

## Raising Awareness One Community Member at a Time *by Jen Wong*

About a month ago I went to the grocery store deli to get dinner. I was wearing one of my CDC awareness shirts. While waiting, the employee noticed my shirt and asked what CDCs was. I gave her my CDC 101 spiel. She asked me a few questions and then said “I’ll have to look it up.” I gave her our website information, thanked her for asking, and left. A few weeks ago, I was back in the store with Emma and the same employee was there. We said “Hi” and I introduced her to Emma. She chatted a bit with Emma and we both went on our way. We frequent the store and every time she sees Emma, she makes sure to talk with her and if she is with another employee, she introduces Emma to them. That’s how easy raising awareness can be. Everyone can be an ambassador for their loved one in their community.

With Awareness Week coming up shortly, this is the time to focus on one big thing to do to raise awareness. Whether it’s participating in the 5K walk/run, providing 5P- fact sheets to medical providers/therapists in your area, wearing striped socks, or talking in your child’s school, May 1-7 is that calendar reminder to do something extra to let the community know how wonderful our children are. This is the time to create awareness just a little further than your community boundaries. Go to the NICUs and Maternity floors of your local and not so local hospitals and give them the 5P- Society’s contact information, along with the fact cards. If you’re able and comfortable, attach your contact information. Can you imagine the positive impact of having a face-to-face person for support just after receiving your child’s diagnosis?

However, just because we have an awareness week, doesn’t mean that May 8, we pack everything up until next year. I would challenge everyone to introduce one new person a

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### 2017 Conference - Festival of Families

You can now make your reservations at the hotel for the conference and register for the conference.

Dates: August 3 - August 6

Location: Milwaukee Marriott West, W231N1600 Corporate Ct, Waukesha, WI 53186 Phone: (262) 574-0888 or online [here](#). If you have any problems or concerns contact Laura at [director@fivepminus.org](mailto:director@fivepminus.org).

Room rate: \$119.00 per night (plus taxes and service charges)

For more info go to our website at [https://fivepminus.org/event/2017-5p-society-conference/?event\\_date=2017-08-03](https://fivepminus.org/event/2017-5p-society-conference/?event_date=2017-08-03)



week to your child or 5p-. That's 52 more people a year that have heard of 5p-. You never know the affect that could have on someone. Emma has a friend who she has known since elementary school. In Fifth grade, her friend wrote an article to submit to the local newspaper about people with disabilities, specifically mentioning Emma in her article. They are in High School now and her friend's ambition is to be a special education teacher. Can you imagine bringing your child to school and the teacher actually knowing what 5P- is? Perhaps your interaction was just enough to pique the interest of a future doctor or geneticist to do their fellowship research on 5P-. Or simply, maybe that interaction was enough to remove the fear, hesitation, and negative stigmas that can be associated with people with disabilities when someone hasn't had the opportunity to be around them.

“Just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far reaching effects.” – 14<sup>th</sup> Dalai Lama

## 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://mikeandbrittanerickson.blogspot.com>
- \* <http://thissideofordinary.blogspot.com>
- \* <http://beautifulunexpectedjourney.blogspot.com>
- \* <http://www.cdcslovehope.com/blogspot.com>
- \* <http://clairematilda.wordpress.com>
- \* <http://crazyincognito.blogspot.com>
- \* <http://myriverside.wordpress.com>
- \* <http://allaboutvayla.blogspot.com>
- \* <http://brennanandcalebsmom.blogspot.com>
- \* <http://praiseyouinthestorm.com>
- \* [www.prayforellee.org](http://www.prayforellee.org)
- \* <http://notquiteearthmother.wordpress.com>
- \* <http://tricia-themama.blogspot.com>
- \* [www.angelarichey.blogspot.com/](http://www.angelarichey.blogspot.com/)
- \* <http://lessonsfrommydaughter.me>
- \* <http://martianmommy.blogspot.com>
- \* <http://www.specialneedsdadchronicles.space>
- \* [www.mydanceintherain.org](http://www.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.
- [International Cri du Chat Syndrome Awareness— Meet Nellie](#)  
<https://www.youtube.com/watch?v=zw2joxiYjR4>
- [Emma's "Steps of Faith"](#)  
[https://www.youtube.com/watch?v=giW\\_iP5ibr8&feature=youtube\\_gdata\\_player](https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player)
- [Documentary by Maria Ripoli](#)  
<http://www.cromosomacinco.com/>
- [Meet James Chalmers](#)  
<https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

### Books to read:

[A Book to my son Nathan](#): <http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=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.

# INTERNATIONAL CRI DU CHAT AWARENESS WEEK

*by Nick Wallace, Vice President 5p- Society*

International Cri Du Chat Syndrome Awareness Week will be upon us before we know it. The dates of this year's awareness week will be April 30<sup>th</sup> – 6<sup>th</sup>. We have a lot of great things in the works for this year. Due to the amazing success of our past Virtual 5k's, we will be hosting the Virtual 5k again this year. We are trying to obtain proclamations from all 50 states wherein May 5<sup>th</sup> will be known as Cri Du Chat Syndrome Awareness Day. We will also keep wearing our striped socks.

We will also require your help with keeping our Where Is C5 campaign alive. This idea was brought to us last year by one of our board members, Gloria Griffin, and the idea started to take off. We believe this idea can really help spread awareness and hope you do too. For those of you who don't know about the Where Is C5 campaign, it is essentially like the book Flat Stanley. The premise of the project is that kids send a printed version of Flat Stanley to a school, a celebrity, a family member, a politician or anyone of interest and the recipient returns the little flat guy along with a completed journal and perhaps some souvenirs such as post cards, photos, or special items.

The 5p- Society has our own mascot, C5, and we are going to make a version of C5 available to print and send like the Flat Stanley project. Our goal is to get photos from across the globe of people posing with C5 during awareness week. We will use the hashtag #C5 and #criduchat to help spread the awareness on Facebook and Twitter. Our hope is that we can get as many people involved in this project as possible, and by starting early, we might be able to get some big names to help us raise awareness by posing with C5 and posting the photo on their various social media pages.

Keep an eye on our Facebook group (<https://www.facebook.com/CriDuChatSociety>) for more information on this project and our 50 states proclamation project. We will also be posting details on our website [www.fivepminus.org](http://www.fivepminus.org).

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



## CAREGIVER'S GUIDE UPDATE BY LAURA CASTILLO

I would like to thank all of those who are participating and have given some wonderful information in the internal research project of the 5p- Society. All four of the initial questionnaires are finished and have been sent out. Over 100 families have answered the 1st initial Family History Questionnaire, and are in the process of finishing the remainder of the questionnaire. Reminders will go out to those who haven't finished the 2nd (Medical History), 3rd (Educational History) or 4th (Therapies & Treatment) questionnaires. The 5th questionnaire designed strictly for Adults will be sent out soon.

I would also like to thank Adela Castro for offering to translate the questionnaire into Spanish to reach even more families. As soon as the Spanish version is complete we will announce that to our members and the International community of 5p-.

It is not too late to participate!! For the first initial questionnaire please go to <https://form.jotformpro.com/62796530604964>

I will continue to update you on the progress of the Caregiver's Guide for Individuals with Cri du Chat Syndrome through our FaceBook pages. Questions or concerns, please contact me at [director@fivepminus.org](mailto:director@fivepminus.org).

## AWARENESS WEEK EVENTS



Download and print the coloring page version or the colored version of C5 (above), or the kids' document and share with your child's classroom.

Take C5 with you wherever you go. Take pictures and upload to Instagram or Twitter at @5pminus or FaceBook using the #C5 and #cri duchatawareness



### Stripy Socks Campaign

Wear your striped socks, one long and one short to show the whole and deleted 5th chromosome and create a conversation starter. Don't forget to take pictures and post on social media with #stripysocks #cri duchatawareness

Wear them especially on May 5th, Cri du Chat Awareness Day!


**Your body is made up of trillions of cells, too small**


**to see, even with a microscope!**

**Inside these tiny cells are**

**23 pairs of chromosomes,**

that make you the person you are. The information in your chromosomes

determines your hair  color,

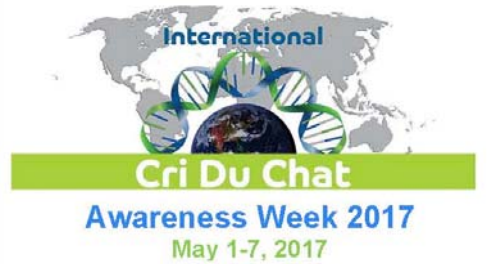
your eye  color, how you **grow**,

and all of the other things that you can do.

**People with Cri du Chat Syndrome are missing a small part of Chromosome 5.**

*It sometimes makes it tricky for them to do things, and it might take a little longer for them to learn to walk and talk.*

*😊 Sometimes, they might need your help.😊*



For additional downloads go to [https://fivepminus.org/event/awareness-week-events/?event\\_date=2017-05-01](https://fivepminus.org/event/awareness-week-events/?event_date=2017-05-01) including Fact Cards, First Responder Info Card.

Have an event or idea, please pass it on!!

Need some 5p- gear? See page 8 for more info on how to order.

# SLEEP PROBLEMS, LOW FERRITIN AND PPIS

BY RACHEL STANFORD

Let me preface this first with the following disclaimer: I am a lawyer, not a medical doctor. This is intended to arm families encountering sleep issues with their children information to discuss with their children's pediatricians.

Miles, now eight years old, has never been much of a sleeper. As an infant, doctors suspected GERD and colic were the reasons for his sleeplessness. At two months old, Miles was prescribed Prevacid for his GERD. Although he was able to feed better, he still had massive reflux after eating. We tried propping him up to sleep. Most nights, though, my husband and I would alternate holding him up in the rocking chair of his room to help him get some rest. We were exhausted. Doctors offered no solutions, saying that he would hopefully grow out of it. Looking back now, I think the pediatricians we spoke to thought we were exaggerating. It couldn't possibly be as bad as we were saying, right!?

Yet, Miles did not sleep through the night consistently until he was about four years old, when we got him a tent for his bed and tried a little "cry it out." To be sure, he still screamed frequently in his sleep, but he usually was quiet after about five minutes (our "time limit" on how long we'd let him scream). However, after about a year, he began waking more and more frequently. By age seven, he was back to waking five times per night, screaming inconsolably. We bought an extra bed for his room and my husband or I (usually my husband) started sleeping in Miles' room with him.

Incidentally, he had also started having unexplained seizure episodes, for which we had started seeing a neurologist. She also offered no solutions for his lack of sleep, explaining sleep problems are not unusual for children with Cri du Chat Syndrome, as well as other developmental disabilities.

Once again, after a while, the exhaustion took its toll on all of us and we hit what I felt like was a breaking point. I finally called Miles' pediatrician's office in tears one day, asking what we could do. The pediatrician referred us to a sleep neurologist at Texas Children's Hospital in Houston. Oh, how I wish we had called sooner!

At Miles' visit with the sleep neurologist, she asked a ton of questions and then made her recommendations. She said our first step would be to have some blood work done, because oftentimes children can have Restless Leg Syndrome, caused by low iron or ferritin levels. See, e.g., [http://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/restless-legs-syndrome/what-is-rls/causes.html](http://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/restless-legs-syndrome/what-is-rls/causes.html).

Sure enough, when Miles' bloodwork came back, he had extremely low ferritin levels! The sleep neurologist prescribed ferrous sulfate supplements for him and said it would take about six months of daily use for his ferritin levels to return to normal. After about 1-½ months of being on the iron supplements, Miles started sleeping through the night again. And, almost a year later, he still sleeps all night! Further, he hasn't had any additional seizures.

Of course, being curious, I wondered how Miles' ferritin levels had gotten so low. He has a highly varied diet, he eats plenty of meat and leafy greens. At that point, the only medication Miles' took was Prevacid. So, I googled "PPI ferritin iron." Sure enough, I found medical journal articles revealing a possible link between long term PPI use and iron malabsorption (among other vitamins and minerals). See, e.g., <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4110863/#bibr49-2042098613482484> (summarizing completed studies linking PPI use and possible malabsorption issues in certain populations).

After extensive discussions with Miles' GI specialist, we slowly weaned Miles off Prevacid. The slow-wean period took about three-months, during which time, Miles' did display some rebounding. However, I am happy to report he no longer takes the drug, nor does he have any visible reflux (so long as he doesn't eat chocolate or mint or drink citrus juices). We are continuing to monitor his esophagus and stomach with his GI to make sure he doesn't have silent reflux.

Since I have shared this information with other families with sleepless children, I know of two others who ended up with the exact same issue. I hope to circulate this information to help other families! **If your kid is having sleep problems, you might want to see a pediatric sleep neurologist and make sure to ask him or her if low ferritin levels could be an issue, especially if your child has used PPIs for GERD long term.**

# SELF ABUSE

## *THE AUTISM DISCUSSION PAGE ON ANXIETY, BEHAVIOR, SCHOOL, AND PARENTING STRATEGIES: A TOOLBOX FOR HELPING CHILDREN WITH AUTISM FEEL SAFE, ACCEPTED, AND COMPETENT* *BY BILL NASON*

Shared on FaceBook group page:

Hand/arm biting, slapping self and head banging are very common with children with emotional regulation problems. All three behaviors result in strong stimulation that release stress chemicals when the nervous system is overloaded. Hand/arm biting is especially effective, because of the strong proprioception (resistance to joints and tendons) that it gives. The child gets both strong proprioception into the jaw, as well as into the hand or arm. When the child gets frustrated, the stress chemicals build up to boiling point and the child seeks out strong proprioception through self abuse, aggression, or property destruction to release stress chemicals from the nervous system. To reduce self abuse you have to do several things:

1. Identify conditions that cause the stress and help reduce them. Keep track of the events that precipitate the agitation and build in proactive strategies to reduce the stress. More times than not the demands (sensory, task performance, social, emotional, etc.) of the situation are greater than the child's current skills for dealing with them. Eliminate, modify, or accommodate these conditions to lower the demands on the child, or provide greater assistance to support the child. Often sensory overload, too much uncertainty, or physical pain is at the root of self abuse. Use the "fragile world on the spectrum" (appendix \_\_\_\_ ) document to help identify and accommodate for the condition that commonly cause problems for your child.
2. Young children, until they develop speech, will engage in self abuse as a means of communicating distress. Self abuse becomes their major way of communicating pain, discomfort, or need to escape the situation they are in. If your child is nonverbal, try to teach your child to uses picture communication, manual signing, or standard gestures to help him communicate.
3. Identify the function that the behavior serves. All behavior serves a function for the child (to escape something they do not like, communicate frustration, gain something that they want, etc.) Once you determine the function, than teach another behavior to take its place. If the child is engaging in the behavior to escape or avoid something, then identify another way of escaping (using break card, ask to leave, etc.). If they are doing it for proprioception, then give them another way of getting it (biting tubing, chewing gum, etc.). If the child bites himself when upset, how do you want him to react when upset? If he hits himself to say "leave me alone", how do you want him to communicate this?
4. Once the replacement behavior is determined, have the child practice it when calm and reinforce heavily. You cannot teach new behavior when the child is upset. Practice the new response and, if possible, role play common situations to practice the response. When the child starts to get upset, prompt the replacement behavior and reinforce the child for choosing that behavior over the biting.
5. If the child has good control over his behavior, you can simply reinforce the lack of biting behavior. For example, develop a sticker chart with four or five boxes in a row on it. Have the child pick out a reward that he wants to work for (e.g. rent a video). Place a picture of the reinforcer at the end of the sequence of squares. Each day that he displays no incidences of biting, praise the child and have him put a sticker on his chart (in one of the boxes). Make a big deal over it and have him count how many stickers he needs to earn the video. Once he fills up the boxes with stickers he gets to rent a video. If he doesn't earn a sticker for the night, then take him to the chart and let him know he cannot have one tonight but he can try again tomorrow.
6. If it is harder for the child to control the behavior, you can use the 1-2-3 approach. Once he starts to bit, you count one, then two, and if you have to say three...he loses his sticker. This way it gives him a chance to regroup himself. If the child has multiple incidents of biting each day, then reinforce start with first decreasing the frequency of biting per day. If he averages four episodes of biting a day, put up board of four tags. Each time he bites himself have him take one tag off the board; if he loses all four tags then he doesn't earn his sticker at the end of the night. However, if he has at least one tag left he gets his sticker for the day. Once the child learns to hold himself to just three biting incidents a night, then you reduce the tags to three, then to two, etc. until the behavior is infrequent.

This series on challenging behavior can be found in the green book, "Autism Discussion Page on Anxiety, Behavior, School and Parenting Strategies." [https://smile.amazon.com/Discussion-anxiety-behavior-parenting-strategies/dp/1849059950/ref=sr\\_1\\_fkmr0\\_1?ie=UTF8&qid=1490463875&sr=8-1-fkmr0&keywords=Autism+Discussion+Page+on+Anxiety%2C+Behavior%2C+School+and+Parenting+Strategies.%E2%80%9D](https://smile.amazon.com/Discussion-anxiety-behavior-parenting-strategies/dp/1849059950/ref=sr_1_fkmr0_1?ie=UTF8&qid=1490463875&sr=8-1-fkmr0&keywords=Autism+Discussion+Page+on+Anxiety%2C+Behavior%2C+School+and+Parenting+Strategies.%E2%80%9D)

# NEW STRATEGIC PLAN OF THE 5P- SOCIETY

The Board of Directors of the 5p- Society approved the 5p- Society's new 3 year strategic plan at its annual board meeting.

## **Our Vision (New)**

Our vision is that individuals with 5p-, their families, and their team of service providers have a comprehensive resource to turn to for accurate up-to-date information, support, and acceptance.

## **Our Mission (New)**

To maximize quality of life for individuals with 5p-and their families.

## **Who We Serve**

The 5p-Society supports families primarily in the United States and Canada, with over 2,000 families as members. As the largest 5p-support organization in the world, we are a resource to families everywhere.

## **Our Programs and Services**

The 5p-Society accomplishes its mission in six ways:

1. In-person support at the annual conference and regional get-togethers.
2. Provide informational content and support via its web site, Facebook page, newsletter, and network of Regional Support Coordinators.
3. The Executive Director manages day-to-day operation of the society, communicates with families to direct them to appropriate services and resources, and produces the annual conference.
4. The Board of Directors, composed of parents and grandparents of individuals with 5p-, oversees the functions of the society and participate in quarterly meetings, committees, and workgroups.
5. The Professional Advisory Board, composed of medical, academic, and therapy professionals, act as an expert resource for our members and makes recommendations on research projects.
6. The Ambassador Outreach Program is responsible for spreading awareness of 5p-by representing the society at health fairs, medical symposiums, school resource fairs, community events, and other resource events.

## **Background and Context**

- The 5p-Society was founded in 1986 to fill a void in information and support for families having a child with a chromosome number five (5) short arm (p) partial deletion (-).
- We are a pay it forward organization in that our members receive support (get help), provide support to other families (give help), and document best practices for future families (leave a trail).
- We have a people first approach to put the person before the disability and focus on maximizing strengths, not defining limitations.
- We provide a big tent as we serve individuals with all variations of 5p-, including but not limited to terminal deletions, interstitial deletions, unbalance translocations, and mosaicism. The resulting spectrum of abilities found in these individuals requires a broad range of support strategies.
- As an organization focused on a rare disorder, we are constantly challenged to raise funds, enable research, and progress organizationally. This is due to the low geographic concentration of members in any city, state, or province, and the high level of care required by our children. We are also challenged to be of service to families with adult children and keep families engaged with our organization over the years.

## **Our Goals**

1. Strengthen and enhance our face-to-face family support.
2. Manage and expand our social media and web presence to deliver many of our services online.
3. Proactively drive research that will directly and materially benefit our families.
4. Create predictable sources of revenue to fund our mission and goals.
5. Formalize data collection and ensure its protection and appropriate use.
6. Implement organizational improvements to support growth.



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RETURN SERVICE REQUESTED



### Meet C5

The Mascot of the International  
Cri du Chat Awareness Week

May 1-7, 2017

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

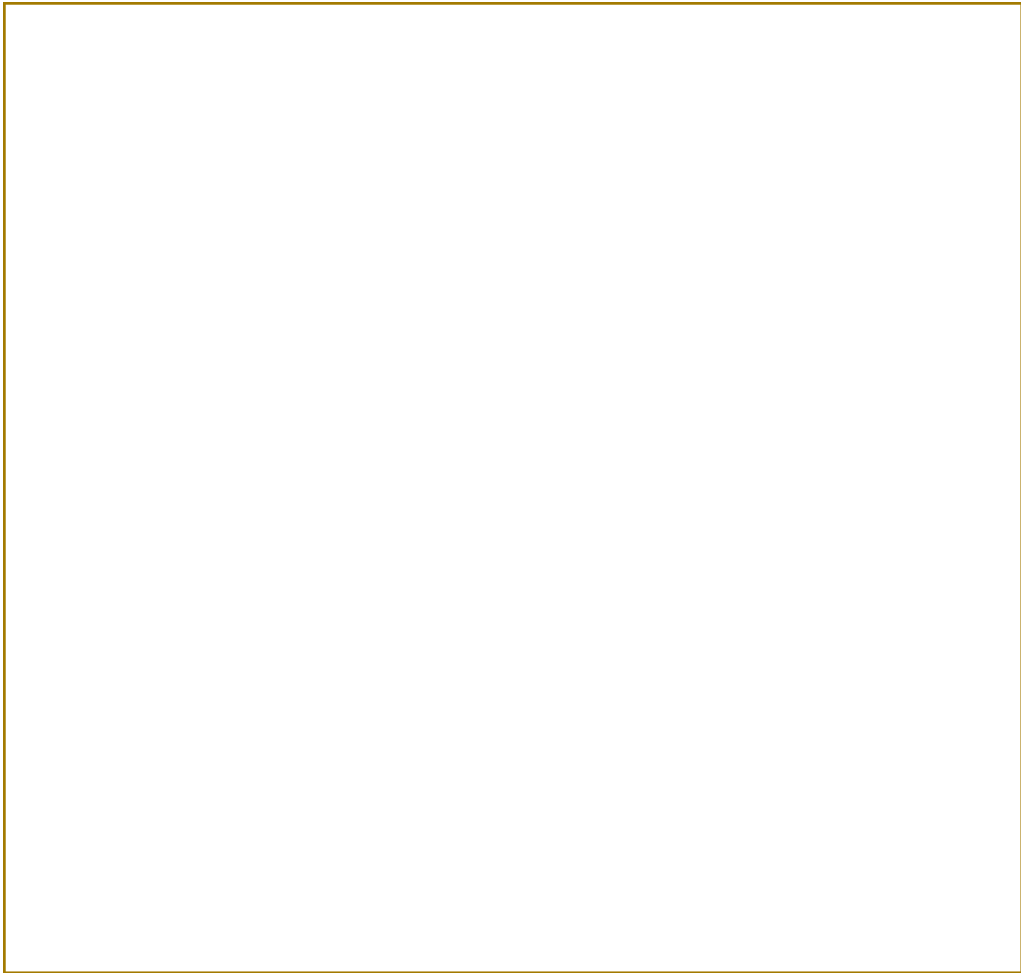
We're on the Web  
[www.fivepminus.org](http://www.fivepminus.org)

Find us on FaceBook at [http://  
www.facebook.com/  
CriDuChatSociety](http://www.facebook.com/CriDuChatSociety)

Yahoo Group Page: 5pminus  
[http://health.groups.yahoo.com/  
group/5pminus/join/](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](https://www.youtube.com/watch?v=2AEvN0-6M6I)



## 5P- GEAR ITEMS

There are several places that you can get your 5p- Gear. Many items can be found at

[www.cafepress.com/5pshop](http://www.cafepress.com/5pshop)

There are also several items at the 5p- Society Square Market store. You can shop at

<https://squareup.com/store/5p-society>

Items available:

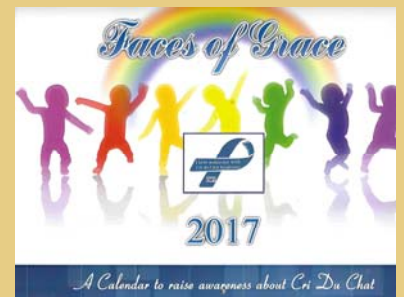
- ⇒ Hats—\$20.00 each
- ⇒ Waterbottles—\$10.00
- ⇒ Decals—\$10.00
- ⇒ Magnets—\$8.00
- ⇒ Coffee Tumblers—\$10.00
- ⇒ Wristbands—\$5.00
- ⇒ Keychains—\$5.00
- ⇒ Calendars—\$20.00

2017 Faces of Grace—Cri du Chat Syndrome Calendar is now available.

The calendar features twelve beautiful individuals with Cri du Chat Syndrome.

Limited quantities available, get yours today!!

Calendars are \$20.00 each (includes shipping to anywhere in US and Canada) Can ship Internationally, please contact Laura at [director@fivepminus.org](mailto:director@fivepminus.org) for more information.



*A Calendar to raise awareness about Cri Du Chat*