5P– NEWS

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

2017 GOAL #1 EFFECTIVE COMMUNICATION

by Jen Wong

Communication is the key to many doors. It's the key to relationships, information, and awareness. Being a smallish organization in this giant world we live in, communication is critical to our success and our members. Facebook has shown us the importance of communication. It brought together many families who would have other-wise never met. The friendships and information shared are invaluable to all of us not feeling alone in our unique journeys.

The Society has many items in the works to increase our ability to increase both knowledge and awareness of 5P-. Be on the lookout for our updated website. Kristi Furnari, Laura Castillio, our Board of Directors, and many others have put long hours into creating a website that will disseminate information both to and from the 5P-Society. One of the most important projects that is currently active is the Caregiver's Guide. We are trying to create one of the most comprehensive and current booklets on Cri du Chat out there. However, we cannot do that without EVERYONE'S participation. I encourage everyone to fill out the series of questionnaires to the best of their abilities. We are really excited to get this booklet out to our Society members and the medical community.

We cannot talk about communication without talking about awareness. Awareness week will be coming up May 1-7, which is just around the corner (remember how much time you thought you had before the Holidays, and then you didn't? J). The Board of Directors will be discussing upcoming events at our January Board meeting. We ask that everyone try to complete at least one awareness activity. Whether it be as simple as wearing striped socks and telling people why, to organizing a Virtual 5K run, or presenting an informational talk at your child's school or local hospital, every bit counts.

By the way the Board of Directors have submitted their three year strategic plan. We have updated our Mission and Vision statements.

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

Vision Statement: 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.

Looking forward to a productive 2017. Jen Wong, President, 5p- Society

VOLUME 32, ISSUE 1

WINTER 2017

In this issue:

2017 Conference - Festival of Families

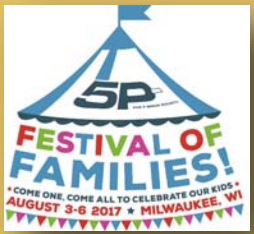
You can now make your reservations at the hotel for the conference.

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.

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

See page 2 for more information



FESTIVAL OF FAMILIES
2017 ANNUAL CONFERENCE

We are happy to announce the following confirmed speakers:

Dennis Campbell, Ph.D.(Cri du Chat 101), AmySue Reilly, Ph.D. (Behavior Modification), Kent Nicholls (New Parent Orientation), Lisa Juliar (Technology as a Tool), Jennifer Rosinia, Ph.D.(Sensory Processing Disorder), Nick Wallace (Father's Workshop), Shanida Mathieu (Understanding the IEP Process), Mary Anne Elhert, Protected Tomorrows (Planning for the Future), Erin Syverson, Genetic Counselor (current research and more) . . . waiting to hear back from individuals on the following topics - GI issues and Cri du Chat Syndrome, Couples Therapy, and Speech Therapy.

We will also have our Sibling Workshop and Grandparents Workshop!

Family Outing will be at a local park -

Sibling Outing has not been confirmed -

Registration will open in March 2017

Scholarships will be available beginning in March 2017

There is a lot to do in Milwaukee!! Go to www.visitmilwaukee.org

More information will be coming soon!!

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://mikeandbrittanyerickson.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
* http://www.specialneedsdadchronicles.space
* 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

Documentary by Maria Ripoli
http://www.cromosomacinco.com/

Meet James Chalmers
https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/

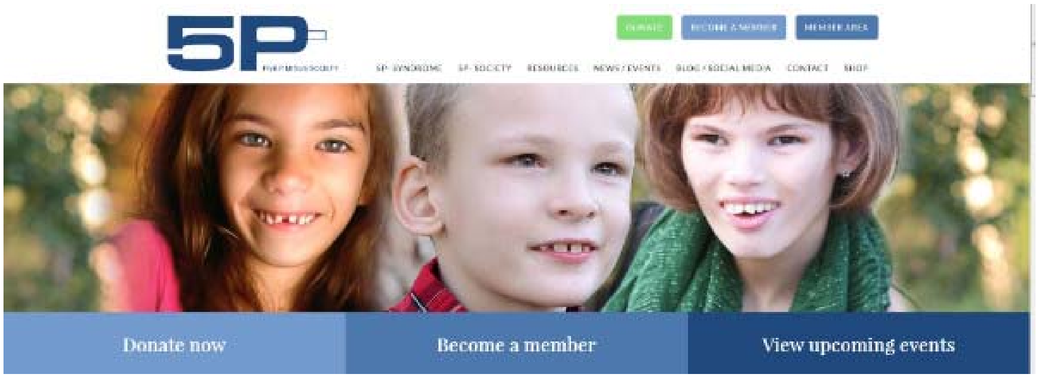
Books to read:
A Book to my son Nathan: http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=ymWDidOAWC

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.

NEW WEBSITE LAUNCHED *BY KRISTI FURNARI*

The 5p- Society is proud to announce the launch of the new and improved fivepminus.org website! The updated site has a modernized look and feel, and is also mobile friendly.



The site will continue to be an informational resource about the Syndrome and the Society, but will also have new some new features for members only.

In our member area, you will have access to current and historical newsletters, annual conference presentation packets and our caregiver guide information. Another exciting functionality of the member area is the ability for each member to share their family story and photo of their loved one to the website. These family stories are posted on the bottom portion of the front page of the site. These stories are of great inspiration to others, and we encourage you to share yours!

Going forward, we will work on adding new and exciting material to the member area. This material will include videos of conference presentations, interviews with caregivers and service providers, and an online knowledge base for commonly dealt with topics that affect 5p- families. If there is something you would like to see in the member area, please let us know!

To gain access to the member area if you are a current member, click on the blue "member area" button in the upper right hand corner. Type in your email address associated with your 5p- membership then click on "lost your password?". This will bring you through a set of prompts to update your password.

Not sure if you are a member, send Laura an email at director@fivepminus.org. Not a member, click “Become a member” and fill out the information.

We hope you like the new site!

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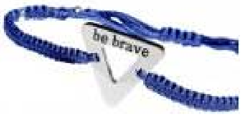
amazonsmile
You shop. Amazon gives.

Do you like to shop at Amazon.com? Do you have Amazon*Prime?* Help the 5p– Society raise some *easy* money by shopping through Amazon*Smile*. 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 Amazon*Prime* too!! Thanks for your continued support!!!

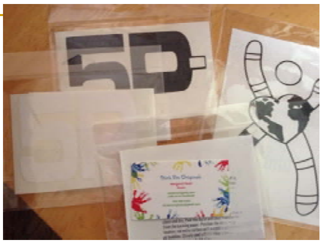
Bravelets™
be brave



The 5p– Society will get $10 for each Bravelet ordered. Several colors and styles are now available. Two different sites to order from - check out the new styles

https://bravelets.com/bravepage/cri-du-chat-syndrome-support and https://www.bravelets.com/bravepage/virtual-5k-for-5p

5p– Society client Margaret Hood, has create vinyl decals that you can put on your vehicle (in the window) or in the home. Our own C5 can be proudly displayed or our 5p– logo. Cost for each is $10.00 with a portion of the funds going to the 5p - Society. Colors available will be black, white, grey and blue.



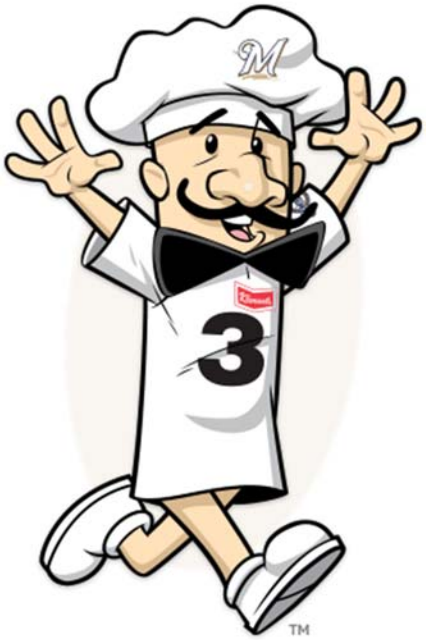
To order these, please go to this link. http://mkt.com/5p-society/car-decals

2017 ANNUAL CONFERENCE
RACE FOR REWARDS FEATURING THE RACING SAUSAGES AT MILLER PARK

Brett Wurst a Bratwurst

Stosh Jonjak a Polish Sausage

Guido an Italian Sausage



Raise money for the 2017 Annual Conference and get rewarded:

Raise $1,500 and get Reward #1 presented by Brett Wurst

You will receive Conference Registration for UP TO 2 adults and 2 children

Raise $3,000 and get Reward #2 presented by Stosh Jonjak

You will receive Conference Registration for UP TO 2 adults and 2 children AND one night stay at the Milwaukee Marriott West*

Raise $5,000 and get Reward #3 presented by Guido

You will receive Conference Registration for UP TO 2 adults and 2 children AND three nights stay at the Milwaukee Marriott West*

*Reward recipients to make their own hotel reservations, internal change will be made for payment of room. Conference registration form required.

Please submit all monies by June 30th to participate.

2017 AWARENESS WEEK *BY STACY SANDERS*

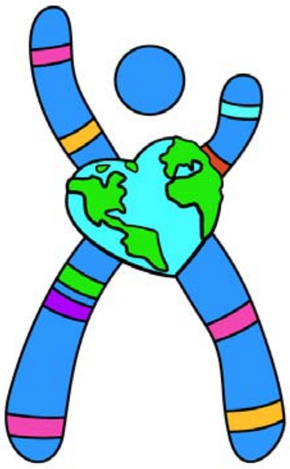
Each year, the 5p- Society promotes a week of international awareness of 5P- Syndrome, or Cri du Chat. This purpose of this week is to raise awareness and encourage support of those with the Syndrome. We are excited to start planning for 2017 Awareness Week, taking place May 1-7, 2017.

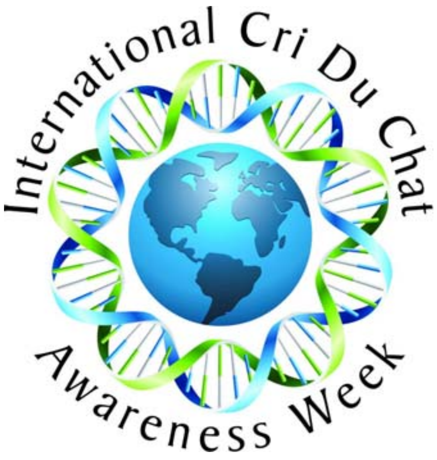
We have many ways you can participate and help spread awareness:

- Download and print the Awareness Week materials that will soon be available on the 5p- Society website.
- Show us "Where in the World is C5?" Pose with a picture of our mascot, C5, and share via your Social Media using the hashtags #SeeC5 and #criduchatawareness.
- Wear your stripy socks on May 5th in honor of Cri du Chat Awareness Day. One short, one long…and be sure to snap a pic and share!
- Sign up for the 3rd Annual Virtual 5k for 5p-. You can create a team, organize a local event, or sign up solo…the only requirement is to have fun! As in years past, we will have t-shirts and medals available for purchase; however, new for 2017, we will be sending out shirts and medals BEFORE Awareness Week. We will again have the team fundraising option, which will have a shareable link to share with your friends and family. Families attending the Annual Conference will also have the opportunity to apply their team fundraising money towards Conference Rewards. More information to come so be sure to "like" the Virtual 5k for 5p- on Facebook and stay up to date!

We encourage everyone to use Awareness Week as a way to share information with friends, peers, co-workers, and the people in your community. We can't wait to see what everyone has planned!

For Proclamation information, please see page 6





CRI DU CHAT SYNDROME DAY MAY 5
STATE PROCLAMATION INFORMATION

BY JULIE WATT FAQIR

How to Get Your Governor to declare May 5 as Cri Du Chat Awareness Day

Before we know it, May will be here and that means CRI DU CHAT SYNDROME AWARENESS DAY!

For those of you who live in the United States, here is how to request a proclamation from your Governor requesting that they declare May 5 as Cri Du Chat Awareness Day.

First, just because a Governor declared May 5 as Cri Du Chat Awareness Day in 2016 – you still will have to ask in 2017 **and all future years!**

Start Early – the best thing to do is make your request before March 1 as most states say it takes up to six weeks to determine whether or not the request will be granted and to issue the Proclamation.

Do a google search “Governor OF STATE?” (for ***your*** state) This will take you to the Governor’s website.

On the Governor’s website, on the home page search for “Request a Proclamation” – usually there will be an online form to request the proclamation.

You are the “requestor” – the requesting organization is “The 5p-Society”

Sample language is shown on page 7 – ALL STATES WILL ASK YOU TO PROVIDE LANGUAGE.

Some states do not have online forms – so when you search for “Request a Proclamation” you will be directed to an office – call there and ask how to send an email request for a proclamation.

Keep a copy of the request and write down the date you submitted it. This will be helpful when you call or email to follow up the request. I suggest that you do this about 2 weeks after you submit the request. Be prepared to call back several times!

You may have to call a general phone number from the web page and ask to speak with the person who handles requests for proclamations.

And remember, Governors get hundreds of requests every month for them to declare given days so if the request is turned down, do not take it personally!

If you run into issues feel free to email me at Jaggerwatt@hotmail.com

Continue to page 7

Continued from page 6

Whereas, the 5p- Society of North America, along with support organizations from Argentina, Australia, Belgium, Brazil, Canada, Chile, China, Columbia, Denmark, Ecuador, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Malta, Mexico, Netherlands, New Zealand, Panama, Peru, the Philippines, Poland, Russian, Slovakia, Spain, Trinidad & Tobago, Turkey, the United Kingdom and Venezuela are proud to announce that April 30 – May 6, 2017 will be designated as International Cri Du Chat Syndrome Awareness Week.

Whereas, May 5 has been designated internationally as Cri du Chat Syndrome Day.

Whereas, Individuals with Cri Du Chat deserve to be recognized for what they can do versus what they cannot do and our hope is that we can raise awareness, of Cri Du Chat Syndrome, by spreading our message to each and every person we meet.

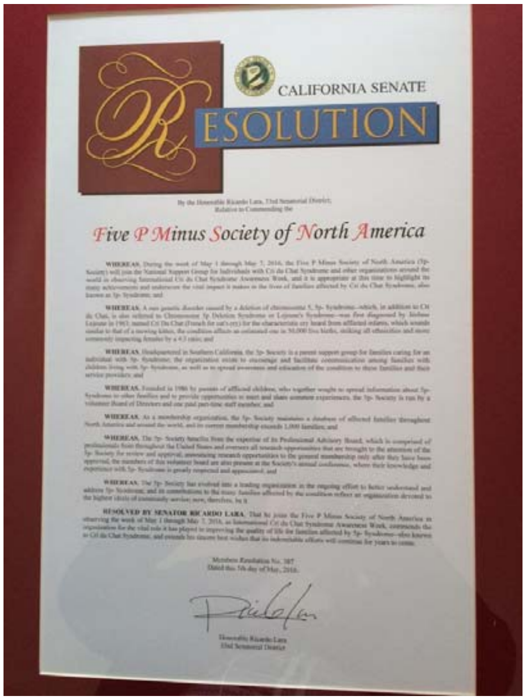
Whereas, each year in the United States alone, approximately 50 to 60 children are born with ***5p- Syndrome*** (five p minus), also known as ***Cat Cry*** Syndrome or ***Cri du Chat*** Syndrome. Some common characteristics of Cri du Chat Syndrome at birth are a high pitched cry, low birth weight, poor muscle tone, microcephaly, and potential medical complications. "5p-" is a term used by geneticists to describe a portion of chromosome number five that is missing in these individuals.

Whereas, one of the goals of Cri Du Chat Awareness Week is to end the outdated misinformation given to families when their child is diagnosed with Cri Du Chat.

Whereas, children born with this rare genetic defect will most likely require ongoing support from a team of parents, therapists, and medical and educational professionals to help the child achieve his or her maximum potential.

Whereas, there are many families with family members with Cri Du Chat living in Iowa with the syndrome that are members of the 5p- society and over 1,000 families in the Country.

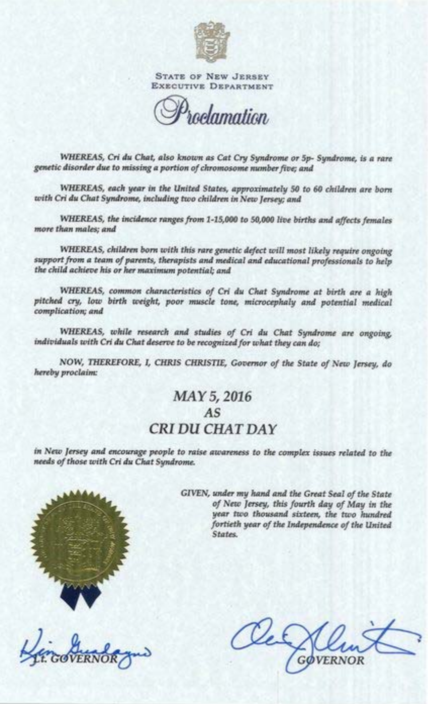
Resolved, I Governor (FILL IN YOUR GOVERNOR's NAME) declare May 5, 2017 as Cri Du Chat Awareness Day in (FILL IN YOUR STATE.)



CALIFORNIA SENATE

RESOLUTION

Five P Minus Society of North America



STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, Cri du Chat, also known as Cat Cry Syndrome or 5p- Syndrome, is a rare genetic disorder due to missing a portion of chromosome number five; and

WHEREAS, each year in the United States, approximately 50 to 60 children are born with Cri du Chat Syndrome, including two children in New Jersey; and

WHEREAS, the incidence ranges from 1-15,000 to 50,000 live births and affects females more than males; and

WHEREAS, children born with this rare genetic defect will most likely require ongoing support from a team of parents, therapists and medical and educational professionals to help the child achieve his or her maximum potential; and

WHEREAS, common characteristics of Cri du Chat Syndrome at birth are a high pitched cry, low birth weight, poor muscle tone, microcephaly and potential medical complication; and

WHEREAS, while research and studies of Cri du Chat Syndrome are ongoing, individuals with Cri du Chat deserve to be recognized for what they can do;

NOW, THEREFORE, I, CHRIS CHRISTIE, Governor of the State of New Jersey, do hereby proclaim:

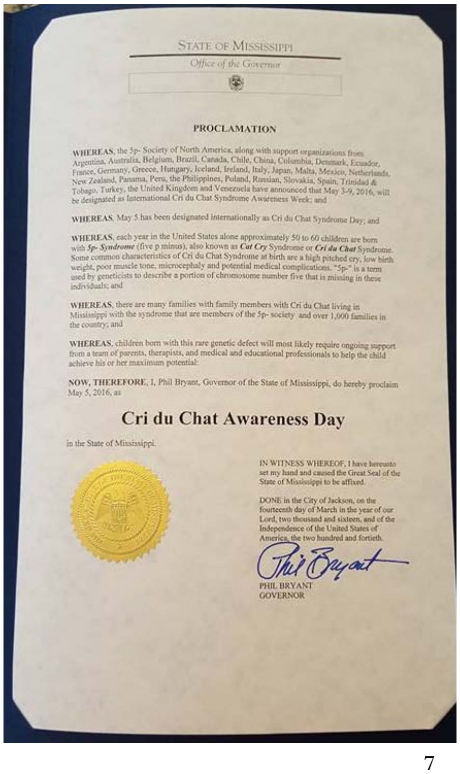
MAY 5, 2016
AS
CRI DU CHAT DAY

in New Jersey and encourage people to raise awareness to the complex issues related to the needs of those with Cri du Chat Syndrome.

GIVEN, under my hand and the Great Seal of the State of New Jersey, this fourth day of May in the year two thousand sixteen, the two hundred fortieth year of the Independence of the United States.

Kim Guadagno
LT. GOVERNOR

GOVERNOR



STATE OF MISSISSIPPI
Office of the Governor

PROCLAMATION

WHEREAS, the 5p- Society of North America, along with support organizations from Argentina, Australia, Belgium, Brazil, Canada, Chile, China, Columbia, Denmark, Ecuador, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Malta, Mexico, Netherlands, New Zealand, Panama, Peru, the Philippines, Poland, Russian, Slovakia, Spain, Trinidad & Tobago, Turkey, the United Kingdom and Venezuela have announced that May 3-9, 2016, will be designated as International Cri du Chat Syndrome Awareness Week; and

WHEREAS, May 5 has been designated internationally as Cri du Chat Syndrome Day; and

WHEREAS, each year in the United States alone approximately 50 to 60 children are born with ***5p- Syndrome*** (five p minus), also known as ***Cat Cry*** Syndrome or ***Cri du Chat*** Syndrome. Some common characteristics of Cri du Chat Syndrome at birth are a high pitched cry, low birth weight, poor muscle tone, microcephaly and potential medical complications. "5p-" is a term used by geneticists to describe a portion of chromosome number five that is missing in these individuals; and

WHEREAS, there are many families with family members with Cri du Chat living in Mississippi with the syndrome that are members of the 5p- society and over 1,000 families in the country; and

WHEREAS, children born with this rare genetic defect will most likely require ongoing support from a team of parents, therapists, and medical and educational professionals to help the child achieve his or her maximum potential:

NOW, THEREFORE, I, Phil Bryant, Governor of the State of Mississippi, do hereby proclaim May 5, 2016, as

Cri du Chat Awareness Day

in the State of Mississippi.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Mississippi to be affixed.

DONE in the City of Jackson, on the fourteenth day of March in the year of our Lord, two thousand and sixteen, and of the Independence of the United States of America, the two hundred and fortieth.

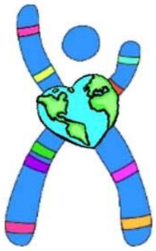
Phil Bryant
PHIL BRYANT
GOVERNOR

FIVE P MINUS SOCIETY™

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

May 1-7, 2017

Tweet with Us
@5pminus

We're on the Web
www.fivepminus.org

Find us on FaceBook at http://www.facebook.com/CriDuChatSociety

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

5P– GEAR ITEMS

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

www.cafepress.come/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	$2.00
⇒ 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 for more information.