

Tis the Season! *BY JEN WONG*

This time of year this phrase can mean many things to different people. One of the biggest “reasons for the season” for me and many is to connect and share with family and friends. I am thankful to Emma for how many of my truest friends she has brought into my life. Friends who have taught me how to be strong against the biggest foes, the ones we cannot change. Friends who will drop everything to help despite they have more on their plate than me. Friends who can see right through a fake smile and know when something is wrong. Friends who there is no such thing as TMI.

I’m thankful to all my family who has been there for us when we needed them, especially my mom who would fly in every year for Emma’s IEP meetings to care for my boys. Emma’s aunts and uncles who have discussed Cri du Chat Syndrome to their children so they have a better understanding on how to play with her, prompting two of her cousins to write papers for school on CdCS. Family members who step up, EVERY TIME, I ask for donations of time or donations for The Society.

In our crazy mixed-up busy lives, we don’t always have the time to tell those who mean so much to us how much we appreciate all they do. In-between all the Christmas shopping, parties, decorating, baking, errands, and kids’ activities, I am trying to take a minute to let the special people in my life know how much I appreciate them.

With that said, I wish to warmly thank my CdCS family for all the love, support, and advice throughout the years. A friendship with someone who is living the same experience is an invaluable resource and support. I wish you all Happy Healthy Holidays filled with family, friends, and fun.



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WINTER 2015

30 YEARS RACING FOR AWARENESS

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

The 2015 conference will be held at the Sheraton at Keystone Crossing in Indianapolis, Indiana. Conference Brochure with registration form will be available in March 2015. Stay tuned!

RACE TO REWARDS

Earn rewards as you raise money for the 2015 conference. Raise \$1500.00 and your registration fee will be covered for up to two adults and two children; Raise \$3000.00 and your registration fee for up to two adults and two children and one night at the hotel will be covered; Raise \$5000.00 and your registration fee for up to two adults and two children as well as three nights at the hotel will be covered. See <https://adobeformscentral.com/?f=70tEq6U9rETr9wx3Qe9tnA>

FAMILY FUN EVENT

We will be heading to the Indianapolis Zoo for the family outing.

SIBLING OUTING

The siblings will be going to Caribbean Cove Water Park! Don’t forget your bathing suits, towels and sunscreen!!

The 5p– Society is proud to announce the launch of our new website. The new website at www.fivepminus.org was revealed on December 1st. We are very happy with the clean new look. We would love for you to visit the new site and take a look around.

Some of the new features:

- An interactive news feed with our twitter account @fivepminus on the home page.
- Event page with the ongoing events, special events and fund-raising events.
- A comprehensive resource page.
- Sibling and grandparents connection pages.
- Family stories and pictures. If you are interested in having a page, please contact Laura at director@fivepminus.org. You will be given your own page url, username and password. You can showcase your child, update your child’s progress or link to your blog.
- Frequently Asked Questions area
- Call me and Email me features.
- Join me button
- Donate button and links to other ways to support the 5p– Society through AmazonSmile, Igive, Cars4Causes, etc.



LEARN SHARE CONNECT

Blogs to follow:

- * <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>
- * <https://www.facebook.com/sophieourgift>
- * <http://mydanceintherain.org>
- * www.nourishedpoint.blogspot.com
- * www.kbhatch.blogspot.com
- * www.disabilitypride.com
- * www.emilyrosegodsgift.com
- *
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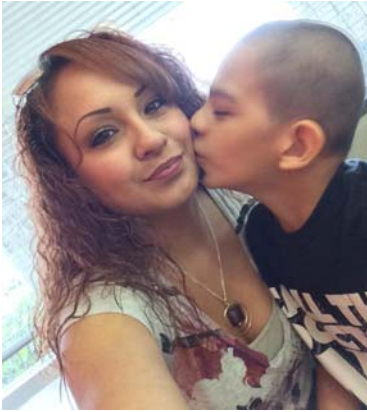
YouTube Videos to Watch

- [5p– Society “I Can” video](https://www.youtube.com/watch?v=2AEvN0-6M6I)
<https://www.youtube.com/watch?v=2AEvN0-6M6I>
- [Adam & Tyler Buckner on KASA morning news! 5/30/2014](http://kasa.com/2014/05/29/cru-du-chat/)
<http://kasa.com/2014/05/29/cru-du-chat/>
- [Cri du Chat Awareness US](https://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](https://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](https://www.youtube.com/watch?v=A47tRTi8YPw)
<https://www.youtube.com/watch?v=A47tRTi8YPw>
- [International Cri du Chat Syndrome Awareness—Meet Nellie](https://www.youtube.com/watch?v=zw2joxiYjR4)
<https://www.youtube.com/watch?v=zw2joxiYjR4>
- [Emma’s “Steps of Faith”](https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player)
https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player
- [Documentary by Maria Ripoli](http://www.cromosomacinco.com/)
<http://www.cromosomacinco.com/>

Books to read:

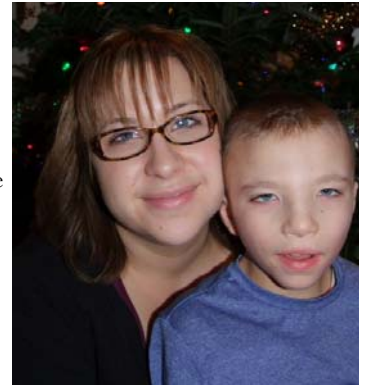
- A Book to my son Nathan*: <http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=ywWDIdOAWC>
- Raised by my Child* by Sally D. Yantis-Grube, 2011—Mom to Heidi, 18-year-old with Cri du Chat Syndrome.
- Her Name is Montel*, by Casey Evans, 2005—Dad to Montel, 20-year-old with Cri du Chat Syndrome.

MEET THE NEW AMBASSADORS



Hi I'm Angela De La Garza, mother to three amazing kids. My second is Angel 9 years old, with autism and cri du chat syndrome. My son was diagnosed when he was three years old, since then we have consistently worked on his many goals. As Angel's mommy I begin to focus on the joys of his innocent soul and prayed through the dark moments of his condition. I very quickly discovered I had to explain CDC to doctors, therapists, and even specialists, most often than not. I began to advocate for my son every opportunity I got. Some of my proactive activities include hosting a CDC and Coffee presentation, speaking to the general public at expos, conventions, founding an international support group, setting up booths at local fairs & genetics festivals. Handing out brochures and information on the syndrome, newspaper, billboards, parades, a therapy facility commercial featuring Angel, and interviews with Univision and Fox News. I look forward on continuing my efforts to educate and represent the many families affected by cri du chat syndrome. My motivation isn't solely inspired by my son but by the bond and love, hope and faith, we all share for our very special children.

Hillary Losen is a registered nurse with 13+ years experience in various fields including Cardiology, Gastroenterology, Obstetrics, Dermatology, Allergy, Geriatric, and Public Health. She is married, and the mother of 3 amazing children, Jacob 6 (CDCS), Evelyn 4, and Marian 2. Hillary is passionate about educating medical professionals, teachers, therapists, and the general public about Cri Du Chat Syndrome. When Jacob was diagnosed at 6 months old, they were given a grim outlook, and told he would likely never walk, talk, stand, or function independently. Since that day, they have vowed to help Jacob achieve as much as possible. Happily, he has and is achieving these milestones and therefore bringing hope to countless others. During the 2014 Awareness Week, she contacted their local newspaper with Jacob's story, and an article entitled "Living With Cri Du Chat" was released to over 100,000 residents in the Kendall County, IL area. Her goal with the Ambassador program is to bring awareness to the community and encourage more research, funding, and acceptance. Recently, the Losen family relocated back to their home state of Wisconsin, in the Mukwonago area. As a full-time mom and household manager, Hillary enjoys exercising, attending Badger football games, drawing/painting, and church.



Rachel is an administrative assistant and team lead for the National Fraternal Order of Police. After work hours are done, she most looks forward to cuddles, tickles and laughs with Anna. Anna, the only child, is 11 years old and affected with CDCS. Moments of downtime don't happen anywhere near enough, but when they do Rachel enjoys reading contemporary fiction, watching television and playing video games while curled up with Anna. Friends say Rachel is stubborn, sincere and goal-oriented. She describes herself as an average person blessed with an exceptional life, and an exemplary daughter.

Mona Witman, of Flanders, New Jersey, is the proud grandmother of 3 year old Jordan Moore of Eastchester, New York. Mona received her M.Ed in Vocational and Rehabilitation Counseling from Columbia Teachers College in NYC. She was a career counselor for 27 years specializing in the support of displaced homemakers. Mona is excited to become an Ambassador for 5P- and educate the community about Cri Du Chat.





VIRTUAL 5K FOR 5P- MAY 3-9, 2015

The 5p- Society is asking families and supporters to bring awareness of Cri du Chat Syndrome and support for programs that benefit the Cri du Chat/5p- community. Virtual Walk activities can be developed by local families and can include activities such as an in-person walking (individual, family or teams), or an event on a specific day - A Virtual Walk can be anything you want it to be? We are asking that you plan to complete the Virtual 5k for 5p- during International Cri du Chat Syndrome Awareness Week May 3-9, 2015.

For its 4th Annual International Cri du Chat Awareness Week, we are looking for ways for families to spread awareness and benefit the 5p- community. This includes annual conference, regional gatherings, research, Ambassador Program, advocacy, outreach, newsletters and other communications that help to bring our families and community together.

There are various ways to participate. Registration will open on February 1st through a company called RaceWire.

- **Form a Team:** Gather friends and family and form a Virtual Walk team! Create your 3.1 mile or 5k route, a date and a start time. Meet up for a run or a nice leisurely walk with families and friends. Take lots of pictures and don't forget to share those pictures and information about your team on the 5p- Society social media pages:

Facebook.com/CriDuChatSociety or Facebook.com/Virtual5kfor5pminus

Twitter - @5pminus

Instagram - @5pminus and use #5pminus5k

- **Individual Participation:** Pick a day, take the dog for a walk, or walk/run on your own. Create your 3.1 or 5k favorite route. Use one of the tracking apps such as Runkeeper, Map my Run, Runtastic to track your route. Save your route and share it on one of the 5p- Society social media pages.
- **Cost to participate:** \$5.00 registration per person (children/adults with Cri du Chat Syndrome are free)
- **Participation medals:** \$5.00
- **T-shirts:** \$5.00—T-shirt order must be received by April 10 to be available for International Cri du Chat Awareness week. Shirts ordered after April 10th will be available in limited sizes and quantities, or until sold out.
- **Wear your stripy socks!!** Don't forget to wear your stripy socks while you are running/walking. Even if you cannot participate in the Virtual Walk, it would be great if you could participate in the Stripy Socks Campaign (no cost to participate) and post on Social Media with the #stripysocks #criduchatawareness #5pminus

GOLD LEVEL - \$1000 DONATION

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

2015 VIRTUAL 5K FOR 5P- SPONSORSHIP OPPORTUNITIES

SILVER LEVEL - \$500 DONATION

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



BRONZE LEVEL - \$100 DONATION

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

Registration
opens
February 1,
2015

<https://racewire.com/register.php?id=4810>



Like us on FaceBook for up-to-date information

www.facebook.com/virtual5kfor5pminus



The 5p- Society is a 501(c)3 not-for-profit organization. For more information, please contact director@5pminus.org or visit www.5pminus.org.

2014 5P- SOCIETY DONORS & SPONSORS

The 5p- Society would like to thank each and every individual, corporation, family, and friend who contributed to the 5p- Society. With your donations, the 5p- Society is able to continue to support its mission, improve its programs, and create new programs. Below is a list of the 2014 donors. Many of these donations assist with the annual conferences.

Platinum Sponsors

+ \$2000

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Brad & Christy Hammond
Nicholas & Christina Cutrara & Family
Derek Stevens & Maria Corrado
Give with Liberty
Harrison High School
Jason & Michelle Myatt
Melissa & Daniel Morin
Michael & Jennifer Lee
Underground Fitness, LLC
William & Rita Bourne

Gold Sponsors

\$1000-\$1999

Allstate Giving Campaign
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C&M Sporting Goods, Inc.
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Jason & Hilary Losen (Give with Liberty)
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John & Christina Yauch
Jose & Rebecca Rocha
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Matthew & Rachel Stanford
Pfizer Foundation
Quantlab Financial
The Witman Scholarship Foundation

Silver Sponsors

\$500-\$999

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Johnna & Racann Sleith
Judy Nguyen
Kathryn Knapp
Kimon & Christine Rumanes

L. Keeley Construction
Maple Leaf Foods Inc.
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Mark Erhardt
Mary Pluska (Give with Liberty)
Modera Charitable Foundation
Thomas Jefferson Middle School
Thomson Reuters
Tim & Dawn Turner

Bronze Sponsors

\$100-\$499

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Alice Kowalski
American Meat Science Association
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Ashley Wright
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Bradley Tocher
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GE Foundation
Geoffrey & Jolene Towers
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 Yechiel Meir Man
 Zachary & Leah Moore
 Zela Mohamed

***Please note that all efforts have been made to make sure that these lists are correct. If you feel that you were left off the list, please contact the 5p- Society so that they can confirm your donation.

NEW FAMILIES FOR 2014

Welcome to our new families who joined the 5p- Society. Your membership strengthens the organization, allows more families to be able to connect with each other and assist researchers. Please welcome the following:

Tim & Sue Blakley - Cerritos, California
 Billy & Monica Masson - Sullivan, Missouri
 Blair MacDonald & Tanya LeFort - Summerside,
 Prince Edwards Island, Canada
 Tom & Brittani Shipke - Concord, Ohio
 Anne-Sophie Rondeau - Oxley Park, Australia
 Debbie Van Broeck - The Netherlands
 Tim & Rachael Reid - Fullerton, California
 Jerrod & Amber Estep - Sias, West Virginia
 Michelle Wright - Princeton, Illinois
 Stockton & Amy Martin - Ripley, West Virginia
 Charles & Monica Zamudio - Burbank, California
 Sasha "Nichole" Gregory - Bedford, Texas
 Island Borgela - Canada
 Richie & Sylvia Aker - Cullman, Alabama
 Shante Walker - St. Louis, Missouri
 Belinda Martinez - Poteet, Texas
 Jason & Michelle Williams - Pearland, Texas
 Mark & Melanie Sheppard - Lewiston, Idaho
 Brenda Chamlee - Ellenwood, Georgia
 Jaqualyn Wilson - Meridian, Idaho
 Tiffany Stone - Norman, Oklahoma

Karina Guzman - Wood Dale, Illinois
 Robert & Sunamita Leming - San Diego,
 California
 Anel Burger - Centurion, Republic of South Africa
 Laura Ragland - Wallan, Victoria, Australia
 Regina Erdly - Lewisburg, Tennessee
 Bill & Rita Bourne - Rochester, Minnesota
 Chris & Misty Bailey - Cheyenne, Oklahoma
 L. Jo Hoermann - Peterson, Iowa
 Dan & Ashley Rouillard - Welland, Ontario,
 Canada
 Eve Ferraro - Pittsburgh, Pennsylvania
 Megan Wood - Hanford, California
 Teresa Jones - Levelland, Texas
 Eric & Amber Erickson - Bondurant, Iowa
 J Christian & Megan Leston - Brooklyn,
 New York
 Manuel & Araceli Maldonado - San Antonio,
 Texas
 Jordan Beard - Mansfield, Ohio
 Derek Stevens & Marie Corrado
 Ashley's Moon Shadow, Inc.- Mentor, Ohio

Ivan & Julia Perez - Glendora, California
 Tommie Lautzenhiser - Edon, Ohio
 Ashlee Mick - Santa Maria, California
 Matthew & Samantha Gansen - Calmar, Iowa
 Sean & Jessica Fox - Jonesborough, Tennessee
 Kristal Duffin - Lethbridge, Alberta, Canada
 Mona Witman - Flanders, New Jersey
 David & Kimberly Bennett - Madison, Alabama
 Carin Torre - Los Angeles, California
 Tia Wilcox - Dover, Delaware
 Peter & Kathryn McGuire - Brooklyn, New York
 Brodie & Elizabeth Wright - Berthoud, Colorado
 Fiora DalCanto - Park City, Utah
 Evan & Ashley Warden - Toccoa, Georgia

THE MANY FACES OF CRI DU CHAT SYNDROME





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

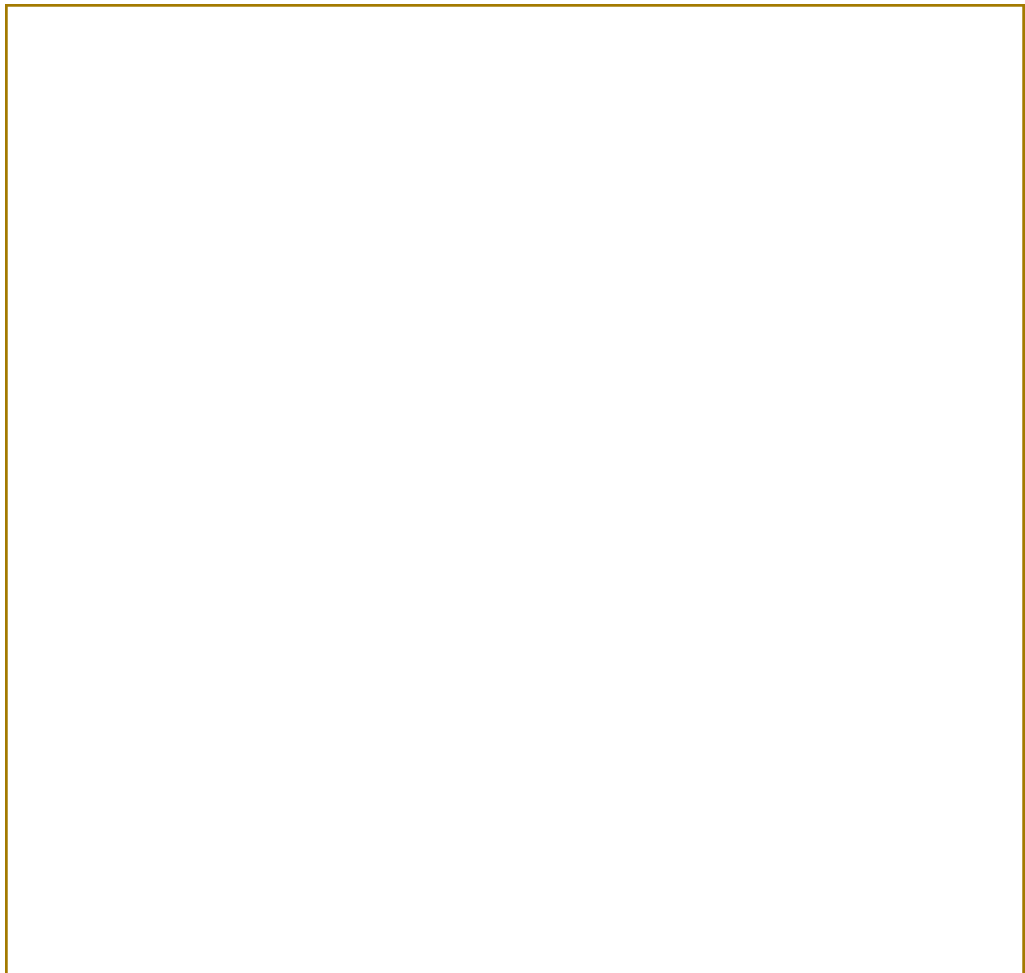
Tweet with Us
[@5pminus](https://twitter.com/5pminus)

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/>

"I Can" video production is complete.
 You can see it at <https://www.youtube.com/watch?v=2AEvN0-6M6I>



RECOMMENDATIONS BY PARENTS FOR PARENTS

Sleep and sleep issues are one of the most common behavior problems that children with Cri du Chat Syndrome might have. Many parents have gone to a tented bed to help keep their child safe at night. Here are a few examples of tent beds that some of the 5p– Society families use. <http://www.thesafetysleeper.co.uk>



Myreadysetbloom.com



www.cyrdesigns.com



SleepSafer® - HIGH BED



SleepSafe Beds
 SleepSafeBed.com

Hats, wristbands, magnets, keychains, calendars and tumblers with the 5p– logo can be purchased through the 5p– Society. Other Clothing, drinkware and logoed items through www.cafepress.com/5pshop.