

ARE YOU AWARE? BY NICK WALLACE

I know this is a silly question to pose as the title of my article, which will reach families from the 5p- Society, but as many of you know there are a lot of people out there that are not aware that 5p- / Cri Du Chat exists, and if they are aware they only have antiquated information.

Does this scenario sound familiar to anyone?

Friday at four thirty in the afternoon, thirty minutes before most of the hospital staff leaves for the weekend, and an ominous presence has just entered the room. A middle-aged woman, upon whom age took no mercy, appeared, with gaudy jewelry and a dress that looked like it was made by a fashion designer tripped out on rubber cement and sharpie markers. Mr. and Mrs. Wallace we have discovered that your daughter is missing a large part of her fifth chromosome. This is a syndrome that is called Cri Du Chat, five p minus, or cats cry syndrome. Your child will never be able to walk, talk, she will be mentally retarded, and always be in special education."I know that she said more then that but I think I started looking around for candid camera. Was this really happening? She finished by giving us a paper, from the 1970's, offering a bleak outcome and a couple test results that were obtained. If you have any questions please feel free to contact me on Monday. Have a good weekend.'She said as she left the room.



Cri du Chat Syndrome Awareness Week Logo by Nikki Lattig

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Blogs to follow:

- * <http://lifesunexpectedblessings.org>
- * www.sophieourgift.wordpress.com
- * <http://livingwithcriduchat.blogspot.com/>
- * <http://elastamom.com>
- * <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

80/20 RAFFLE WINNER

Thank you to everyone who participated in the 2012 80/20 cash raffle. Eighty tickets were sold this year and the winning ticket received \$1,600.00.

The winning ticket was pulled

on July 15 by Christian Zepeda, (a non-related individual to the 5p- Society.) The winner is Joan Demeike from St. Louis, Missouri.

The remaining 80% of the raffle

monies will be used to cover expenses by the 2012 conference or will be carried over to the 2013 conference in New York.

THANK YOU FOR YOUR CONTINUED SUPPORT!!

Continued from page 1 . . .

I know that several of the families, with a child that has Cri Du Chat, that I have talked to have had similar experiences. What would you do if I told you that we could make stories like Angie and mine a thing of the past? Well, steps have already been taken to make this happen.

May 13th, 2012 kicked off the first annual International Cri Du Chat Awareness Week. The idea of an awareness week was the brainchild of Laura Castillo, Executive Director of the 5p- Society. She posed the idea and off we ran with it. We believe the first awareness week was a huge success, and here are three reasons why:

- We were able to bring together 5p- / Cri Du Chat support groups from 20 different countries. This enabled us to spread awareness of 5p- / Cri Du Chat on a global scale the likes of which has never been done by the 5p- Society before.
- We created an awareness week website (<http://www.criduchat.org>) and an online store (<http://www.cafepress.com/5pshop>) where we could sell merchandise to help us spread awareness during the year, and not just during the awareness week. The store also accepts other currency and will ship from locations across the globe. The money that is made from this store will be filtered into the International Awareness Week project to help us create informative brochures / videos, viral campaigns, and various other projects.
- We made at least one person aware that 5p- / Cri Du Chat exists. You may say that only one person is not much to cheer about, but in my mind, it only takes one person to make a big change. I know one little girl, my daughter Allison, who has Cri Du Chat, changed my life in so many positive ways.

So, what is on tap for next year? We plan to host the event starting May 5 – 12, 2013. We plan to create an international committee to help the awareness week grow to even bigger heights. We plan to start working on an “I Can” viral campaign. The campaign will include kids and adults from across the globe showing that they can do what the doctors said they would never be able to do.

Lastly, we are looking for more involvement from families of the 5p- Society. I want to state that this is not a fundraising initiative. If funds happen to come in because of an event that has been held, to spread awareness, that is great, but our main focus is to spread awareness to anyone and everyone.

I know that there are parents out there that state that they will do anything for their child. Now is an opportunity to do so. I know there are parents out there that have stated that they wished they could get the services that you get with an Autism diagnosis. By participating in awareness week, this is your chance to help our kids get the services they need. Once again, I reiterate, that it only takes one person to create big changes. Is that one person you? Could you be the one who educates the person that helps bring Cri Du Chat into the medical limelight? It only takes one and I challenge you to be that one.

HAMMOND GOLF TOURNEY BY BRAD HAMMOND

The Hammond family (Grant) from Ingersoll, Ontario, Canada held their 3rd annual golf tournament in support of the 5p- Society on Father's Day weekend. The tournament took place on Saturday June 16th at the Tamarack Golf Course and was attended by 80 golfers of all levels of ability (and inability). An additional 35 friends joined the tournament for dinner. A good time was had by all.



Brad and Christy Hammond along with Doug and Joan Gould and a host of family and friends organized the fun-filled day that featured 18 holes of golf, a steak dinner, and both a silent and live auction. The Hammond's are pleased to report that the tournament raised \$8,000 for the Society, a \$1,500 increase over last year.

Amateur Auctioneer Paul Crow donated his time and talent to make sure the bidding at the live auction stayed at a fever pitch. The big item at the auction was a pair of Toronto maple Leaf Hockey Tickets donated by Bryan Dyke of BDI Canada. In Canada these tickets are more valuable than gold, no matter how bad the leafs are doing.

The golf course has been booked again for 2013 so mark your calendars for June 15th.

ALLOW ME TO INTRODUCE MYSELF BY JEN WONG

As I come back home from another fabulous Conference with renewed energy to start another school year, this year I have another reason to be excited. Every year I anticipate going to our conference reconnecting with friends and my CDC family, learning new information from speakers, and enjoying a relaxing vacation in a new part of the country. This year was no different, except for one thing. When I left the Conference this year, I left as the new President of the 5p-Society!

I am very excited and admittedly a bit anxious. Jolene Towers did such a wonderful job the last five years, I hope to continue taking the 5P-Society in the positive direction she led us. I am confident with the passion and ideas the Board of Directors, our Professional Advisory Board (PAB), and Laura, our Executive Director have, the Society has a bright future. I remember coming to my first conference many years ago so overwhelmed by the unknown. Through many speaker sessions, parent panels, and the very important late night hospitality room talks, I have learned so much. A few years ago, I decided to give back to the Society that has given so much to me and my family, so I joined the Board of Directors. It was an eye opening experience as to what our Society accomplishes on a shoe string budget and a bunch of volunteers. It's very clear that if it wasn't for the passion of everyone involved, we would not be who we are today.

It has been a very rewarding experience to help educate and support parents out of that scary unknown place I was in a few years back. So this year I decided to up my commitment. I was honored to be elected President. I thought, although I know many of you, there are some families out there who might not know me.

Let me introduce myself. My name is Jennifer Wong. I grew up in St. Louis MO, and became a RN in the Air Force, where I met my husband, Cedric in San Antonio, TX. After a bit of moving around (Korea, back to Missouri), the Air Force took us to Alaska. While in AK, we had Emma (10). We received her CDC diagnosis at 4 months old. I will say the AF was very quick to provide her with great quality services. Unfortunately, they were also quick at deploying her Daddy, 10 days after she was born. It was a very emotional time for me trying to figure out why it was so hard to simply feed my baby girl. I many times questioned my skills as a mom, the one and only thing I ever wanted to be. I finally received her diagnosis the day before Cedric came home from deployment. To this day, one of the hardest things I've ever had to do was welcome my husband home from deployment with the news his beautiful daughter has CDC. But through the grace of God, we had THE BEST support system of neighbors and medical staff.

Everyone was incredible and helpful would not begin to describe what they did for us. After the initial whirlwind settled, we decided to leave the Air Force and settle in Folsom, CA. In Folsom, we added three brothers to Emma's support team, Christopher (8), William (6), and Daniel (4). While it's been stressful, overwhelming, and crazy at times, we have always had friends to help carry us through.

Emma has introduced me to some of my closest friends I will ever have. She has brought so many blessings in my life. She has brought out strength in me I never fully realized. This is what I hope to help other families accomplish, to realize the potential of not only their child with CDC but the strength they didn't know they had.

Living in AK my favorite theme was, "Nothing is stronger than a Momma Bear protecting her cub". I often wear my jade bear necklace I bought in AK to Emma's IEPs to remind myself of my Momma Bear strength.... and maybe to remind others there of my strength too!

I look forward to meeting more and more families and helping them and the Society in any way I can. If you need to discuss anything with me you can email me at akjenwong@yahoo.com.



INTRODUCING . . . RACHEL

Hi my name is Rachel, I am 27 and I have Cri Du Chat but I am a mosaic which means some of my cells are affected but not all of them. I live in New Zealand and I live independently away from my parents in a house that my Dad's trust has recently brought me. I volunteer three mornings a week, the first morning I volunteer at a shop called Trade Aid where I help my boss do the banking (I am the only volunteer who is allowed to do this), I dust and I can serve customers and use the till. Last year in November I overcome my not looking customers in the eye and only saying good morning to them but one morning I asked three customers if they would like any help. So now when people walk into the store I say good morning and ask them if they would like any help. The other two mornings I work at the YMCA doing a programme called Boogie Buddies for two to five year olds it is so much fun and it is good therapy for me. At Boogie Buddies I set out a circle of mats on the floor when I arrive and then I help one of my bosses set up the gym equipment for the circuit that the children do upstairs. When the children arrive we ask them to take off their shoes and socks and leave them neatly along the wall and then we get them to sit down on the mats and then we do warm up exercise with them and then we do a warm up song like the bird dance, here comes a bear, the Hokey Pokey. After we have done the warm up song we tell the kids to set on the benches to split them into two groups, one group stays downstairs and the other goes upstairs to climb on the gym equipment and then downstairs we set up a floor circuit with hula hoops, a throwing target with beanbags, a wobbly bench with hula hoops one at each end and the children have to crawl through them. Sometimes we do other activities like at the end of the term we get out the parachute and put balls and feathers on the parachute and we have to get them off and then we sit underneath the parachute with all the kids and make it a tent. Another activity we do with the kids is we have four buckets of coloured balls around the floor and then when the music starts the kids have to put the right balls in the right box and so for the balls we have green, yellow, red and blue and us teachers go and put the wrong balls in the wrong boxes because we trick them into thinking we don't know our colours.

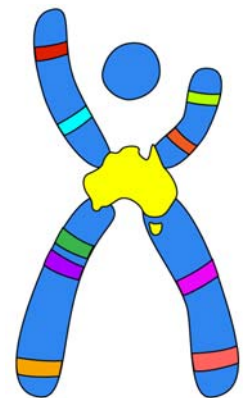


I also can read and write (I prefer typing). I am writing my own blog which is www.livingwithcriduchatmosaicism.com and I don't drive but I can walk long distances to where I want to go and I have dinner with my Dad and my stepmum on a Wednesday night and I have lunch with my Mum during the week which is usually on a Wednesday at lunchtime. I am currently making a collage of all my CDC brothers and sisters for my house which hopefully by the next time that the newsletter comes out that I will have a photo to show you. I also have a boyfriend of four years called Bryan.

I am a daughter, sister, person living with a disability, an aunt, a friend, a granddaughter, a niece, a girlfriend, an inspiration, a role model, an adult, I am a cook and a member of society, a cousin, and a light in this world, I am all of these things and so much more. I have **CRI DU CHAT SYNDROME!!!**

CRI DU CHAT SUPPORT GROUP OF AUSTRALIA

Families from all around the world who are affected by Cri du Chat Syndrome or other anomalies of chromosome 5 are invited to join the Australian Support Group for a family weekend and conference in Australia. This event is taking place at Sea World Resort on the beautiful Gold Coast, from March 1-3, 2013. They are looking forward to bringing together over 30 families, many of whom have never had the opportunity to meet with others affected by CDCS. There will be times for learning and celebration, but most of all they look forward to strengthening connections and making new friendships. For more information, email info@criduchat.asn.au.



ALTERNATIVE THERAPY BY BRENDA CHACON

Hello, my name is Brenda Chacon and I'm the proud mother of Cruz Chacon (almost 3 years old).

I want to share my story of a therapy I found that has helped my son immensely and I hope this opens the door for others to share types of alternative therapies or anything else you have found that has helped your child.



I first learned of CranioSacral Therapy when Cruz was about 8 months old. I spent too many hours in the emergency room and hospital due to pneumonia. No doctor was able to prevent Cruz from getting sick. In fact I had to wait until my son got really bad in order for him to be treated (which I'm sure is a familiar story to most parents). I was beyond frustrated. A distant relative recommended I take Cruz to CranioSacral therapy. It is a gentle, hands-on therapy that releases tensions deep in the body to relieve pain and dysfunction and improve whole-body health and performance. My relative said to keep an open mind and have Cruz treated. I figured if it wouldn't harm him I'd try it.

Shortly after he started treatment he seemed to stop getting so sick. The next time he got sick after being treated was the first time I didn't have to visit the doctor's office, he fought off being sick on his own. His development was extremely slow (Cruz has more than Cri-du-Chat, he has another chromosome translocation that creates a more severe outcome for him). He was receiving therapy at home (physical, occupational and feeding but didn't seem to connect with any of it). Pretty soon, the in-home therapists started to inquire if I was doing anything different with him. They observed him and felt that he seemed more aware and that it seemed like 'a light turned on' in his brain.

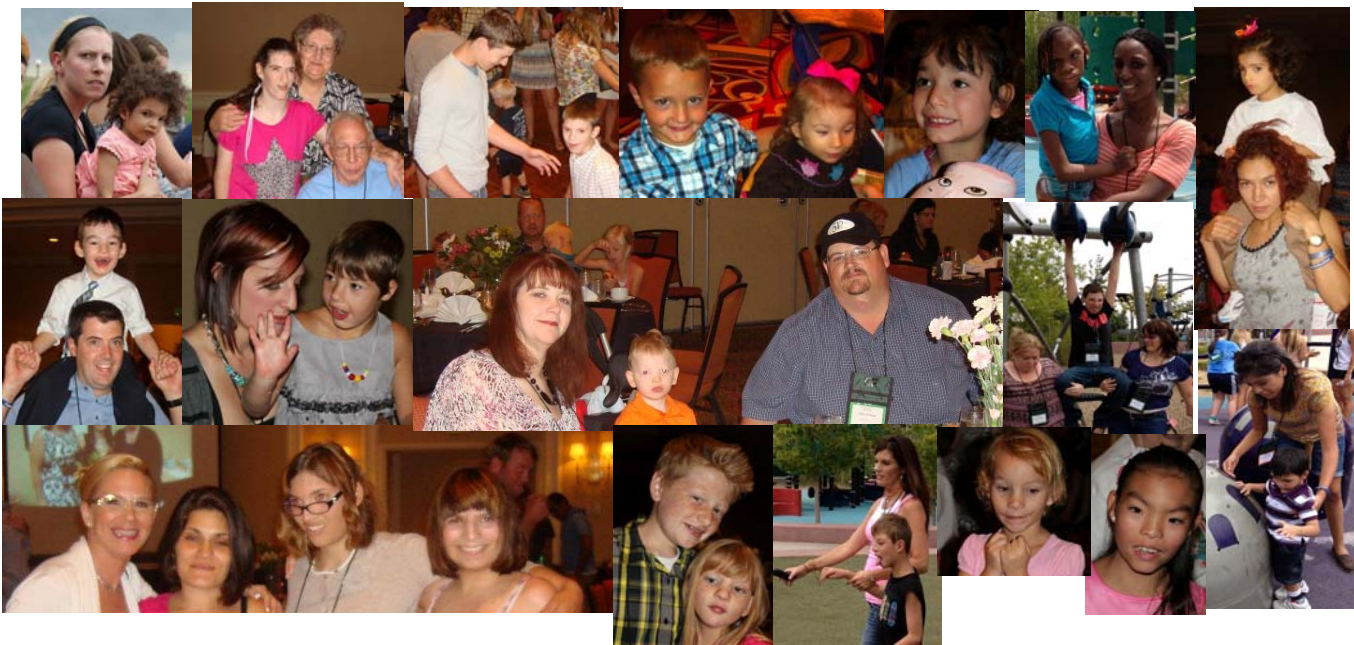
My son wasn't crawling, sitting or chewing before April of this year. After 5 days of intensive treatment, he began to sit up his own, started to army crawl and started to chew for the first time.

Another thing that I add to his diet is 1,000mg of DHA Omega fish oil (3,6,9) each day (mix it into a smoothie, as recommended by a developmental pediatrician), this seems to give a little extra push in his vocalization and communication.

I hope others share their stories and we can all learn together and find different ways to help give our children any extra assistance they may need. The way I see it, we may be on the cutting edge of something that may be the mainstream 20 years from now. (look how far we've come in the last 20 years).

I can share more about CranioSacral therapy if anyone is interested or you can look up information about it at the Upledger Institute (I would recommend finding a therapist that has trained through this program and reading about it there because if you google it there is a lot of negative comments). I should also mention that I was a complete skeptic and have a scientific mind and background. I was raised that anything alternative is nonsense, but I am a true believer in this therapy, so much so that I hope to be a practitioner someday to help other children and families.

CONFERENCE PICS



2012 HALL OF FAME RECIPIENTS



Congratulations to Charity Deleon, the 2012 Parent of the Year. Charity's nominators describe her as a "genuine friend & advocate." Charity, mom to six beautiful children, including Sophie her daughter with CDGS, came to the aid of the 5p- Society when it was looking for someone to assist with the International CDGS Awareness week creative designs. Charity immediately joined in and created many of the designs that were used to sell through the Cafe Press site. Despite her heavy home-life schedule, she took the time out to enhance the image of the 5p- Society, as well as of the syndrome.

Charity also has a very popular and heavily read blog, www.lifesunexpectedpleasures.org, that she uses to not only help her through her journey of having a child with Cri du Chat Syndrome, but to help others through their journey.

She has created a spin-off of the blog (www.sophieourgift.wordpress.com) with a Sophie's friends section for families to share stories. Charity is also one of the 5p- Society's parent-to-parent support coordinators.

Congratulations to Maggie Castillo, the 2012 Sibling of the Year. This was one of the toughest groups to choose from . . . the nominated siblings have really gone above and beyond for the past several years in support of the 5p- Society.

Maggie's nominators say this about her: "Maggie's summers have been dedicated to preparing and planning for the 5p- Society conferences where she prepares the name badges, sorts and assembles the registration packets, runs errands, picks up printing materials and divides up the t-shirts." Maggie also makes and prepares deposits for the 5p- Society. At the conference Maggie has co-led the sibling mixer for the past several years. "This includes gathering materials, planning games, and actual running of the event." Maggie knows that at the conference she is working and is available to assist wherever needed, be it in child care, setting up and/or working at the Friday outing (usually face-painting, hair coloring or tattooing), and leading a group of younger kids at the sibling outing.

Personally, Maggie, recent high school graduate and honor student, will be attending the University of the Pacific in the fall, majoring in Athletic Training. She played on her HS softball team and she has been part of the Confirmation leadership team for the past several years at her church. Maggie was a very desired sibling as her sister Katie wanted a baby sister (she has two younger brothers) so badly she would rub her mommy's tummy saying "my sister, my sister." Needless to say Katie cried the day she was born. Maggie is a great little sister. She takes Katie on "sissy days" where they will go shopping, get Starbucks and maybe lunch. She is always there to watch Katie, makes sure she gets on her bus and puts up with Katie's mess (they share a room). Katie will definitely miss her baby sister, as Maggie journeys onto her next chapter in her life.



Congratulations to Gloria Griffin, the 2012 Grandparent of the Year. Her nominators said this about her: "Gloria has over the years stood as an "example" of what is needed in any organization. She puts in countless hours arranging for and promoting fund raising events for the 5p- Society and has collected over \$30,000 since 2003 with her jewelry sales." "Gloria has been a very passionate advocate for our children." "Gloria is an active member of the board, and being a grandparent is able to take concerns, suggestions and/or comments to the board." Gloria also is one of the Grandparent Facilitators for the 5p- Society.

Gloria is also grandparent to 9-year-old Landen!! Gloria attended her 1st conference just days after his birth to gain knowledge and to bring home information to her son and daughter-in-law. . . She has never looked back!!!

WINE TASTING & SILENT AUCTION FUNDRAISER BY RACHEL STANFORD

A few years ago, the Texas 5p- families were asked to assist in raising money for the 5p- Society annual conference and get together in Dallas, Texas. As a brand new family who had never attended a conference, we did not know where to begin. Luckily, my mother was a pretty active fundraiser for the Leukemia and Lymphoma Society and had some ideas. She suggested we have a party and invite our friends and family to attend for a small donation to the 5p- Society.

I quickly decided if I was going to get *my* friends to attend, there would have to be drinking involved!! And, thus, our annual Wine Tasting & Silent Auction fundraiser was born. This year, we had over 100 attendees and six Houston-area 5p- families* involved in the event, which was held at Archway Gallery, in Houston, Texas. Through our event, we managed to raise \$12,869.00 for the 5p- Society, all of which is going to assist with the 2014 San Antonio Texas conference.

If you would like to replicate this event in your city, here is how we do it:

We seek out a free venue for the event. The first year of our event, we held it in an apartment club room. A family friend, who co-owns an art gallery, attended that event and offered up the gallery's space for our future fundraising events. The Wine Tasting has been held at Archway Gallery for the last three years, thanks to Liz Conces.

Next, we find wine sponsors who donate 6 bottles of one type of wine. These are mostly our family members, although this year, Miles' geneticist donated 3 wine sponsorships. The wine sponsors compete in the Wine Tasting, and all those in attendance at the event vote on their favorite wine. The winner of the Wine Tasting wins one of each bottle from the wine tasting. This year, we had 12 different wines for the tasting.

In the past, my husband and I have provided the food (assorted cheeses, Italian deli meats, olives, fruit and such). However, this year, Michelle Williams was able to get most of the food at the event donated.

Last, we ask friends and family for donations of silent auction items to sell for donations at the event.

This is an easy and low cost event to put on. We ask for a minimum donation of \$35 to attend the event. We have had such wonderful feedback from friends and family, who always enjoy attending. We hope to grow it again next year and include even more Houston-area families.

*Matt and I hosted the event this year, along with David and Amy Ratliff, Heather Bui & Jason and Michelle Williams. Additionally, Carol Li, and James Jiang, & Patrick and Kimberly Matthews attended the Wine Tasting and invited friends and family.

To view a slides show of pictures from the event go to: share.shutterfly.com/view/flashShareSlideshow.jsp?sid=2AauWzVq3btXNw

MORE CONFERENCE PICS





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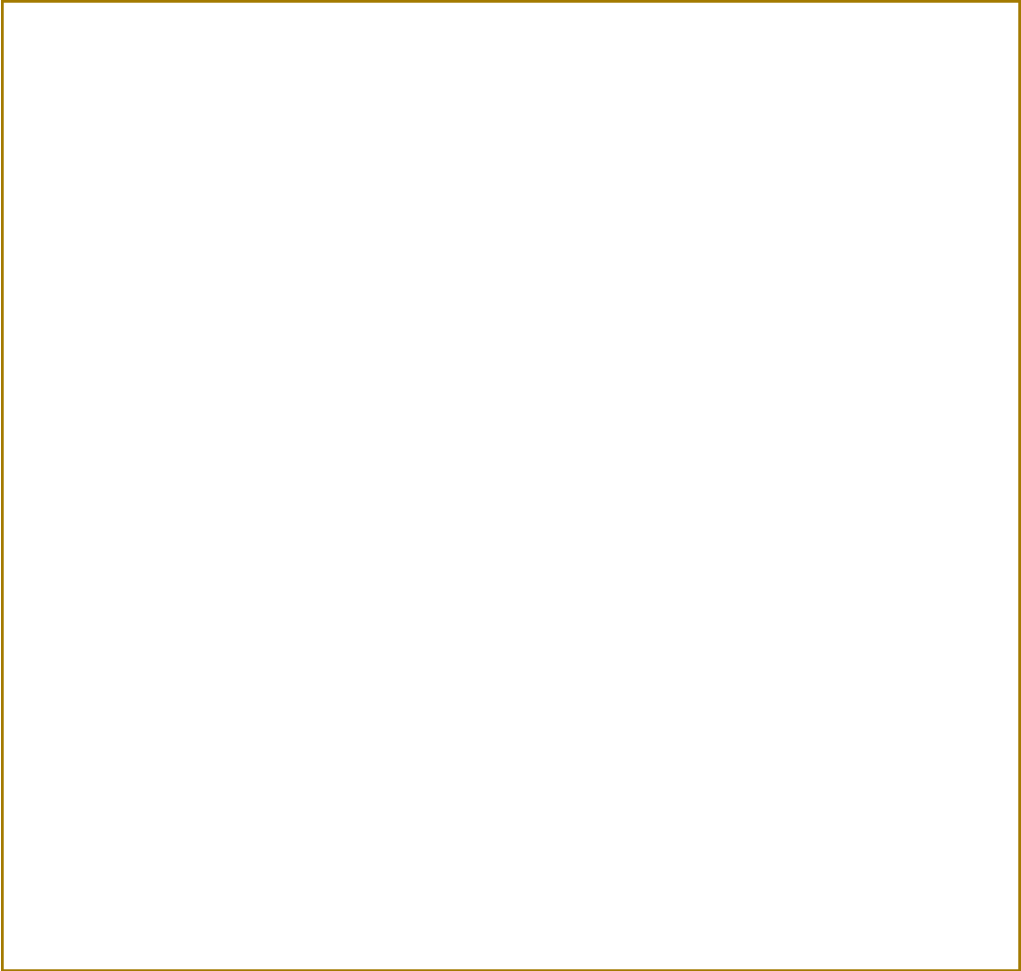
*You Don't Know What
 Your're Missing*

We're on the Web
www.fivepminus.org



Car Magnets will be available from the 5p- Society office..

Thank you to Melissa Jones for all her assistance and support.



2012 CONFERENCE SUCCESS

Many thanks to Mike and Tina Brewer and David and Carren Hutchinson for hosting a wonderful and very successful conference. The Brewer and Hutchinson families spent over two years planning events, securing volunteers and raising monies to spend on the conference attendees.

Some of the highlights . . . Friday outing to Stapleton Park and the BBQ lunch (ribs were outstanding!!!); Attending the Rockies baseball game (okay they lost, but still fun); the many topics and awesome speakers who donated their time to come and enlighten us on their expertise; and the Saturday Banquet and Family Dance with a LIVE Band.

Thanks to the many volunteers who assisted with child care, the sibling support shop, the sibling outing, the board of directors for all their continued support and families and

friends who gave monetary support.

Conference booklets can be obtained on a flash drive for \$10. Send your check to 5p- Society, PO Box 268, Lakewood, CA 90714.

The 2013 conference will be held in Long Island ,New York, July 25-28. Keep checking the www.fivepminus.org website for more information.

The 2014 conference is scheduled to be held in San Antonio, Texas.

The 5p- Society is now accepting locations for the 2015 conference. If you are interesting in hosting or would like more information, please contact director@fivepminus.org.