sentence for you, or just walk away. Perhaps they don’t really believe that you even have anything worthwhile to say, since you are “cognitively delayed”. They have no idea about your abilities and capabilities. You have a super-sense for whether they are ones who care or not. Either way, when they walk away, you are left alone.

Somehow you have gotten the idea that it doesn’t matter so much. You’ve got a lot of things to distract yourself with. You could watch ants on the sidewalk for hours. Easy! Videos are great, too, and you have a lot of apps you can navigate on the iPad.

Sometimes it does matter. It really, really matters. But no one has taken the time to listen to you, to talk you down from an anxious situation, or note the signs that you are about to melt down. Can you imagine your desperation? What do you do? Whine, cry, pinch? Run away? Hide under a blanket?

Imagine this: You’re a child, with an active, inquiring mind. You have a variety of interests, and enjoy a lot of things other kids like. You cannot keep up with the others, but you can and do enjoy learning at your own pace and level. You are happy to just be with everyone else, to go to the same programs as your brothers do.

Imagine that you are able to participate in typical activities with typical kids in typical settings, all summer long without having to be “removed”. You have a 1:1 assistant with you, and you have confidence that your person will be right at your side until the end. You listen happily and nod as your assistant tells your mom about all the cool new things your class learned about today. Later, at dinner, your family members share information about their day, and you also have something to say!

ASK HER BY TIFFANY TOWNSEND [HTTP://ELASTAMOM.COM](http://ELASTAMOM.COM)

I see you watching her. She is walking to the ocean, filling up her bucket and then walking back with her unsteady, wobbly gait, spilling most of her water, emptying out what’s left and doing it again. She has a big smile on her face, especially when she almost falls. That always cracks her up.

I see you watching her and wondering about her. She’s tall like an almost 12-year-old but you know she acts more like you. You look like you’re about 4. You have very few pre-conceived judgments about people yet, you’re just curious. I can tell you want to play with her. But I think you’re a little afraid. You’re unsure of what will happen or how she will act, but you want to.

Just ask her. Take a chance and come over and play with her. Please. I’m sitting here watching with so much hope in my heart that you will just walk over and say hi and play with her. Ask her.





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RETURN SERVICE REQUESTED



Happy Thanksgiving

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/>

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.

Special Announcement

Our prayers and wishes for a speedy recovery go out to all of our families who were in the devastating path of Hurricane Sandy.

The 5p- Society and Friends of Cri du Chat Support Group, would like to assist in getting the word out if any Cri du Chat Syndrome family is in need of equipment, food, medicine, clothing, household goods, or money.

Please contact Janet Dickneite of Friends of Cri du Chat at friendsofcriduchat@gmail.com or Laura Castillo at director@fivepminus.org and let them know you are in need.

Announcements will go out via social media, and email tree to all members in hopes that many families will be able to respond and assist where needed.

If you have items to donate, please contact either Janet or Laura.