

# 5P- NEWS

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

## WE ARE NOT ALONE!! *BY JEN WONG*

Often when I'm waiting for the kids to get out of school or at appointments, I flip through Facebook. I've often thought about the difference between the levels of support we have now compared to even 10 years ago. I can get support from my 5p- family literally 24 hours a day. I can't imagine how lonely families must have been before we had the ability to get together face-to-face or on Facebook. Think about how many friends you have that you have never met or don't know what they look like. But often these people know more and understand more about the lives we live day to day than the people who actually live around us. The fact that posts about bodily fluids (or solids) and lack of sleep instantly get 30 comments says a lot. Increasingly, I am noticing friends from various countries, on our Facebook group, sharing their experience from Denmark, Australia, China, Spain, Brazil, and many more. We are friends with people that we don't even speak the same language! There are 40 countries with family members with CdCS that are on our database, but I'm sure there are more out there. As I looked at our database at the number of countries where we only have 1 family registered, I think, "Wow to be the only family who has a child/adult with CdCS in the whole country! Now that's lonely!" I'm sure there are more than those; they just haven't found us yet. But because of social media and the internet, these families are able to connect with us and be a part of our global community. We are currently working with our International support groups to get the number of families they have in their databases. We are then going to take these numbers and update our International Cri Du Chat website. We want to make sure families can go and see that no matter where they are in this world, they are not alone. Through social media and our International CdCS Awareness Campaign, we can spread our support to even the most remote of areas.



I love hearing about the smaller get-togethers that are starting to pop up. No matter if it's an organized weekend event or simply a few families getting together at a park, that tangible support is invaluable to all of us. At the New York Conference, I can't wait to see how many names and faces I can connect. There are so many people I feel like I know already. So I will see you all in New York, where we will be debuting yet another way we can "Start Spreading the News" about CdCS.

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#### SUMMER 2013

#### Conference Info

The New York conference was held July 25-28, at the Hilton Long Island Huntington in Melville, NY. There were 96 families in attendance and over 450 people.

Conference highlights: Rachel Coleman's Signing Time concert;; Gladys Night and the Pips special appearance at the banquet; Fun camp for child care; family outing at Lido Beach and the hospitality suite . Presentations on topics relevant to our children and adults were very well received.

Wrap up article and photos will be in the Fall newsletter.

Looking forward to 2014—San Antonio, Texas, July 24-27 at the Hyatt Grand Regency on the Riverwalk

## GET TOGETHERS AND FUNDRAISERS

In different areas of the country there were a couple of fun gatherings and fundraisers.

A Phoenix gathering had about 13 families from not only Arizona, but also California in attendance. A fun time by all, beautiful weather and a park with lots of water sprays. Families brought their favorite dish to share. Thanks to Sam Brown for organizing this event. This plans on being an annual get together.

This year's Ohio gathering was hosted by the Boring family. Approximately 11 families throughout Ohio met for some fun, food and surprises.

The Houston based families hosted their Wine & Cheese fundraising event. There were quite a few families who got together with their families and friends to raise money for the 2014 San Antonio Conference. Thanks to everyone who was involved in the planning, preparing and participating in the very successful event.

Sacramento California was the site of Hailey's annual fundraising golf tournament hosted by Todd Winslow and family.

The Hammond family sponsored their annual golf tournament in Ingersoll, Canada. This annual event keeps getting bigger and better every year. The Hammonds have also included the 5p- Society as one of the charities to benefit from a local lawn bowling team.

Birdies for Charity - In affiliation with John Deere Classic Golf Tournament. A great way to sponsor the 5p- Society. Thanks Art and Pat Strong for coordinating this event.



## LEARN SHARE CONNECT

### Blogs to follow:

- \* <http://mydanceintherain.org>
- \* [www.sophieourgift.wordpress.com](http://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://www.prayforellee.org)
- \* <http://notquiteearthmother.wordpress.com>
- \* <http://tricia-themama.blogspot.com>
- \* [www.angelarichey.blogspot.com/](http://www.angelarichey.blogspot.com/)
- \* <http://lessonsfrommydaughter.me>
- \* <http://martianmommy.blogspot.com>

### YouTube Videos to Watch

#### [5p- Society "I Can" video](#)

<https://www.youtube.com/watch?v=La1D4cNQ5kQ>

Phase 1 of "I Can" video campaign for 2013 International Awareness Week

#### [5p- Society 2012 Conference Pictures](#)

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

Pictures from the 2012 Conference

#### [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](https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player)

#### [Janine Can Read](#)

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

Have a video to share? Send the link to 5p- Society office at [director@fivepminus.org](mailto:director@fivepminus.org)

## INTERNATIONAL CRI DU CHAT AWARENESS WEEK RECAP

BY NICK WALLACE

Well, the Second Annual Cri Du Chat Syndrome International Awareness Week has come and gone, and in my opinion I think it was another successful week. Some may ask what I use to qualify a success versus a failure. Well, here you go:

First I ask myself, “Did I educate one person about Cri Du Chat Syndrome?” Well, I know that I did that, so to me that was a success. There is a story, about the lives a person touches, that I read and it likened our lives to ripples in the water. Our action is like a pebble being thrown into a pond, and the ripples that are made by that action connect with other people’s ripples and their ripples connect with other people and so on and so forth. I like to think that by educating one person, I may have just educated an infinite number of people and therefore the awareness of Cri Du Chat Syndrome has spread.

When people look at projects, like awareness week, they tend to think that they have to be grandiose events, but sometimes it is the little things that make all the difference. Wearing your awareness bracelet, a 5p- shirt, using a bumper sticker, taking time to talk CALMLY (as I know sometimes this is a very hard thing to do) to the person that is staring at you child about your child, can raise more awareness than you may think.

So, now to explain why I feel that this week was a major success:

This awareness week came with three major events.

- The first major event was our revamped website, thanks to one of our parents, Adam Buckner. If you have not visited, please visit <http://www.criduchat.org>.
- The second major event was the release of phase one of our International Awareness Week “I Can” video. Many thanks to all of you for your overwhelming response to submitting your videos and to Adam Greenberg for compiling, editing and producing the video. Since the launch of the video, it has now been viewed 9,474 times from countries across the globe. You can watch the video at <http://www.youtube.com/watch?v=La1D4cNQ5kQ>. You can also post the video on your Facebook page or even email it to your friends and family.
- The final event was the spike in our Facebook group membership. Not only is Awareness Week a time to raise awareness of CdCS to other people, but it is a time to raise awareness of what services we can offer to our families, and one of these is the ability to converse with other families. Our Facebook group helps do just that. Since awareness week we have noticed a major spike in people joining our Facebook page. The number of members has increased to 1,025. This is up about 400 members since this year’s awareness week.

I hope you agree with me that this awareness week was a major success. We have already started working on next year’s event, but the awareness week is not a success without you. Please take a moment to plan a way to spread the word. You can also help support the cause by purchasing from our CafePress site ([www.cafepress.com/5pshop](http://www.cafepress.com/5pshop)). This helps to spread the word, but also to provide funding to the project.

Please join the chat on the Facebook group and let us know about any ideas you have for the next awareness week.



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F:562-920-5240

E:director@fivepminus.org

## AMBASSADOR PROGRAM

### What would I do as a Volunteer Ambassador?

**A Volunteer Ambassador of the 5p- Society will be responsible for spreading awareness of Cri du Chat Syndrome by preparing for and attending tabling events at health fairs, medical symposiums, school resource fairs, community events and other resource events.**

#### Ambassador Responsibilities

- \* Ambassadors are responsible for researching and attending tabling events in their area. This will include obtaining permission, signing up and submitting forms (if necessary) for the events. If a fee is involved with the tabling event, the Ambassador will submit to the 5p- Society for approval/payment;
- \* Ambassadors must commit themselves to a minimum of two tabling events in a 12 month period;
- \* Ambassadors are responsible for spreading awareness of Cri du Chat Syndrome/5p- Syndrome at these events by engaging in conversation with individuals during the tabling events. The 5p- Society will provide the Ambassador with a basic script with the ability for the Ambassador to personalize with his/her own experience;
- \* Ambassadors shall keep records of their events including amount of participants/interactions, picture taking and submit a brief report after each event;
- \* Ambassadors can use social media to announce the event and to report on the experience;
- \* Ambassadors will be responsible for maintaining their box of information after each event by contacting the 5p- Society; The box will contain a table cloth, brochures, PowerPoint presentations, I Can video and give-a-ways. Ambassadors may add displays to their presentation and/or personal video to assist in the promotion of the 5p- Society and awareness of the syndrome.
- \* As a representative of the 5p- Society, an Ambassador will conduct themselves in a professional manner. A uniform shirt and an identifying name tag will be provided.

### *Interested in becoming an Ambassador?*

Please fill out and return the information to receive an application. An interview will be conducted after application has been completed.

Ambassadors can be parents, grandparents, siblings, teachers, therapists, doctors or friends.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Address

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Email

\_\_\_\_\_  
Phone

\_\_\_\_\_  
Signature

As an Ambassador of the 5p- Society, I pledge to carrying on its Mission Statement :

To encourage and facilitate communication among families having an individual with 5p- Syndrome and to spread awareness and education of the syndrome to these families and their service providers

# A Research Study

+ Blood samples are needed for important research on microdeletion/duplication syndromes

Who is eligible?

- Couples who have a child diagnosed with a microdeletion/duplication syndrome (a positive microarray test).

## What is the purpose of the study?

The goal of this study is to develop a non-invasive prenatal blood test that can diagnose genetic disorders in the fetus by looking at fetal DNA (genetic material) found in the mother's bloodstream during pregnancy.

Specifically, the abnormalities in the fetus that we are looking for are microdeletions/microduplications (small missing or extra pieces of DNA that can cause problems) or specific genetic disorders. Parents of a child diagnosed with a genetic disorder (and their children) will be asked to participate.

If this study is successful, this will reduce the need for invasive procedures during pregnancy such as amniocentesis and chorionic villus sampling (CVS) but still enable women to find out accurate information regarding their baby's health early in the pregnancy.

## + What does participation require?

Both biological mother and biological father need to provide a blood sample. There will be 4 tubes collected from the mother (approximately 3 tablespoons) and 1 tube from the father (2 teaspoons). The child with a known genetic disorder will need to provide a blood sample (4 tubes) as well as his/her siblings who do not have a known genetic disorder (4 tubes). Study participants will need to provide medical records with genetic information to study sponsor. The samples will be collected at no cost to the family.

Neither subjects nor their doctor will receive any results from the study. Therefore, there is no direct benefit from participating. This study and the subjects who participate may help other women in the future if the study results in a new test available to pregnant women.

Each subject will receive \$100 for their participation. Parents will receive \$50 for each minor child who participates in the study.

**Call Sallie McAdoo at 877-476-4743 X 322 or email at [smcadoo@natera.com](mailto:smcadoo@natera.com) if interested**

This study is sponsored and conducted by Natera, Inc. All patient samples and information will be treated in full compliance with HIPAA privacy laws.

## SIBLING CORNER

Dear 5p- Society,

I would like to extend my sincerest gratitude to the individuals that initiated the International Cri du Chat Awareness Week. I was ecstatic last year when I first learned about this week. My older brother, Timmy, has Cri du Chat, and ever since I was little I have wondered why no one ever talked about or researched Cri du Chat as much as other syndromes -- I have always been open to talking about my brother, teaching others about his syndrome and telling our family's story. As a matter of fact, I told Timmy's story during an assembly my junior year of high school, and I had so many people come to me wanting to learn more, wanting to know more about Timmy, and praising the remarkable young man he has become. Watching him succeed and grow has been the most inspiring thing in my life. Doctors told my parents in 1987 that if Timmy lived more than a few months, he would amount to nothing -- he would be useless, he would do nothing, he would literally just be a vegetable for his entire life. They couldn't have been more wrong. Timmy is turning 26 this coming Monday, March 4. He



has graduated from our local high school in Middletown, CT, he has the best jokes I've ever heard, he loves to watch movies, he has a remarkable imagination, he loves science, he's physically strong (stronger than I am), he loves to swim... he has literally beaten the odds and proven every doctor wrong, and it is truly amazing. It inspired me to study Special Education and devote my life to giving kids the same wonderful opportunities Timmy had growing up.

So, awareness about this syndrome means the world to me. People look at Timmy and treat him like he's different, and he is -- but so is everyone else in the world. We're all different... but different never has and never will mean "bad." I always get asked if I prefer Timmy was born "normal." My response? Timmy is normal -- Timmy is exactly how he is supposed to be. My entire family feels blessed to have Timmy in our family, because he is perfect the way he is. He is an inspiration to so many people.

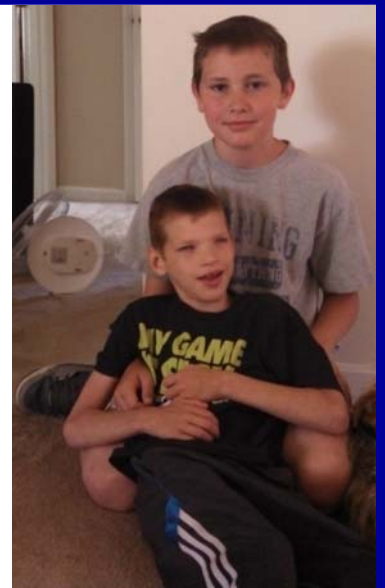
I apologize for the long speech, but this is why I am so grateful for the creation of Cri du Chat Awareness Week. I could go on for pages in detail, but I figure this is more than enough. Thank you for your time, and thank you for everything you've done for individuals with Cri du Chat Syndrome,

Sincerely,  
Jenny Del Sole=

### A Brother's Love

Five P Minus has affected all of us in a different manner. Our ten year old son, Brandan Wilson, has watched since the age of two the struggles and triumphs of his eight-year-old brother, Aiden. Brandan decided he wanted to make a difference not only for his brother, but for all the kids who have been diagnosed with 5p minus. So, he decided to have a fundraiser for his brother. He gathered information and wrote his principal asking for an out of uniform day; in which, the students at St. Michael School in Brookville, Indiana would pay one dollar. With the money raised, he called his grandmother, Denise Kruthaupt, and asked if Schnieder Electric, her place of employment, would donate money. Schnieder Electric almost matched the amount he raised at school. Brandan raised around \$400 for his brother. As parents and advocates for all special needs children, we could not be prouder.

Chad & Brandy Wilson



## POETRY & PICTURES



Homecoming Queen Beth & date

### HEAVEN'S VERY SPECIAL CHILD

A meeting was held quite far from Earth!  
It's time again for another birth.  
Said the Angels to the LORD above,  
This Special Child will need much love.

His progress may be very slow,  
Accomplishments he may not show.  
And he'll require extra care  
From the folks he meets down there.

He may not run or laugh or play,  
His thoughts may seem quite far away,  
In many ways he won't adapt,  
And he'll be known as handicapped.

So let's be careful where he's sent,  
We want his life to be content.  
Please LORD, find the parents who  
Will do a special job for you.

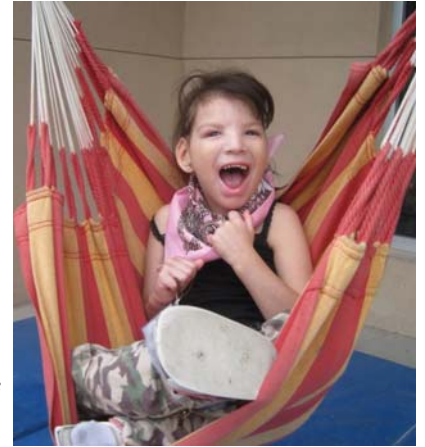
They will not realize right away  
The leading role they're asked to play,  
But with this child sent from above  
Comes stronger faith and richer love.

And soon they'll know the privilege given  
In caring for their gift from Heaven.  
Their precious charge, so meek and mild,  
Is HEAVEN'S VERY SPECIAL CHILD.

by Edna Massionilla  
December 1981  
The Optomist- newsletter for PROUD  
Parents Regional Outreach for Understanding Down's Inc.

*"She's here to teach me  
How to live in her world  
While I struggle to show her the ways of  
mine, although  
It's not for me to wonder why the two can't  
be entwined  
I still can't help but be sad for the child left  
behind  
Who's to say that my ways right and that  
her way is wrong  
Maybe we've had it backwards all along  
She's come to teach us about a world that the  
naked eye can't see  
It's only because I met her that she's changed  
so much of me"*

Natalia Rodriguez  
Mom to Neese



Neese

Peyton

*Some say that you are "different", but you're an angel in disguise.  
You touch everyone you meet, by gazing in their eyes.  
A fighter with a heart of gold, is what I see in you.  
Through all the struggles we may have, God always sees us through.  
Day by day you show us, what it really means to love.  
I know there is a reason, that you were sent from God above.  
You are what keeps me going, when I'm feeling sad,  
Just a laugh and hug from you, and I instantly feel glad.  
You will always be my baby, and for this I will rejoice,  
But most of all, your mommy will forever be your VOICE.*

By: Kelly Manteiga  
Mom to Peyton



Kelly & Peyton



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RETURN SERVICE REQUESTED

Tweet with Us  
[@5pminus](#)

We're on the Web  
[www.fivepminus.org](http://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/>

*"It's amazing how a deletion can add so much to your life."*

Lindy O'Hara



### VIRTUAL SIGNING TIME FUNDRAISING OPPORTUNITY!!

Virtual Fundraising.....The 5p- Society is an affiliate of the Two Little Hands/Signing Time virtual fundraising program. We were contacted the end of May in regards to this new Fund Raising Affiliate Program and immediately signed on. What makes this program so easy is that we don't have to purchase any products or order anything in advance.

All the society has to do is share the link with our family and friends and when someone orders product using the link we will receive 15% of that sale. This is open to anyone who is willing to use the 5p- Society link when ordering anything from Signing Time. All I ask is that you share our link through email, websites, blogs and social media. When people click the link and buy products, 5p- Society earns 15%.

Links:

Shop Baby Signing Time Now - <http://www.shareasale.com/r.cfm?B=470465&U=816319&M=46567&urlink=>

Shop Get Signing Time Videos - <http://www.shareasale.com/r.cfm?B=469832&U=816319&M=46567&urlink=>

Shop Signing Time! As seen on Nick Jr.! - <http://www.shareasale.com/r.cfm?B=470470&U=816319&M=46567&urlink=>

Shop Signing Time - <http://www.shareasale.com/r.cfm?B=470458&U=816319&M=46567&urlink=>

Shop Potty Time - <http://www.shareasale.com/r.cfm?B=470459&U=816319&M=46567&urlink=>