

## A BLESSING OR A CURSE: It's all perspective by Jen Wong

Perspective (noun)- a particular evaluation of a situation, especially from one person's point of view.

We've all had those days when, for example, your daughter has just dumped the laundry basket for the fourth time after you have just finished folding it, for the third time, because every fashionista needs to change her clothes at least five times a day. From one perspective, I could look at this situation and be angry at the extra work she is creating for me.....again, that I don't have time for. From another, I can be exhilarated that she has learned how to dress herself independently. Lately, I have reacted with the first. This year hasn't been the greatest; with a death in the family, three different water damage issues with our home, and Emma's school program heading down the rabbit hole. The fires are raging out of control with no water to help extinguish them (that's a CA fire and drought reference). When things are going against us, it's very easy to lean toward the negative perspective. The problem is the more you take this negative route, the easier it is to stay on it. The science of neuroplasticity has shown that, similar to a well-worn forest trail, our brain develops paths that when used over and over develop a solid path. This will be the path your brain will take first because it's easy. It's literally the path of least resistance. Luckily, the science of neuroplasticity also shows that we can, with conscientious effort, change and create new paths. This, I've decided, will be my New Year's resolution to try and create a positive pathway as my "Path of Least resistance". I know it's already there, but the events of this year have allowed the path to become overgrown. I will just have to hack through the overgrowth and make it the well-worn path, I frequented in the past.

In our Cri-du-Chat journey, we are all going to have our ups and downs. The key is to not get stuck in the downs. In this crazy busy overstressed time of year, let's all take

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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.

See page 5 for more information!

# INTERNATIONAL CRI DU CHAT AWARENESS WEEK

BY NICK WALLACE

It is only January, but International Cri Du Chat Syndrome Awareness Week will be upon us before we know it. The dates of this year's awareness week will be May 1<sup>st</sup> – 7<sup>th</sup>. We have a lot of great things in the works for this year. Due to the amazing success we will be hosting the Virtual 5k again this year. We also have one of our committee members working on trying to obtain proclamations from all 50 states, that state that May 5<sup>th</sup> will be known as Cri Du Chat Syndrome Awareness Day. We will also keep wearing our striped socks.

One of our new plans for this year will require your help. This idea was brought to us by one of our board members, Gloria Griffin, and we believe this idea will really take off. 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 (pictured to your left) is the mascot of the International Cri du Chat Awareness week. Our plan is to make a version of C5 available to print and send like the Flat Stanley project. Our goal is to get photos, from across the globe, of people posing with C5 during awareness week. We will use the hashtag #C5 and #criduchat to help spread the awareness on 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.

Keep an eye on our Facebook fan page [www.fivepminus.org/CriDuChatSociety](http://www.fivepminus.org/CriDuChatSociety) and the closed group [www.facebook.com/groups/385907554759706/](http://www.facebook.com/groups/385907554759706/) for more information on this project. We will also be posting details on our website [www.fivepminus.org](http://www.fivepminus.org) and on the international awareness website [www.criduchat.org](http://www.criduchat.org).

I can't wait for this year's awareness week, I believe it will be one of the best ones yet.

## 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://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=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](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=ywWDIdOAWC>

[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.

time out to remember the positive side of our journey. I've seen many of them on Facebook. While Emma does create lots of extra work for me, she also can, with a simple smile or laugh, remind me why this journey is so worthwhile. I would like to wish everyone a blessed Holiday season. My hope for all our CDCs families for the New Year is good health and happiness.

(If anyone would like to know some ways to help create a new habit to replace that old bad one using neuroplasticity, this article broke it down into easy to understand steps.

<http://themindunleashed.org/2014/03/train-brain-let-go-habits-10-methods-creating-new-neural-pathways.html>)

## 2016 FACES OF GRACE CALENDARS NOW AVAILABLE

2016 Calendars are now available. 10 beautiful kiddos with Cri du Chat Syndrome are featured in the Calendar. Get yours today!! You can order online at this link: <http://mkt.com/5p-society/calendar-faces-of-grace>

You can also order by contacting the 5p- Society office. Calendars are \$20.00 each.



Thank you Cordelia Braxton for your assistance in completing the calendar.



Continued to page 4



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/cr-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>

## PARENT REPORT BY DANIELLE KARCZ



Recently I attended the New England Regional Genetics Group's (NERGG) annual conference, "Genetics Gateway to Precision Medicine" in Portsmouth, NH. Throughout the two day conference I attended 4 sessions, plus the meet and greet:

- Genetic Counseling Via Telemedicine
- The Critical Role of Molecular Diagnostics and Precision Medicine
- Reimbursement for Genetic Services
- Using Life Experience to Promote Awareness and Inspire Empathy in Schools: A Consumer's Story

While this conference was geared more towards professionals and students in the field of genetics, it was nice to be a representative of the 5P-Society. Admittedly my background in Mathematics, IT, and currently, as a stay at home mom left me lost at times.

The session I attended, which was about **Telemedicine**, I found very interesting, especially in the cases for families that live in rural areas. The prime example of this was for families that live in Northern Maine where the closest geneticist was typically about 4 -6 hours away. For these cases a typical initial appointment would be face to face, but subsequent appointments could be done at a local medical center. The geneticist would be back in their office communicating to the family through a skype or FaceTime type of application. A nurse would be in the room with the family to aid the geneticist. The telemedicine option is a great opportunity for these rural families to have some additional on-going support if they feel they need it.

The session on **Molecular Diagnostics and Precision Medicine** was a bit over my head. I did learn that more genetics labs are trying to share rare genetic cases via the EmV class website. This will help families in the future diagnose and treat rare conditions and cancers.

Attending the session on **Reimbursements for Genetics Services** opened my eyes on the level of frustration many of these doctors face. In my opinion, these are smart people spending countless hours wasting their time on getting through paperwork and loop holes just to give a family a definite diagnosis. Just to receive prior authorization for genetic testing, on average, it takes a genetic counselor 3 – 6 hours.

By far my favorite session was the final one for the conference, "**Using Life Experience to Promote Awareness and Inspire Empathy in Schools**". This conference typically ends with a real life experience. In this case they had Sam Drazin present. Sam has Treacher Collins Syndrome, which is a syndrome that affects the facial structure. Sam spoke about his life experiences from a child's point of view and then from a teacher's point of view. He told us stories of how he was treated once he hit 5<sup>th</sup> grade and on, and how his "friends" turned on him. As a teacher Sam was able to teach empathy and awareness to students and watch the wonder and understanding in the kids. In working with his students, it inspired him to start a non-profit called Changing Perspectives ([www.cpne.org](http://www.cpne.org)). This organization develops a 6 week curriculum with online platforms for schools to enable students to understand disabilities. They typically gear the curriculum to elementary students so that by the time they hit middle school the acceptance of differences is natural. Sam's talk captivated the entire audience while bringing tears to this mom's eyes.

While the conference was over my head at times, it was very educational. It would be great if the meet and greet could be geared more towards an open forum to encourage more parents, care givers and individuals with genetic disabilities to mingle with the professionals. The meet and greet I attended had only a handful of people. I was able to tell my story and explain about the 5P- Society. I feel that even if I educate one person it is worthwhile.

*Thank you Danielle for attending and representing the 5p– Society.*

## FILM CREW REWARDS PROGRAM

Be part of the Film Crew and help fund the conference, get Rewards!!



**Special Effects Crew**—Donate \$1,500 and your ticket (family registration of up to 2 adults and 2 children will be waived).



**Camera Crew**—Donate \$3,000 and your ticket (family registration of up to 2 adults and 2 children will be waived) AND one night of your location (hotel room) will be waived.



**Set Designer**—Donate \$5,000 and your ticket (family registration of up to 2 adults and 2 children) AND three nights of your location (hotel room) will be waived.

### Participation Requirements

1. Participations must be a member of the 5p- Society and in good standing.
2. Participant to make their own reservations at the hotel. The 5p- Society will make an internal change with the Hilton before the end of the conference.
3. ALL monies must be received by June 1, 2016.

*Coming Exclusively to the Hilton Orange County / Costa Mesa July 28, 2016*

# #takehatcriduchat

*A syndrome that doesn't define me!*

A production of the 5p- Society and the California Conference Committee  
Starring: Boys and Girls, Young and Old with Cri du Chat Syndrome



# VIRTUAL 5K FOR 5P- BY STACEY SANDERS

Preparations are officially underway for the 2016 Virtual 5k for 5p-! Last year's inaugural event was a HUGE success, with over 1000 participants from all around the world and over \$20,000 raised for the 5p- Society. There are many events and fundraising opportunities centered around the Rare community as a whole, but having a specific event for 5p- Syndrome and having it be so successful is a testament to how powerful we are when we come together!

We had a number of teams gather in their local areas to complete their 5k, which was a great tool in garnering support from their communities and help raise awareness for Cri du Chat Syndrome. We would love anyone interested in becoming a Team Captain to email us at [virtual5kfor5pminus@gmail.com](mailto:virtual5kfor5pminus@gmail.com)!

Registration is slated to open February 1! For more information, feel free to "like" and share the Virtual 5k for 5p- Facebook page at [www.facebook.com/virtual5kfor5pminus](http://www.facebook.com/virtual5kfor5pminus). Also, be sure to use our dedicated #5pminus5k hashtag on Social Media so we all can keep track of the fun!



Thank you and looking forward to an amazing 2016 Awareness Week!



Enjoy some pictures from the 2015 Virtual 5k for 5p- Event!

## GOLD LEVEL - \$1000 DONATION

- Acknowledgement on Virtual 5k for 5p- Facebook, all 5p- Society Social Media, and website
- Donor listing in 5p- Society Annual Report and Newsletter
- Logo on Race Bib and Event T-Shirt
- Logo on Website, flyer, and all printed materials
- Ten free participant registrations for the Virtual 5k for 5p- (includes medal and t-shirt)



The 5p- Society is a 501(c)3 not-for-profit organization. For more information, please contact [director@fivepminus.org](mailto:director@fivepminus.org) or visit [www.fivepminus.org](http://www.fivepminus.org).

# 2016 VIRTUAL 5K FOR 5P- SPONSORSHIP OPPORTUNITIES

## SILVER LEVEL - \$500 DONATION

- Acknowledgement on Virtual 5k for 5p- Facebook, all 5p- Society Social Media, and website
- Donor listing in 5p- Society Annual Report and Newsletter
- Logo on Race Bib and Event T-Shirt
- Five free participant registrations for the Virtual 5k for 5p- (includes medal)



## BRONZE LEVEL - \$100 DONATION

- Acknowledgement on Virtual 5k for 5p- Facebook, all 5p- Society Social Media, and website
- Donor listing in 5p- Society Annual Report and Newsletter
- One free participant registration for the Virtual 5k for 5p- (includes medal)

Sponsorship Opportunities are now available for the 2016 [#5pminus5k!](https://twitter.com/5pminus5k)

If you or someone you know would be interested, please contact us via PM or email at [virtual5kfor5pminus@gmail.com](mailto:virtual5kfor5pminus@gmail.com). We will be happy to provide you with additional information!

[#criduchatawareness](https://twitter.com/criduchatawareness) [#teamwork](https://twitter.com/teamwork) [#5k](https://twitter.com/5k) [#sponsorship](https://twitter.com/sponsorship)

## CRI DU CHAT SYNDROME AWARENESS WEEK

The 5p- Society is already beginning to plan for the 2016 Cri du Chat Syndrome Awareness Week—May 1-7.

Julie Faqir, Aunt to Aaron Watt of Lexington, Massachusetts, was able to get the Governor of Massachusetts to declare May 5 as Cri du Chat Awareness Day last year. She has suggested that one of the ways to raise awareness for Cri Du Chat is to ask the Governor of your state to declare May 5 "Cri Du Chat Awareness Day." So far received requests are being made to the Governors of California, Massachusetts, Texas, Kansas, Tennessee, Illinois, Oklahoma, Florida, Ohio, Wisconsin, Pennsylvania and New York.

If you would like to ask your Governor to declare May 5 as Cri Du Chat Awareness Day, contact Julie Watt Faqir at [jaggerwatt@hotmail.com](mailto:jaggerwatt@hotmail.com). She will assist you with the process. Thanks Julie!!





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Fax: (562)920-5240

Email: [director@fivepminus.org](mailto: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)

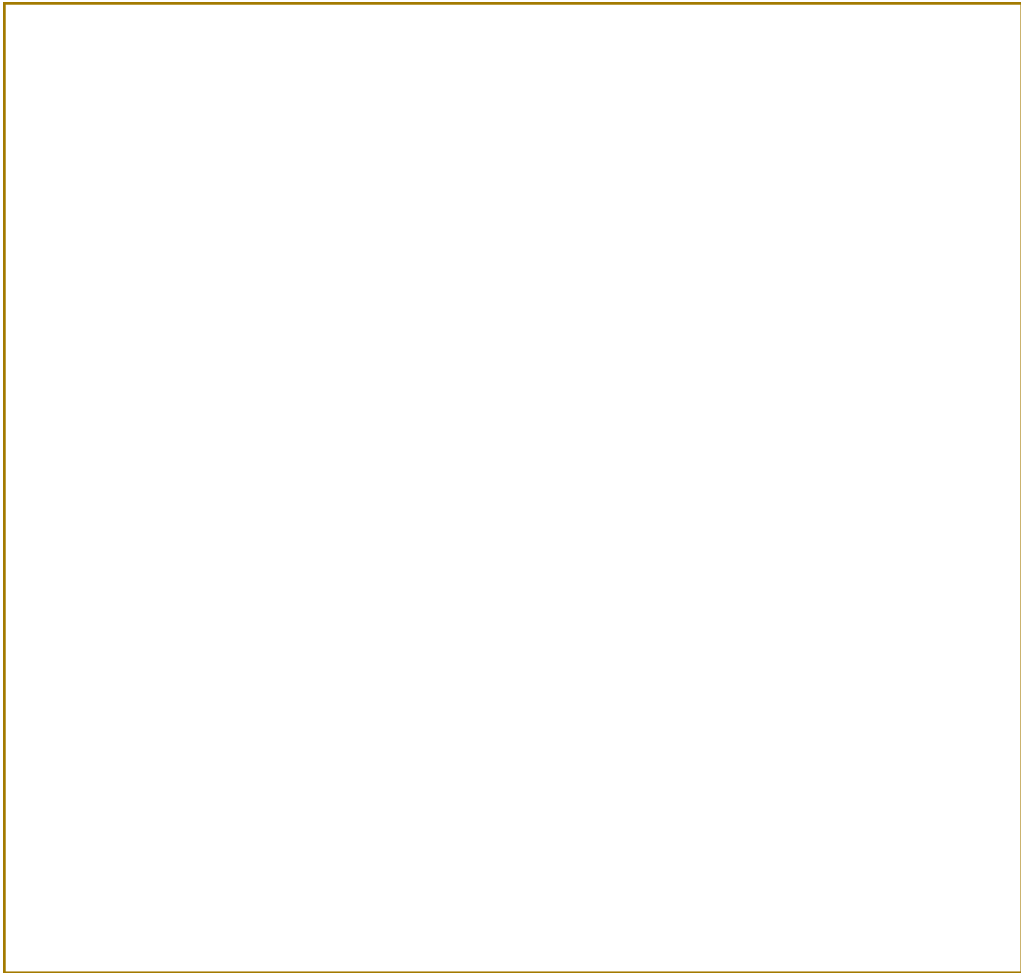
We're on the Web  
[www.fivepminus.org](http://www.fivepminus.org)

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>



## FUN EVENTS

### Be a Voice for 5p- Fundraiser

Saturday March 5, 2016  
6-9pm  
Barnaby's of America  
Havertown, Pennsylvania

Advanced tickets \$25 (\$35 at the door)

For more information contact Heather Grasso at [Heather.Grasso@aol.com](mailto:Heather.Grasso@aol.com) or 610-659-4865

### Poker Fundraiser for the 2016 Conference

March/April 2016 - contact Laura at [director@fivepminus.org](mailto:director@fivepminus.org) if you'd like more info.

Many thanks to the Smith family of High Level, Alberta, Canada for their very successful fund-raising event. They hosted an online auction through Facebook and raised over \$28,000 (Canadian) for the 5p- Society and specifically for the upcoming conference.

We are looking forward to meeting Bonnie, Blaine and Turner at the 2016 conference!!

### East Coast Get-Together

June 25, 2016—More info to come or contact Holly Gattone or Amy Severson for more information. [gattonh@amtrak.com](mailto:gattonh@amtrak.com) or [amysever73@gmail.com](mailto:amysever73@gmail.com)