



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

December 2004

President's Message *by Greg Abbruzzese*



Hello again everyone! I hope you all had a healthy and happy Thanksgiving! As the St. Louis conference draws closer, we are gradually getting everything pulled together to make this year's conference the best yet! The Eickmeier family is already ahead of the curve as they have begun regional fundraising efforts to offset our growing expenses at the conference. Renee is doing an excellent job in her preparation; however, we are always looking for additional support and volunteers.

We are in the process of aligning the speakers for St. Louis and hope to retain the top speakers from previous conferences. One of the major concerns from previous conferences was that certain topics conflicted with other key speakers. In an attempt to

alleviate that problem, we are requesting that certain speakers hold extra sessions throughout the day. In addition, based on feedback that we received in Philadelphia, Renee is looking to having a dietician speak, along with someone on sleep disorders, orthodontia, and grief counseling. Some more highlights that we hope to incorporate are: developing a sensory lounge, augmentative communication workshops, and more in-depth sibling workshops. There were some concerns with certain aspects of the Fathers' workshops that we hope will be more constructive in the next meetings.

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5P- NEWS, published four times a year, is a publication of the 5P- Society, the national support group for families who have children with Cri du Chat Syndrome also known as Cat's Cry Syndrome or 5P- Syndrome.

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Mission Statement: To encourage and facilitate communication among families with a member who has 5P- Syndrome and to spread awareness and education about the syndrome to these families and their service providers.



WANTED: YOUR STORIES

By Renee Eickmeier

Happy Holidays! We are continuing to plan our 2005 Annual Conference and Get-Together in St. Louis. We are lining up speakers and planning the Friday afternoon “inning”. We are also working on expanding the spiral bound book of notes and handouts. This is where you come in.....

We would like to hear from you. Please send us your stories and anecdotes, both funny and heart-rendering, about life with your child with Cri du Chat Syndrome. Think of it as a “Chicken Soup for Cri du Chat Families’ Souls”. We would love to publish these stories in the Conference Book.

We are also interested in hearing your great tips and suggestions. We are looking to expand the “What Works” table into a printable format. We still want your items for the “What Works” table at the conference, but some tips and suggestions are just as easy to write down. It would be great to hear things that have made your lives easier, like recipes, clothing modifications, household modifications, toy ideas, etc. No idea is too small.

We’d love to give your name, but if you’d prefer to leave your stories and ideas anonymous, that’s okay, too. Your contributions will provide all the attendees with a wonderful resource to refer back to over the year and stories that families with children with 5p- can really relate to.

Please email your stories and tips to me at Reickmeier@sbcglobal.net or mail to my home at 414 Wildbrier Dr. Ballwin, MO 63011. Thank you in advance for sharing what you have learned from your child.

Editor’s Note: The 5p- Society does not endorse any products or therapies. All information shared in this newsletter is for you to determine if it is right for your child and own situation. We appreciate and thank all contributors to this newsletter. Thank you also to Lora Piepergerdes for her continued assistance in the preparation of this newsletter.

On behalf of the 5p- Society
We'd like to wish you a very Merry Christmas,
Happy Hanukkah, Kwanzaa, Boxing Day and New Year.

In the year 2004 we've added over 60 families to our database,
Had over 100 families attend our Annual Conference;
Increased our number of volunteers
Added new members to our Professional Advisory Board;
Added new members to our Board of Directors
Answered dozens of emails and phone calls

In the year 2005 we will need to make new brochures
(we're almost running out)
Continue to support research of our volunteer professionals
Look forward to another fantastic conference
Keep the website updated
Meet more families

Of course none of this could be done without your
continued support.
Thank you to all who donated throughout the year;
You're annual donation to the Society is greatly appreciated!!

With all my love to all of you -- LauraCastillo

Parent Report by Linda Mischley

Bobby Mischley - update

Listen to this exciting news about Bobby. Dr. Bob, the Wing Lake School Psychologist, called me at work because every three years the kids have to have a Psychologist evaluation. (Who knows why . . . they probably are evaluating the well-being of the parent really). Any way . . . One question lead to another and soon I was telling Dr. Bob all about Eniva and how it has helped Bobby's health, and learning potential. As I talked, Dr. Bob looked at the Eniva website at all the products I was telling him about. Today, I got a note in Bobby's school daily notebook from Dr. Bob that says: "Thanks for sending the Eniva information this morning. I had a chance to read some of it already. Sounds interesting. It fascinates me about how much progress Bobby has made."

Last night at the parent meeting, Bobby's teacher told me that they were all amazed with Bobby. Bobby went to his PECK board (picture board). Leafed through the picture board until he found the DONUT. Took the picture of the donut out of the book. Closed the book. Gave the picture of the donut to the teacher and signed EAT. His teacher told me that is the highest level of achievement to get the kids to do. He followed all the steps to get what he wanted without commands or prompts. How cool is Eniva to make Bobby feel so good that he is able to concentrate and learn in school.

For more information about the Eniva products please email Linda at mischley@northwood.edu or go to www.eniva.com.

President's Message continued from page 1

Again, we can only improve these conferences with your input. Please contact me, or any of the Board members, if you have any thoughts as how to improve these conferences.

As far as the children go, Renee has scheduled some great events! The theme for this year's "inning" is "A Day at the Fair". Lunch and entertainment will be the same room at that time. Food will be hot dogs, hamburgers, potato salad, chips, popcorn, cotton candy, ice cream with waffle cones and cups. Entertainment will be two small ball pools for kids under 3, bounce dome, inflatable slide, and an obstacle course. We are also looking to get jugglers and a DJ to play music.

In early February the Board will be visiting the San Jose area to secure a location for the 2006 conference. If there are any families that have not contacted Laura yet and would like to help, please contact her directly (or any Board member). We are targeting late July (roughly 27th-30th) for the West Coast conference, so mark your calendars! Looking further ahead, we are looking at Minneapolis for 2007.

Thank you all for your continued support of the Society. I hope everyone has a happy and healthy holiday season and New Year!

Greg

Research

Several of our professionals are now conducting or will be conducting approved research projects for children and adults with Cri-du-Chat syndrome. If your child or adult meets the criteria set forth by the researchers you will receive a letter from the 5p- Society office telling you about the research and the contact information. Currently, the following research projects have been approved.

Adult Study - Kim Cornish, Ph.D. , McGill University, Montreal, Canada. Letters and forms were sent out in October to all parents/guardian's of the adult Cri-du-Chat community. **Please continue to return the questionnaires ASAP!!** Dr. Cornish would like to get more responses so she can help identify the core concerns and move forward towards helping to reduce the impact of difficulties associated with caring for an adult with Cri-du-Chat Syndrome. Parents can contact Dr. Cornish directly at kim.cornish@mcgill.ca to request another copy of the questionnaire.

Missing TERT gene in 5p- syndrome - Dr. Monica Bressler, Washington University, St. Louis, Missouri. Dr. Bressler and her team would like to study as many Cri-du-Chat individuals as possible to determine if there is a relationship between the missing TERT gene in 5p- syndrome and specific symptoms that occur with the syndrome. More information will be divulged in our next newsletter. Dr. Bressler plans on speaking about her research at our 2005 conference in St. Louis and how you can participate in the study while at the conference.

Webmaster Change

The 5p- Society would like to thank Todd Winslow for setting up and maintaining the website. The site looks great and we are very appreciative of all the hard work and will miss you. We would also like to thank Rob Vaden for agreeing to take over the maintenance of the Website. If you'd like to put your child's picture on the website please send all information to director@fivepminus.org.

Grandparents' Newsletter

If any interested grandparent would like to receive the newsletter, please contact Patricia Strong, by email at odah@gmtl.net or by phone at (563) 659-9530. Thanks Pat for putting your time into this endeavor.

Resources

Correction to website: The Cri Du Chat Syndrome Support Group from the United Kingdom has offered their 2nd Edition Cri du Chat Syndrome booklet as a resource that you can download from the internet. The direct link is <http://www.cridchat.u-net.com/booklet/booklet.pdf>. Thank you to Dr. Kim Cornish and all the authors and especially the United Kingdom Support Group for this valuable resource for all families.

The Arc of Illinois - Consumer Stipend program. The Arc of Illinois will assist in paying for conferences that relate to your child. Go to www.thearcofil.org to learn more information about the program and the requirements.



Parent Report

A Loving Tribute by Mom, Linda Sink

George "Bunky" Marvel

From the day George was born the doctors knew something wasn't quite right. My former husband and I were referred to genetic counseling and Bunky was diagnosed with Cri du Chat Syndrome at three months of age. We were told what could be expected. Severe mental retardation and physical disabilities. We were told he may never walk, but finally at age 8, he did. He never had any speech. Over the years he became what my idea of "true love" is. If there was something he wanted, he would take my hand and lead me to it. We had our own special communication. He understood the words "eat", "bath", "ice cream", "cake", "sissy" and "MaMa." His favorite thing to play with was a bandana. The brighter they were in color, the more he loved them. He would sit and twirl them together, or carefully fold them from corner to corner. He would sit and toss them to me or his big sister, or whoever he could get to play. He was an 18-24 month old in an 18-year-old man's body. He love to eat, and he loved balloons. Most importantly, he loved me and I knew it. Every morning when I went to his room he would pucker up his lips for a kiss. When I would walk him down the driveway to the school bus in the morning, sometimes he would stop suddenly and look at me and put his head on my shoulder. Bunky was "true love." He asked for so little in life, and was always so content.

I have a deep appreciation for his teachers through the years. His middle school years were so happy, and our relationship with his teachers at the Junction City Middle School was wonderful. His school agendas are now my diaries for him. His relationship with High School teachers was continuing to grow as well. George had a way of climbing into everyone's hearts. He would walk to different classrooms and go in the door and make his presence known, sometimes even sitting on the teacher's lap. He could be a real comedian, and the sound of a sneeze would make him laugh. Also the sound of a "zipping" noise as someone ran their fingers through his hair, or a whistling sound. I could go on about my "Bunky" forever. I wish I could have had him forever, but for reasons I will never understand, he was taken from me on October 20, 2004. His funeral service was beautiful. The chapel was full of people who grew with him through his 18 years. His casket was draped with colorful bandanas and flowers. Before his casket was closed, Bill, his step-father, took a bright orange bandana from his hand and gave it to me. I sleep with that banadana under my pillow some nights. After his service, I had him cremated, so I could bring him back home with me. I just couldn't bury my son. His father and I are still having very hard days. Bunky's passing has pulled us closer after twelve years of bickering over senseless things. They say everything happens for a reason. I'm still searching for reasons. Bunky left behind a family that loved him dearly, grandparents, sisters, brothers, aunts and nephews. There is a huge hole in my heart that I know can never be filled. Whoever may read this, please cherish your "special" children.

Dear friends,

As consumers, we often have concerns about what our providers know (and don't know) about genetics, but often we don't have a chance to describe what we think providers need to learn. Now we have an opportunity to be heard by an organization that teaches health care providers about genetics - the National Coalition for Health Professional Education in Genetics (NCHPEG - pronounced "NITCH-peg").

The Genetic Alliance is partnering with NCHPEG in a survey. The purpose of this survey is to ask families living with genetic conditions about their perceptions of their health care providers' knowledge of genetics. The information from this survey will be used to develop genetics education for specific types of health care providers.

This is an opportunity to be heard and to have our members' voices heard. Please send this message with your own modifications and this link to your members:



Travis was diagnosed with Cri du Chat Syndrome when he was 2 yrs. old. He was developmentally/speech delayed and we were told he didn't have a lot of hope at a future. (not a lot of information that many years ago.) Travis now attends middle school (7th grade) where he continues to learn new things daily. He loves to read, he has a sight vocabulary of over 100 words, and he loves math. He is a happy, healthy, and energetic 13-year-old young man. Who loves sports, Playstation, and NASCAR.

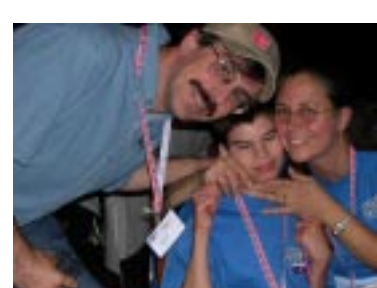
Travis has a little sister (Breonna-1 yr old) that he adores. God blessed our family with two wonderful children, and we believe the sun rises and sets on them. I would love to hear from other parents of children with Cri du Chat.

Please e-mail me at mlmartin@hsc.wvu.edu

Monica Martin

Conference 2004 Pictures

As you can see from the smiling faces on these many pictures, we have a lot of fun at our conference. Most of these pictures were taken at our Family Dance after the banquet!!





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Return Service Requested

2005 Calendar

The color 2005 Calendars are still available for members. The cost of each calendar is \$15.00 US (plus fee for shipping). These calendars make great gifts for friends, family and teachers. To order your calendar(s) please fill out and return the attached order form. Make your check or money order payable to the 5p- Society and send it to PO Box 268, Lakewood, CA 90714-0268. Your calendars will be shipped to you as soon as the orders are received.



Please send me _____ copies of the calendar. I have enclosed \$15.00 US for each calendar, plus appropriate shipping from the table listed below.

Send the calendar(s) to: Name: _____ Total Amount Enclosed: _____

Address: _____

Add for Shipping: (All Canadian and Foreign countries will need to contact the 5p- Society office for shipping amounts)

1 calendar = \$1.50 2 - 4 calendars = \$ 5.00 5-10 calendars = \$8.00 10 and more please call Society for amount