

## President's Message

*Nick Wallace*

Wow, where did 2017 go? As my kids get older, because we all know that I am not getting older, I find that the years start to go by faster. I find that during this time I start looking back at years past as well as looking forward to the years ahead. Obviously this time of year we start talking about New Year's Resolutions and our plans for the upcoming year.

I did a little research on the tradition of the New Year's resolution and was interested to find that the tradition dates back around 4,000 years ago. It is believed that the Ancient Babylonians were the first people that made New Year's resolutions. During the festival of Akitu, a 12 day religious festival, the Babylonians would make promises to return objects that they had borrowed and to pay their debts. This festival took place in March, when they planted crops, versus January, but it is believed that this marked the start of the New Year for the Babylonians. So, most people believe that this is the first record of the New Year's resolution.

Hopefully the Babylonians did a better job at keeping their resolutions than I do, because they believed that if they didn't keep their resolutions they would fall out of favor with their gods and would have a pretty rough year. I think I might think twice about that second piece of cake if I knew I had someone ready to smite me if I ate it.

So, what resolutions are you making this year? If you are having issues figuring out what resolutions to make, let me throw out a few.

### Take Some Me Time:

It is not easy being a parent of a special needs child and at times it can push you to your breaking point. Often we feel guilt over taking time to do something for ourselves, but for the sake of your sanity you really need to make sure you take care of yourself. Just like on an air-plane, if the masks come down, you need to deny your first

instinct of putting the mask on your child first and put the mask on yourself and then your child. You won't be of much help to your child if you have passed out due to the lack of oxygen and this will cause you both to suffer. So, this year make a resolution to take some time for yourself. Put away the guilt and understand that you are doing this for both you and your child.

### Connect:

Taking time for yourself is not always an easy thing to do because of various circumstances, but this one should be a resolution that you can keep. Over the year take time to connect with another person/family that has a child with Cri Du Chat Syndrome. Make a resolution to call, email, text, or message another person/family. It is amazing what talking to another person, who understands what you are going through, can do for your mental health. So, make a resolution to make contact once a month for the next year.

*continued on page 2*

### In this issue

President's Message	1
Welcome all the New Families to the 5p- Society	2
Finding Beauty in Broken Dreams	3
Join C5's Carousel of Possible Dreams	4
Effective Behavior Change First Starts With You	5
People with Cri Du Chat Syndrome in the Society by Zip Code	6
Learn Share Connect	7
5p- Gear Items	7
2018 Calendars	8

**Participate:**

In some ways, this resolution ties into the resolution of connecting with another family/person. Yes, the 5p- Society has an executive director and a board of directors, but we need help from our members. Yes, we can always use help raising funds for the society, and if you would like to make this a resolution that would be great, but my thought on this one is helping to spread awareness and help support other families like yourself. A great way to participate is by starting an event during our annual Cri Du Chat Syndrome Awareness Week. You can participate by creating a team/group for the Virtual 5k and plan an event at a local park or fitness center to mark the event and to raise awareness. You could also take it one step further and host a gathering for other families who have a child/adult with the syndrome. This would help other families to connect with

people who know what it is like having an individual with Cri Du Chat Syndrome and it will also help you to connect with other families as well. If you wanted to have a small gathering of families, it doesn't have to happen around awareness week, but it can take place whenever you want.

No matter what resolution you make this year, may the odds be ever in your favor! On a serious note, from my family to your family, our wish for you is that your 2018 be filled with joy and laughter. We know that there will always be rough times, but we hope that they are few and that you know that your Cri Du Chat family is here to celebrate the joys and to support you during those not so great times.

Cheers,  
Nick

## Welcome all the New Families to the 5p- Society

60 new families or extended families from around the globe joined the 5p- Society's database from the following locations in 2017.

Almena, Wisconsin	Elkton, Ohio	Pleasant Valley, New York
Ankara, Turkey	Fairfield, California	Newfoundland, Canada
Auburn, Alabama	Farmington Hills, Michigan	Ontario, Canada
Auburn, Washington	Fort Mill, South Carolina	Pittsburgh, Pennsylvania
Aurora, Illinois	Fresno, California	Placentia, California
Boyertown, Pennsylvania	Glen Burnie, Maryland	Post Falls, Idaho
Brentwood, California	Grayslake, Illinois	Quincy, Illinois
Buda, Texas	Hartland, Wisconsin	River Falls, Wisconsin
Canoga Park, California	Heath, Texas	Sao Paulo, Brazil
Cape Town, South Africa	Jacksonville, Florida	Silverwood, Michigan
Chevy Chase, Maryland	Knapp, Wisconsin	Spencer, Iowa
Clara City, Minnesota	Lahaina, Hawaii	Spokane, Washington
Columbia, Illinois	Leesburg, Virginia	St. Augustine, Florida
Constantine, Michigan	Luxemburg, Wisconsin	Tavare, Florida
Decatur, Georgia	Maharashtra, India	Vienna, Virginia
Deer Park, Texas	Markesan, Wisconsin	Villa Park, California
Downers Grove, Illinois	Mesa, Arizona	West Warwick, Rhode Island
Eagle, Idaho	Middletown, New York	Whitmire, South Carolina
Egg Harbor Township, New Jersey	Mobile, Alabama	Woodstock, Georgia
	Mount Pleasant, South Carolina	

# Finding Beauty in Broken Dreams \_\_\_\_\_ By Kathy McClelland



In the summer of 2013 my husband and I sat anxiously across the table from a geneticist in a sterile NICU conference room. I don't know what exactly I was expecting because we were pretty sure we knew our son's diagnosis. We had the results of an initial blood test, and my husband, who is a physician assistant, already suspected our son had Cri du chat syndrome based off his cry and physical characteristics.

The geneticist's first words to us were, "Congratulations Dad, you correctly diagnosed your son." It hardly felt like congratulations. She went on to say that he may never walk, talk, or be able to live independently. She told me that I would probably need in-home nursing care for him in order to take a shower, curl my hair, and paint my nails. I rarely do the latter two and I'm not sure why she found the need to say those things. She didn't know me. She painted a very bleak picture for what life would be like with our then two week old son. I felt unknown, angry, and hopeless after I left that conference room. It was definitely my darkest day. We received a lot of information, but very little hope.

Four years later, our son is doing some things we didn't expect him to do. He is signing many words and even has some word approximations. He is walking with the help of a walker and can pull himself up onto the couch to sit next to his brother when he's watching TV. He makes great eye contact and is super friendly and cuddly. There are other things we are still patiently (or not so patiently) waiting for, like his ability to eat by mouth.

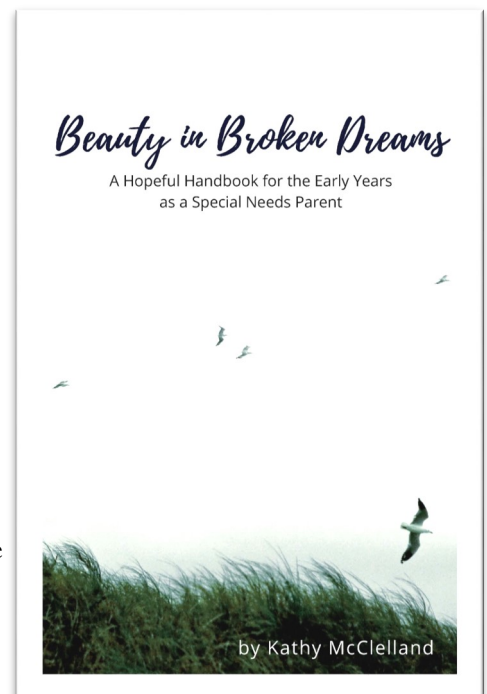
When I think back on that day with the geneticist, I don't feel as angry as I did then. I've been in a process of forgiving and healing. Hers is not an easy job of delivering "bad

news" to parents. While the delivery of information was not how I hoped, it did offer me a gift. It was the gift of low expectations. Expectations that he is exceeding. And I don't just mean in the physical things he is doing, but in who he is. There is a very special boy entangled in this disability. A boy who is so sweet and will stare deeply into your soul, cuddle you, and giggle contagiously. A boy who will click at you with his tongue or grunt like a bear to get your attention. A boy who gets feisty when he wants to do something on his own or explore this world we all share, albeit in different ways.

Our whole family is at a very different place than where we started. The first two years of Nathan's life were incredibly disorienting. During that time I wrote a book chronicling our story. [\*Beauty in Broken Dreams\*](#) shares what it's like to have a medically complex child and the many lessons we learned in the beginning. It's full of practical advice and encouragement for parents who receive a special needs diagnosis in the early years.

[\*Beauty in Broken Dreams\*](#) shares how you might practically, emotionally, and spiritually find your way through the beginning of a special needs diagnosis. It's hard to have hope. You may feel isolated, ill-equipped, and devastated even, but you are not alone. This is the story of how God can take broken dreams and turn them into something beautiful and redemptive.

[\*Beauty in Broken Dreams\*](#) is available on Amazon.





# Join C5's Carousel of Possible Dreams

**OUR GOAL: \$37,500**

## HOW?

We are building a team of riders to help us achieve our dream and **we want YOU** to join us!

As a rider of The RARE Carousel of Possible Dreams, your participation is key to the success of our fundraising campaign. With your other team mates, you will expose the 5p- Society to a wider audience and help raise funds that will bring our possible dream to life.

Over the course of the campaign, you will use an online fundraising platform to reach out to friends, family, co-workers and businesses to achieve your personal fundraising goal. It is a fun and easy way to get the word out about the mission of the 5p- Society, share why the cause is important to you, and give your personal network an opportunity to donate directly towards a high-impact program.

## DO I HAVE TO RIDE A CAROUSEL?

Riding a Carousel is not a requirement! This is a virtual fundraiser. But it's a great excuse to get a group of friends together and visit a carousel at your local shopping mall or park and jump on a horse. Take pictures and post on social media along with the link to your fundraising page. Make a bigger footprint by bringing your friends and family to join you on the carousel.

All Riders who raise \$50 or more will receive a t-shirt with C5 riding a carousel horse.

February 28, 2018 is Rare Genes day. Global Genes and Festival of Children's Foundation will be at the Children's Creativity Museum in San Francisco, California with participants riding the carousel at 6:00 PM. If any of our Rider's would like to attend, please let the 5p- Society know.

The RARE Carousel is a unique partnership between Festival of the Children Foundation and Global Genes that provides an exciting and innovative way for RARE organizations to **raise funds, cultivate new donors, and increase awareness**. The 5p- Society is excited to be a participating organization in the 2018 RARE Carousel and C5 would love for you to join us by being a Rider!

## OUR DREAM: FAMILY MEETUPS

*INSPIRATION, FRIENDSHIP AND EDUCATIONAL POSSIBILITY THROUGH REGIONAL GATHERINGS*

### Program description

The 5p- Society has grown tremendously in the past 5 years since the inception of Cri du Chat Syndrome Awareness week. Many families of a child with the syndrome indicate the desire to meet other families, but do not have the time or ability to organize a casual gathering.

The 5p- Society would like to sponsor regional gatherings throughout the United States and Canada. These gatherings will be casual meetups at parks, community centers or church halls. The 5p- Society will identify five areas each year for the next five years and assist the families in those regions to organize the meetups.

The 5p- Society will fund the meetups with a minimum cost of \$500 and a maximum cost of \$1500 per meetup. The monies will be used to pay for facility costs, insurance, and food and beverage for each meetup. The organizing families can choose how they want to run their meetup. The organizing families can also bring a speaker to their meetups and use funds to pay for the speaker.



# Effective Behavior Change First Starts With You

For those of you who have attended any of the behavior sessions at the conference lately, we have discussed effective behavior strategies and how to change behaviors in your kiddos many, many, many times together. WELCOME back for a quick refresher on how to make changes in your kiddos behavior. This will be the only quick part of this behavior change process. This is the guidance approach to discipline change. Your goal is to find those actions and conscious inactions that parents (you) engage in to enhance the probability that your kiddo, individually and in groups, will develop effective behaviors that are personally fulfilling, productive, and socially acceptable (Walker & Shea, 1999).

A friendly reminder is that the FIRST STEP for behavior change to begin is with you. You are the one that must first change your response pattern to your child's behaviors before you can change your child's behavior. In other words, you must change the way you respond to a behavior. YES, it starts with you and it is all about you. You then need to figure out how you are going to respond differently to your child's inappropriate behavior, BEFORE your child does that unwanted inappropriate behavior. Remember, behaviors are followed by your response that reinforces the behavior in a negative or positive way. So when your kiddo is doing the right thing give them the attention it deserves. If they are pushing your buttons, realize it and use the new response pattern you have developed. YES, you need to practice before you implement your new response pattern. YES, your new response must be, "quick, smooth, and as natural" as your initial response (old response) you gave a thousand times that did not result in the change of behavior you desired. YES, it will take time, practice, more time, and more practice to get the new response down. AND YES, your kiddo is going to push all the right buttons to get you to respond the *old way* because those buttons gave them the result they wanted. IF your response had resulted in the way YOU wanted, then we would not be having this conversation. And remember, they know exactly what they are doing, and you and everyone else must be consistent.

WELCOME to being a parent and adult in your kiddos world. SECOND STEP, is a reminder that ALL behaviors will get worse before they get better in ANY plans that are effectively changing inappropriate and undesirable behaviors. YOU have to weather the storm and YES, it will feel

like the "bomb cyclone" that slammed most of us recently. It will be icy, treacherous travel over this chosen path, while trying to change your behavior response patterns and your kiddo's behavior response patterns. When it is getting worse you will know that you are having an effect on the inappropriate behavior.

THIRD STEP when you are planning how to come up with YOUR New Behavior Responses, you can refer back to the intervention strategies we discussed in previous conference presentations. A quick reminder of the four most common, effective intervention strategy responses you can give your kiddo. Actually, you can use these with anyone and at anytime. They are quick effective strategies for changing any one's *undesirable* behavior patterns. You are welcome to try them and let us know how they worked for you. We always enjoy y'all participating and sharing your stories in our presentation, it makes it more real for all of us going through the perils of change.

Here are FOUR Intervention Strategies that can be used when implementing a guidance approach to discipline:

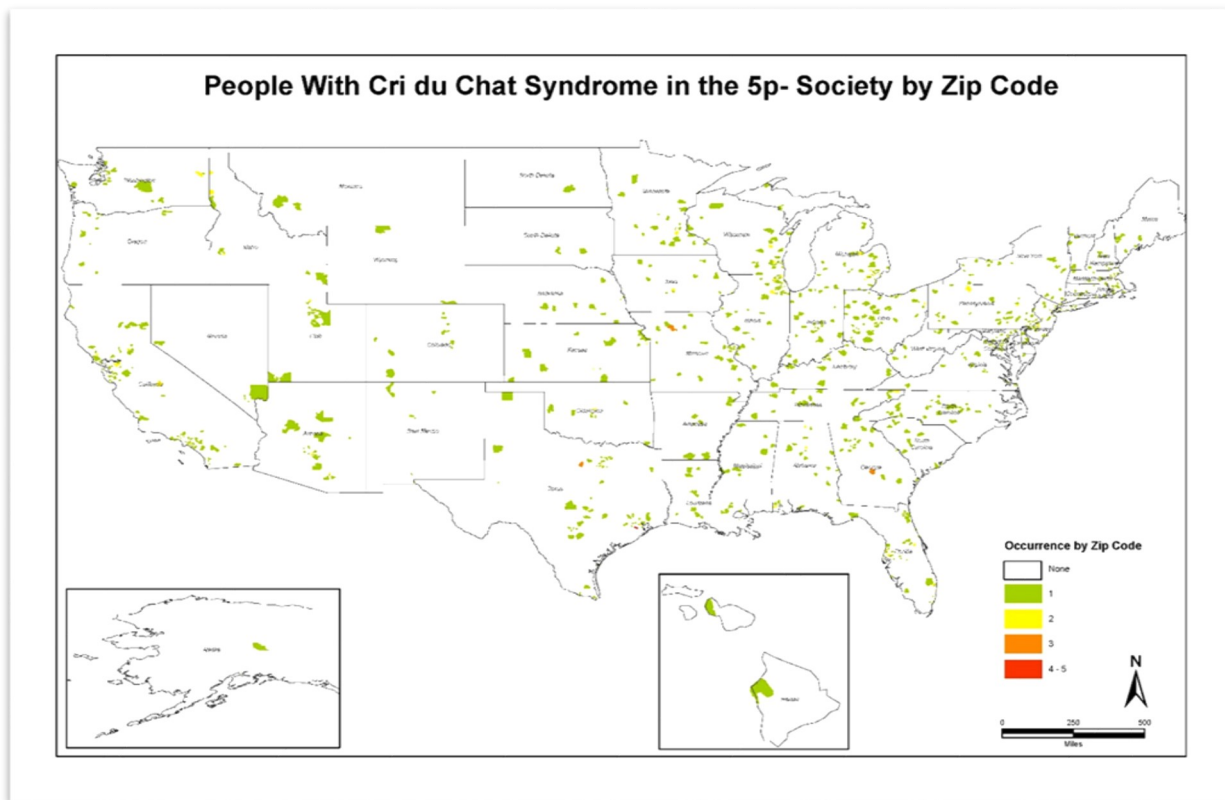
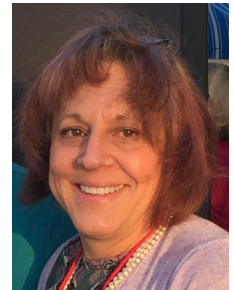
- 1) *Humor as Problem-Solver*—Use humor in difficult situations. This strategy helps relieve some of the tension that can occur when dealing with difficult situations.
- 2) *Nonverbal Techniques*—Use nonverbal techniques, such as eye contact, physical proximity, body carriage, gestures, and facial expressions, to remind children about guidelines without drawing attention to and embarrassing the kiddo. We also learned to use voice noises to get a heads-up or reminder.
- 3) *Brevity*—Use appropriate language that the kiddo is developmentally able to comprehend. Be clear, concise, and use as few words as possible. You may repeat the same words repeatedly.
- 4) *Being Direct*—Be firm and direct while still allowing for appropriate choices to be made by the kiddo. Adults can do so by (a) describing behavior without labeling the kiddo, (b) expressing displeasure without insulting the kiddo, and (c) correct by appropriate direction (i.e. use positive statement when establishing guidelines and direct them toward alternative, appropriate behaviors).

LASTLY, a reminder to take data collection to measure

kiddo’s progress. YOU must have the numerical information across time, location, settings, and people, to know if your Revised Behavior Intervention Plan is working. When implementing a guidance approach to discipline, adults need to collect data on certain behaviors that adults wish to increase, decrease, or maintain. Adults may use one of the following measures depending on the behavior: (a) frequency count, (b) duration, (c) latency, (d) accuracy, (e) rate, (f) intensity, (g) percentage of correct responses/ behaviors, or (h) interval (whole or partial) recording. Tak-

ing the data is critical in being able to measure change. Remember the end goal of the guidance approach is to be rewarding appropriate behaviors, rather than inappropriate. So the attention that kiddos are looking for is achieved by being their lovable social selves, which Cri du chat is known for. As stated earlier: Your goal is to find those actions and conscious inactions that parents (you) engage in to enhance the probability that your kiddo, individually and in groups, will develop effective behaviors that are personally fulfilling, productive, and socially acceptable (Walker & Shea, 1999).

Dr. AmySue Reilly is an Associate Professor of Special Education at Auburn University. At the 2018 conference in Pittsburgh she will make her 15th presentation on Positive Behavior Support, a Guidance Approach to Discipline and Behavior Management.



Thank you to Mike Brewer (former Board of Director) for having this map created for us of the location of members of the 5p- Society in the United States. Hopefully you can enlarge the picture on your devices. With the inception of the new Family Meetups Program, the 5p- Society can see where there is a larger concentration of families.

This map was created with information provided to Mike of individuals who are registered with the 5p- Society. Not sure if you are on the map? Please contact Laura at [director@fivepminus.org](mailto:director@fivepminus.org) to see if you are on the 5p- Society database. Not yet a member of the 5p- Society? You can register online at <https://fivepminus.org/become-a-member/>. We will be updating the map a few times a year. We are also working on a Canadian map. THANKS MIKE!

# LEARN SHARE CONNECT

## 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>  
[2015 Virtual 5k for 5p- video Recap](https://www.youtube.com/watch?v=EWX6NHj0nwY&feature=youtu.be)  
<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/)  
<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.  
[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](https://www.youtube.com/watch?v=giW_iP5ibr8&feature=youtube_gdata_player)  
[Documentary by Maria Ripoli](http://www.cromosomacinco.com/)  
<http://www.cromosomacinco.com/>  
[Meet James Chalmers](https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/)  
<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=ywWDIdOAWC) <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.  
[Beauty in Broken Dreams: A Hopeful Handbook for the Early Years as a Special Needs Parent](https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr_1_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams), by Kathy McClelland, 2017, mom to Nathan a four-year-old with Cri du chat syndrome. [https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr\\_1\\_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams](https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr_1_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams)

## Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- [www.kathymcclelland.com](http://www.kathymcclelland.com) 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://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)

## 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
- ⇒ 2018 Calendars—\$20.00





PO Box 268  
 Lakewood, CA 90714-0268  
 Toll: (888)970-0777  
 Phone: (562)804-4506  
 Fax: (562)920-5240  
 Email: [director@fivepminus.org](mailto:director@fivepminus.org)

**RETURN MAIL REQUESTED**



**Meet C5**

The Mascot of the International  
 Cri du Chat Awareness Week  
 May 5-12, 2018

**WE'RE ON THE WEB**  
[WWW.FIVEPMINUS.ORG](http://WWW.FIVEPMINUS.ORG)

**TWEET WITH US**  
[@5PMINUS](https://twitter.com/5PMINUS)

**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/)  
[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>

**2018 Faces of Grace Calendar**



There are still plenty of 2018 Faces of Grace Calendars available. If you haven't ordered one yet, they can be ordered at <https://squareup.com/store/5p-society/item/calendar>.

February special . . . each calendar will be \$15.00 including shipping.

Questions or concerns, please contact Laura at [director@fivepminus.org](mailto:director@fivepminus.org) or 888-970-0777.