

IT'S IEP SEASON *by Jen Wong*

Summer has quickly flown by! We had a great time getting together with old and new families in Southern California, but now it's time to get back into school mode. For most, it's trips to the store for new outfits and school supplies. For us, there is an added and often dreaded piece, the IEP. Will the school follow through with the plan? Will the new staff care for my child in a positive and purposeful way? The IEP process has caused many of us sleepless nights, upset stomachs, headaches, and more.....but it doesn't have to be that way. As the saying goes, knowledge is power. The earlier we can start introducing ourselves to the IEP process and Special Education Law, the less stress we will have. If you are a late starter to this process, no worries, late is better than never.

A few easy resources to start with are seminars and books about IEPs. Wrightslaw.com has a great book I always recommend for newcomers, it's called. It's The Complete IEP Guide (FYI Wrightslaw.com gives a military discount). It's great at gently guiding you through the process, even providing sample letters you simply input your name into and send. Many libraries carry copies of their books. Autism, Down Syndrome, and local school district's (not just your own) are great resources to look for free seminars. Seminars are great because you can get your questions answered on the spot. I've rarely paid for an IEP seminar. The best resource I have found are parents that have "been there and done that" and bonus if they also live/attend in your child's district/school. At the start, this process can be overwhelming. Having a support person that has the knowledge and encouragement to keep you calm during this process is important. However, all of these resources will be wasted if you do not have a positive attitude going into the meetings. I know this can be easier said than done. One thing that helps tremendously is to request (email or written) all reports to be given to you at least a week prior to the meeting. This is so the information presented isn't new and shocking during the meeting. Despite being aware of your child's abilities, having their delays presented to you over and over can be

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FESTIVAL OF FAMILIES 2017

Milwaukee, Wisconsin

The 2017 conference committee is in full swing of planning for next summer's conference. Dates for the conference will be August 3-6. The location will be at the Milwaukee Marriott West. A great room rate of \$119.00 (plus tax and service charge) per night has been negotiated. Reservations can now be made by calling 877-651-7666, or by the online link (see page 3 for the online link and additional information).

About the theme . . . The Milwaukee Host families have chosen Festival of Families because Milwaukee is known as the Festival capital of the world. What better what to celebrate our families!!

emotionally overwhelming. Getting reports ahead of time allows you time to process the information and communicate, individually with each therapist, any questions/concerns you have with their reports. This helps to expedite the meeting.

Another thing I always tell parents is to be respectful. Remember most of the non-administrative people in the meeting are working long hours, sometimes without their legal mandated lunch/breaks, underpaid, and working in classrooms that are severely underfunded. If you are knowledgeable about IDEA and your state's special education law, you do not have to get loud and disrespectful. If the district is not following the law, calmly ask questions and do not move on until your question is answered to your satisfaction, and documented in the IEP notes. If the district states they cannot do something because of a policy, ask for a copy of that policy. Policies are documented guidelines. If the IEP is getting contentious, I suggest audiotaping the meeting (usually requires a min. 24hr notice to the district). Another option is to bring your own note taker (parental support) to take notes for you (it's best if they have some experience with the IEP process). I have been in many meetings for Emma where there was no sight of resolution; however the meeting never got heated. Because I respected the IEP team and they respected me, we were able to have a discussion and eventually come to a solution that met Emma's needs. Due to our positive relationship, Emma's IEP team has been willing to listen to my suggestions and implement them in her plan. When meetings become Us v. Them, the meeting no longer becomes about the child and his or her needs but about which group is going to "win". This ultimately leads to the child ALWAYS losing. Nothing positive can come from negative attitudes. If a meeting is going round and round, it could be best to request to stop and reconvene at a later date. Depending on the circumstances, it may be necessary to hire an advocate or attorney to assist you.

Another key to reduce stress is to keep an organized binder of all paperwork. I put Emma's together for the year, with tabs separating each therapy/departments, with the completed IEP in front. I keep every school year separate, either in binders or I put the past years' IEPs in individual folders and store in a file box. In case you need to go the direction of legal action, it's best to keep all information in chronological order, with the most current on top (that's usually how lawyers prefer the paperwork and you do not want to pay a lawyer to sort your papers!). There have been times in an IEP because I was organized, I have had documents readily available for production, that the district had trouble finding. Finally, a simple gesture of bringing some treats/drinks (coffee and bottled water) to the meeting is always a great way to start the meeting off on a positive note and show you appreciate everyone's time/knowledge they have committed to your child.

Our 5P- group has many knowledgeable people that you can always post your question to on our Facebook group. One thing to keep in mind, especially with timelines, laws varies slightly from state to state, so always be sure to know what is accurate for your state.



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



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/cr-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>

RESEARCH OPPORTUNITIES

1. Dr. Pedro Sanchez from CHLA/USC in Los Angeles, California is performing research on 3D Facial Recognition for 5p- Syndrome. If you would like to participate, please contact Dr. Sanchez at: pedro.sanchez@chla.usc.edu. For information about the research please visit: www.facebase.org/project
2. Juan Odendaal would like to invite you / people belonging to your organization to complete an anonymous online survey on a person in your life who has Cri du Chat Syndrome. This project is being conducted as part of my Masters of Educational Psychology degree at Victoria University of Wellington in New Zealand and is the first of its kind. The study will be titled **The Form and Function of Communicative Behaviours in Individuals with Cri du Chat Syndrome**. If you would like more information about the survey and study, please contact Juan at: engelbjuan@myvuw.ac.nz

If you are interested in participating in this survey, please fill out the survey at https://qtrial2016q2.az1.qualtrics.com/SE/?SID=SV_9n9HtucU5Axm8l

LEARN SHARE CONNECT

Blogs to follow:

- * <http://livingwithcriduchat.blogspot.com/>
- * <http://elastamom.com>
- * [All Things Beautiful by Kathy McClelland](http://AllThingsBeautifulbyKathyMcClelland)
- * <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>

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
- [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=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.

IT'S A WRAP 2016 CONFERENCE

Over 90 families gathered for the 31st Annual 5p- Society conference in Costa Mesa, California. A record breaking 31 first time conference families were in attendance. The California Conference committee were able to meet the needs of many families with their continuity of the Lights, Camera, Action theme throughout the conference -- from the Welcome Reception to the Hall of Fame Awards. The committee of Tim & Rachael Reid, Shawn & Katie O'Connor, Marcel & Kelly Szabo, Tim & Joslyn McNaughton, Jeremy & Adrian Roberts-Gonzalez, Eric & Stephanie Blakely, Jim & Fran Bodle and Josh & Thu-Truc Rencher worked effortlessly for several months planning and preparing for the Family Fun Event, Childcare, Sibling Event, Banquet and Family Dance, Welcome Reception and the first time ever Teen/Adult with Cri du Chat syndrome outing.

Thanks to our varied speakers and topics, conference goers were able to learn about the basics of Cri du Chat with parent and professional Dennis Campbell and Dr. JoAnne Nguyen, how to exercise your rights and prepare for your child's IEP with parent and advocate Shanida Mathieu, get information about full inclusive programs with parent Rebekah Rocha, watch how Picture Exchange Communication System (PECS) works with parent Linda O'Connor, find out more about the Transition programs for young adults, and the difference between Hippotherapy and Therapeutic Horseback Riding. Dr. Geoff Towers talked to us about Puberty and Cri du Chat Syndrome, and Melissa Gran explained about Vital Stem and an overview of Feeding and Swallowing. We also were wowed by a presentation by Dr. Doug Sidell on Head & Neck Manifestations of Cri du Chat Syndrome. Dr. AmySue Reilly, Kelly Campbell and Dennis Campbell provided an impromptu interactive presentation on Effective Behavior Modification with one of our 5p- kiddos. We were also introduced to a new therapy called Anat Baniel Method by trained therapist Karrina Barlow.

Families enjoyed authentic food from Southern California Taco man, along with train rides, face-painting and fellowship at Irvine Regional Park for the family fun outing. Siblings had fun at Knott's Berry Farm's Soak City and the Teens and Adults with Cri du Chat Syndrome had their own off-site adventure where they went bowling, played arcade games and enjoyed their own water-park adventure at the Irvine Spectrum.

Even the hospitality suite was transformed into a Movie Theater with popcorn, boxed candy, soda, water, beer and wine . . . lots of wine.

The conference wouldn't be complete without the Saturday night Banquet and Family Dance. This year we entered the banquet room that was transformed into a night at a Premiere with a red carpet and back drop for picture taking, Hollywood Sign, photo booth, beautiful red rose centerpieces and the best DJ's!! Everyone had a great time.



THANK YOU TO OUR REWARDS PROGRAM PARTICIPANTS

Thanks to all of our Film Crew Reward participants for your donations to the conference and continued support. The participants each submitted a logo to grace our step and repeat banner for the Red Carpet. Thank you to the Smith Family, the Borrello Family, the Grasso Family, the Blakely Family, the Jones Family, and the Fernandes/Roberts-Gonzalez Family.

Many thanks to all the individuals who donated to our silent auction and raffle.

Winner of the 80/20 raffle was Heather Grasso. \$13,200 was raised and Heather was given a check for \$2640.00. Thank you to everyone who participated!!

2016 HALL OF FAME RECIPIENTS



Co-Parents of the Year:

Bonnie Smith of Alberta, Canada. Bonnie and her family raised over \$28,000 CAD for the 5p- Society with an online auction. She is also a big advocate for her son Turner and for spreading awareness of Cri du Chat Syndrome in her community.



Billy Masson of Sullivan, Missouri is one of the 5p- Society

Ambassadors. Billy's wife and daughter both have 5p- Syndrome and he is their number one fan and advocate. Billy also instituted an awareness program for the entire week of International Cri du Chat Awareness Week. I'm sure he would be happy to share his program to anyone interested.

Sibling of the Year:

Noah Juliar of Shoreview, Minnesota is his little brother Cooper's number one fan. He has dedicated many awareness projects to his brother and for the 5p- Society. Many of you will remember the truck tail gate that was transformed into an awareness advertisement for Cri du Chat Syndrome. Yep, that is Noah's truck!! He also raised quite a bit of money during awareness week with some local projects, including a stripy sock campaign. Cooper is very lucky to have a brother who is so dedicated to teaching the world about the syndrome.



Grandparent of the Year:

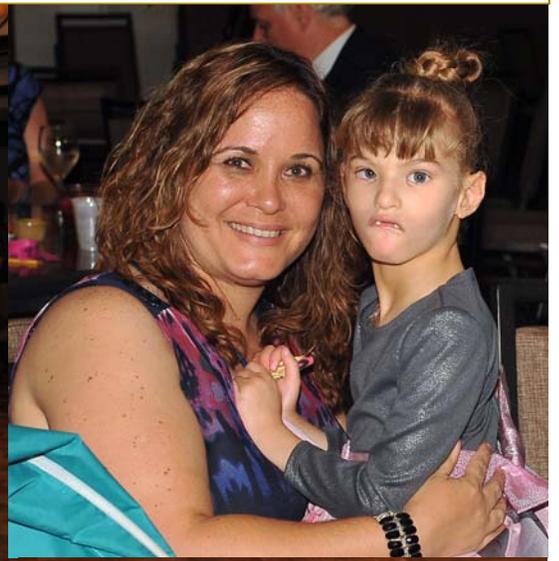
Donna Grasso of Havertown, Pennsylvania is very dedicated to her grandson Matthew and her entire family. Donna leads the 5p- Society t-shirt fundraiser that is held twice a year. Donna is also one of the 5p- Society Ambassadors and holds awareness events several times throughout the year and has a tattoo on her forearm that she uses as a conversation piece to teach others about the syndrome.

Volunteer of the Year

Julie Watt Faqir is from Holliston, Massachusetts and is the aunt to 23 year old Aaron Watt. Julie joined the International Cri du Chat Syndrome Awareness committee a few years ago and has taken the lead in many awareness programming events. This year she dedicated herself to reaching out to as many states as possible to declare May 5 as Cri du Chat Awareness Day. Through her efforts over 25 states made the declaration. That is over 1/2 of the states. I know next year she is planning on getting more families involved and more states to make the declaration.



ENJOY SOME CONFERENCE PICTURES BY VISUAL IMPACT PHOTOGRAPHY



#TAKETHATCRIDUCHAT

FESTIVAL OF FAMILIES 2017

As we prepare for the 2017 conference, we'd like to provide you with some pertinent information.

Dates: August 3-6, 2017

Location: Milwaukee Marriott West, W231 N1600 Corporate Court, Waukesha, WI 53186

Room Rate: \$119.00 (plus tax and service charges); reservations are now being accepted. You can reserve your room at 877-651-7666. Please let them know you are with the 5p- Society. You will need to let them know if you want a king or 2 doubles (also let them know if you need crib or roll-a-away). There are limited connectors. Please note that the connectors are a king size room to a room with 2 doubles (there are no double to double connectors). You can also make your reservations online at http://www.marriott.com/meeting-event-hotels/group-corporate-travel/groupCorp.mi?resLinkData=5p-%20Society%20Annual%20Conference%5Emkeww%60sjsjua%60119.00%60USD%60false%604%607/30/17%608/7/17%607/6/17&app=resvlink&stop_mobi=yes.

PLEASE NOTE IF YOU ARE MAKING YOUR RESERVATIONS ONLINE THE SYSTEM IS GOING TO TELL YOU THAT THE ROOMS ARE SOLD OUT. DO NOT TAKE THAT MESSAGE TO HEART. CONTINUE WITH YOUR BOOKING. THE HOTEL HAS DEAUTHORIZED ALL DOUBLES SO THAT NO OUTSIDE INDIVIDUALS WILL HAVE ACCESS TO THESE ROOMS. WE HAVE ALL THE DOUBLES RESERVED IN THE HOTEL, AND WHEN YOUR RESERVATION GOES THROUGH, THE RESERVATIONIST WILL ASSIGN THE ROOM. I know this is not what we are accustomed to and if you have any questions, please contact Laura privately at director@fivepminus.org.



Conference Registration: Conference registration will open in March. Early Registration must be received by July 1, 2017 and will be \$150.00 for UP TO 2 adults and 2 children; additional adults will be \$50.00 each and additional children will be \$25.00 each. If you register after July 1, 2017 you will pay \$200.00 for UP TO 2 adults and 2 children. Each additional adult will remain at \$50.00 and each additional child will remain at \$25.00 each. Non-Members will pay \$225.00 for UP TO 2 adults and 2 children. (no change on the additional adults and additional children prices).

Rewards Program: We will once again institute our rewards program for those who fundraise for the conference. The breakdown and rewards are as follows:

- Raise \$1500.00 and your conference registration for UP TO 2 adults and 2 children will be covered;
- Raise \$3000.00 and your conference registration for UP TO 2 adults and 2 children will be covered and one night of your hotel stay will be covered;
- Raise \$5000.00 and your conference registration for UP TO 2 adults and 2 children will be covered and three nights of your hotel stay will be covered.

Keep up to date with conference planning by visiting the 5p- Society website at www.fivepminus.org/Next_Conference.



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

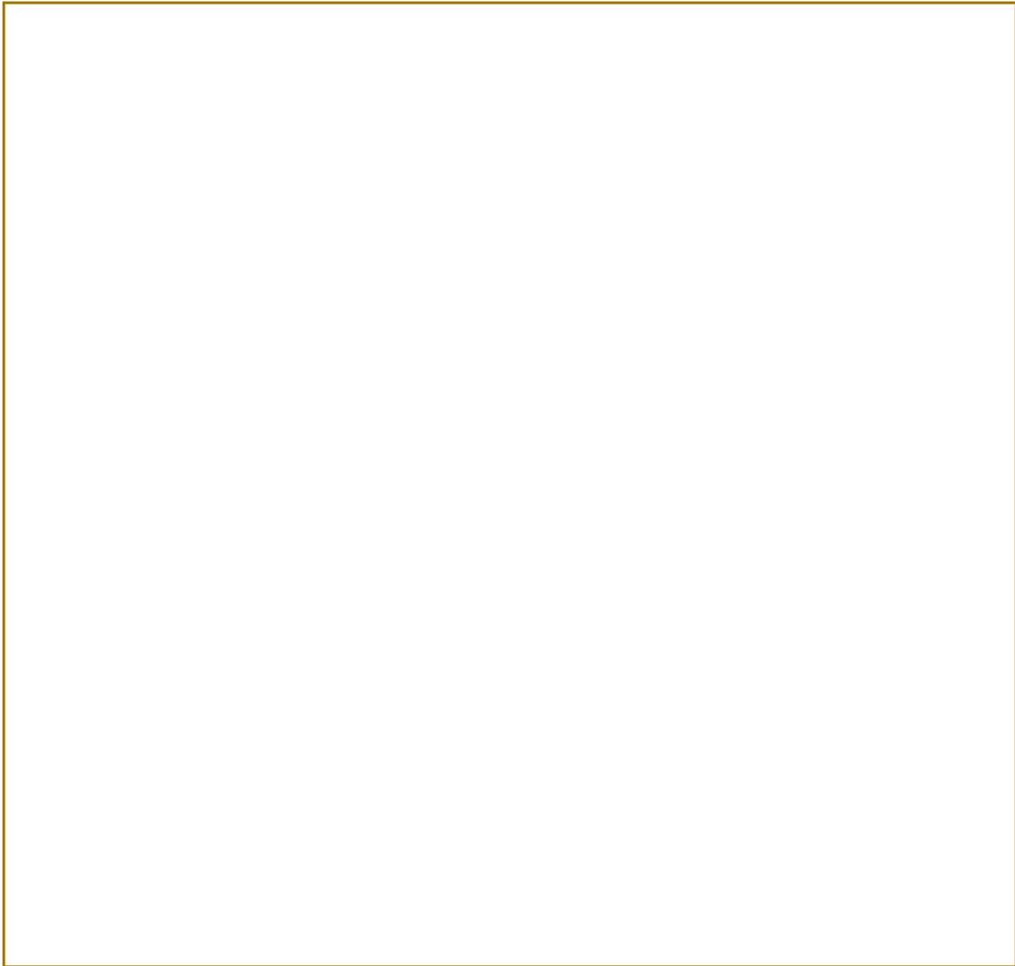
Tweet with Us
[@5pminus](https://twitter.com/5pminus)

We're on the Web
www.fivepminus.org

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

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>



EVENTS & ITEMS

2ND Annual Pig Roast

When: Sunday, October 2, 2016, 1:00 - 4:00 PM CDT
Where: American Legion Hall, 920 Monroe Ave, South Milwaukee, WI
Cost: \$15.00 for Children
\$30.00 for Adults

Please register online at <https://5psociety.regfox.com/2nd-annual-pig-roast-for-5p-minus>

Wades5kfor5p-

When: Saturday October 8, 2016 8:30 AM CDT
Where: Lodge Park, Monticello, Illinois
Cost: \$15 for Kids Fun Run
\$20 for 5k Run and Recreational Walk
Prices increase after September 23rd

For additional information please visit the website at www.wades5kfor5p.com

Get your 5p- Awareness Gear at

www.cafepress/5pshop or

The following items available at [www.fivepminus.org/5p- Logo'd_Items](http://www.fivepminus.org/5p-Logo'd_Items)

Baseball caps now available in Blue, White, Beige and Black (one size fits most) \$20 each + \$5.00 shipping

Key Chains \$5.00 + .50 shipping

Wristbands \$2.00 +1.50 shipping

