

President's Message

Nick Wallace

Happy Spring Everyone,

Well, we have now entered Spring, at least most of us in the northern United States hope we have. I think of this season as a renewal. A time when dead grass turns green again, the bare trees start to get their lush foliage back, and a time when the flowers start to bloom. Some of the new things we have coming your way are nothing to sneeze at ... sorry I know it was a bad spring allergy joke. I believe this season is a lot like the season we are entering for the 5p- Society. All year round we work to raise awareness and to provide parent support, but this is the time of the year when we really ramp up our awareness efforts and start our final preparations for the annual conference.

Like the season of Spring, we have some events coming up that are new and other events that are coming back, and may have some new blooms for us to enjoy. We are once again bringing back our International Awareness Week. It will take place May 5th - May 12th. We are once again trying to get proclamations from the 50 states that declare May 5th Cri du Chat Syndrome Awareness Day. We are also having our Annual Virtual 5k during awareness week. Once again there will be medals and shirts, but this year we will have some specially designed 5p- socks! These will be awesome to wear during the week because we will be asking people to wear their striped socks. We will also be promoting the fact that this year is the 55th anniversary of the identification of Cri du Chat Syndrome.

This year the 5p- Society will be sponsoring five regional family gatherings. You will find more information about these gatherings in this newsletter. It is something we are very excited about. The goal of the 5p- Society is to assist our families, and we feel that one way we can do that is to connect families with one another.

As I stated above, we are gearing up for our annual conference. The Pittsburg host families have been working closely with Laura, and they have a great conference planned for you. The board is also looking into taking a technological leap at our conference by utilizing a conference app. More to come on that as the conference gets closer.

So, as you can see we have some awesome things coming your way. As always, please keep connected with us via our Facebook group.

Happy Spring!

Nick

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Celebrating 55 Years Since Cri du Chat was Discovered!

By Laura Castillo

2018 marks the 55th year of the discovery of Cri du Chat Syndrome. Help us celebrate by participating in spreading awareness of 5p- Syndrome throughout the world. May 5 has been designated as Cri du Chat Syndrome Day, and May 5-12 is International Cri du Chat Syndrome Awareness Week.

Ways to participate:

Create a team and walk, run, stroll, skate, window shop, or whatever you want to do during awareness week, May 5-12, 2018, by signing up for the Virtual 5k for 5p- (or create your own event). There is only a \$5 donation to participate. If you'd like a medal and t-shirt, it is \$20.00 to participate. If you'd like a medal, t-shirt and striped socks, it is \$30.00 to participate (additional fees for International participants due to shipping costs).



Register here: <https://5psociety.redpodium.com/2018-virtual-5k-for-5pminus>.

You can even set up and be a Fundraiser Ambassador for the 5p- Society.

Seek out other families in your area and host an open house or meet at a park for a get-together. Contact the 5p- Society to get a list of families in your state or province at: director@fivepminus.org.

Wear your stripy socks. Wear one short and one long to represent the whole and the deleted 5th chromosome. The stripes represent the bands on the "p" arm of the 5th chromosome.



Become a 5p- Society Ambassador!! We are always looking for Ambassadors to represent the 5p- Society at health fairs, medical symposiums, community fairs and other events. For more information contact the 5p- Society at: director@fivepminus.org.

Ask your governor, senator or mayor to declare May 5 as Cri du Chat Awareness Day. Information and how to submit can be found on the 5p- Society website at: https://fivepminus.org/event/awareness-week-events/?event_date=2018-05-05.

Ask your child or adult's teachers/program directors if you can give a little talk about Cri du Chat Syndrome. We have ideas for how to share, including a coloring page of C5 at: https://fivepminus.org/event/awareness-week-events/?event_date=2018-05-05.

Post pictures and your own story about your child or adult on social media.

Change your profile picture and use one of the many picture frames that have been created on FaceBook.

Pass out Brochures, Fact Cards and First Responder Cards. To get them in time, contact the 5p- Society by April 21st (a small mailing fee would be greatly appreciated), or you can download and print your own from our website at: https://fivepminus.org/event/awareness-week-events/?event_date=2018-05-05.

The 5p- Society's mission is to maximize quality of life for individuals with 5p- and their families. 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 and solutions for future families (leave a trail).

We have a "people first" approach to put the person before the disability and focus on strengths not limitations.

As an organization focused on a rare disorder, we are constantly challenged to raise funds and progress organizationally 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 older children and keep families engaged over the years.

We thank you for your continued support!!

Regional Family Get-Togethers

By Jolene Towers, Committee Chair

Over the years, many wonderful families have reached out to other Cri du Chat families in their area, joining together for fun and social activities; including, for example, picnics at the park or weekends spent together. I know from my own experience that I cherish any amount of time that I can spend with other 5p- families, as does my daughter, Taylor, who refers to other children with Cri du Chat as "like me." It's a time for our family to feel "normal" no matter where we are or what we are doing.

The 5p- Society is pleased to announce that we will be sponsoring 5 Regional Family Get-Togethers in 2018. Our first one will be in Arizona in April and our others will follow later in the year. Watch our Facebook pages and events for upcoming dates and times. Also be sure to watch your email if you live near one of the following locations:

Arizona – Sam Brown – April 14 (see page 6)

Southern Illinois – Jason & Michelle Myatt – TBA

Alberta Canada – Clara Thomsen – TBA

Florida – Rob & Cathy Vaden – TBA

Massachusetts – Danny Watt & Ruthie Lieberman – TBA



Conference Updates

By now you should have received your Conference Brochure with information about the upcoming conference. If you have not received it either by email or snail mail, please go to the following URL to download your own copy:

<https://fivepminus.org/wp-content/uploads/2016/10/conference-brochure-2018.pdf>.

Don't forget **EARLY BIRD registration** goes until July 1, 2018. After July 1, 2018 the fee goes up \$50.00.

Scholarships to attend the conference are available. The online application and additional information can be found at: <https://goo.gl/forms/Bq3CKFHgTq9V5Ug72>. A Financial Assistance Scholarship will pay for three nights at the hotel and your conference registration fee.

We are in the process of creating a conference app. More info will be included in the conference confirmation packet that attendees will receive in June.

The speaker schedule has been set, and we'd like to share it with you (please note this is the speaker schedule only; events have been omitted).

Thursday, July 26, 2018

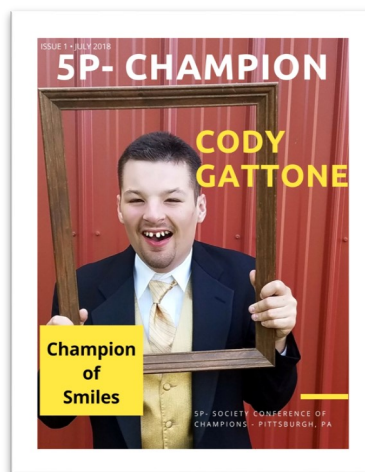
7:00-9:00 PM

New Family Orientation: Kent Nicholls, Founding Father, 5p- Society

Friday, July 27, 2018

8:15-9:00 AM

Laura Castillo, Executive Director
 Nick Wallace, President
 Michelle Myatt, Vice President
 Host Families Welcome
 Derek & Marie Stevens
 Johnna & Raeann Sleith
 John & Christina Yauch
 Patti Fowler
 Matthew & Heather Grasso
 Holly Gattone



9:00-10:20 AM

Parent Panels

- 1) Birth to 3
- 2) 5 to 8
- 3) 9 to 12
- 4) 13 to 17
- 5) Adult

10:30-11:50 AM

Concurrent Breakouts

- 1) Cri du Chat 101: Dennis Campbell, Ph.D.
- 2) Understanding the IEP and Creating an All About Me Book: Shanida Mathieu
- 3) Anat Baniel Therapy: Kathy O'Neil



Conference Updates

Continued from page 4

Saturday, July 28, 2018

8:30-10:00 AM

Concurrent Breakouts

- 1) Sleep Interventions: Intervention Fundamentals
- 2) Journey Through the Eight Step Special Needs Planning Program: Mary Ann Elhert, Protected Tomorrows, Inc.
- 3) Power of Friendship: Matthew Sousa, Best Buddies Program

10:15-11:45 AM

- 1) Toilet Training Practices: Intervention Fundamentals
- 2) ABLE Act Explained: Mary Ann Elhert, Protected Tomorrows, Inc.
- 3) Power of Genetics: Caleb Bupp, MD

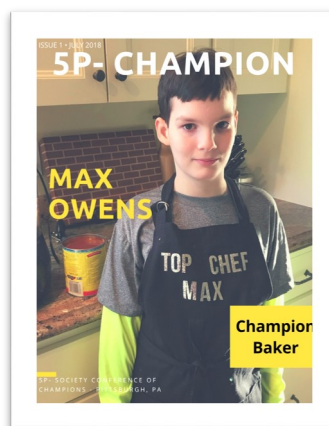
2:00-3:30 PM

- 1) Nutritional Deficiencies and Immune Dysregulation in a Child with 5p- Syndrome: Scott Faber, MD
- 2) Life After High School: Erin Gilsbach, Esq.
- 3) Effective Positive Behavior Modification: AmySue Reilly, Ph.D.

3:40-4:00 PM

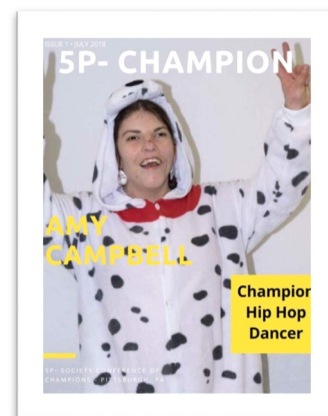
General Meeting of the Membership
Nick Wallace, President

Awards & Acknowledgments
Kent Nicholls, Founder 5p- Society
Laura Castillo, Executive Director



4:00-5:00 PM

Professional Panels
Dennis Campbell, moderator
AmySue Reilly
Shanida Mathieu
Scott Faber
Erin Gilsbach
Caleb Bupp
Matthew Sousa
Intervention Fundamentals



Sunday, July 29, 2018

9:00-10:00 AM

My Life with Cri du Chat Syndrome: Justin Valenti
2019 Portland, Oregon: Becky Owens

Caregiver's Guide Update

Great News!! The bulk of the Caregiver's Guide is done and has been sent to a select few individuals to proof read and provide feedback. I'm hoping it gets back to me in a few weeks to finalize and to send to the Board of Directors for their approval. The GOAL is to have it posted and available by Awareness Week.

I want to take this opportunity once again to thank each and every one of you who participated and those who have helped bring this to fruition, especially Maryline & Julien Ducry from Switzerland for their generous donation to create the Caregiver's Guide!! A true International effort!!

Western Regional Family Get-Together

By Sam Brown, Host Family

Hello from Arizona!! Almost 5 years ago the families in Arizona decided to start having yearly picnics. Our first picnic was a success, and we had roughly 10 families join us; 2 came in from California! It was amazing to meet everyone! What was even better was watching all of our CdCS kiddos and young adults interact with one another. Every year we have managed to have our picnic, and what makes it special is the bond we have all grown to have and even more is to see the growth in our kids: how tall they get, how much more they have learned. It can be hard on us all as we take this journey through CdCS life, but getting together has made it easier. As hostess of this year's 1st Western Regional get together I would like to invite all those in the state of Arizona and surrounding states to join us! Let's meet, eat and have some fun! And best of all make new friends!! Hope to see you there!!



*C5's Carousel
of Possible
Dreams*

5p- Society
www.fivepminus.org

The 5p- Society is happy to sponsor the first of five Regional Family Get-Togethers throughout North America to help families connect, share experiences and create friendships.

Western Regional Family Get-Together Information

Date: Saturday, April 14, 2018
Time: 12:00—3:00 PM
Location: Folley Park (Poppy Pavilion)
601 E Frye Rd
Chandler, Arizona 85225
Host: Samantha Brown

Please contact Samantha and let her know if you will be coming so she can get a head count for food and beverage at:
browns66@gmail.com



To maximize quality of life for individuals with FDD and their families



LEARN SHARE CONNECT

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=youtu.be
Documentary by Maria Ripoli
<http://www.cromosomacinc.com/>
Meet James Chalmers
<https://www.facebook.com/james.chalmers.3994/videos/10207221038346912/>

Blogs to follow

- <http://livingwithcriduchat.blogspot.com/http://elastamom.com>
- 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://notquiteearthmother.wordpress.com>
- <http://tricia-themama.blogspot.com>
- www.angelarichey.blogspot.com/
- <http://lessonsfrommydaughter.me>
- <http://martianmommy.blogspot.com>
- <http://www.specialneedsdadchronicles.space>
- <http://lifesunexpectedblessings.wordpress.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.
Beauty in Broken Dreams: A Hopeful Handbook for the Early Years as a Special Needs Parent, 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.

5p- Gear Items

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





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Fax: (562)920-5240
Email: 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

TWEET WITH US
@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>

Newsletter Articles

Wanted

We welcome articles for the newsletter. Please submit articles to Shari Campbell at [djcschc@mchsi.com](mailto:djcshc@mchsi.com)

