

5p- News

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://www.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

5p-Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506, toll free (888) 970-0777, fax (562) 920-5240 email: lc5pminussociety@aol.com

"You Don't Know What You're Missing" Success!!!

Congratulations to the host families of the 2011 Ohio Conference and Get Together— Nick & Angie Wallace, Geoff & Jolene Towers and Dan & Jessica Hoover— for a job well done. 100 families attended the conference, of those 33 were first time conference attendees. We had families from Australia, China and Spain.

The highlight of the event was the duet of Jolene & Nick singing a beautiful rendition of "The Prayer" at the banquet.

Our volunteer speakers provided the families with a wide range of topics including Cri du Chat 101 (Dr. Dennis Campbell), sign language and communication (Dr. Laurel Daniels Abbruzzese), behavior modification (Dr. AmySue Reilly), feeding issues (Dr. Scott Pentiuik), sex education (Ms. Natalie Folino), transition (Dr. Dennis Campbell/Dr. AmySue Reilly), the IEP process (Mrs. Shanida Mathieu), Guardianship and future planning (Mr.

Scott Hayes), coping strategies (Ms. Kimberely Toronto), group homes and respite care (Mr. Marty Fagans), dolphin therapy (Dan & Jessica Hoover), hippotherapy (Ms. Renee Casady), and sensory strategies (Ms. Joyce Peet) and the new family orientation (Mr. Kent Nicholls).

Thank you to our professionals who provided the 5p- Society community with a forum to ask questions and get answers to topics not covered during the conference, especially orthopedic (Dr. Cedric Wong), puberty (Dr. Geoff Towers) and dental issues (Dr. Keith Sanger), as well as Dr. Dennis Campbell, Dr.

AmySue Reilly, Dr. Laurel Daniels Abbruzzese, and Ms. Natalie Folino.

We'd like to thank our many volunteers, who provided hours of assistance, including the Board of Directors, Professional Advisory Board, and the Child Care volunteers. We would also like to thank Kelly Campbell and Maggie Castillo for the sibling mixer, Ms. Kimberely Toronto for the sibling workshop, the many Grandparents who assisted including Ida Reaveley, Edward & Kathy Wallace, Barbara Triplett, Marc Triplett, Rick & Barbara Wallace, Jim & Fran Bodle, Gloria Griffin and Art & Pat Strong.

Inside this issue:

PAB Research Family History	2
Friends of Cri du Chat	3
Research Request Books, DVD's, Publications	4
Hall of Fame Recipients	5
Picture Gallery	6
Charity Deleon — Blog page	7
Silicon Bands & Key Chains	8



OHIO STATE BUCKEYES

Ingredients

- 1/2 cup butter, melted
- 1 pound confectioners' sugar
- 1 1/2 cups peanut butter
- 1 teaspoon vanilla extract
- 2 cups semisweet chocolate
- 1 tablespoon shortening

Directions

Combine the melted butter or margarine, confectioners' sugar, peanut butter and the vanilla together and mix well. Refrigerate for 1 hour or until firm. Roll into 1 inch balls and place on waxed paper.

In the top half of a double boiler melt the chocolate chips and shortening, stirring constantly. Use a toothpick to dip balls into the melted chocolate, leaving a small uncovered area so balls resemble buckeyes.

Place balls on waxed paper. Use fingers to blend in toothpick holes. Refrigerate until chocolate is firm. Enjoy!

Friday's Family Event brought live animals from the Columbus Zoo; what a great treat for the kids!!! Parents and kids alike enjoyed showing their stuff on Dance Heads (Event partially underwritten by the Boring family).

Continue on page 5

80/20 Raffle Results:

Congratulations to EMMA WONG of Folsom, California. She had the winning ticket of the 2nd Annual 80/20 raffle of the 5p- Society. Breakdown: 279 tickets sold at \$50 a ticket. Winner—20% = \$2790.00; Conference—64% \$8928.00; 5p- Society 16% \$2,232.00. Thank you for your continued support!!!

Professional Advisory Board-Family History Questionnaire

by Dennis Campbell

As chair of the professional advisory board I often get questions about what research is being done on Cri du chat syndrome and a 5P deletion. The society often gets questions like, why don't they support more research? Frankly, the society can't afford to monetarily support research given its current budget. It does, and has for many years, supported research in other ways. The professional advisory board consists of professionals who have experience with the syndrome. Some, like me, are parents of a child with Cri du chat Syndrome. Others are professionals who are willing to voluntarily contribute their time. One of the primary functions of the Professional Advisory board is to review requests for research with our families. We review these requests and make sure that they meet all of the ethical requirements of research using human subjects. We also try to protect families' privacy and time. That is why you will usually see a request to participate in the newsletter. If a mailing goes out the society is careful to protect the mailing list and your time.

Many of you have filled out the family history questionnaire over the years. At the last Professional Advisory Board Meeting we agreed, with the Society's board approval, to take that questionnaire and update it. We are currently adding a research component to the 5P Minus data base. The information provided by you will be gathered to increase and update the information on the syndrome. Through this effort, we hope to learn more about cri du chat syndrome, support ongoing research, identify commonalities among individuals, provide teachers and providers common characteristics, program needs, and areas of concern. With each additional piece of research we are encouraged that new information will lead to better educational programming. Also the discussion of what types, intensity, and strategies of both educational and related services that are provided to our children will result in better learner outcomes.

Here is how it will work. We have developed a series of questionnaires that can be sent to anyone who would like to participate. At the end of this article will be an email address to volunteer to participate. We also request that you let us know if you have completed the Family History in the past. If so we will add that information to the forms you will be sent. In that way you can simply make changes where needed. This will be especially helpful for families who completed this many years ago who may not recall some of the developmental information on their child. Upon agreeing to participate, you will receive an email with a form to fill out. When you return the form the information you provide will go into a database. We have decided to send out the forms by specific areas. In this way it should take you about 30 minutes to enter the information for any given area. Also you won't be asked to provide information about development that is not appropriate. For example, you will not be asked for information on puberty if your child is only five.

So what are we going to 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. We can also provide information to other 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 in multiple studies, while encouraging research on our kids.

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 Minus Society.

I want to personally thank everyone for their support of research in the past. If you are interested please send an email to: 5pfamilyhistory@gmail.com. Remember to let us know if you have already completed the Family History Questionnaire. We will also provide a link to this information on the 5P- web site.

iPad Raffle

The 5p- Society and the Denver Conference Committee are raffling off an iPad to assist in raising funds for the July 26-26, 2012 Annual Conference & Get Together.

Tickets are \$20.00 each (Suggested Donation)

Drawing date December 15, 2011, just in time for Christmas!!!

Friends of Cri Du Chat *by James Dickneite*

In life, there are quite a number of surprises. For me and my family, one of those “surprises” happened to be Cri Du Chat. It was discovered our oldest son had 5p- syndrome after a long emotionally draining quest to figure out his developmental delays. Then came the next discovery, he inherited it from me (his father). There wasn’t much information we were given or even a clear direction about what to do next. In this time of need my wife reached out on the internet searching for anyone who might be facing the same type of situation we were. Those she found quickly became more than just random strangers; they became our Cri Du Chat family. It was from this experience that the idea for Friends of Cri Du Chat was born.

It is our intention that no one who is newly diagnosed should be left holding out dated pamphlets with no clear direction. In our vision the doctors would hand those patients not just a pamphlet, but a way to reach someone who’s been in their very shoes. They would have the option to call Friends of Cri Du Chat and be joined with a parent mentor. Although not medical experts, the mentors have firsthand experience raising a child with Cri Du Chat. As many of us know, the outlook doctors tend to give is not always pleasant. Having a parental resource available could be beneficial in giving hope to those who otherwise might only see darkness. They need to be assured that their child is an exceptional individual with his or her own unique personality.

In addition, Friends of Cri Du Chat, is there to offer open ears during the difficult times as well. We understand the challenges of this diagnosis, but with confidentiality and respect, we are here to listen and encourage. Above all we want those with 5p- syndrome not to be seen as a burden, but as a blessing whose potential is endless.



By way of support we make a way for possibilities. Each day brings new challenges; but with friends we draw the determination and inspiration to meet those challenges head on.

If you are interested in becoming a parent mentor and helping parents cope with the new diagnoses of their baby or child, please contact the 5p– Society at director@fivepminus.org (please see below).

We look forward to hearing from you and working with you to change the lives of many.

Additional info about Friends of Cri du Chat Outreach Program

If you are interested in assisting the 5p– Society and the Friends of Cri du Chat Outreach program, please fill out the form below and return it to the 5p– Society, or you can email all the pertinent information to director@fivepminus.org. Your information will be forwarded to the coordinators of the program, Janet & James Dickneite, Angela de la Garza and/or Sam Brown.

Please keep in mind this is a totally voluntary opportunity to assist new families looking for assistance, an ear to lend, and a friend to share information. The 5p– Society and the Friends of Cri du Chat Outreach program coordinators will be developing guidelines for interested family members. This program will not replace the Regional Family Support Coordinators or the Parent Partners program, but will be used in conjunction with to improve and enhance the existing programs.

Although you do not need to be a member of the 5p– Society to be involved in the program, membership is strongly suggested to keep your information with the 5p– Society current and to provide you with additional information and support for your family and individual with Cri du Chat syndrome.

Friends of Cri du Chat — Outreach Program — Questionnaire

Name: _____ Phone #: _____

City: _____ State: _____

Email : _____ Child/Adult with CDCS age: _____

What areas of interest or development do you feel you can confidently talk to a new parent about? (i.e. feeding, vision, speech and language, IEP goals, cognitive, fine motor, etc.) _____

Research Study-Medications Use in Cri du Chat

We invite you to be part of a study looking at medicine use in people with Cri du Chat. This information will let us know which medicines are most useful for people with Cri du Chat. It will also let us know how it affects him/her. The survey will take 15 minutes of your time.

If you would like to be part of this survey, please visit the website: <http://cdcmcd.survey.nchri.org>

Who is doing the study: Nationwide Children's Hospital in Columbus, Ohio
Parul Vora, MD; Developmental-Behavioral Pediatrics

If you have any questions, please e-mail Parul.vora@nationwidechildrens.org.

Those who complete the survey will have their names put into a drawing for a \$25 gift card. Thank you for being a part of this study.

STUDY CLOSES ON OCTOBER 25, 2011 — DON'T MISS OUT — ALL MEDICATIONS INCLUDING HOLISTIC REMEDIES NEED TO STUDIED. THANK YOU.

Books, DVD's and Articles *(just a few)*

The "Cry of the Cat" video produced by parent Helen McGrath is now available on DVD thanks to parent Adam Greenberg. Many thanks to Adam for his donated time and expertise to convert the video to DVD, and make this available to the community. Cost for the DVD is \$15.00 USD and can be ordered by sending a check to the 5p- Society, PO Box 268, Lakewood, CA 90714. The DVD's will also be available at the 5p- Society conference.

Raised by My Child, Reflections on Raising a Child with Special Needs by Sally D. Yantis-Grube. Sally is the mom to 16-year-old Heidi with Cri du Chat Syndrome. Many poems, reflections and short stories about raising a child with Special Needs. You will Cry, you will Laugh, you will thoroughly enjoy this book. This book can be ordered through Amazon.

Her Name is Montel by Casey Evans. Casey is the dad to 18-year-old Montel with Cri du Chat Syndrome. Casey shares his story, his ups and downs and dreams for the future of his daughter. This book can be ordered through Amazon.

Sweet Pain by Nancy & David Norris. Nancy & David write about their experience of raising their son, Nathaniel with Cri du Chat syndrome. This book can be ordered through Amazon.

My Baby Rides the Short Bus , The Unbashedly Human Experience of Raising Kids with Disabilities. By Yantra Bertelli, Jennifer Silverman and Sarah Talbot. The 1st Chapter, *Rebirth*, written by parent Emily Zolten, mom to 5-year-old Lucy with Cri du Chat Syndrome. This book can be ordered through Amazon.

Booklet distributed through the United Kingdom Support Group: <http://www.cridchat.u-net.com/booklet/booklet.pdf>

Booklet distributed through the Italian Support Group: <http://www.criduchat.it/documents/ABCSCDCBookEN.pdf>

Blog: Life's Unexpected Blessings. My life, a stay at home mother of six one with Cri du Chat Syndrome by Charity Deleon. http://www.lifesunexpectedblessings.com/Lifes_Unexpected_Blessings/Charitys_Blog

Blog: Elastamom's Excerpts. Tiffany Townsend. www.elastamom.blogspot.com

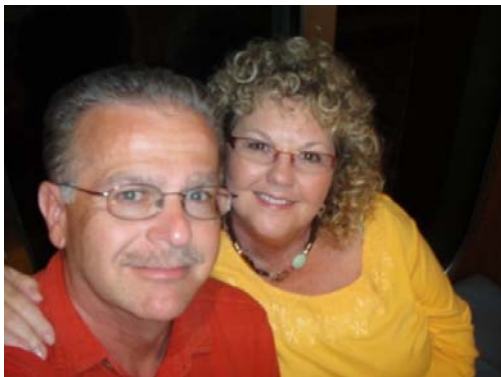
Glamour Magazine June 2011— "What Happened When the World Found Out . . ." page 210 — Tiffany Townsend interview.

HALL OF FAME RECIPIENTS

Congratulations to the inaugural recipients of the 5P- SOCIETY HALL OF FAME. There were several excellent nominations for each category. The winner received a glass trophy and their name will be at the top of the annual plaque.

MEMBER OF THE YEAR — KENT NICHOLLS

Without Kent, we wouldn't be here. Kent is the driving force in the creation of the 5p- Society. It is only fitting that Kent is the first recipient of the award. Kent has served as the President of the Board of Directors and has continued to serve on the Board of Directors since it's inception. Kent is also the proud father of three, his oldest, Kelli with Cri-du-Chat Syndrome.



SIBLING OF THE YEAR — KELLY CAMPBELL

Kelly is the younger sister to Amy Campbell. Kelly has assisted the 5p- Society with the planning and execution of the sibling mixer for the past four years and assists with child care. She also is a peer counselor at several camps during the summer. Kelly plans to be a Special Education teacher and is currently attending University of South Alabama.

I think, at a child's birth, if a mother could ask a fairy godmother to endow it with the most useful gift, that gift should be curiosity.

Eleanor Roosevelt

GRANDPARENTS OF THE YEAR — JIM & FRAN BODLE

Jim & Fran Bodle have been actively involved with the 5p- Society for over 15 years. They allowed the 5p- Society to house the office in their Mail Boxes, Etc. franchise. They have spent many hours preparing the newsletter for mailing. For the past 8 years have transported materials from the 5p- Society office to the city of the conference. They are also AWESOME grandparents to Katie Castillo.



Ohio Conference continued. . .

Siblings went to Cosi Science Center, thanks to Nationwide Children's Hospital, for a fun and educational experience. The volunteers were treated to Panera Bread Sandwiches on Saturday afternoon thanks to CRSI. The evening hotspot was the Hospitality Suite where families could unwind and share more experiences. Thanks to all the friends and family members who contributed to the food at the hospitality suite.

A special guest appearance by Brutus, the Ohio Buckeye's Mascot, greeted the banquet goers on the red carpet. The adults and kids packed the dance floor and showed off their many moves. BJ Gray of Victoria Secret donated the VS signature dog stuffed animals for the kids. ~Thanks BJ.

A conference of this magnitude could not exist without it's many supporters and contributors who donated both monetary and in-kind items, especially the Hammond, McCoy, Townsend and Myatt families for their fundraising events, Gloria Griffin and Raeann Sleith for their jewelry items, the Weber's for their handmade items and Thomas Brown for his beautifully handcrafted jewelry box. Thank you also to the Murphy family for the wickless candle donation.

Conference booklets are available on a 5p- Society flash drive for \$15.00 each — updated database also available.

PICTURE GALLERY



Hunter "Little Bit" Goins



Lovely Sandra Barnes



Beautiful Brooke Beall



Special Olympian Heidi Hanson



Best Buds —Breanna & Bella



Dancing Dylan Morningstar



Allie Wallace—Pretty in Pink & Polka Dots



Happy Boy — Grant Hammond



Isaac Hoernig having fun at the 5p- Society Conference



Life's Unexpected Blessings

My life, a stay at home mother of six one with Cri du Chat Syndrome

Sophie has been diagnosed with a rare Genetic Disorder called Cri du chat Syndrome, also known as Cat cry Syndrome.

Research

Cri Du Chat Syndrome (CDCS) is a rare chromosome disorder affecting approx 1 in 37,000-50,000 live births. The syndrome is known to result from a deletion from the short arm of chromosome 5 and represents one of the most common deletion syndromes in humans. This condition is found in people of all ethnic backgrounds and is slightly more common in females. They result from a chromosomal deletion that occurs as a random event during the formation of reproductive cells (eggs or sperm) or in early fetal development. Humans usually have 23 pairs of chromosomes in each cell of their body. These are named in pairs 1,2,3,4,5,6 etc. A chromosome consists of smaller components called genes which contain instructions in a code made up of proteins. This code contains the plans or blueprint for each human being. When something goes wrong with the chromosome in the process of creating a new human being, the code cannot be read properly and the child's body and brain may not develop correctly. When a problem results from this genetic mistake it is called a genetic disorder. Cri du chat syndrome is a genetic disorder; it is not an illness or a disease therefore there is no cure. A child born with this disorder has specific physiological problems which can result in their development being delayed both physically and intellectually. They may also have health problems because parts of their physiology have not developed correctly. Remember, nothing the parents have done has caused this deletion to occur. Affected people typically have no history of the disorder in their family. The size of the deletion varies among affected individuals; studies suggest that larger deletions tend to result in more severe intellectual disability and developmental delay than smaller deletions in people with cri-du-chat syndrome. Children with cri du chat syndrome can lead happy, fulfilling lives as valued members of their families and communities.

Our Message

We have decided to open up to family and friends about Sophie's disorder. We don't ever think something like this can happen to us. You think if you do everything right it will all turn out fine. Life does not work that way, sometimes we have no control over it at all. Sophie has already brought so much more love to our family, her tough start in this world has taught us to look at life in a different way. When we found out that Sophie has Cri du chat syndrome it felt as if time had frozen for us, we questioned why this would happen to us. There are no answers to our questions because the answer is far beyond our understanding. We have accepted our reality and our focus now turns to our children not just Sophie but our entire family. So far Sophie has escaped severe medical complications that are usually caused by the syndrome. All of her vital organs are normal and she has been developing normally. Most of Sophie's health issues have not been related to the syndrome. We are blessed because out of all the physical and medical features caused by this syndrome Sophie has only minimal symptoms. Only time will tell if Sophie will have any disabilities; there is no way of knowing what will happen not even the doctors can tell us. We have tremendous faith in GOD he is ultimately her protector we have seen his work in her already. We ask for good thoughts. We ask not for sadness but for encouragement and support. Please do not feel sorry for us, we are not experiencing a loss, we are celebrating a new beginning. Knowledge is power and with this power we will ensure Sophie has all the support she needs to live a happy, healthy and fulfilling life. We appreciate all of the love and support we have received so far. We truly feel blessed to have her in our lives.

~Deleon Family~

Personal Note

I know GOD has a plan and there is a reason Sophie is here. I believe she is here to teach us, she has already taught me so much, what the world will learn from her is not yet known but I am sure it will be wonderful!

~Charity~



PO Box 268
Lakewood, CA 90714-0268

Return Service Requested

Thanks to the Hoffman Family for donating the cost of the silicone bands and key chains for the 5p- Society. They look great!! The bands and key chains are available through the 5p- Society. Cost will be \$2 each for the bands and \$4 each for the key chains. SHOW YOUR SUPPORT!!! Please add \$1.00 for each 3 bands for shipping/handling and \$1.50 for each 3 key chains. (Overseas shipping available contact 5p- Society for cost).

