

# 5P- News

## Family Support Group for Children with Cri du Chat Syndrome

*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.*

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

### Resources

- Message board: Post a message or respond to another parent's questions at [http://groups.yahoo.com/group/Cri-Du-Chat\\_Syndrome/](http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/) Need to join group to participate. New members joining this active group daily.
- Chat Room: address posted next newsletter
- Reading Videos and DVDs: <http://www.loveandlearning.com>
- Signing Videos and DVDs: <http://twolittlehands.com>
- Speech/Language and Feeding tools: <http://talktoolstm.com>
- Specialty toys – Abilitations: <http://www.schoolspecialtyonline.net/>
- Identification bracelets: <http://www.stickj.com>  
<http://www.mypreciouskid.com>  
<http://www.911destiny.com>  
<http://www.laurenshope.com>

### President's Message *by Greg Abbruzzese*

Dear Five P Minus Society Members:

We all owe a special thanks and enormous gratitude to the Eickmeier family, Laura Castillo and all of the volunteers who helped make the St. Louis conference such a tremendous success. I have received several e-mails and calls complimenting how successful this year's conference was run. The Eickmeier family and friends did an exceptional job with childcare, Joe leading the charge with field trips (and no lost children!), and the very successful sibling workshops. In addition, we are all waiting for Ms. Valeri Eickmeier's wonderful homemade bags to go retail. The bags, in concert with Gloria Griffin's jewelry, were a tremendous hit!

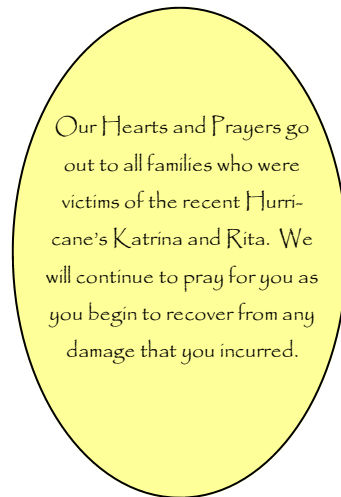
By using the template refined by Renee and the St. Louis Conference, we hope to continue the momentum in San Jose.

In addition to the Eickmeier family, I would like to extend a special "thanks" once again to Laura Castillo and the rest of the Board members who helped run a very professional and family friendly conference. With the addition of several new families attending the conference, I received several notes on how warm and comforting all the Society members were to these new members. For that I thank you all . . .

For those of you who were unable to attend the conference, I received numerous correspondences to put more of the meet-

ing's information on the web site. We are working toward updating the web site to include more such information. Some additional feedback that I received was to include additional speaker handouts for parents '

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### Can You Help? *By Eileen Sherman, Treasurer*

These three words imply so much without spelling it out. We have just had a wonderful conference in St. Louis and our host families for San Jose are busy planning for next summer. Each year our conferences get bigger and the families keep raising the bar to make each

conference the best it can be. That's why these three words mean so much.

The larger the Society gets, the more expense grow. We added a membership fee this year to try to help offset some of our operating expenses. The mem-

bership fee helps to pay for the quarterly newsletter and mailing. Many of the expenses of the conference are paid for with donations and registration fees but that does not always cover the bill

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## Can You Help? *continued...*

Another source of income of the Society is fundraising. People hear the word fundraising and think it has to be big and elaborate. This is not the case. Fundraising can be anything from a lemonade stand to a golf tournament. We all have resources that we can tap into without a big gala event.

I hope that the following will give you some ideas for fundraising that do not take a lot of time and effort but will help the society to provide the services that our members need:

- Write letters to friends and families asking to make a donation in honor of your child (birthday, goal achieved, holiday, etc)
- Hold a garage and bake sale and donate the amount to the society.
- With Halloween coming up, ask for a donation in lieu of candy (Will save a trip to the dentist).
- If you have time organize a softball tournament, golf

tournament, silent auction, mouse races, foot race, etc.

I hope this will get you thinking of how to answer the question, "Can You Help?" The answer is yes, and if you have any questions, please feel free to contact me at [eilsher@sbcglobal.net](mailto:eilsher@sbcglobal.net).

Thanks!

Eileen Sherman

*"Great location . . . Best conference we've been to yet"*

*"Great job and kudos to the Eickmeier Family for such a job well done."*

*"This was a great opportunity for me and my family to meet so many other families.."*

*Some of the responses from families who attended the conference.*

## Meet Us In St Louis Annual Conference Wrap Up *by Laura Castillo, ED*

A trend has begun, it started in Memphis and has continued all the way to St. Louis — another record breaking year for attendance. This year 118 families attended, over 500 people!!! We had a lot of extended family members—so much so that we ran out of hotel space and many families had to stay at surrounding hotels. Thank goodness St. Louis has a Metro-link system in place which made it easy to get around.

Joe and Renee Eickmeier served as our host family and did a fantastic job. From organizing childcare, securing speakers and vendors, obtaining the numerous amount of donors, working the hospitality suite, enlarging the Speaker Note's Conference booklet to include stories and anecdotes, organizing two, not one, sibling outings and enlisting Joe's mom to making over 150 handmade quilted bags — I'd say they did a more than fantastic job. I would like to personally thank them for everything and making my

job easier!!!

We had several returning speakers and a few new ones that enlightened us with topics of interest. Returning and providing us with updated and of interest information **Dr. Dennis Campbell**— *Cri-Du-Chat 101*, **Dr. Jennifer Rosinia**—*Sensory Processing and Role of Emotions and Stress Response System on Child Development*, **Dr. Amy-Sue Reilly and Dr. Joan Henley** — *Behavior Applications (included IDEA and IEP information)*, **Dr. Geoff Towers**—*Puberty and Cri-Du-Chat Syndrome*, **Dr. Kim Cornish**—*Adults with Cri-Du-Chat Syndrome Study Results*, **Sarah Rosenfeld-Johnson**—*What Can I Do to Improve my Child's Speech?* and *What Can I Do to Improve my Child's Feeding?*

This year's new presenters/topics included: **Christine Schneider**—*Augmentative Communication in the Classroom*, **Ashley Nanney** — *Supportive Employment*, **Cathy Raney**—*Dietary Needs of Kids with 5p-*

and **Dr. Kirt Simmons**—*Orthodontia*.

We were fortunate to have two studies being conducted during the conference. Dr. AmySue Reilly and Dr. Dennis Campbell continued gathering data samples for their ongoing study on early learning and educational issues. A big thank you to all who participated. They have already secured their spot for next year's conference in Santa Clara so please be prepared to join in the study. Dr. Monica Bessler and her group of students are conducting a study of members with 5p- Syndrome by collecting data and blood samples to study the end points of the deleted 5th chromosome for similarities and possible answers to why our children/adults have symptoms of early aging — i.e. graying of hair. The data and blood samples were not only of the children/adults with the syndrome, but also the parents/siblings. That came as a big surprise as I handed them

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Erin & Catherine at the World's Fair Carnival

## President's Message *continued . . .*

sessions, highlighting a message board to contact previous conference attendees, and expanding the scholarship opportunities. We are currently taking all of these suggestions under advisement to help the Society as a whole.

Looking ahead to Santa Clara in 2006, we are moving along preparing the conference with a committee of several families so that the entire responsibility does not fall on one family. The facility is outstanding. A theme park, dining and the theatre are

all within one-half mile. As you saw in St. Louis, all volunteers were very helpful. If you can spare a half-hour in childcare, assist in the hospitality suite, or even help out at registration, all volunteers are welcome! To avoid the over-booking situation that we ran into in St. Louis, we would caution and advise that you send in your registration earlier than later to avoid any hiccup with the accommodations.

In 2007, Alison and Paul Bakken and friends are raring to go

in Minneapolis. The location is all set and they have already established contact to help out with childcare. Way to go Paul. Great news for 2008 . . . Christy Blount and Anne Zettlemoyer and their families and friends have agreed to host the conference in Virginia Beach, VA. They are really excited about the prospects of hosting the conference and already have some great fundraising ideas (most notably a 5K race).



Well, that's all for now. Please keep your suggestions coming and I can be reached at:  
gabbruzzese@converse.com  
or (201) 287-1871.

Greg

## Meet Us in St. Louis Wrap Up *continued . . .*

my arm for my blood sample. Dr. Bessler's result's should be available and she is planning to present them in 2006 in California.

Many of the speakers also consulted with the families on an individual basis. We would like to thank them for the continued support and dedication to the 5p- Society to ensure that families are well informed and comfortable.

The sibling events once again proved to be needed and were very successful. Over 50 siblings attended the Mixer, outing to the Arch and the outing to the Putt-Putt Glow in the Dark Golf. A special treat to the kids was the open-aired trolley that took them to the Arch. All events were sponsored by donations secured by Joe and Renee. A big thank you to Joey Castillo, Heather Frayn, Derek Ward, Joe Eickmeier, Bob Eickmeier, Dale Von Hoffmann and Jim Bodle for overseeing and supervising the sibling events.

Our Welcome Reception and New Family Orientation on Thursday evening once again set the tone for the entire event. Many thanks to Jim and Pam Frayn and Manhard Consulting, Ltd for sponsoring the Welcome Reception. Kent Nicholls once again was able to encourage and set aside any fears that families attending their first conference may have by providing them with a top notch New Family Orientation meeting.

The Friday Family Event was sponsored by the Erin Eickmeier Foundation and Gannett Foundation. The kids enjoyed a fun-filled afternoon with inflatable jumpers, slides, face painting, crafts and food. The themed-carnival event of the St. Louis World's Fair brought us an array of food including hot dogs, popcorn, potato salad, pretzels with cheese sauce, corn dogs, hamburgers, and ice cream in waffle cones.

I'd like to personally thank Carolina Kretschmar for once again

providing us with her sewing and craft talents for the 2005 Quilt. The raffle for the quilt, along with a special handmade quilt made by my mom, Fran Bodle, and a series of DVD's from Signing Time, generated over \$700.00 dollars.

Renee was able to secure over 40 volunteers for childcare and we are very grateful for those friends, families, co-workers who gave so much of their time. Although the rooms were crowded, the kids were able to produce a craft and play games. Many thanks to Jennifer Wong, Susan Donnelly and Claudia Sanger for all their assistance with childcare. I'd also like to thank Greg Abbruzzese for his continued support of childcare by providing the volunteers with donated Converse tennis shoes.

A representative from the Make-A-Wish Foundation provided us with information on how to apply so that your child and family can enjoy a well-deserved vacation. Disney World being the most sought

after location for a vacation destination.

Parent Panels were brought back again this year where parents can share information with one another based on the age-group of the child. Many thanks to the moderators for each group, many of whom are board members of the society. Many evaluations suggested lengthening the time for the panels because a lot of information is being exchanged and time ran short. This will be taken in to serious consideration for 2006.

Thank you again to everyone, and if I've forgotten to mention your name I do apologize, but know you are in my heart for the support you have provided for the conference and to the Society.

I look forward to "Meeting" you all again in 2006.

Laura

## Gross Motor Skill-Tips and Suggestions *by Laurel Daniels Abbruzzese, EdD, PT*

The key to acquiring gross motor skills is **PRACTICE**. Every individual will reach gross motor milestones at a different rate, but if they are not given an opportunity to practice emerging skills, delays may be prolonged.

**Example 1:** If your child is still unable to **sit independently**, it may be tempting to always put them in a bouncy seat, super saucer, high chair, stroller, or other fully supportive seat.

**Instead:** Hold your child on your lap, giving assistance at the lowest point possible. Start at the waist, move down to the pelvis, then the thighs. There may be a lot of wobbling at first, but it gives your child an opportunity to actively engage the postural muscles in the trunk needed for sitting independently. Supportive pillows like the "Boppy" are also very useful when your child is sitting on the floor alone. Instead of fully supporting the torso, the pillow can just wrap around the hips. The pillow also cushions a fall if they tip over. Every "tip" is a learning experience that helps the child learn limits of stability. Set up the environment to prevent injuries from tipping (mats, soft rugs, pillows), but not to prevent tipping over.

**Example 2:** If your child is working on **standing up from the floor and cruising**, keep the toys off of the floor.

**Instead:** Put all of your child's favorite items up on the couch, chairs, and coffee tables. Increasing the motivation and the opportunities to stand will help strengthen the legs in a functional way. Once your child pulls up to the first toy, he/she may drop it on the floor. If they can squat to pick it up, GREAT. If they plop down to play with the toy on the floor, pick it up and move it a little further away on the couch to encourage a few cruising steps. You may feel like you're ALWAYS picking up toys. Just think, though, you'll have a nice, uncluttered path as you walk through the room. Having siblings help move toys from the floor to higher levels can also be turned into a fun game.

**Example 3:** If your child is standing and walking, but still has **poor balance and coordination**, fear of injury may make you inclined to restrict **play activities**.

**Instead:** Encourage your child to try EVERYTHING with close supervision. Don't limit those opportunities to explore movement. Take weekly trips (if not more) to the playground. Walk up and down ladders, ramps, across wobbly bridges, on narrow beams, etc. Bounce on trampolines. Take Karate. Take gymnastics. You may think, "My child is tripping and falling just running across the yard, you expect me to put him in roller skates!" "YES" Physical and Occupational Therapists will use "play" activities in order to engage your child in gross motor skills that are still challenging, but PT 2-3 times a week is not enough. If you are weary about guarding your child so closely all the time (It will be physically demanding and at times exhausting) bring help. Consider getting high school volunteers that need community service credit to commit to a once a week as a mother's helper to go with you to the park.

In some kids, low muscle tone is accompanied by tight structures in the lower extremities. Stretching is something you can do with your child as well. In addition to balance and coordination problems, ATTENTION is a big issue. You can be of great assistance by cueing your child to look at their feet when safe foot placement is an issue. Again, give as little physical assistance as possible while still ensuring safety. Challenge them, keep them safe, and have fun!

## California Conference 2006

Looking forward to 2006 . . .

The conference will be held July 27-30 at the Santa Clara Marriott, 2700 Mission College Blvd, Santa Clara, CA 95054 (408) 988-1500. Room rates have been secured for \$89.00 per night. A limited number of one-bedroom suites are available at \$250.00 per night. Santa Clara is just 45 minutes south of San Francisco and 10 minutes from the San Jose International Airport.

The California Host Conference Committee is looking for assistance with identifying speakers, childcare volunteers and equipment/toys, and sponsors for the events. If you are able to help, please contact the 5p- Society office.

## Grandparents of the Year Award

Congratulations to the following Grandparents who were awarded the GRANDPARENTS OF THE YEAR award for their continued contributions to the 5p- Society.

- Eileen Abbruzzese** Speaker sponsorship, volunteer, major contributor
- James & Frances Bodle** Grandparent facilitators, sibling event facilitators, office volunteers, major contributors
- Gloria Griffin** Board of Director, major contributor
- Arthur & Patricia Strong** Grandparent facilitators, Grandparent Newsletter, Discovery Toy sales, major contributor
- Millie Wiegand** Grandparent facilitator, speaker sponsorship, volunteer, major contributor

Nominations are now being accepted for the 2006 Grandparent of the Year Award. Please submit the name of the Grandparent(s) and why you feel their contributions to the Society earn them the award.

Cookbooks are now available. The Grandparents of the 5p- Society have gathered and published their first cookbook. They are now available through Pat Strong at odah@gmtel.net or by phone at (563) 659-9530.



Emma, Helen and Briana having fun in childcare.



Each year our 5p- kids design their own square to be placed in our annual Quilt that is raffled off at the dinner dance. Here's the 2005 quilt. The green quilt underneath was also raffled off this year.



Catherine and Weston just hanging out!!



The three handsome Piepergerdes boys!!

