

5P-NEWS

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

WE ARE NOT JUST A FACEBOOK GROUP BY JEN WONG

While Facebook has certainly increased awareness for the 5P-Society, it is not ALL we are. We have two websites, one for the Society and one for International Awareness. We have a CafePress “store” where you can buy 5P- items. We have an annual conference that bounces back and forth across the U.S. to bring resources and families together to provide education and support. We have an Ambassador’s program developed to spread awareness. We have an Awareness week, which just passed. I encourage everyone to take time and explore all the options/information, the 5P- Society has to offer.

Just like most, I would like to focus on the FB site for a bit. To have a resource like FB, to be able to reach out to families who have never spoken to or met another CdCs family, is priceless. To be able to get advice and opinions from parents/family members who have “been there and done that,” once again, is priceless. However, FB does come with a price. We have been lucky, our price has not been steep, but we have paid a price for having the site. It’s a sad price. On a few occasions, we have had to remove posts/comments due to people attacking or making negative comments to someone who simply came to our safe place to vent or ask a very sensitive question.

Last year, we decided to make the site closed so that families could ask personal/sensitive questions without them being seen on their own page for “friends” to see. We closed it to protect the privacy of our families. It truly saddens, and honestly at times, angers me to see CdCs family members attacking one of our own. Isn’t it bad enough we have to defend our child from schools, insurance companies, medical professionals, and sometimes even family/friends because they don’t understand the needs of our child/family member?! I can’t believe we need to defend ourselves to each other.

Everyone needs to remember, just because we are “friends” does not mean we know each other. For most, the ONLY thing you have in common is having a child/family member with CdCs. For most, the only thing you know about other families is they also have a

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SPRING 2015

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30 YEARS RACING TO AWARENESS

<http://5pminus2015conference.blogspot.com/>

The 2015 conference will be held at the Sheraton at Keystone Crossing in Indianapolis, Indiana. The dates will be July 30 to August 2. The Sheraton is in a sold out situation for sleeping rooms. Fortunately we have identified an overflow hotel. Please see page 2 for more information.

SPEAKER UPDATES

James Chalmers will be our KeyNote speaker on Saturday morning. James is a 43 young man with Cri du Chat Syndrome who has participated in 6 marathons. He will tell you a little about himself.

Jennifer Grillo and Teresa Keathley from Childrens TherAplay Foundation, Inc. will be discussion Hippotherapy and its use as a treatment strategy for physical, occupational & speech therapy

INDIANAPOLIS CONFERENCE OVERFLOW HOTEL

The 2015 annual conference will be held at the Sheraton at Keystone Crossing in Indianapolis, Indiana. Unfortunately, the Sheraton has sold out of sleeping rooms in our room block and cannot increase our room block. What this means is that the hotel still has rooms, but can only sell those rooms at the prevailing rate (over \$200 a night). This has happened in the past and will probably happen again in the future. Even with careful planning and projections it has occurred.

Have no fear . . . An overflow hotel has been identified



The TownPlace Suites at Keystone Crossing is located across the street from the Keystone Mall and is within walking distance to the Sheraton. We have contracted 10 Studio Suites at the discounted group rate of \$149.00 per night (more rooms can be obtained if needed). The Studio Suite has a queen size bed and a pull out full size bed, a full kitchen, including full size refrigerator, microwave, oven and stove. Some of the amenities of the hotel - complimentary breakfast, complimentary parking, complimentary 24 hour access to the exercise facilities, complimentary high speed internet. If you are a Marriott Rewards member you can also earn points. To make your reservations, please contact the hotel at 800-619-3224 and tell them you are with the **5P Minus Society Group Block**.

Last chance to get your conference t-shirt pre-order in. Please send in your conference t-shirt orders (even if you are attending the event) no later than June 25. T-shirts ordered after that date are subject to availability.

Hall of Fame nominations are still being accepted. If there is a parent(s), grandparent(s), sibling(s) or volunteer who has gone above and beyond the call of duty for a superhero within our community and/or for the 5p- Society, please nominate them for as a Hall of Fame recipient. Please turn in your nomination request by June 25th.

Thank you to all the Race for Rewards participants. Over \$20,000 was raised through the program to assist with the conference expenses.

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://myriversride.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>
- * <https://www.facebook.com/sophieourgift>
- * <http://mydanceintherain.org>

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.
- [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
- [Documentary by Maria Ripoli](#)
<http://www.cromosomacinco.com/>

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.

child or someone with CdCs. One thing we all know is while our children might have similarities, they ARE individuals with their own unique gifts and challenges. Each family is also uniquely diverse. You may have one parent, two, or four. You may have extended family living with you or helping you...or not. You may have an extended community support system...or no one near you who you can count on when needed. You may only have our FB group as your only source of support and comfort. If this was you, how would you feel to be attacked by your only source of support for simply asking a question, seeking support, or simply venting on your worst day? My heart breaks when I see this happen?

I know we all have our own trigger words or situations, that when touched, can create instant emotion, whether that's rage or something else. We all were raised in different cultures, religions and environments that shaped who we are and how we think. We all do not think alike. We do not share the same beliefs or life style choices. This does not mean one is right and one is wrong, it simply means they are different. Is someone wrong for believing in God or not, or a different God than yours? Isn't it more important how we treat each other than who we pray to (or don't)?

Our kids, with CdCs, were all made different and I know that we would not stand for our special kids to be attacked for being different than a typical kid. So, why would we be ok with someone attacking another person because they may have different views than we have?

I am asking everyone in our FB group to simply BE KIND. If you come across a post you don't agree with, if you cannot comment without staying positive, please just scroll on. We have created this site where we can come SAFELY and ask those tough questions or vent those feelings that anyone else would think we are monsters for thinking because they have never experienced the lows we have. We understand that everything is not peaches and cream and some responses will be hard to say and/or hear, but even these types of responses can be done with the utmost respect to the situation.

My main reason for writing this is due to one particular incident (I will not give specifics) of a parent being attacked for venting. All it made me think about was what if this parent was at their breaking point and was coming to their CdCs family for support and instead was attacked? How would those who attacked them felt if they found out they committed suicide later that day? I'm not being dramatic, murder/suicide has happened in our CdCs family. It was horrible and tragic. Those who knew the family struggled to try and understand what made them feel so helpless that they had no other alternative, no one to help them from their darkness.

We have families in our group from around the world. Some families are the only ones they know of in their country. Luckily, by joining our group, they have found out, not only are they not alone in their country but they are not alone in this world of CdCs. Let's keep that world positive. Let's remember we are a world-wide family with differences, and that's okay. We have a wealth of knowledge and experience we can share with one another that no doctor can. We all get our unfair doses of negativity from many other groups, let's make this the one place EVERYONE can go for positive support, no matter what. Put yourself in that person's place and think "if that was me, how would I want someone to respond to me".



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>



Friend of the 5p- Society, Michele Hardin will donate a portion of her proceeds for each item order. Please email Michele at michelhardin@comcast.net after you have ordered and provide her with your order number. Create your own unique design.

<https://www.keep-collective.com/with/michelehardin>



USING ESSENTIAL OILS *BY DL SWEET*

Many of you have been talking about the use of Essential Oils, one of my friends is a distributor and I asked her to write a little something up about the products. DL is one of many distributors. If you would like more information about a specific product please send her an email, or find a distributor near you. There are other vendors also that provide essential oils. DL has donated a bottle of Lavender to be used at the Indianapolis conference.



Essential oils have also been used for thousands of years for cosmetic purposes, as well as for their spiritually and emotionally uplifting properties. Young Living has always been at the forefront of bringing this ancient tradition to modern users, introducing millions to a total mind/body wellness they may never have dreamed possible.

Primarily extracted through careful steam distillation but also through cold pressing, the purest essential oils are far more powerful than the botanicals from which they were extracted. Any time you hold a bottle of our powerful essential oils, you are holding nature's pure essence.

Love the way the spritz of fragrance from a fresh orange peel can brighten your day? Each essential oil's complex, pleasant, and unique scent activates the limbic system—the brain's center of emotion and memory—differently. Essential oils can be your key to a more fulfilling and balanced emotional life.

To help you rediscover peace, balance and joy, use these essential oils and blends for diffusion, soothing baths, massage, inhalation, or topical application: Joy, Lavender, Gathering, Peppermint, Jasmine, Orange...

Our community of wellness started small in 1993, when Gary Young developed his first organic herb farming and distillation operation. At the time, Gary had already discovered the incredible power of essential oils, but because the quality of available oils varied so greatly, he'd been unable to fully harness their potential. While he knew that pure essential oils had the ability to produce spectacular results, he found that the chemically altered or adulterated oils on the market were often ineffective and even harmful.

Young Living changed all that. As Gary developed more farmland in Utah and Idaho, he began cultivating lavender, peppermint, melissa, clary sage, and many other herbs. Fueled by a growing demand for pure essential oils, Young Living designed and built the largest, most technologically advanced distillery for the production of essential oils in North America. Our company has also developed the groundbreaking Seed to Seal® process, which preserves the integrity and potency of essential oils.

Our Premium Kit #4672 which features our Start Living Kit with the 10 Everyday Oils is the best value. Receive a Free Diffuser with purchase. Email me for 171 Ways to use the Everyday Oils kit.

For information on how to obtain these powerful blends or to schedule a class on aromatherapy for your group or organization contact: *D.L. Sweet* Member ID#1967631- (310) 489.8373. dlsweetyoga@gmail.com www.youngliving.org/dlsweet1 Enter #1967631 as your enroller/sponsor.

Please note that the 5p— Society does not have any affiliation with Young Essentials or any other Essential Oil company or organization, not does it promote or endorse the use of essential oils. The above article is for information only.

BIRDIES FOR CHARITY

It is with great sadness to announce the passing of one of our beloved grandparents, and the recipient of the grandparent of the year award in 2013, Arthur Strong. Art, and his wife Patricia, have been very active participants with the 5p- Society since the birth of their grandson Max. Together, they started the Grandparents Workshop at the conference, have donated items to be raffled off and have donated the registration fee for several conference attendees throughout the year.

Art worked for and retired from John Deere Tractor Company and was introduced to the Birdies for Charity fundraising platform. The Strongs arrange each year for the 5p- Society to be recipients of funds raised through the Chip in for your Charity and John Deere Classic Golf tournament July 6-12. Patricia let me know in a note that Art was stuffing envelopes to be sent out the night before he died. Below you will find the form that is used to participate in this fundraising event.

Art, you will be truly missed at the 5p- Society Annual Conference and thank you for all your time and dedication to our organization!!

5P- Society

1814

CHARITY SOLICITED FOR

BIRD NUMBER

I pledge and promise to donate:

\$_____ one-time flat donation.

OR

\$_____ for every birdie made during the 2015 John Deere Classic to the John Deere Classic Charitable Corporation for use by participating charities.

GUESS THE BIRDIES & WIN A TWO YEAR LEASE ON A 2015 LEXUS NX!

I guess that _____ birdies will be made.

Only 1 grand prize will be awarded. Void where prohibited by law.

BIRDIES SCORED (YEAR)

1974 (2006)	1914 (2009)	2113 (2012)
1863 (2007)	2010 (2010)	2142 (2013)
1921 (2008)	2160 (2011)	2040 (2014)

PLEDGE INFORMATION (Please print)

NAME _____

ADDRESS _____

CITY _____

STATE _____

ZIP _____

PHONE OR EMAIL _____

Chip in for your chance to win

When you chip in to help area charities, you can win some great prizes. But your favorite charity will be the real winner. That's because participating charities receive every single penny of the donations from this program, plus a bonus from the Birdies for Charity Fund which historically has been a 5-10 percent match.

HERE'S HOW IT WORKS

Simply make a one-time flat donation OR pledge one cent or more per birdie. After the tournament, you'll be mailed a notice of your pledge amount due.

To enter the contest, guess the number of birdies that will actually be made by Tour Pros during the tournament, Wednesday through Sunday. A grand prize will be given to one person who guesses the correct number. In case of ties, winners will be randomly selected.

CONTEST RULES

- Only 1 grand prize awarded. Ties and other prizes determined by random drawing. Judges' decision final
- All guesses must be on an official pledge card and received at the tournament office by July 10, 2015.
- Rules are available at www.birdiesforcharity.com.
- No pledge or purchase required. Need not be present to win.

GRAND PRIZE: TWO YEAR LEASE ON A 2015 LEXUS NX



LEXUS
LEXUS OF QUAD CITIES

One lucky supporter of the John Deere Classic's Birdies for Charity program will win a 2 year lease on a 2015 Lexus NX, courtesy of Lexus of the Quad Cities.

OTHER CONTEST PRIZES

- John Deere riding mower
- John Deere Classic teemarker signed by the 2015 John Deere Classic champion
- \$500 credit to be used at any local John Deere dealership.
- Over 100 other great prizes



Signed by the 2015 John Deere Classic champion

KEEP FOR YOUR RECORDS

Your pledge is based on actual number of birdies scored.

I pledge \$_____ one-time donation

OR \$_____ per birdie

If 1,800 birdies are made, my total pledge would be:

1¢ = \$18	3¢ = \$54	5¢ = \$90
2¢ = \$36	4¢ = \$72	10¢ = \$180

I guessed _____ birdies would be made

Thank you to all who have participated in the past and will be participating again this year. All pledge forms should be sent to Birdies for Charity, 15623 Coaltown Rd, East Moline, IL 61244



VIRTUAL 5K FOR 5P-

WE DID IT!!! Our first Virtual 5k for 5p- was a HUGE success. We had over 1000 participants (registered and unregistered)!! Raised a whole lot of awareness in our own communities!! Raised some monies too!! Learned a lot of how the racing fundraising platforms worked and had a lot of fun doing it!! The event could not have happened without YOUR participation!!! This event could not have happened with the fantastic Social Media campaign led by one awesome volunteer Stacey Sanders.

It all started in October 2014, after joining the I Run 4 Michael program and getting a “buddy” for Katie (many of you also have buddies for your child/ren), Katie and I did a few 5k’s. So I started to ask myself—can we (5p- Society) do this, can we do an event where individuals around the world can participate in to help raise awareness and raise money at the same time—Virtually. Almost immediately after my thought process began, I get an email from Stacey asking the exact same thing and wanting to put together a Virtual 5k event. After several conversations we put the plan together and presented it to the board in November. I think the biggest question on everybody’s mind, WHAT IS A VIRTUAL 5K. Stacey did a great job of explaining the event, identifying sponsors and creating an entire Social Media Campaign. She also did an awesome job of maintaining the enthusiasm around the event, answering all the questions, and tying the event in with the International Cri du Chat Syndrome Awareness week by encouraging the Stripy Socks Campaign.

A BIG THANK YOU to everyone who participating, every one who donated and every who created your own events. If you did not participate this year, we hope you will plan to participate next year. We will begin the planning stages for next year’s event soon.

Enjoy some pictures from the event!!

Some of our sponsors . . .



**5p- Society's
Hall of Fame
Honoree Submission Form**

**Parent of the Year, Sibling of the Year, Grandparent of the Year or
Race Car Driver of the Year**

To honor that special parent, sibling, or grandparent, or Race Car Driver (Super Hero) who has gone *above and beyond the call of duty*, for the 5p- Society, please fill out the below form and submit. Please be sure to include all of the information, especially the honoree's mailing address and phone number (we need that information in order to contact your honoree). Also, be sure to tell us how this person went above and beyond for the 5p- Society. We look forward to hearing from you! Awards will be presented, during the banquet on August 1, 2015 at the 5p- Society's National Conference, in Indianapolis, Indiana.

Deadline for submission is: June 26, 2015.

Please submit forms via email or mail to:

5p- Society
Attn: Hall Of Fame Nominations
PO Box 268
Lakewood, CA 90714
director@fivepminus.org

Nomination for:

- Parent of the Year
- Sibling of the Year
- Grandparent of the Year
- Race Car Driver of the Year

Full Name of Nominee:

Nominator's Full Name:

Nominee's Email Address:

Nominator's Email Address:

Nominee's Phone Number:

Nominator's Phone Number:

Nominee's Street Address:

Nominator's Street Address:

Nominee's City / State / Zip:

Nominator's City / State / Zip:

On a separate sheet of paper, please tell us why you feel your nominee should be awarded the Hall of Fame award for 2015.



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



Meet C5

The Mascot of the International
Cri du Chat Awareness Week

Tweet with Us
[@5pminus](https://twitter.com/5pminus)

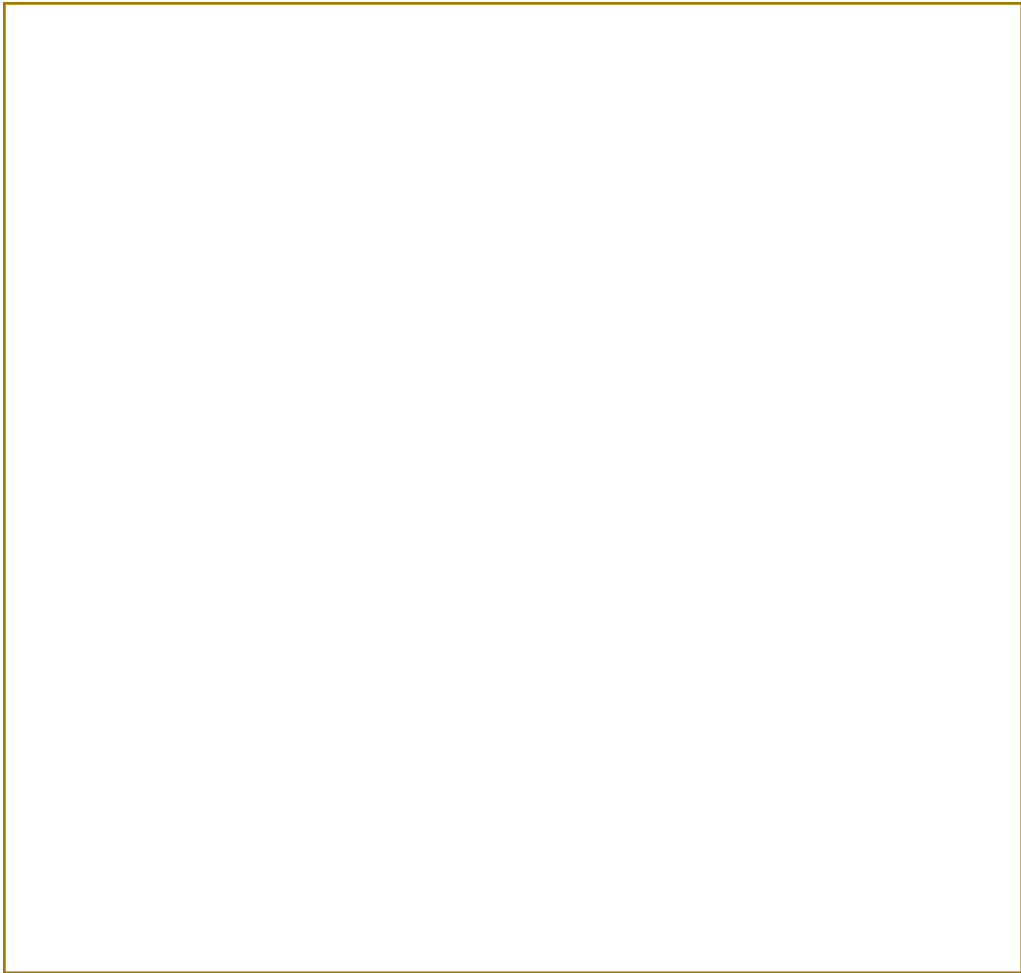
We're on the Web
www.fivepminus.org

Find us on FaceBook at <http://www.facebook.com/groups/385907554759706/>

Yahoo Group Page: 5pminus
<http://health.groups.yahoo.com/group/5pminus/join/>

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>



INTERNATIONAL CRI DU CHAT AWARENESS WEEK AND STRIPY SOCK CAMPAIGN

Our 4th annual Cri du Chat Syndrome Awareness Week was once again very successful with the Stripy Sock Campaign. Thank you to everyone who participated.



Start planning now for 2016 International Cri du Chat Syndrome Awareness week May 1-7.