

# 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, Lakeview, 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.
- Clothing: <http://www.special-clothes.com/>
- Patient Travel <http://www.patienttravel.org>
- 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,

I hope everyone had a safe and happy Thanksgiving. I would also like to extend my best wishes for the upcoming holiday season! During the holidays we should all take the time to reflect on how blessed we are to have our special children as part of our lives. Remember, it is their special needs that are our special gift...As we are aggressively planning for the Santa Clara conference, we are all set at the Santa Clara Marriott for \$89.00 per night (special thanks to Laura for haggling down the price) on July 27<sup>th</sup>-30<sup>th</sup>. For those of you driving to the conference, or those having access to a car, parking has been negotiated down to \$9.00

per day. I would highly recommend confirming your attendance early this year, so that we can avoid any vacancy issues that arose last year.

By using the very successful template refined by Renee and the St. Louis Conference, we hope to continue the momentum in Santa Clara. Don Hille, Laura Balance and Dawn Ward are our gracious hosts on the West Coast and they are in the process of gathering speakers, child care, and coordinating several fun and eventful activities in and around the Santa Clara/San Jose area. On Friday, one of our key activities will be the poolside Luau. I expect to see plenty of floral printed attire and some hula moves

grooving to Don Hoe. Micah Hoerning, a new Board member from New York, has reached out to his contacts on the West Coast to solicit child care assistance. Thank you Micah! In addition, because of our close proximity to Stanford University, and numerous other leading medical hospitals/research centers, we have invited several of them

Thank you to everyone who made donations throughout the past three months. Your generosity is greatly appreciated. Also, thank you to all who have sent in your membership dues. We currently have 220 members.

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### Bragging Rights!!

Do you have someone you want to brag about!!! An accomplishment of your little one or adult with Cri du Chat Syndrome. Your spouse/therapist/teacher or doctor who deserves mentioning. How about a sibling who has gone above and beyond the call of siblinghood!

Here's your chance. The 5p- News is seeking "bragging" articles.

Send all articles (and pictures) to the 5p- Society either electronically at [director@fivepminus.org](mailto:director@fivepminus.org) or by fax at (562) 920-5240 or by mail at

5p- Society, PO Box 268, Lakeview, CA 90714-0268.

Deadline for March 2006 newsletter is March 1, 2006.

## Parent's Page—Sleeping Problems

My daughter is seven-years-old and continues to have sleeping problems. She goes to sleep at 8 PM, she is tired and can't stay up any longer. She goes to bed, falls asleep quickly and then wakes up anywhere from 4-6 hours later. Sometimes she is awake for one hour, sometimes she is awake for three to four hours. She tries to go back to sleep but can't. We've tried all kinds of behavioral things, we've tried music and lots of other things. We are at a point of where we want medication.

We are all tired and need to sleep. My appointment with the Children's Hospital Sleep clinic left me with the option to try melatonin again. We tried it when my daughter was two. Can anyone tell me about medications that their child uses successfully? There's got to be something. Thank you so much. If you know of anything please email me at familyreal-tor@hnet.net, or call me at 262-335-6280.

Thanks, GERALYN MAURER

*Editors Note:* Families who have children with sleep disorders, this was talked about in great depth on the Message Board. You may want to visit the board and look in the archives. Also, just to let everyone know we are looking into a sleep disorder specialist for the California conference.

## What Makes Your Child Tick?

### *Equipment Donation*

*Rifton Pacer gait trainer, size small with sling seat. If interested please contact Kate Jensen at jensens@tcinternet.net or (952)920-6544*

What makes your child tick? What do they enjoy doing? Can anyone help me/us with ideas on how to keep my daughter entertained, occupied and happy? She gets very fitful and destroys whatever is close by. The behavior seems to stem from not being able to make something work, or her thinking that it is broken and then she has a fit and gets very destructive. Paper seems to be one thing she enjoys. She loves to have a new tablet to write in and she diligently colors/writes on all the pages and then she just starts shredding it angrily, not necessarily because it is filled-up. We are tired, and I do mean tired of cleaning up rooms full of shredded paper. If she has a pair of scissors, she cuts tiny bits of paper up all over the floor. She does not enjoy watching videos, maybe on rare occasion a short Barney or Blue's Clues. She does enjoy one favorite

baby doll and the necessary baby items, bottle, blanket, pacifier, etc. She does love to have a fake cell phone with her and usually a purse. She has spent a good deal of time playing with MAGZ, magnets that make shapes. Another favorite is a sandbox. And she does enjoy a game of UNO. My daughter is also into "typing" email on the computer to understanding friends and family. Of course this activity requires hands-on assistance. Whatever toys are in her room or the den are on the floor and she will not clean up without a huge fight. I am just curious to know what other activities might keep her interest at this state. Plus, her 14th birthday is right around the corner and I need ideas!!

Also, has anyone had any luck with incontinence alarms, wrist watch type or other items that would help to keep my daughter dry during the

day, night time would be awesome too!! She can stay dry all day at school, traveling, out in public, but at home she just really doesn't care to even try to stay dry. There are days when she wets all day long, but only at home in her comfort zone. If she has an accident in public, she is terribly embarrassed and bursts into uncontrollable crying. We comfort her but we do not let her think that it is okay to wet. We have tried a kitchen timer, treats, positive reinforcement, you name it! We have been checking into watch-type count down alarms or set specific alarms and they run about \$75. Any advice or suggestions will be welcome.

If you would like to provide suggestions or advice to Shari please feel free to contact her at djschc@bellsouth.net.

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

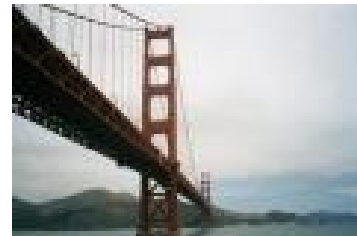
down to our conference as well. We are slowly receiving confirmation from our traditional speakers, as well as trying to incorporate new speakers/topics for this year's conference. Some additional key topics that have been requested for this year's conference are: sleep disorders/deprivation, reading, diet, and impulse behavior. In addition, I have heard from some parents/grandparents as to what they would like to see, so I encourage you to contact me directly if there are any new topics that you would like to review as well ([gabbruzzese@converse.com](mailto:gabbruzzese@converse.com)) or 201-287-1871.

Paul Bakken and friends are laying a strong foundation in Minneapolis for the 2007

conference. They have an established site, the Sheraton South, and are looking at local child friendly activities as well. Currently, they are working on fundraising efforts and securing childcare. The 2008 conference being run by Christy Blount and Anne Zettlemoyer is actually up and running as well. The Board will be visiting the Virginia Beach area in late January to sure up a site and check out the surrounding area.

As the Society grows, the cost of maintaining the Society and cost-effective conferences grows. We are in grave jeopardy this year of not reaching our minimal goal to keep the Society afloat. Once again, Paul Arango and family have generously supported the Society by earmarking funds

for the general operation costs; however, far more is needed if we are to continue. We are falling far short in our fundraising efforts. We have received and submitted sporadic grant proposals, we no longer have charity golf tournaments or cruises being held on behalf of the Society, etc. All of these events were major efforts for the Society which are no longer being held on our behalf. We are thankful for all of those efforts in the past, however, we need new programs in the future. Again, I encourage all members to investigate their employers to see if we can contact their company/foundations to apply for various grants. Lastly, there are still members who have not signed up for the \$25 dollar membership fee. If you have not signed up yet,



please send it in at your earliest convenience.

Well, that's all for now. Please keep your suggestions coming...

## Amanda Mertinooke, Age 25

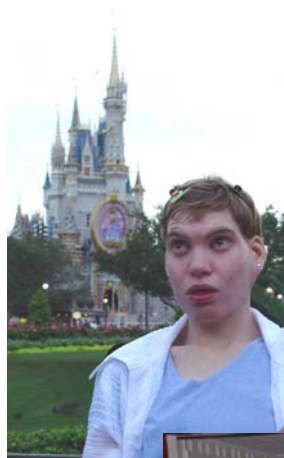
Amanda is now living in a local group home with three other clients. There is 24 hour awake staff and all clients go to workshop programs Monday through Friday. They do various activities weeknights such as bowling, dance club and entertaining another group home of women once a week for supper. Amanda rarely wants to come visit her boring parents unless we promise there is a big family gathering. She also is now an aunt. The Agency monitoring Amanda's house and twenty-seven group homes in several surrounding towns is Turning Point, Inc.

Amanda's housemates are like her extended family to each other. They visit each others' houses every time someone

has a birthday. Any excuse to throw a party. They even have Superbowl and World Series parties. They bowl once a week, meet with horizon club and have cookouts in warm weather. Amanda loves her new home and she and her housemates have become quite comfortable with each other.

Hope all is well with everyone ...

Peter and Pam Mertinooke  
Amesbury, Massachusetts



## Communication Resources *by Laurel Daniels Abbruzzese, EdD, PT*

This was our sixth consecutive year participating in a 5P- annual conference. Every year that we have attended we have learned new strategies for enhancing our daughter's communication abilities. This is a summary of some of the resources and devices that have helped Lydia.

### Year 1

- Early intervention speech and language therapy.
- Introduction to sign language.

Don't let anyone tell you that your child is too young to begin speech therapy. At a minimum, oral-motor programs for feeding can begin, and non-verbal communication strategies can be initiated. All of our girls learned to sign before they could speak. It's so exciting to see them bring their finger tips together to say "more" instead of the screaming that used to indicate that they wanted more to eat. I highly recommend the Garlic Press Sign Language board books for children. <http://garlicpress.com>

### Year 2

- Picture Exchange Communication Systems (PECS)

PECS is a low-tech non-verbal communication option using small picture cards that you can make yourself. I went to Staples, bought binders, sticky Velcro, laminating sheets, and started making my own books after I saw one at the conference. We had a big notebook sized book at first with pictures cut out of magazines of Lydia's favorite foods, toys, etc. We also took pictures of people and items around the home. We expanded the use of picture cards to magnets on the refrigerator, Velcro and felt pads in the living room, and smaller, business card books for the car. As Lydia got older, she no longer needed true-to life pictures, and did well with drawings and smaller images. I recommend <http://www.talklc.com/handout/Outline.html> and <http://trainland.tripod.com/pecs> as PECS resources. Boardmaker software was also useful for various picture-based projects. <http://www.mayer-johnson.com>

### Year 3

- Hip Talk Plus
- Tech Speak

As Lydia got older, and more active, she needed a portable system for key phrases that were not intelligible when she would try to speak. For example, "I need to use the potty" "Excuse me" "I need help, please" "I need a break" "You're not understanding me" and "I'm mad!" The hip talk was lightweight, and she wore it everywhere, including the playground. It was invaluable as we were beginning toilet training and trying to teach appropriate social interactions and expressing feelings. The Hip Talk communicator plays a message when you push one of its buttons. To activate, simply reach to the waist and press. You can record and rerecord messages as often as you like. It comes in a comfortable nylon fanny pack. [www.enablingdevices.com](http://www.enablingdevices.com)

The Tech Speak also allowed for pushing buttons in order to access pre-recorded words or messages. Lydia's had 6 levels, and allowed for expanded vocabulary as she worked in various pre-school activities. We made a special board for circle time, for arts and crafts/ colors and shapes, for choosing toys/activities, for choosing food, classmate names, playing house, and cooking. The Tech/Speak is made by AMDI (Advanced Multimedia devices, Inc.) <http://www.amdi.net/techspeak.htm> and worked well with Mayer-Johnson Boardmaker.

### Year 4

- Vantage (A Prentke Romich dynamic communication device)

Transitioning to this very expensive, high-tech device was no small task. She had a formal AAC evaluation, and was tested on a number of different dynamic devices. We also met initial resistance getting the school system to purchase the device. Lydia, however, needed a device that would allow her to access more vocabulary and be more spontaneous. With previous systems, she was limited by the 32 words that an adult expected she might need, and she didn't have the dexterity to change overlays on her own.

Three years later, Lydia still is not fully independent using the Vantage. Much like her signs, picture exchange, and speech, she mostly communicated with nouns. This past year is the first year that she has really been able to start putting sentences together, which has corresponded to improved verbal abilities as well. We see the Vantage as a useful tool for sentence building and writing assignments now that she's in 2<sup>nd</sup> grade, and her writing skills are still quite deficient. It's really a little computer, and can be connected to a printer. If you are interested in testing the Vantage out, you can download a free demo at the Prentke Romich website <http://prentrom.com>. For current PRC device users, Gail Van Tatenhove has a great site and activities for Prentke devices. <http://www.vantatenhove.com>.

## Communication Resources, continued

### Year 5

- Talk Tools and the Rosenfeld-Johnson approach to oral-motor therapy
- Daily learning experiences with typically developing peers

Despite years of using assistive technology and sign language to augment expressive language, we never gave up on speech clarity. I am a Cri du Chat parent, but my professional expertise is in the area of motor control and motor learning. I was attracted to Sara Rosenfeld-Johnson's program because the strength and coordination needed to produce intelligible speech sounds is gained through graded, goal-directed fun activities.

Speech is a highly complex motor task. The jaw must be strong enough to produce stability for independent lip and tongue movements. Volitional air flow must be well coordinated with lip closure or rounding. Rosenfeld-Johnson designed progressive activities using horns, bubble blowers, straws, and chewing devices to prepare the speech system. Lydia had functional ways to communicate, and was beginning to expand her language skills, but prior to a dedicated oral-motor program she lacked the muscle strength and motor planning skills to produce clear speech. We have been fortunate enough to have Sara Rosenfeld-Johnson as a speaker at our last two conferences. You can learn more about her exercises and treatment ideas at the Talk Tools website: [www.talktools.net](http://www.talktools.net)

Lydia also transferred back to our neighborhood public schools for kindergarten and 1<sup>st</sup> grade. Being around her peers who are ALWAYS talking definitely helped. Lydia has made incredible gains in speech clarity these last two years.

### Year 6

- Vantage Plus
- Leap Pad Products

Starting 1<sup>st</sup> grade meant reading, writing, and spelling. Lydia's speech was becoming clear enough to have her basic needs met, but not clear enough to talk about a science trip or to talk about a book that they read in school. The upgrades to the Vantage device (Now the Vantage Plus) included an icon tutor on the top row. This made it easier to find vocabulary as her language experiences expanded. As I mentioned earlier, the Vantage is being used a lot for spelling, sentence building, and writing tasks as well as for speech output. <http://prentrom.com>.

The Leap Pad books are excellent for emerging readers. The pen can activate an entire page to be read, or can be used to sound out individual words. The Leap Pad plus writing and microphone accessories make working on speaking and writing fun. <http://www.leapfrog.com> You'll love their products for all of your kids.

### Year 7

- Speaking Dynamically Pro (Windows Compatible)

At this year's conference I learned about a new program called "Speaking dynamically Pro." I plan to talk to special educators that may have experience with it and see what they think. According to the website, you can use this program on your computer as a powerful speech-output device or to create interactive educational activities. They suggest creating customized "talking" books, writing activities, student portfolios, social stories, schedules, worksheets, games, and more! <http://www.mayer-johnson.com>

Improving communication skills in our children is a goal we all share. As your child's ability to communicate improves, you are also likely to see a reduction in certain problem behaviors and improved peer relationships. The resources listed here are my personal recommendations, and are not necessarily endorsed by the 5P- Society. My suggestion to you is to check out the web sites and do your own investigating.

If you have success stories to share using these or other resources, I encourage you to share your experiences in the next 5P- newsletter.

## Grandparent's Corner

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.

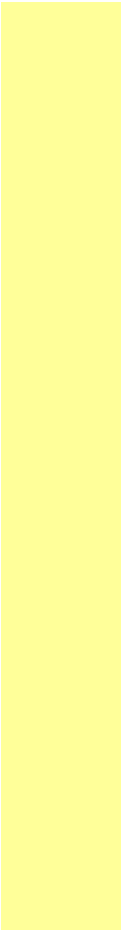
Cookbooks are now available. The Grandparents of the 5p- Society have gathered and published their first cookbook. They are now available through Pat Strong at [odah@gmtel.net](mailto:odah@gmtel.net) or by phone at (563) 659-9530.



5p- Society  
PO Box 268  
Lakewood, CA 90714-0268

Return Service Requested

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## 2006 Calendar

The COLOR 2006 calendars are now available for members. These calendars make great gifts for friends, families, doctors and teachers. The cost of each calendar is \$15.00 US (shipping/handling) included. To order your calendars, please fill out and return the attached order form. Make your check or money order payable to the 5p- Society, PO Box 268, Lakewood, CA 90714. Your calendars will be shipped to you as soon as the order is received. Thank you to Tiffany Townsend for once again donating her time laying out and organizing the calendar. They look great!!!

2007 Calendar pictures and sponsors are now being accepted – please contact the 5p- Society for more information.

Please send me \_\_\_\_\_ copies of the calendar. I have enclosed \$15.00 US for each calendar.

Send calendars to:      Name: \_\_\_\_\_      Total Amount Enclosed: \_\_\_\_\_  
   Address: \_\_\_\_\_  
   \_\_\_\_\_

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