

RESEARCH IS NOT A FOUR LETTER WORD *BY JEN WONG*

When my husband was in the Air Force, he was given an unaccompanied assignment in Korea. I decided to move back home for the year. There was a friend of mine from nursing school that offered me a job that was flexible enough so I could leave and visit Ced in Korea a few times that year. It was doing research, not exactly my cup of tea....or so I thought. I was an Air Force neuro/trama ICU nurse at a Level 1 trauma center. I loved the fast pace areas of medicine, and research seemed far from that. While I was right about the pace, I was totally wrong about everything else. Like a lot of people, I made uneducated assumptions about research that were totally wrong.

When I joined my friend doing Asthma and Allergy research, I LOVED it. I couldn't believe the lack of education adults and parents of children had about managing their asthma symptoms and medications. I found out research wasn't about just discovering new medications but about educating people on their health as well as providing medical care for people who were in-between health care plans or whose health care plans didn't cover (or poorly covered) their medical needs. We spent a lot of our time going over daily asthma management to help prevent attacks and proper use of medications. We were available to our participants 24/7 to answer any questions or provide asthma-related health care, at no cost. In fact, most research participants are paid for their time.

I do not want people to think participating in research is all about the money. You need to do your research to make sure a study is right for you or your child. While the money is nice, many studies can greatly benefit you in providing education on your health in the area of study by specialists in that area of medicine.

One thing I think we all realize, there is very little and outdated research out there on Cri-du-Chat syndrome and its related conditions. In the last few years, I've loved seeing researchers reach out to us to research CDC related conditions. From the aging-study that looked at how missing the end of the 5th chromosome affects telomeres and telomerase, to the current PCD study, to Amy Sue Reilly and Dennis Campbell's IEP services study, to Laurel Abbruzzese's Physical Therapy and Movement study, more and more current research is emerging.

When the 5P- Society is approached by a research team to participate in their study, we send their information to our Professional Advisory Board (PAB). The PAB will look over the study to ensure it will benefit our community as well as that it is a well-developed ethical study. The PAB sends their recommendations to the Board of Directors who then vote whether or not to support the study. We then post the study information on our website, newsletter, and FB group page. We encourage all members to look over the studies and participate, if able. The only way we can create awareness and information about CDC syndrome is to support research about it and its related conditions. This is one way we can all be ambassadors for CDC awareness.

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FALL 2013



Who's your Super Hero?

The Grand Hyatt on the Riverwalk will be full of Super Heroes next July!! More info to come. You can keep posted on the 5p- Society's conference dedicated website

<http://5pminus2014conference.blogspot.com/>

With Halloween quickly approaching keep an eye out for capes for the conference committee that they can personalize!!

SOMEONE HAD TO BRING IT UP BY NICK WALLACE

Well, someone had to bring it up and I guess I drew the short straw ... so don't kill the messenger! The holiday shopping season is almost here! Ok, take deep breaths and calm down ... breath in Breath out ... ok, now that the panic has subsided, I wanted to let you know that the 5p- Society is here to make your shopping a little bit easier.

As most of you may already know, the 5p- Society has items to sell and some of these items would make great holiday gifts. Our Executive Director, Laura Castillo, has several items that won't break the bank and would be great gifts for teachers, aides, support staff ... let's just face it ... they would be good for just about anyone. She currently has bracelets (\$4), key chains (\$6), and tumbler mugs (\$5). Just keep in mind that shipping charges are not included in the pricing. Shipping will need to be calculated.

If you are looking for something that is a little more ,we have several items listed on our Cafepress store (<http://www.cafepress.com/5pshop>). This store has sweatshirts, jewelry, electronic cases, handbags, and a whole lot more. We continue to update the product line when possible, so stop by and see what is new. Also, a portion of your purchase at Cafepress goes to our International Awareness Week Campaign.

Lastly, if you are buying gifts online this year, please take a moment to visit <http://goodsearch.com> and <http://igive.com>. It is free to sign up. All you have to do is select the 5p- Society as your charity and for every search you do, the society will get money. Now if you are shopping, the society will get a percentage back from every purchase you make at one of their online partners. (Amazon, Best Buy, Expedia, Wal-mart, and several more) To make it even easier, these sites have toolbars that will automatically let you know when you are on one of their partner sites and will also let you know if they have special coupons for these sites. For those of you that may worry that the site will raise the price of the goods sold, that does not happen. The site will work exactly as it would if you just went directly to it without using one of the sites above. It is an easy way to give a gift to a loved one and also a gift to the 5p- Society.

We hope you enjoy your holiday season and hopefully the options above will help ease your holiday shopping ... maybe you could sneak in a purchase for yourself too.

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>
- * www.angelarichey.blogspot.com/
- * <http://lessonsfrommydaughter.me>
- * <http://martianmommy.blogspot.com>

YouTube Videos to Watch

- [5p- Society "I Can" video](http://www.youtube.com/watch?v=La1D4cNQ5kQ)
<https://www.youtube.com/watch?v=La1D4cNQ5kQ>
Phase 1 of "I Can" video campaign for 2013 International Awareness Week
- [5p- Society 2012 Conference Pictures](http://www.youtube.com/watch?v=D16fsTN9I7g)
<https://www.youtube.com/watch?v=D16fsTN9I7g>
Pictures from the 2012 Conference
- [Cri du Chat Awareness US](http://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](http://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](http://www.youtube.com/watch?v=A47tRTi8YPw)
<https://www.youtube.com/watch?v=A47tRTi8YPw>
- [International Cri du Chat Syndrome Awareness—Meet Nellie](http://www.youtube.com/watch?v=zw2joxiYJR4)
<https://www.youtube.com/watch?v=zw2joxiYJR4>
- [Emma's "Steps of Faith"](http://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player)
https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player
- [Katie Sings the Star Spangled Banner](http://www.youtube.com/watch?v=3zJ_KRifAFE)
https://www.youtube.com/watch?v=3zJ_KRifAFE

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

KINDRED SPIRITS BY JACKIE MARENDA

The beach at was quiet except for the everyday sounds of the shore - waves, an occasional gull cry, the pretend outrage squeals of a teenager splashed by her mischievous boyfriend. Most beachgoers hid behind oversized sunglasses. Some slept; others read magazines and books - until the screaming began.

One by one heads turned, their interest now held by the temper tantrum of a 7 year old boy. He lay at the ocean's edge, rolling, kicking, tearing at his shirt and swim trunks. His mother, a toddler in her arms, stood watching as her hysterical son pulled his hair and gnawed at his arm.

A woman who sat to my right remarked. "What a brat. That's what happens when they aren't disciplined properly."

Someone else added, "One good kick in the ass would stop that right now."

A third person wondered aloud. "Why is the mother just standing there? Why doesn't she do something?"

I rose from my beach chair. I'd never met the criticized woman. Yet, I knew her. It wasn't shame, or embarrassment, that creased her face. A grief, a sadness I know all too well, enveloped her.

I wound my way past the assortment of chairs and towels to her side. "My grandson has Cri Du Chat syndrome. His meltdowns are horrific too. Would you like me to hold the baby while you tend to your son?"

There was no hesitation. She nodded and handed the baby to me. She doesn't know my name, but we're not strangers. We are kindred spirits on an erratic life journey called Special Needs.

The boy eventually calmed down and returned to play. Yet I knew, that for the rest of his stay at this resort families of 'ordinary' kids would avoid him. Such is the life of a family who has a child with disabilities.

It's discouraging that many people "look the other way" when the family of a special needs child is in distress. They seem to lack comprehension that a child is but a child - no matter what label has been assigned to them. Unfortunately, this disregard often extends to physical as well as emotionally disabilities.

While waiting to board the plane for my return flight to New York City I saw a woman struggling to push her son's wheelchair while she dragged a suitcase that had just broken a wheel. Having already passed the security checkpoint, I was unable to cross back to help her. I watched as dozens of people passed her by. Finally an older man, accompanying his Downs Syndrome son, gave her the help she needed. It took him less than 5 minutes.

Daily I find myself grateful to the community of special needs parents. You don't just meet them in neurologists' offices, or at Early Intervention meetings. They are everywhere - enthusiastically supporting with praise when their child finishes last in a race, or smiling encouragingly at a party while helping their child sing the words to *Happy Birthday*, aware that their child was only invited to the party because someone *insisted* on it.

Our children did not ask to be born different from other children, nor should they have to be reminded daily that their acceptance by society is conditional. Yet each day seems to bring them another hurdle during which they are judged according to a set of standards impossible for them to meet.

My grandson waited at the airport gate for my return. Due to bad weather my flight was delayed, so Patrick had been at the airport past his tolerance level. He probably would have had a tantrum if not for the security officer who helped my daughter find ways to amuse him.

When I thanked the officer, he shrugged. "My grandson has developmental problems too, so I know how it goes. Good times. Bad times. Times you don't know how to rate, so you don't. You just go on taking it as it comes."

I smiled. Patrick shook his hand. We left the officer, - a man we will probably never see again, - but we won't forget him. The bonds of the special needs families - how strong they are!



Grandma Jackie & Patrick at the school play

2013 NEW YORK- CONFERENCE WRAP UP



A special thank you and congratulations to the 2013 New York Conference Committee for a very informative and well organized conference. Special thanks go out to Laurel Abbruzzese, Kat Lindholm, Larry & Natasha McSeed and Joe & Anna Tiralongo and to all their friends and family members who participated in assisting at the conference. The long hours and months of planning really paid off. The highlight of the conference — Signing Time concert by Rachel Coleman. All who attended had a fantastic time. A close second to the highlight had to be Gladys Night and the Pips (aka Nick Wallace as Gladys, Jen Wong, Jolene Towers and Laura Castillo as the Pips) performance of Midnight Train to Georgia at the banquet on Saturday night.



The Pasquale Family
Frank, Jen & Gunner (15 mos)

One couldn't have asked for better weather for the beach outing to the on Friday afternoon. What a wonderful way for families to enjoy Long Island at its best (and the food was REALLY good too). The sibling enjoyed the bowling alley and private room on Saturday's sibling outing!! Of course a conference would not be complete unless the Hospitality Suite got shut down by hotel security!!! This year the child care rooms turned into a *Fun Camp*. Kids had instruction in Yoga, scrapbooking, dancing, picture frame making and got to take their picture with a Justin Bieber cut out!!

There were over 95 families in attendance from all over the US and Canada. There were 31 first time attendee families!!

We also had a family from Iceland who fit right in to our "normal" Cri du Chat family!! Sharing and family interaction continued throughout the weekend and resonated on Sunday morning with a special presentation by the Barnes family about their daughter, Sandy. Sandy, who is 51-year-old, paved the way for many of our families and participated in some of the original studies done back in the 1970's and 80's. Proud parents Jim & Janet, shared a video of their sweet daughter and gave a moving and inspirational speech!!

The conference could not have happen though without the financial support of all the families, friends, and dedicated fundraising events. Many thanks also goes to the host families, board of directors, volunteer speakers, child care and Fun Camp volunteers, and dedicated grandparents. We are very blessed to have each and every one of you involved in the planning & preparation of such a successful event.



Sandy Barnes

LESSON'S FROM MY DAUGHTER, BLOG REPOST

BY PASCALE LEBRASSEUR

I didn't cry

Repost from July 28, 2013

Well, this is it! We will be back home shortly. 10 days away, exploring New York City for the first half and participating in the 5p- society conference for the 2nd half. By now, you all know that Emily has the cri du chat syndrome. Over the last 4 days we've met other families who have a child with the cri du chat syndrome.

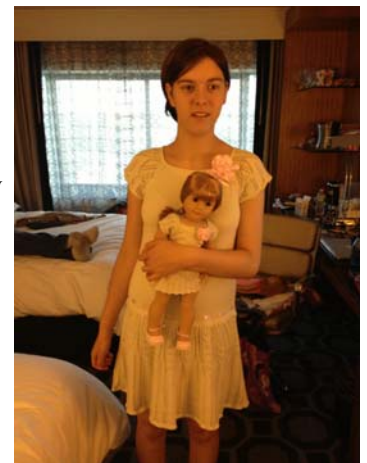
Emily is 15, this was our first conference... For the first time ever our little family was just plain normal... There was 94 families in attendance and 24 or 25 first timer like us... One family came all the way from Iceland and their little girl was so amazing. This tiny 2 year old was walking around. What a joy it was to just look at her go!

Most families were from the US but we had a nice Canadian representation too. We've met a little guy who is 15 months old and a 51 year old lady.

As per usual, Emily was first attracted to the little kids but slowly realized that the teenagers here were different, in a good way. They either had Cri du Chat or had a sibling with cri du chat so to reach out to them was easy for Emily.

We had some struggles over the weekend and I will get to those in other posts...

Today, I want to tell you about the banquet/dance we had last night. I didn't ask permission to post



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CRI DU CHAT SYNDROME AND SOCIAL SECURITY DISABILITY BENEFITS

BY MOLLY CLARKE

If your child has Cri du Chat syndrome he or she may qualify for Social Security Disability (SSD) benefits. Securing SSD benefits can be a lengthy process, but is often a necessary lifeline for families affected by illness or disability.

This article will discuss the SSD benefits available to your child and will provide you with the information needed to begin the application process.

SSD Benefit Options

The Social Security Administration (SSA) oversees two distinct disability benefit programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income. As a parent of a child with Cri du Chat syndrome, Supplemental Security Income (SSI) will likely be best suited to your child's needs. Here's why:

In order to qualify for **SSDI**, a person must be disabled, have extensive employment history, and must have paid Social Security taxes throughout their career. Learn more about SSDI, [here](#).

SSI is not funded through payroll taxes and does not require a work history. SSI is intended for elderly and disabled people with limited income. In most cases, those who qualify for SSI are also automatically awarded Medicaid coverage. Since individuals with Cri du Chat syndrome are disabled from birth, they are not likely to have held jobs, which automatically disqualifies them from earning SSDI benefits.

To qualify for SSI, your child must meet strict financial requirements. If your child is under the age of 18, the SSA will assess part of your income and resources on behalf of your child as part of a process called '[parental deeming](#).'

Compassionate Allowance Listing (CAL) and Medical Criteria

The SSA understands that individuals with severely disabling conditions may not be able to wait the standard processing times to receive disability benefits. For this reason, the SSA runs the "Compassionate Allowance" program. Through this initiative, individuals with inherently disabling conditions can qualify for benefits in as little as ten days. Fortunately, Cri du Chat syndrome is among the conditions that qualify for Compassionate Allowance processing.

Although your child is eligible for expedited processing, you will still need to submit a full application to the SSA.

As part of the disability benefit application process, the SSA requires that the candidate meet certain medical requirements. These can be found in the SSA's 'blue book.' The blue book is divided into adult listing and child listings. Cri du Chat syndrome is listed in Section 110.08B of Congenital Disorders that Affect Multiple Body Systems. To qualify, the candidate is required to provide:

- A laboratory report of the definitive test that documents your disorder (in this case, a genetic test showing at least partial deletion of chromosome 5) signed by a physician.
- An unsigned laboratory report *and* a report from a physician confirming your child's diagnosis.

A report from a physician stating that your child has the disorder with the typical clinical features of the disorder and that your child had definitive testing done.

Learn more about medical eligibility for [Cri du Chat syndrome](#).

The Application Process

To begin the application process for disability benefits, you should call the SSA and inform them of your intent to apply. If your child is under the age of 18, you will want to schedule an appointment to attend a mandatory interview. Be sure to explain that your child has Cri du Chat syndrome and is eligible for Compassionate Allowance processing.

If your child is older than 18, you can fill out the application online or in person. There is no mandatory interview for adults applying for SSD benefits.

Gather documentation of all medical visits and statements from caregivers and other professionals. Remember to bring your own financial information as well if you are applying for SSI benefits on behalf of your child. For a complete list of necessary records and documentation, visit the SSA's "[Interview Checklist](#)."

Even if you receive benefits through Compassionate Allowance, be sure to finish the entire application process in a timely manner to avoid delays. If your claim is denied, know that this is a common outcome for many and it is not the end of the road. You will have 60 days to begin filing an appeal with the SSA. Applying for Social Security Disability benefits is hard work, but the payoff—financial assistance to keep your child healthy—is huge.

For more information about applying for disability benefits on behalf of a child with Cri du Chat syndrome, click [here](#) or email Molly Clarke at mac@ssd-help.org.

SOPHIE'S STORY BY CHARITY DELEON

CRI DU CHAT & PRIMARY CILIARY DYSKINESIA

When I saw her beautiful face for the first time my heart sank, I watched as she struggled to breath and I knew. I knew deep down inside something was not right, fear began to take over what was supposed to be one of the most joyous moments of my life; but somehow I knew my life would never be the same again.



She is tiny at five pounds three ounces and seventeen inches long; her name is Sophie. Sophie is my fifth child and the little girl we had hoped for. I held her briefly for barely a moment before they took her away; I heard her cry and remember saying she sounded like a kitten meowing. She struggled to breath and regulate her body temperature; she had tremors and the list of complications and anomalies began to grow. Within twenty-four hours she had sepsis (blood infection), and pneumonia. Days later she needed a blood transfusion or she would not survive, her condition worsened and no one could give us answers. We were asked if they could perform a genetic analysis, she was two weeks old when we were told that our little girl had Cri du Chat Syndrome. We were told she only had a 25% chance of surviving past the age of two and if she did she would never learn and most likely be in a vegetative state. We were devastated and in disbelief. I wandered in the dark for several months trying to understand it all until I saw a glimmer of light through another CDC family; this family was my saving grace.

She survived 6 weeks in the hospital and we took her home. I was in unfamiliar territory; I had to learn to be a mom all over again but this time I was terrified. Despite the grim outlook we were given I swore that I would never give up on Sophie and would spend the rest of my life fighting for her if that's what it took. Sophie's health only continued to deteriorate and with it my heart broke a little more; we soon realized she had chronic RSV requiring monthly vaccines to keep her lungs functioning. Her lungs were compromised from birth; we were in a very bad place. Her hearing loss was severe, she was diagnosed with sinus disease and she was always sick. Her failure to thrive only complicated her body's ability to strengthen itself; the list of medical issues just kept growing. There were no answers; no one understood why her health continued to deteriorate despite our many efforts to keep her healthy. On more than one occasion we had to face the difficult truth that our child may not make it through yet another uncontrollable infection, each time Sophie get's sick I'm paralyzed with fear.

Sophie became immune to antibiotics and we had no choice but to turn to medication not approved for children to save her life. While it cleared up the infection briefly we could not eliminate the bacteria from her body and weeks later we were back to square one. Her liver began showing signs of overexposure to bacteria and medications; it was always something she was fighting, a sinus infection, respiratory infection, ear infection or asthma; it is a never-ending cycle.

We moved out of state temporarily and new doctors were treating Sophie. As we prepped for her second sinus surgery the ENT felt that it was critically important to have pulmonary evaluate Sophie. The ENT could not shake the feeling that there was something more and while the pulmonologist felt that it was a long shot they wanted to test Sophie for PCD, Primary Ciliary Dyskinesia a rare lung disease. Coincidentally one of the doctor's had been participating in a research study on this disease; It only took this one doctor to link Sophie's symptoms with the possibility of PCD. Two weeks shy of her fourth birthday Sophie had sinus surgery and her lungs cleaned out; It was there that biopsy's of the lungs were taken to test for PCD. I did not think much of it because my search for answers seemed like a dead end. Almost two months after the surgery I received a phone call confirming that Sophie did in fact have PCD.



I was beyond devastated; it felt as if the world had stood still for me. I cried for days and found it almost impossible to put myself back together. This new diagnosis was the missing piece of Sophie's medical puzzle; it also validated my fears of losing her even more. I now understood why Sophie has been so sick from the moment she took her first breath. Cilia are like a filter for our bodies, it filters out the bacteria we breath in and rids our body of it, when an individual has PCD the body does not filter out the bacteria appropriately therefore causing many different symptoms including sinus and respiratory infections.

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CONFERENCE PICTURES



Lessons from my Daughter Continued from page 5 . . .

the kids pictures here so I can only show you my little girl but I can tell you about the first time in 15 years where I've danced with Emily until we were completely exhausted... Emily got herself and Madison ready for the ball. Earlier that day, Jon and I noticed balloons going in the banquet room... Emily is afraid of balloons... We've been working on her fear of balloons for years so before getting ready for dinner, we took her to the banquet room to look at the decor. She didn't like it but agreed to give it a try. We brought her iPhone and headsets to help her cope with the noise level in the room.

It's always good to be ready. She ate her main course while we had our salad and then she was ready to leave. She wanted to get out of there before the music would start. We kept talking to her, explaining we wanted to eat too, hoping to keep her there long enough for her to realize it could be fun. Alex stopped by, then Celia, Rachel, Taylor and many more.

Slowly, Emily relaxed. Something amazing happened... Emily started enjoying herself, recognized a song and decided to get on the dance floor... After each song, she asked if we could leave then recognized the next song... We danced till 10pm. Only stopping for the silent auction and draws. Emily bought some DVD in the silent auction!

We worked up a sweat. I looked at Emily dancing with boys her age and older than her and watched her dance with many girls.... She joined in line dancing madness. It was beautiful!

I didn't cry this past weekend during the conference but last night, while dancing with Emily and watching her having fun with other kids, I came really really close to crying... I just couldn't allow myself too as Emily might have thought I was sad or upset and my fairy tale evening would have been ruined!

Over the coming days, I will write about our trip, our success and struggles.

I will put pictures and tell you about the array of feelings/emotions that have hit me in the last 10 days. I will update you on our trip, the trip that started all this blogging madness. The trip that triggered Emily's desire to talk about her syndrome which forced us out of our protective bubble...

Was it worth it? Was it worth busting our safe bubble? What do you think?

Sophie's Story Continued from page 6

My little girl, my daughter Sophie has this rare genetic disorder that will affect her abilities to become the independent individual we all hope for our children to become; she also struggles to survive everyday. And, now she also has lung disease. It all makes sense now and while I now know the why, I am still devastated. The mere thought terrifies me. Sophie is now receiving airway clearance therapy twice a day with a compression vest. Despite all the challenges we have been faced with I am hopeful for tomorrow and I am thankful for answers. In an effort to help others we have volunteered our DNA in a study to help understand the disease and possible links to other disorders. Knowledge is power, if I could help just one family by sharing our journey than I have accomplished my goal.

CRI DU CHAT & PRIMARY CILIARY DYSKINESIA

As of today there has been four confirmed cases of Cri du Chat Syndrome and Primary Ciliary Dyskinesia also known as PCD. Because of this the 5p- Society was approached by a team of doctors who would like to study and hopefully identify more cases to look for improved treatment and prognosis. We are happy to announce that a research project is now in the middle stages of getting the appropriate approvals needed to begin the study. In the next newsletter you will find an article by the lead physicians and a survey to begin the study. The survey will be used to identify potential participants. If you would like to learn more about PCD, please visit their website at www.pcdfoundation.org. The 5p- Society would like to thank Charity for sharing Sophie's story!



T-Shirt Fundraiser

Many of you asked about the t-shirts from the conference this past year that were in the different colors with the big 5P— across the front. One of our grandparents, Donna Grasso, from Pennsylvania is spearheading a short term fundraiser for the 5p— Society where you can order and get your t-shirts in time for the Holidays!!

Below is the information for the 5p- shirt fundraiser.

Website is: <http://cmsportinggoods.net>

1) Go to the link 2) Click on Promotions 3) Go to the 5p- promotion and type in promo code 5p
 4) Click on CHECKOUT 5) Choose SIZE, COLOR, and QUANTITY 6) Click ADD TO CART
 7) Click on CHECK OUT at the bottom of the screen Complete billing information 9) Complete Shipping Information

The shirts will cost \$10.00 with \$3.00 going to the 5p— Society.

The fundraiser will run from November 1st through November 15th. At that point, the website will be shut down. It will take approximately 2 weeks after November 15th for the shirts to be shipped. Just in time for Christmas.

The fundraiser will be held only in the United States and Canada because they cannot ship overseas.

If anyone is having any kind of trouble with the website or ordering they can contact me through FB or cell # 610-517-6567 or e-mail grassoparis@yahoo.com.

THANK YOU DONNA!!!

HALL OF FAME RECIPIENTS



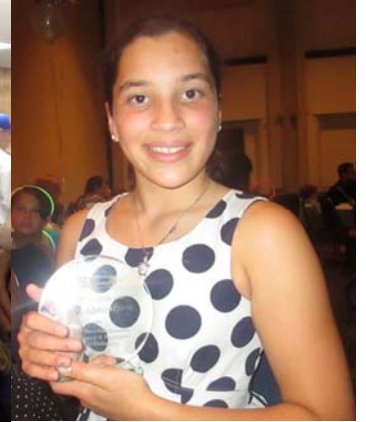
Parents of the Year:
Jerry & Carolina Kretschmar.
 Jerry & Carolina have attended 20 conferences, only missing one since 1993!! In 1999 Carolina approached the 5p— Society into creating a keepsake quilt made by the 5p— kiddos. She would take the designed squares back home after each conference and bring it back next year to raffle off!! They have also served on the Welcoming Committee at the annual conferences.



Grandparents of the Year:
Arthur & Patricia Strong
 Art & Pat Strong have been 5p— Society advocates for the past 15 years after the birth of their grandson Maxwell. Immediately stepping up to serve all the grandparents by facilitating the Grandparent workshops at the conference and have Discovery Toys fundraising events. They also started the Grandparents Newsletter!!



Co-Sibling of the Year:
Raeann Sleith
 Raeann has been a superb advocate and a great little sister to her brother Derek. Raeann, wanting to do something to help spread awareness of Cri du Chat Syndrome to her community began creating and selling bead bracelets. To date she has raised over \$30,000. She has split the monies raised between the 5p— Society and several other entities.



Co-Sibling of the Year:
Emily Abbruzzese
 Emily really stepped up to the plate at the 2013 conference. Helping plan for the “Fun Camp” and assisting with the sibling events. Emily, along with several of her friends at school have done fundraising events for the 2013 conference.

APPLICATIONS NOW BEING ACCEPTED!!!

5P- SOCIETY

T:888-970-0777
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



PO Box 268
Lakewood, CA 90714-0268
Toll:(888)970-0777
Phone:(562)804-4506
Fax: (562)920-5240

Email: director@fivepminus.org

RETURN SERVICE REQUESTED

Tweet with Us
[@5pminus](#)

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/>

Southern California Get Together is scheduled for Sunday, November 10, 2013 from 11-4 at Liberty Park in Cerritos. All are welcome. If you need suggestions for accommodations, please contact Laura at the 5p- Society office at 888-970-0777 or email at director@fivepminus.org

Looking forward to seeing you !!

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=>