

DON'T SWEAT THE SMALL STUFF OR FORGET ITS IMPORTANCE by Jen Wong

So to say this year has been not so great, is an understatement. We lost my brother-in-law to cancer. His fight was one of the most inspiring things I have witnessed in my life. We are currently looking into our third water damage claim on our home, with the last one still not complete. The first one, March 17, took out all the kids' bedrooms and all but one bathroom and the second, the kitchen. All of this in addition to the normal everyday "fun" in our life. To say I have not been the most pleasant person to be around, it a BIG understatement, just ask my husband and kids. Like a lot of us, I can hide my emotions and act like "everything is beautiful" to the outside world. On some days, it's quite the Oscar performance. Many friends will ask, "How do you do it all?" My answer is simply, "Somedays I don't".

I am a staunch rule follower. Watching parents blatantly ignore school rules, in front of their children no less, drives me crazy! Drivers ignoring traffic laws and putting their need to get somewhere in front of the safety of others makes my blood boil. People being rude and attacking others, simply because they don't agree with them (think Facebook) makes me both angry and disgusted. All of these little things take a toll on me if I don't let them go, which is really difficult for me when I have to experience them on a day-to-day basis. It makes me irritable, short with my family and more withdrawn from friends. I've been told, many times to "Let it go." I think I need that to be my theme song.

What people may not realize is that one small act of kindness/positivity can wipe an entire mountain of negative small stuff away, POOF! GONE! Perfect example, today I was racing around trying to get last minute birthday items for my son. I was in one of "those" moods created by the negative Mt. Everest that's been rapidly growing in my head. I went to GameStop to pick up some Skylander items, my son requested. I'm not a fan of electronics but bottom line, my boys love them, so we allow them with limitations (and honestly I can get a sparkly clean home, bathrooms included, with a reward of video games!) I was asking the gentlemen for help with buying traps and figures. With all three of my son's birthdays occurring in the next 3 months and

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SUMMER-FALL 2015

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.

More to come in the upcoming months, stay tuned to the blog listed above.

INDIANAPOLIS CONFERENCE WRAP UP

What a great time to be had at the 2015 Indianapolis conference. We had a record breaking amount of 1st time families attend the conference. It was so great to meet them. I hope that they were able to learn a little bit about the syndrome, and realize that they are not alone in this journey and that families are there to help support them along the way. Thank you to Kent Nicholls for continuing to welcome our 1st time conference attendees at the New Family Orientation.

Many thanks to our host families who really did go above and beyond. All the many conference calls and meetings at the hotel to work on the logistics and needs, as well as all the fundraising done to keep the costs down for the families, were worth every minute. Thank you to Jason and Michelle Myatt, Brad and Kyla Chandler and Foster & Stephanie Pilcher, as well as their immediate and extended families, for all their assistance and help throughout the weekend. We were also fortunate to have a Nursing School offer to have its students attend and assist in childcare. It worked out great.

Our speakers once again did a fantastic job. Topics discussed were Sensory Processing by Karrie Veteto, OT, ABA, Augmentive Communication by Wendy Gahimer, MA, Hippotherapy by Jennifer Grillo, PTA and Teresa Keathley, PT, Cri du Chat 101 by Dennis Campbell, Ph.D., Vision and Learning by Dr. Erin Buck, Planning for the Future by Mary Ann Elhert, IEP courses for beginners and another one as a refresher both by Shanida Mathieu, Overview of ABA Therapy by AmySue Reilly, Ph.D., Transition from Employment and College after High School by Nancy Washburn and Crista McIntosh. We also had a few of our families talk about ways to fundraise for the 5p- Society (especially with the Race to Rewards program for the conference and the Film Crew Awards program for 2016 conference) – many thanks to Bob Fernandes, Heather Grasso, Gloria Griffin and McKenna Myatt.

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LEARN SHARE CONNECT

Blogs to follow:

- * <http://livingwithriduchat.blogspot.com/>
- * <http://elastamom.com>
- * [All Things Beautiful by Kathy McClelland](#)
- * <http://livingwithriduchatmosaicism.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](#)
<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
- [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=yMWDIdOAWC>

[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.

fairness being a very big thing in their life, I was trying to figure out how to buy “fairly” without breaking our bank account. In seeing me weigh the prices vs. the “awesomest” characters, he says “How about I make your sons’ day?” He then brings out a bag full of about 15/20 Skylander figures and traps, ALL the different traps! He said “take him, for free, we can’t sell them, you can have them all”. My sons’ will be elated!! But more important, with that small gesture, he completely leveled my “mountain”. What was nothing to him will have a profound impact on my family.

I know it’s difficult, especially with all that has been unexpectedly thrown at us, but try not to underestimate the impact you can have on someone with what you feel is a trivial act or word. While I’m still working on not sweating the small stuff, I am very cognizant of the impact of small acts of kindness or words and try to use them as frequently as I can.

Think of a small act of kindness that you have done, or that you have received, capture the euphoric feeling associated with the act, and when it seems like your Mt. Everest is about to blow, try and take yourself back to that point and time in your life.

NEW REPORT & CURRENT RESEARCH NEEDS BY DENNIS CAMPBELL, PH.D. AND AMYSUE REILLY, PH.D.

Amysue and I were part of a team that prepared an article for a special issue of the American Journal of Medical Genetics on deletion syndromes that will be published soon. The article is titled *5p Deletions: Current Knowledge and Future Directions*. We would like to thank our co-authors **Dr. Joanne Nguyen** (medical geneticist) and **Dr. Mikhail Alexeyev** (scientist of physiology and cell biology), and **Krista Qualmann**, and **Rebecca Oshkasha** (both certified genetic counselors) for their tremendous contributions on understanding the genetics of 5p deletions which will have an impact for many years to come. As we wrote this article several things stood out which I would like to share.

The Campbell family has actively participated in many studies years before I did my first research on the syndrome in 1999. In 2002, when I completed my dissertation I was very knowledgeable of the literature on 5p deletions. So it was exciting to see how much additionally we know now almost 15 years later- which is actually both “**a lot**” and “**not much**”. Let me clarify.

‘A Lot’ has Changed.

On the genetics side a lot has changed. In the article we mention breakpoints and ‘genetically’ discuss specific genes. We used a different numbering scale that is based on results from **chromosomal microarray** and **RNAseq analyses** *rather than previously*

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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/cri-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://form.jotformpro.com/form/52607730636961>

used Karyotypes and “fish analysis”. There are 314 genes present in the region of the chromosome that is deleted in Cri du Chat syndrome. Probably only 16 to 28 of them are considered by geneticist to be **‘dosage sensitive’** which means from a genetics standpoint the implications for **future interventions are “manageable”**. We discuss **potential avenues for interventions** in the article, but let me **caution everyone** that these are **not currently available** but may be in the future. Much research needs to be done before any of this will be a reality.

In the introductory article for the journal, Drs. Cody and Hale discuss that we are now better able to understand the relationship of phenotypical characteristics (traits that can be observed) and their relationship with genes. Deletion syndromes are an excellent place to do this since we can see differences in traits and compare them with where chromosomal breakage occurs. When the human genome project was underway, there was a lot of work done on 5p deletions for this very reason. I am excited that the **American Journal of Medical Genetics** is publishing this work and I feel it may help many families in the long term. In the short term, it encourages those of us who have been working to understand the 5p minus phenotype to continue in our efforts.

‘Not Much’ has Changed.

This is where the **“not much”** comes in. When it comes to the phenotype for 5p minus, we don’t know much more than we did in 2002. This is not because we haven’t been studying the syndrome, but rather because of the complexity inherent in 5p deletions. The other syndromes discussed in the journal have between 28 and 150 genes present compared to the 314 in 5p minus. Additionally, the variability in our groups is significant, both because of the range in the amount of deletions as well as general variability in any population. So describing a ‘five p minus phenotype’ is a challenge.

The research on traits has occurred in the past decade but has been limited to smaller studies. Even in the article we completed, the largest published genotype phenotype study had only 80 individuals. The family history data that the society has been gathering over the years has many more than that but we do not have the genetics information to match with the traits we have collected. Drs. Cody and Hale talk about the importance of genotype and phenotype comparisons, and the future directions we describe depend on those types of comparisons.

So What does This All Mean?

When Amy was born in 1991, the internet existed primarily in the military and at universities and colleges. Information on the syndrome we got came from Rick Rothwell, president of the 5P board at that time. Now families can search the internet for 5p minus or Cri du chat and get a vast amount of information from a variety of sources. The internet and social media has become a wonderful resource of a wealth of information gathered from a network of other parents as well as sharing. As wonderful as this ‘wealth of information’ is, **it is not equivalent to scientific research.**

As special educators, part of AmySue’s and my job is to do research in the field. AmySue and I have partnered since 2003 doing research on 5p minus. We have collected a lot of data from many of you and are very appreciative of your time and efforts. We will be following up on some of what we have done in the past to be able to document changes as our kids grow.

For example, some of the 14 infants who participated in a 1999 study I did with Dr. Samera Baird, have also participated in the assessments completed in AmySue’s and my studies done in 2003 to 2006. We hope to contact those same families in the next few months to get an ‘assessment of their current development’. We hope to present this at a research conference in the spring and develop a paper for publication from it. We also want to follow up with the group that we collected ‘behavior data’ from to see how it has changed over the last 10 plus years. One study that has had probably the greatest benefit for families was the ‘growth study’ done by Dr. Overhauser and her colleagues. Prior to that work our kids were frequently diagnosed with *“failure to thrive”*. Those families who contributed to that study have made life much better, even though, not specifically for their own kids- their impact is on future generations.

Need for Your Participation in Scientific Research.

There is no doubt that research that has been done on 5p minus has improved the ‘quality of life’ for our kids. This work has been

done by many people since the 1970s. With the change in the genetics field to testing (**chromosomal microarray** and **RNaseq analyses**) we must also have the **‘trait information to pair with those results’**. To further **add to** the 5p minus **scientific research evidence**, we have developed a **‘New Family History Questionnaire’** that we are kindly asking that you complete. Your participation and contribution of information will greatly assist in the contribution of **scientific research results**.

The new questionnaire has been designed so you are able to complete it at your own pace within a reasonable amount. If you have already completed one in the past, thank you so much. If not, please consider doing one now. It will be a short time commitment and will considerably add to what is known about 5p deletions and their impact. If you have any genetic testing scheduled, remember to request that the newer tests are done. By comparing **where** the **deletion occurs** **with** the **individuals traits**, we can further identify **specific genes that are involved**.

Parents and families in the past have donated their time to help future generations. Please consider **‘paying it forward’** and **participating** in the research process which will significantly **add** to the **scientific research data**. *We all thank you for participating in making a difference in impacting the lives of those individuals with 5p minus deletions and their families.*

To complete a “Family History Questionnaire” Please request one from Dennis Campbell at

campbell@southalabama.edu

Here is the article’s citation: Nguyen JM, Qualmann KJ, Okashah R, Reilly A, Alexeyev MF, Campbell DJ. 2015. 5p deletions: Current knowledge and future directions. *Am J Med Genet Part C Semin Med Genet* 169C:224–238.

I think though that the most “in awe” moment though was when James Chalmers stood up on Saturday morning and gave us a presentation about his life and own journey as an adult with Cri du Chat Syndrome. He showed emotion, humor, and pride. It was a very humbling experience for those of us who attended. I know I had tears in my eyes. James (43) is a very spiritual individual and touches those who he comes in contact with. You can see his presentation on the 5p- Society FaceBook page at <https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

The siblings were able to reconnect and create new friendships. Thank you to Jannie & Travis Boulanger for leading the sibling mixer, Michelle Myatt for stepping in on short notice to run the SibShop and McKenna Myatt for raising enough money to pay for the siblings to go on their outing to Caribbean Cove Water Park including the entrance fee, transportation and lunch.

Prior to the conference, members of the Professional Advisory Board, Kent Nicholls and I, along with several key individuals held a Medical Symposium Webinar to discuss the direction of future research. On page 3 of this newsletter you can read some exciting news about a new article published in the *American Journal of Medical Genetics*. Even a few of our kiddos were photographed by world renowned photographer Rick Guidotti from Positive Exposures. Look forward to seeing Brielle McSeed, Christina Brady and Jack McGuire in the publication.

The hospitality suite was once again the happening spot in the evenings with families flowing in and out of the room to finish conversations or start up new ones. Many thanks to the Ohio families who stepped up and hosted the hospitality suite – Geoff & Jolene Towers, Nick & Angie Wallace and Dan & Jessica Hoover for assisting and coordinating the hospitality suite.

Families were able to attend the outing to the Indianapolis Zoo. Lunch was included that consisted of hot dogs, hamburgers, potato salad, cole slaw and all the fixins. Ice cream cups were my favorite though, especially since it was a hot day! The zoo was fun and pretty big. Katie enjoyed the dolphins and her favorite animal – Cheetah.

Parent Panels and Grandparent Workshops usually get the best feedback as parents and grandparents are able to talk *freely* about their child/grandchild without judgment.

Continue from page 5 - Indianapolis Wrap Up

Lastly, the grand finale of the banquet and family dance. Before the banquet, all kiddos (and adults with CdCS) were summoned down to the front of the hotel to pose in and around Noah Juliar's truck (brother to Cooper Juliar). Noah added awareness phrases and items to the tailgate of his truck and wanted all the kids and adults pictured around it. Not an easy task, but it was done and it looked great!! Thanks Noah!!

The DJ was great, raffle items were all claimed and the dancing didn't stop until way past 10:00 PM!!

Thank you everyone who attended, donated, planned, and volunteered – 30 years racing to awareness – is in the history books!!



RACE CAR DRIVERS OF THE YEAR 5P- SOCIETY HALL OF FAME RECIPIENTS

Congratulations to the following individuals for being named the recipients of the 5p- Society's 2015 Hall of Fame.



Parent of the Year: Michelle Myatt

Michelle, one of the 2015 host families and new board of director, has been named the 2015 Parent of the Year. Michelle coordinated many of the events for the conference, has reached out to many new families and hosted several fund-raising events. She also stepped up for us when the SibShop Facilitator that we had scheduled for the conference was unable to attend and put together and ran the SibShop. Michelle and her husband Jason live in Granite City, Illinois with their three daughters, Delaney is her 10-year-old daughter with Cri du Chat Syndrome, McKenna and Reagan. Congratulations Michelle for all your hard work and we look forward to working with you on the Board.

Sibling of the Year: McKenna Myatt

McKenna, big sister to Delaney, had one goal in mind when she found out how close the conference was going to be in 2015 and that was raise enough money so that the siblings could go on the sibling outing without the parents having to pay for it. She raised money by collecting and recycling cans and bottles. She raised enough money to pay for the entrance fee, lunch, and transportation for 75 siblings/chaperones to attend the water park. Congratulations McKenna and thank you for all your support.

Grandparent of the Year: Dale Huffman

Dale is the grandfather to Amy Campbell of Mobile, Alabama. Dale has supported the 5p- Society for over 15 years. Dale was instrumental in ascertaining several grants for the Memphis conference in 2003. Since then he has sponsored the attendance of his son-in-law, Dennis Campbell and family to attend the 5p- Society conferences. Dale and his late wife Joanne, have provided unconditional love and support to his daughter, Shari, and her family. Amy is very lucky to have such an awesome Grandpa!!



Race Car Driver of the Year: Stacey Sanders

Congratulations to Stacey Sanders for being nominated and the recipient of the Race Car Drive of the Year (aka Volunteer of the Year). In October of last year, Stacey approached the 5p- Society because she wanted to do an event to help it spread awareness. She immediately stepped right in and helped create the Virtual 5k for 5p-. She did a lot of research, planning, created a Social Media campaign, and basically ran the event. Our goal was 100 participants. What we got was over 1000 participants. The event took in over \$26,000.00. As you can see on page 9, we have now hired Stacey to assist us and improve our awareness campaigns.

Raising a child with cri-du-chat syndrome is no easy task. That's not a big surprise to anyone reading this newsletter. But some life events can be particularly difficult for our kids, one being the death of a loved one. I wanted to share the story of how Beth and I coped with the recent death of my dad.

At the time that my dad was diagnosed with cancer, Beth had only one prior experience with death. I remember getting the call from her teacher, informing me that one of her classmates, Shane, had passed away unexpectedly in his sleep. I also remember trying to talk to Beth about Shane's death, and how he would no longer be in her class. I've never heard her wail like she did that day. She ran down the hall to her room and refused to hear anything about it. Every time I tried to talk to her, she just wailed so I knew she understood at least a little of what had happened, but I could never get very far with her.

Several years later, when Beth was 18, my dad was diagnosed with stage four colon cancer. He put up a brave fight until the chemotherapy became so unpleasant that he felt he had no quality of life and discontinued the treatment. Beth had become very close to her grandpa after her dad and I divorced. He remembered her reaction to Shane's death and was very concerned with how she would cope when he died. So when he signed up for hospice care, preparing Beth for his death was included in the care plan. We were lucky to have a wonderful hospice staff who were very helpful in finding ways to help Beth prepare.

One of the first things we did was involve Beth in music therapy. She has always loved music so the therapist met with her and grandpa, and they wrote a song together. It was a song about how it's never easy to say goodbye to someone we love, but with faith we can plan to meet each other again. They sang the song every time the therapist came for a visit. The social worker also met with Beth several times to talk about what was happening with grandpa.

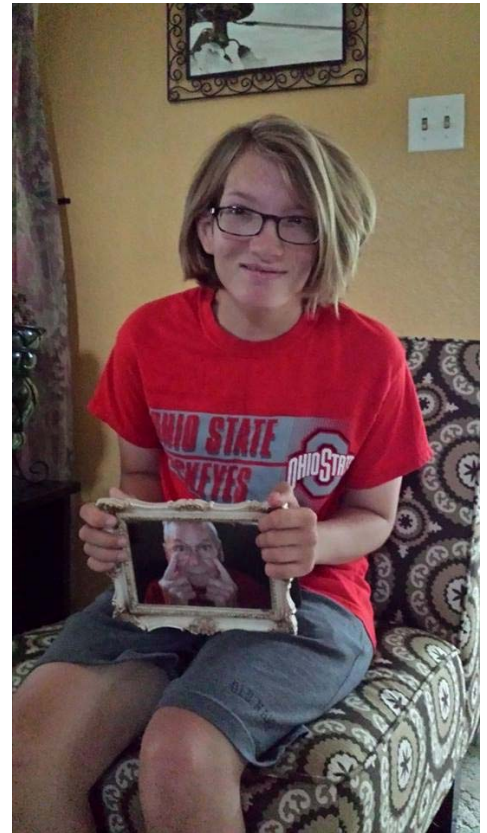
My dad knew there might come a time when he could no longer tell Beth he loved her, so he told her he would point to his eye and that was his sign to say I love you. We took pictures of grandpa pointing to his eye, and put the photo in her room.

Beth was very observant and would notice whenever anything changed, like one day when an oxygen concentrator showed up, and then a hospital bed. She could always tell when grandpa wasn't feeling well and was a little hesitant to give him a hug, so we started doing family "group hugs" with all of us in a circle. It has become a tradition that we still continue.

We made a practice of visiting grandma and grandpa several times a week, so there would be no sudden changes in his condition. So when it came to the "beginning of the end", it didn't come as a shock when grandpa started to sleep more and needed help with eating and going to the bathroom.

Then he stopped eating, and we knew the end was near. Beth spent most of her time in the next room, not wanting to get too close. I knew she was scared, but I wanted her to be aware of what was happening. So when I got that dreaded call in the middle of the night, I woke her up and took her with me one last time. My dad had already passed away when we got there, so Beth laid down on the couch in the next room while I said goodbye. Then I brought her in and explained that Grandpa wasn't suffering anymore. She handled it pretty well but didn't want to stay too close. Since my dad donated his body to a medical school, it took several hours for the attendants to come and remove his body. During that time, more family arrived, and we all had the chance to talk about Dad and reminisce. At one point, I asked my nephew to take Beth home so she could go back to bed. But she had other ideas and refused to go.

When the attendants came, we all gathered around, said a prayer, and said our last good-byes. Beth joined in the circle, gave her grandpa a kiss on the cheek, and we had one last group hug.



She handled the funeral pretty well. Since there was no body at the funeral home, she wasn't scared and to her it probably just seemed like a big party!

It's been over a year now, and every now and then I find that she has turned the picture of her grandpa around backwards. I just turn it back again, recognizing that for her, life has just gone on. We talk about Grandpa on occasion, and laugh at how he used to call her "Lizard-breath" and give her one of his funny winks. I'm glad that we had some time to prepare her for his death. It gave us both a chance to fully experience his illness and passing. It also allowed me to spend quality time with my parents and prepared me for his death at the same time, which helped a lot in my own grieving process.

There will likely come a time when we will have to deal with another beloved family member or friend passing away. I like to think that experiencing this process will help Beth cope with loss in the future.

ASK THE DOCTOR BY PAM PILCHER

ASK THE DOCTOR is a new feature on the 5p- Society website—www.fivepminus.org/Ask_the_Doctor

Dr. Pam Pilcher has a nephew with Cri du Chat Syndrome. She is a pre-residency doctor in family practice with an interest in pediatrics. Dr. Pilcher has provide the 5p- Society so far with two topics of interest to the community (more to come):

Her first topic **Hyperacusis and its Effects on Behavior**, discusses the topic of hyperacusis as it appears to effect both behavior and sleep depending on its severity. The topic will also give behavioral techniques and treatment that might be helpful in some cases.

You can find the entire article at http://www.fivepminus.org/data/_uploaded/file/Ask%20the%20Doctor/Hyperacusis.pdf

Her second topic: **Neuroanatomy of Cri-du-chat (5p-) Brain and Its Affects on Movement.**, discusses the brain and it's affects on movement. This is the first in a series of discussions of the intricacies of the brain and Cri-du-chat syndrome (5p-).

You can find the entire article at http://www.fivepminus.org/Ask_the_Doctor

The 5p- Society would like to thank Dr. Pilcher for sharing her knowledge with us and writing about topics that the community can resonate with and in layman's terms.

This information is provided by 5p- Society and is not intended to replace the medical advice of your doctor or health care provider. Please consult your health care provider for advice about a specific medical condition.

WELCOME, STACEY SANDERS, TO THE 5P- SOCIETY

The 5p- Society is happy to announce the hiring of Stacey Sanders. Stacey was instrumental in getting the Virtual 5k for 5p- event up, running and successful. She will continue to work on the Virtual 5k to make it a bigger event for 2016, as well as work on special projects for the 5p- Society. Stacey's best friend, January, has a daughter with Cri du Chat Syndrome and reached out to the 5p- Society last year to help come up with an event to spread awareness. Stacey has a marketing and HR background. We look forward to working with Stacey, improving our awareness campaign and strengthening the growth of the organization.



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RETURN SERVICE REQUESTED



Meet C5

The Mascot of the International
Cri du Chat Awareness Week

Tweet with Us
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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/>

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

Wades 5k for 5p-

Wade's 5K for 5P- is an annual running and walking fundraising event that supports Wade Jones. other local children with Cri du Chat, and the 5P Minus Society.

<http://www.wades5kfor5p.com/>

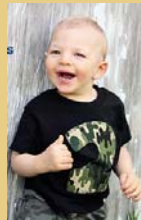
When and Where...

Saturday, October 10th,
2015 - 8:30am CDT

Lodge Park | Monticello,
Illinois

Schedule of events:

7:00-8:15am - Registration / Packet Pick-up
8:30am - 5K Run & Recreational Walk
Kids Fun Run Immediately Following 5K



Pig Roast for 5p-

The 2017 5P- International Conference will be held Milwaukee! The Losens, the Renks, and the Isberners have stepped up to be host families for this conference.

When and Where . . .

Saturday, October 25, 2015

2:00 - 6:00 PM CDT

American Legion Hall in Mukwonago, WI.

There will be food, friends, raffles, and lots of fun! Tickets will be sold at \$30 for adults and \$15 for children. The maximum amount of people we can have is 150. We are asking that people RSVP to this event no later than October 1st. Please mail cash or check (and a note stating who will be in attendance) to:

The Losen family
410 Ahrens Drive
Mukwonago, WI 53149

Checks must be made payable to the 5P- Society.
For more info please contact Hillary or Maria
thelosens@me.com or mariaisberner@yahoo.com