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5p- News

5p-Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506, toll free (888) 970-0777,
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Resources

Message board: Post a message or respond to another parent's questions at http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/ Need to join group to participate. New members joining this active group daily.

Clothing: http://www.special-clothes.com/

Supported Living Services
www.supportedlife.org

Sign Language Vocabulary
http://commtechlab.msu.edu/sites/aslweb/brower.htm

Signing Videos and DVDs:
http://twolittlehands.com; http://www.signingtime.com

Speech Therapy ideas:
http://www.speechtx.com/index.htm

Speech/Language and Feeding tools:
http://talktoolstm.com

Specialty toys — Abilitations:
http://ww.schoolspecialtyonline.net/

Yellow Pages for Kids with Disabilities—State by State resource for therapists and other services.
www.yellowpagesforkids.com

Advocacy — www.protectedtomorrows.com

Fundraising for the 5p– Society through:
www.igive.com — online shopping mall and through www.goodsearch.com —search engine that gives .01 per search to the 5p– Society

Walker Accessory—www.palzomine.com

Cars4Causes-(800)766-2273

Inside this issue:

Where Does All the Money GO? By Jennifer Wong

While discussing our budget during the 5p- Board of Directors Meeting this January, Board members brought up comments made to them during the July Conference in Ohio. Some Members at the conference mentioned that they were not sure how the money they sent to the Society was utilized. The Board Members decided to take this opportunity to answer those questions. 5p- Membership dues, currently $25/year(JAN-DEC), go toward the day-to-day running of the Society. Some of these expenses include, Employee Salary (currently we have only 1 paid employee), accounting, banking fees, insurance, postal expenses, office supplies, utilities (phone, internet), and the printing and shipping of this Newsletter and other Society information. Of our 547 active members, only 93 are current on these dues. If everyone was current on their dues, it would increase our budget by $11,323.00 annually! Think of all the awareness and support we could do with that!! Most of the Society's income is from generous donations and fundraisers from our members, their family/friends, and company matching programs.

Conference registration fees are used for that year's Conference only. What many people don't realize is that fee pays for the Saturday night banquet (food) ONLY. Many of the extras at conferences such as the Welcome reception, Continental Breakfast, Family Outing, Sibling Outing, Childcare, Hospitality refreshments and Conference bags are all possible because of fundraising (mainly by the Host Families) and donations from Local Businesses and Family/Friends of the Host Families. The average expense for the Annual Conference runs about $20,000.00-$25,000.00, depending on the location. This is for the bare minimum Conference, not including the extras mentioned above. The Board of Directors realizes fundraising for a conference is the hardest task for a Host Family to take on when they volunteer to host a conference. We have been making efforts to increase fundraising throughout the Society membership to help reduce this burden on the Host Family(ies). For those of us who are Fundraising Challenged, simple events such as garage sales, restaurant nights, and seeking donations from local companies are simple ways to contribute. Requesting donations to the Society vs. Birthday or Holiday gifts is another. For those who excel at fundraising, golf tournaments, raffles, spaghetti dinners, pancake breakfast and wine and cheese events, are a few that are popular, and raise larger amounts of money. No matter what you do, every bit helps out the Host Family and allows them to put together a successful conference. If anyone has any successful ideas for fundraising that they have used, we always ask that you forward them on to the Society. Sometimes the hardest step in fundraising is coming up with how to do it. The Society can provide you with materials needed for your fundraiser. If you are attending the Conference in Denver, be sure to give the Host Families a pat on the back, they deserve it!!

I know the economy has not been friendly to most of us lately and for some just downright nasty. That is why it is important for ALL of us to try and do our small (big is good too) part to keep our Society going. I know for me, Society Members gave me hope and the real truth when I first read all the dismal misinformation on the Internet regarding Cri du Chat Syndrome (CdCS). The conference always recharges my battery to make it through another year of special education fun. I, and any

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5p– Society Research Registry

by Dennis Campbell

In the last newsletter I asked for volunteers to participate in the Family History Questionnaire project. Several of you did volunteer to participate. Unfortunately best laid plans often fall short of their intended results. To be quite frank I ran into several software issues. The end result being that although I sent out email requests, either they never made it to recipients or folks got busy and did not have time to return them.

So we are moving on to plan B. We are placing forms on the web page for you to complete and return. The form is accessed with Adobe Acrobat. If you can read this newsletter online you should be able to access the form. At the beginning of each form is a letter of consent and basic instructions. This allows us to collect the information and details your rights as part of the research process. Each form will start in this manner. The first form has just basic information about your child and family. To make sure that the process works well we will only have this form on the web page initially. After we are sure everything works correctly we will add additional forms. To access the questionnaire please go to this link 5P consent and medical form_distributed_0001.pdf (https://acrobat.com/?i=gzefwjre0v*zplputoewca) If you are unable to access the questionnaire, please contact director@fivepminus.org and the link will be sent to you in a separate email.

It should take less than thirty minutes to read the information and complete any of the forms.

What will we do with this information? We will be able to aggregate the data and, if we get sufficient response, be able to provide families and their providers with information that is useful in providing care and developing interventions. For instance, a family calls the 5p- Society because they found out that their child needs scoliosis surgery. The 5p- Society can access the records of just those individuals who have had the surgery and provide this family with contact for support and information. This provides another layer to its Parent-to-Parent Support Outreach program.

We can also provide information to researchers after their research has been approved by the Professional Advisory Board and after you give us permission to provide your information. Our intent is to help you by not having to provide the same information over and over again in multiple studies, while encouraging research on our kids. An example of this would be that the 5p- Society and the Professional Advisory Board are presented with a research request on heart defects and Cri du Chat syndrome. With the information provided on the Family History Questionnaire, the 5p- Society can access only those records of individuals with heart defects and contact these families to participate in the study. This would streamline the research process for specific topics of interest.

Your participation in answering questions and providing information in this questionnaire is entirely voluntary. Although we do encourage all families to complete the questionnaire, not participating will in no way jeopardize your relationship with the 5p- Society. Of course, we would love 100% participation!!!

I want to personally thank everyone for their support of research in the past.

Dennis Campbell, Ph.D.
Chairperson, Professional Advisory Board
5p- Society

All Family History Questionnaires received by April 30, 2012 will be entered into a drawing for a $100 Target Gift Card.

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others, have described the Conference as a “coming home”. It is truly the one place we can all let loose and no one will stare, judge, or look at us funny.

One way the Board is looking to help the Society is to have a Multilevel Sponsorship Program for the Society. We are dividing it up in four groups: Platinum, Gold, Silver, and Bronze. Anyone who donates or fundraises will be recognized in the group of their financial support at the Conference and in the newsletter. More information on this Program will be coming soon.

The Board of Director’s goals for the Society do not end with just existing and the Annual Conference. Our hope is to first be a sustainable organization without having to rely on donations and fundraising to exist. We would like that money to go towards further increasing the awareness and research of CdCS in the medical community and Communities at large. We realize how many of us have had to explain to doctors, nurses, and therapists what CdCS is and the positive expectations we have for our family members with CdCS. We want to reach out to Geneticists, Pediatricians, and Children’s Hospitals, to start, to make sure they have information on our Society to offer families receiving the initial Diagnosis of CdCS. We want to create smaller get-togethers in states and cities for families to get together locally to support one another. There are so many programs we would like to start but because of lack of funds, they have to wait until funds become available. I know talking money can be a downer but we felt it was important to our Members to let them know what their money is doing and where we envision it taking the Society in the, hopefully near, future.

Positive Altitude, Climbing to New Heights

Denver, Colorado Conference 2012

We are gearing up for the 2012 Denver Conference. Your room reservations are now being accepted at the Renaissance Hotel. Make sure you mention that you are with the 5p– Society to get your special rate of $109.00 per night. Call 888-236-2427 to make your reservations or you can visit the 5p– Society website at www.fivepminus.org/annconfX.htm to get the link to make your reservations online. For you vacation planners, the room rate will be honored three days before and three days after the conference. If you run into any issues at all while making your reservations, please contact Laura at the 5p– Society office so she can make the appropriate adjustments.

The Renaissance Hotel is located at 3801 Quebec Street · Denver, Colorado 80207. There is a complimentary shuttle from the airport to the hotel. The complimentary hotel shuttle will also take you to a local mall, the Denver Zoo and the Natural History Museum . There is plenty to do and see in Denver. Go to Visit Denver (www.colorado.com) to get ideas when planning your visit.

Some of our confirmed speakers for the event:

Our popular Parent/Professionals Dr. Dennis Campbell, Dr. AmySue Reilly, and Shanida Mathieu. Mary Ann Elhert of Protected Tomorrows; Music Therapist, Carrie Fox; Zen Momma, Betsy Henry (yep you’re going to learn how to be a Zen Parent); Nutrition Specialist, Judy Fowler; The Potty Lady, Susan Hepburn (toilet training tools); and parent Lisa Juliar, certified trainer for proloquo2go and pictella apps for the iPad, along with showing conversation builders and life tools apps.

Don’t forget to bring your extended family members, we have both Grandparent and Sibling workshops planned as well as a Sibling outing on Saturday.

Bring your dancing shoes as we will once again have our Family Dance after the Banquet.

Plans are still underway for the Friday Family outing. More information will be forthcoming.

“Take me out to the Ballgame” — group discount tickets available ($12 each) for the Rockies Friday (7/27) evening game. Reservations must be made and paid for in advance, more info will be available in the near future.

Childcare will be available during the conference session hours for all children and adults with Cri du Chat Syndrome and their siblings.

Conference brochure and registration form will be available soon!!!

Many thanks to your host families, Mike & Tina Brewer and David & Carren Hutchinson, who have spent many hours fundraising and planning to make this event unforgettable.

Life With Cri Du Chat *by Andrea Lembach*

She was born 11 years ago. Hailey Reyann. Eleven years ago, we walked into the hospital in Sacramento full of hopes and dreams for our little girl. We were so excited to have her and her big brother couldn't wait to hold her! She came into the world small, not breathing, with a little tiny head and moles all over her ears. She was blue. The nurses were yelling at my sister to turn the video camera off. We didn't really understand the words coming out of the mouths of the doctors and nurses. I specifically remember thinking that I could see their mouths move but they weren't saying anything...microcephaly...What in the world is that??? They said out loud...ear tags...What are those???...Genetic counseling, a neonatal specialist, specialty nurses...It went on and on. The next few days are a blur of feelings and crying and worrying and measuring other people's heads. Yes that's right, measuring other people's heads! You see the geneticist informed us that small heads (microcephaly) can run in families and doesn't necessarily mean that there is anything to be worried about. He said that he would see us all in three months to see how she did. So, we walked around for three months measuring every family member's head...charted them and brought it in to the geneticists office at that three month appointment. The appointment went well. Our little girl was growing steadily, if not quickly. She was developing, if not quite to the normal standards...etc etc etc. Her dad, big brother and I packed up our things from the geneticist office, with our little girl given a clean bill of health and started out the door. But before we could get out the door, we were stopped when the doctor asked "HOW DOES SHE CRY?" I turned and said, "like a kitten, everyone says so". Shockingly, the geneticist says, "SIT BACK DOWN PLEASE" and began explaining about a "disorder" where the babies "cry like kittens". I really did think, “You are kidding me” but I couldn't make anything come out of my mouth....Besides sobs. And there it is, our little girl was tested and found to have Cri du Chat Syndrome...

As I sit here now and think about it 11 years later, I still sob thinking back to that moment. It is the moment that my life changed, that my family's life changed, that my son's life changed, that my marriage changed, that I changed. I had to become smarter in order to navigate the strange new world and learn this new language. I had to become stronger in order to get out of bed each day and face the questions, the concern, the pity, the whispers in the corner, I had to become softer for my son so that he wouldn't notice that I was becoming harder to everyone else. I had to protect myself, my daughter and my son...It all came down to change.
The best laid plans...you can usually count on those not working out.

Just like when we planned to have a perfect little baby. We planned to have a perfect little girl who loved ballet and girl scouts. She would get married to a very handsome young man after she finished up her college life at Yale and became a brilliant lawyer. Losing those plans, those dreams for her were some of the hardest parts in this journey.

After the shock wore off and we were able to do some research, we realized that a lot of what the geneticists and doctors had told us were not absolute. They told us that she would never walk, that she would never speak. We even had one doctor suggest that we give her up! Once we started learning, we realized that early intervention was a miracle for children with Cri du Chat. We got her started in physical therapy, warm water therapy, occupational therapy, speech therapy, feeding therapy, etc as soon as we could.

First she began to roll over and then to scoot and then a little crawling and finally walking. She was able to pick things up and put things into containers. Picking up her first cheerio was one of those moments that is burned into my memory! All of those little milestones that parents don't really think about were huge successes for her.

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Now at 11 years old, Hailey is a very happy and well adjusted fifth grader. She walks and runs and hops and even tries to skip. She dances and loves music. She is still learning things every day and we are so proud of her. Hailey is learning how to speak now and has had hearing aides for about a year. She loves babies and Barbies. She loves swimming, boating and most of all rollercoastering! She has no fear and has been going on rollercoasters since she was tall enough!
She will never become a lawyer or go to Yale. She will never meet a handsome prince and get married in a white gown. She will never do many things that we planned for her in our dreams while I was pregnant. But when you think about it, does any child ever fit into their parent's dreams? I'm sure that my parents dreamed of me going to Yale and getting married in a white gown to a prince and becoming a lawyer and I did none of that!
So we are just lucky to have her in our lives. We are lucky to feel her love every day. And I feel especially lucky that although she doesn't speak very much, she can say 'Mommy' clear as day!

Visit Andrea's blog at http://livingwithcriduchat.blogspot.com/

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Parent to Parent Support Programs

In the Fall issue of *5p– News,* you were introduced to a Parent Mentoring program called "Friends of Cri du Chat". Unfortunately, due to recent events, the administrators of "Friends" have decided to pursue their program without the assistance of the 5p– Society. The 5p– Society would like to wish the administrators the best of luck with their endeavors, and look forward to collaborating in future events.

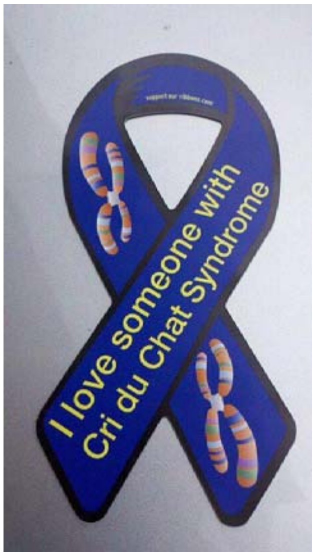
The 5p– Society will continue to provide parent to parent support and encourage members to participate in assisting families in their local areas. The 5p– Society is currently looking for parents to be a point of contact for families in need of support in their local areas. It is looking to expand and improve its own Parent to Parent support programs. Please contact the 5p– Society at (888)970-0777 or send an email at director@fivepminus.org if you are interested in providing parent support.

Wrist Bands, Car Magnets, etc.

Silicone wrist bands and a few keychains still available through the 5p– Society office. They are $2.00 (wristbands) $4.00 (keychains) each and can be ordered by sending a check made payable to the 5p– Society, PO Box 268, Lakewood, CA 90714-0268.

The 5p– Society would like to thank the Picciuto Family for donating 150 car magnets (pictured at right) as a fundraiser for the 2013 New York Conference. The magnets can be ordered through Melissa Jones (thanks Melissa for organizing this). If you are interested in ordering please send a message to Melissa at melissajones3@aol.com or private message her on her FaceBook account. The cost per magnet is $8.00 each plus shipping. Payment for the magnets can be made by check to Melissa at 604 S 16th Street Columbia Pa 17512, or through Paypal.

More items to come in the near future!!!



What I Would Tell You *by a "special parent" like us!*

I sensed someone watching me as I comforted my daughter after a particularly traumatizing dentist appointment at the Children's Hospital. I looked up and saw you staring at us from across the waiting lounge. I didn't pay much attention, as I have grown accustomed to the curious eyes of onlookers. Our daughter was born 7 ½ years ago and after an abrupt lack of oxygen at birth, she changed the course of our lives forever. Perhaps, our lives unfolded exactly as they were meant to — they just didn't unfold in the way we had imagined or planned.

I talked to my daughter, kissed her and hugged her. I was giving her a brief break before putting her through the next traumatic experience of the day ~ the car ride home. Having cerebral palsy is the least of her worries but this condition can turn a car seat into a torture chamber.

I stood up to gather our things, my daughter in my arms, and it was then that I noticed you were holding an infant. It was difficult to know for certain how old she was. I knew immediately, though, that you were one of us. I knew that only recently your life had changed drastically and you sat here in this Children's Hospital wondering, "How did we get here?" I should have recognized that shocked stare because I once had it, too. And I assume that the man sitting next to you, looking equally tired and shocked, was your husband.

I made my way toward the doors and as I passed you, our eyes met and I smiled at you. You smiled back and for a moment I knew that you knew that I understood.

If I could, I would tell you although you might not believe it right now, you will be okay. I would tell you to dig deep within yourself because you will find the strength and resilience somehow and it will surprise you. I would tell you to honor your feelings and let the tears flow when they need to. You will need the energy for more important things than holding in emotions.

I would tell you that the man sitting next to you might cope differently and he might even want to run the other way. But I would tell you to hang on because he is scared and he really doesn't want to leave you. I would tell you to look after yourself so that you can care for your daughter. Don't underestimate the power of good nutrition, exercise, sleep, supplements and an empathetic therapist.

I would tell you that grief will come and it will confuse you because how can something that brings such joy also bring such sadness? I would tell you to let people into your lives to help you. Our children really do require a village to raise them. Access all of the services and resources available. Find someone who can learn how to care for your child so that you can have breaks and so you and your partner can go on dates… even little ones like a twenty minute stroll outside holding hands, sharing wine on the deck or even catching a movie.

I would tell you that you know your child best of all and no matter what you are told by the doctors and other professionals who will be a part of your life, YOU know the answers. You will teach them about your child. At times you will question the validity of your intuition but after a while you will become profoundly aware of how accurate your gut feelings are when it comes to your child.

I would tell you not to be a martyr. Caring for your child will require tremendous focus and unimaginable energy and it can burn you out and make you sick when you least expect it. I would tell you to let your guard down along the way so that you can stay healthy in your mind and spirit.

I would tell you to seek out other mothers like yourself. This is, indeed, the road less travelled and you will feel very alone along the way especially in the company of healthy children and their parents. Yes, you will feel very isolated but know that we are here. Sometimes you have to look a little harder but we are here. You can find us online, in support groups and wandering the halls of the Children's Hospital.

I would tell you that you will know far too much about the human anatomy, neurology, gastro-enterology, feeding tubes, pharmaceuticals, and so on, than a mother should ever have to know. I would also tell you to do some research to inform yourself but be very careful not to be overwhelmed by the internet and all of the information available to you. Having some trust in what your child's specialists tell you can be very grounding. Other mothers and fathers of children like ours can be a wealth of information.

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I would tell you that this isn’t an easy life. It is tough: there is no doubt about it but you are very capable and the rewards are great. You may never see your child graduate from university, walk down the aisle or give birth to your grandchildren but you will feel pure joy when your child laughs for the first time at the age of 3 years and 8 months. You will celebrate the moment when you connect with your non-verbal child. You will call your spouse at work to tell him that she has gained 4oz. because weight gain is always a struggle with our children.

I would tell you that you will have to witness procedures and surgeries and suffering well beyond what any parent should ever have to bear. But, I would tell you that you will be courageous and comforting because your child will be experiencing far more suffering than any child should ever have to endure.

I would tell you that your life will not resemble the life you had planned. It will be as though you landed in Holland instead of Italy but after some time, you will adjust the dreams you had and this reality will be normal to you. You will dream new dreams.

I would tell you that you might find yourself staring death in the face during close calls. You will be asked to fill out DNR (Do Not Resuscitate) forms and although you might make decisions to not resuscitate in the event of a cardiac arrest, when the moment arises, you will panic to think that it could all come to an end. And I would tell you to not feel guilty in the darkest moments when you pray to God to take your child if it would mean the suffering would end. This might horrify you but know that your love for your child is so great that at times you will believe that death would be a blessing.

I would tell you that others will not get it. They can’t. This is a very unique and complex journey on all levels. We cannot expect anyone to get it. And I would tell you that people — the cashier at the grocery store or your insurance broker or even your hair stylist — will say stupid things like, “God only gives these special kids to special mothers” and “God will only give you what you can handle.” You will nod and smile but eventually you will look them right in the face and tell them that those simple maxims are a bunch of bullshit.

I would tell you that imagining your future will be bittersweet and may involve a Plan A and a Plan B. Plan A will be what you will do if your child outlives the predicted life expectancy set forth by the experts and Plan B will come into play if they do not. You will catch yourself casually discussing your future with the code phrases of Plan A and Plan B.

I would tell you that grief will creep up on you after years have passed and you least expect it like at a wedding when the father and bride have their first dance or when you hear a birth announcement. It will also creep up on you when you see yourself in a new mother who is just beginning this journey.

I would tell you that you will recognize her because she is you from 7 ½ years ago. And you will want to run to her and hug her and tell her that everything will be okay. You will want to save her from the pain and the hardship and the unknown. But I would tell you that when you find yourself sitting at the Children’s Hospital and you see a new mom and dad who are just starting this journey, you smile at them and walk by as they have their own path to travel and it will be different than yours. It may be longer or shorter. It may be more or less complicated.

I would tell you that her searching eyes are looking for some sign that she will survive this. And you, smiling as you pass, with your child arching all over your shoulder, will let her know that yes, she will survive this and may even thrive.

Julie Keon
June 29th 2011

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FIVE P MINUS SOCIETY™
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Thank you for your Support/Fundraising

The 5p– Society would like to thank the employees of the following companies for their continued support of the 5p– Society: Microsoft, Raytheon, Pfizer, Allstate, New York Liberty Insurance, Thomson West , Verizon and IBM

Thank you also to those who donate through United Way, Give with Liberty, Community Shares of Minnesota, JustGive, America's Charities, Wells Fargo Foundation, BP Fabric of America Fund, United Way of California, and United Health Group.

If you like to shop through the internet please make your purchases either through iGive.com or GoodSearch.com. The 5p– Society receives a percentage of your purchase. Also, don't forget that through GoodSearch, the 5p– Society gets a penny for every internet search you make through their search engine.

Don't' forget to donate your vehicle through Cars4Causes (see page 1 under Resources). Thank you to the Wood family for their recent donation.

The 5p– Society would like to thank all the families who held fundraising events through the 2011 calendar year. Your dedication to the 5p– Society cannot be measured in words!!!