



# NEWS

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

September 2004

### President's Message

by Greg Abbruzzese

Dear Five P Minus Society Members,

September has arrived and by now, all of the kids have started school again. In our home, starting first grade meant a new school, new teacher, new classmates, new bus driver, new therapists, and a new routine. The first week of adjusting has been quite a challenge, but facing new challenges goes with the territory when raising a child with Cri Du Chat syndrome. There are a few strategies that we've employed that have helped to make this transition a successful one. My wife prepared a booklet that gives a full behavioral profile for our daughter. It included her IEP, a description of her communication device, a behavioral plan, sensory diet, oral-motor program, pictures of the ASL signs that she uses most, contacts, web resources, etc. This book was then shared with the special education teacher, aide, and therapists, and is kept at school as a reference manual. We have also solicited the support of a behavior specialist through New Jersey's Department of Developmental Disabilities that will be working with us weekly throughout the year. We didn't come up with these strategies all on our own. Each year at the annual conference we learn about new ideas and resources that may support our family's needs.

Hopefully many of you are starting the year off with a new strategy that you may have picked up from reading the newsletter or contact with another 5P- family. It was certainly one the goals of our annual conference to provide an opportunity for families to network with other families and learn from professionals that could speak on issues pertaining to Cri du Chat Syndrome. I have received several e-mails and written

correspondences suggesting that we met this goal. Despite a few complaints about the hotel elevators, and a few about the food, most of the feedback has been very positive.

We all owe a special thanks and gratitude to the host family team, Holly Gattone, Laurel Abbruzzese, Carin Connor, and Linda & Paul Magin for hosting such a wonderful conference in Philadelphia this year! I offer a special thanks to Holly for scouting out hotel locations, coordinating most of the Philly Olympics activities and decorations, dinner dance decorations, and for managing the hospitality suite. Thanks also to Rick Rothwell for supplying libations for the suite. I want to give a special thanks to Carin for organizing the sibling outing, securing the DJ for our dance, assisting with Philly Olympics activities, organizing the final t-shirt orders with her parents, and recruiting local childcare volunteers.

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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.

## 5p- Philly Style - Wrap Up

Records were being broken in Philadelphia this August. Not Olympic records, but attendance records. This summer 108 families attended our Annual Conference and Get Together. Eighteen of these families were brand new having joined the Society less than a year ago. There were a total of thirty-six families that came to a conference for the very first time. Our members ranged in age from 42 years, Sandra Barnes (Maryland) to 2 month old, Jude Chavez (New York). Not only that but a record number of extended family members came, the most grandparents we've ever seen.

For the first time we had a vendor/exhibit area. Small (four vendors) but effective and growth in this area expected in the future. Discovery Toys, Talk Tools, Braintree Labs, and Prentke Romich Co. all showed their products. Also the 5p- Society "What Works" Table was available to members to share information with other members.

Events for the conference were sponsored by companies and family members. A special thank you to the Maurer family, the Harms family, KONE Elevators and Escalators, Braintree Labs, Talk Tools, Prentke Romich Co, Discovery Toys, the Vaden family, the Erin Eickmeier Foundation, the Rogers family, the Geneizer family, TGI Enterprises and Tracy Copeland. We also would like to thank our host families, Greg & Laurel Abbruzzese, Holly Gattone, Carin Connor, Paul & Linda Magin for not only their monetary donations, but also their time -- many hours, phone calls and emails were needed to pull off such a successful event and they did it.

On Thursday evening we had an overflowing New Family Orientation that has been presented for the last several years by our founder Kent Nicholls. First time conference attendees were given information on how to get the most out of the conference -- and especially how not to be shy!! There was also a sibling mixer where the siblings got together for a short time and interacted to make or renew friendships during the conference. A special thank you to Heather Frayn and Becki Hajduch for leading the group in games. Members were able to meet and greet after registering at our Welcome Reception. Our welcoming committee, Shari and Dennis Campbell, Jerry & Carolina Kretschmar, Jim & Pam Frayn, Diane and David Eaton and all the board of directors of the Society welcomed the attendees to a weekend full of networking, information and fun.

After checking in and getting all the necessary information it was up to the hospitality suite. We'd like to thank Rick and Ronnie Rothwell for stocking the hospitality suite with beverages and to Randy Strong and his mom Pat for taking charge of the hospitality suite as well as Holly's parents for keeping the food and beverages flowing. We'd also like to thank all the members and friends who contributed to the hospitality suite by way of food or monetary donation, especially the Ansell Family.

Friday began with a slide presentation set to the tune of "Philadelphia Freedom" by Elton John to get everyone in the Philly Spirit. A lot of topics were available for the members to choose from, including the Basics of Cri-du-Chat Syndrome (Dennis Campbell, Ph.D.), IDEA and the Individualized Education Plan (IEP) (Wanda Poole and Dionne Beaman), Dental Care (Dr. Angela Stout), Housing for Individuals with Disabilities (Barbara Prince) Guardianship/Trust Planning (ACHIEVA), Transition from School to Adulthood (Poole/Beaman), Early Intervention and the IFSP (Stacy Antoniadis) and Understanding Medicaid & SSI (Julie Barol).

Approximately 50 siblings went to the Sports Center for a morning of Miniature Golf (because of recent storms and flooding, that was the only thing open). When they returned many of the siblings assisted with the Family Fun Event "Philly Olympics." Kids of all ages and abilities got to try their hand at basketball, hockey, gymnastics, bean bag toss, soccer and other assorted "sport related game." There was also a spirit station to get your Red, White and Blue tatoos, stickers, or hair painting. I'd like to thank the siblings that assisted -- Joey, Mikey and Maggie Castillo, Heather & Taylor Frayn, Becki Hajduch, Amanda Jessa, Scott, Josh and Melissa Palma, Kelly Campbell, Madison Seidel (and Samantha, too), Derrick & Kevin Ward, Apryle Townsend, Adam Smith, Jeff New, Justin & Evan Gibbs, Chris, Katie & Emily Bruns, Alyssa & Gabriella Galvagni, Kay Dee Inks, and Julia & Rachel Sanger,

On Friday afternoon, while most families headed for the pool (or naptime if you had little ones), the Grandparents met in the hospitality suite for their own workshop. Thanks to Millie Weigand and Art & Pat Strong for leading the group in sharing and discussion. I heard they are planning to put together a cookbook. Look for your Grandparents' Newsletter for more information. If you are not on the Grandparents' Newsletter mailing list please contact Pat Strong at ( 563) 659-9530.

On Saturday, the group broke into the following presentations: Improving Feeding and Speaking (Sara Rosenfeld-Johnson), Self Determination (Bonnie Miller), Behavior Strategies (Dr. Amy Sue Reilly), Intro to Sign Language (Dr. Laurel Abbruzzese), Augmentative Communication (Cynthia Cohen and Jared Bauer), Sensory Integration (Jennifer Rosinia), Clinical Aspects of Cri du Chat Syndrome (Dr. Toni Kline), Research Update for Children (Dr. Dennis Campbell) and Research Study of the United Kingdom Cri du Chat Syndrome group (Dr. Kim Cornish). The day ended with a well attended Professional Panel Group that was comprised of Dr. Campbell, Dr. Kline, Dr. Cornish, Dr. Towers, Jennifer Rosinia, Sara Rosenfeld-Johnson and Dr. Reilly. They first answered pre-addressed questions on a multitude of subjects such as feeding and behavior control. Then answered questions from the group. A big thank you to all who participated in this first time panel session.

Ending the day was our banquet dinner and dance. The kids just love music and love to dance and this year even did a little karaoke for us. We once again raffled off a beautiful quilt. The squares for the quilt were drawn by our Cri du Chat kids at the Memphis conference and put together by Carolina Kretschmar and her sister-in-law Pauline. The quilt drawings taken from this year will be raffled off at our St. Louis conference.

As you can imagine with 230 kids in attendance, 94 of these kids with Cri du Chat Syndrome, childcare was quite busy. Many thanks must go out to all the extended family members and friends of the host families for assisting in child care and especially to all of you who answered our call for assistance in the last newsletter. We could not have done it without you. TGI Enterprises and Tracy Copeland need a special thank you for donating all the t-shirts for our volunteers and Greg & Laurel Abbruzzese need a special thank you for donating all the Converse Chuck Taylor (TM) high-tops to all our child care workers.

--Laura Castillo

At this year's conference, we not only had a record number of families in attendance, we also had a record number of grandparents and extended family members in attendance. For some of us, it is hard to imagine how we would get by without your support. This is an extra special **thank you** to the grandparents that were in attendance. **Thank you** for your support. **Thank you** for coming to learn more about 5p-. **Thank you** for helping with child care. **Thank you** for all that you do!!

I'd like to extend a "Welcome" to Ms. Chloe Ryan Abbruzzese, born 8/20/2004, third daughter of our President and Philly Host Family volunteer Greg & Laurel Abbruzzese. I'd especially like to thank Chloe for waiting until after the conference to arrive -- Laura Castillo

A very special thanks to the Magins who volunteered to help organize childcare at their first ever conference!! They didn't know what they were getting into, and still pulled through magnificently. Thanks to the Magins, our 5 childcare rooms were well stocked with cribs, bouncers, toys, TVs & VCRs, and local childcare recruits. Last but not least, I want to thank my wife, Laurel, who started recruiting speakers the week after last year's conference in Memphis, and made it through this year's conference (just two weeks before our third daughter was born). Laurel researched and recruited the 20 speakers, solicited sponsorships and organized our first exhibitor room, designed the t-shirts, recruited and organized childcare volunteers, and was still making copies and punching holes to put together the conference booklets by hand two days before the conference began. She got a little flack for putting so many pictures of our kids into the slide show, but she insists she used what she had to work with. These host families did an exceptional job organizing the event and we commend them on their hard work.

In addition to the host families, I would like to extend a special "thanks" to Laura Castillo, our Executive Director, and the rest of the Board members, who, once again, helped run a very professional and family friendly conference. Thanks also to all of the other volunteers that donated their time as childcare workers or speakers, or who contributed equipment, food, t-shirts, and donations. Many do not realize that the conference fee doesn't even cover the full cost of the Saturday night dinner anymore. Everything else was made possible through direct donations and tremendous fundraising efforts from society members across the country. The success of this conference was really the result of many individuals and families coming together to support the society.

I look forward to continued enthusiasm and fundraising support from society members this year to help Renee and Joe Eickmeier coordinate the 2005 event in St. Louis. They have already secured a beautiful location for the conference, the Hyatt Union Station, which is centrally located. The hotel is near several regional tourist sites and mass transportation. The Eickmeiers have also invited the first few speakers. We would like to be able to continue offering conference scholarships to assist selected families with conference costs (hotel fee and registration fee) so that families can socialize and network each day, and comprehensive speaker note booklets, so that you can take some of what was learned home. We also have plans to videotape some of the sessions next year, and will investigate having web-based video links to some of the more popular conference presentations. If you have fundraising ideas or grant contacts that my help, please let us know.

We want to improve our efforts to reach out to the families unable to make it to the annual conference. We hope to expand the content available on our website and in the newsletter. We'd also like to support and facilitate more small, regional gatherings around the country. If you have any ideas, and would like to help support these efforts, please contact me. We always welcome new volunteers.

Looking ahead to 2006, we have decided on the California's Bay Area to celebrate the conference. In 2007, it looks like Minneapolis has taken the lead to host the conference. We hope that families in these areas will volunteer to help coordinate those conferences.

I look forward to another exciting year supporting the society. Again, I want to thank everyone for all of their efforts in Philadelphia and we look forward to all of your support in St. Louis!

Sincerely,

Greg Abbruzzese

President, 5P- Society Board of Directors

## Grandparents' Newsletter

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

# Resources

At the Sign Language Seminar we learned that there is a website that allows you to look up a word and see it signed via a video stream. The site is <http://commtechlab.msu.edu/sites/aslweb/brower.htm>. Thanks to Patti Fowler for this information.

For educators, there is a program available called NEWS -2- YOU. You can learn more about this on the website [www.news-2-you.com](http://www.news-2-you.com). Stories and lessons are developed using Picture Communication Symbols. This is a great way to get your child reading by looking at a picture and seeing the associated word. Common symbols are used throughout the stories. After you go on the site, take the tour and visit "Joey's Locker." You can even get a sample newspaper. This a subscription based program.

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.criduchat.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.

Do you have a resource for our families? Please forward all resources to 5p- Society either by mail, fax or email (see bottom of first page for this information).

## ***Congratulations to your New 2004-2005 Board of Directors***

President	Greg Abruzzese	(New Jersey)
Vice President	Jolene Towers	(Ohio)
Secretary	Renee Eickmeier	(Missouri)
Treasurer	Eileen Sherman	(Illinois)
At Large	Paul Arango	(Florida)
	Paul Bakken	(Minnesota)
	Laura Bruns	(Ohio)
	Sandra Cooley	(Alabama)
	Gloria Griffin	(Kentucky)
	Tim Hopkins	(Delaware)
	Kent Nicholls	(Kansas)
	Georgia Richey	(Utah)
	Ken Robison	(Mississippi)
	Cathy Vaden	(Florida)
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## ***Professional Advisory Board Members***

Chairman	Dennis Campbell, Ph.D.	(Arkansas)
	Kim Cornish, Ph.D.	(Montreal)
	Elizabeth Dykens, Ph.D.	(California)
	Robert Hodapp, Ph.D.	(California)
	Antonie Debra Kline, MD	(Maryland)
	Adam Mezzoff, MD	(Ohio)
	AmySue Reilly, Ph.D.	(Alabama)
	Jennifer Rosinia, M.Ed, Otr/L	(Illinois)

## ***Regional Family Support Coordinators***

East Coast US	Ruthie Liberman	(781) 861-3962
Southeast US	Deanna Bryant	(870) 802-2193
Midwest US	Joan Steele	(618) 687-3006
Plains States US	Crystal Marshall	(316) 669-8367
Rocky Mtn States US	Kathy Phelps	(970) 259-3588
West Coast US	Dawn Sadler	(907) 474-0956
Eastern Canada	Dan & Julie Deyell	(705) 887-4770
Western Canada	Patricia Wheatley	(403) 251-9855

All of these above listed individuals deserve a very special thank you for their time and commitment to the 5p- Society.

## MEET US IN ST. LOUIS

It's just September and my husband, Joe, and I are already busy planning the 2005 Annual Conference and Get-Together in St. Louis, July 28-31, 2005. We are looking forward to an awesome conference experience with something for everyone.

First of all, the site of the Conference, The Hyatt Hotel at Union Station, is extraordinary! It's beautiful, historic, and posh! It's like no other place the 5p- Society has been before. It is located in St. Louis' historic Union Station, which is now home to fun shops and eateries. There is a food court within Union Station, as well as sit-down restaurants. Also located on the complex are the Hard Rock Café, Landry's Seafood, and a Hooters for you chicken wing fans. There are paddleboats outside in the lagoon, singing fudge makers, and from what I hear lately, an indoor trampoline. I hope you will still find time to attend our speaker's presentations!

And speaking of speakers, we are planning on having many of your favorites back this next year, including Jennifer Rosinia, Sara Rosenfeld-Johnson, Dennis Campbell, and Kim Cornish. We are also trying to plan a hands-on sensory lab, where you can provide your child with the needed sensory input and learn about different sensory techniques.

Did you know the ice cream cone, the hot dog, and cotton candy made their first appearance at the 1904 World's Fair in St. Louis? In keeping with our World's Fair Theme, we are planning an "inning" for Friday afternoon that will be an afternoon at the fair. There will be fun food, giant inflatables, and enjoyment for everyone.

We are planning on videotaping some of the more popular presentations in an effort to reach and assist more of our membership. We will also try to continue with an Exhibitor's Area and a Conference Program, complete with session notes, two great ideas pioneered at the last two conferences.

So please mark your calendars for the last weekend in July. St. Louis is a great city with many fun and exciting attractions. Make a vacation out of it and see the sites! I am available by email for any questions or comments about the upcoming conference or attractions in the St. Louis area, [Reickmeier@sbcglobal.net](mailto:Reickmeier@sbcglobal.net). See you there!

## 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.

**Assessment of Communicative Abilities of Individuals with Cri du Chat Syndrome** -- Dr. Dennis Campbell, Arkansas State University & Dr. AmySue Reilly, Auburn University

**Examining Sensory Processing in Young Children with Cri du Chat Syndrome** --Jennifer Rosinia, M.Ed, OTR/L The Erikson Institute/Loyola University, Chicago, IL

**Adults and Cri du Chat Syndrome** -- Dr. Kim Cornish, McGill University, Montreal, Canada

**Early Intervention for Repetitive or Self-Injurious Behavior in Young Children** -- Dr. David Richmond, University of Maryland



*"MEET ME IN ST. LOUIS"*

2005 5p- Society Annual Conference  
July 28-31  
Hyatt Regency St. Louis  
at Union Station

One St Louis Union Station  
St. Louis, Missouri 63103  
(314) 231-1234

Host Family - Joe and Renee Eickmeier have already begun to plan for your educational and fun event. Plan on bringing the whole family. There will be sibling events and grandparents' workshops. If you are interested in assisting Joe and Renee, please feel free to contact them at reickmeier@sbcglobal.net or (636) 227-9811 (Home).

***Ways that Society members can help make this event a huge success:***

- 1) Identify potential speakers for event.
- 2) Help to secure sponsorship for the event from your employer or a connection you may have.
- 3) Hold your own fundraiser to benefit the 5p- Society.
- 4) Donate or loan goods or services for the event:
  - Babysitters (extended family members, friends or community service groups that are in the area)
  - AV equipment
  - Children's entertainment
  - Toys/equipment for child care rooms
  - Room decorations

***Sponsorship Opportunities***

Because 5p- is so rare, families are spread out all over the country. The annual conference is an opportunity to meet other families, exchange important information and resources and attend educational seminars. Conference fees are kept low so that as many families as possible can attend. As a consequence, we are dependent on contributions and sponsorship to make this event happen.

Diamond Sponsor - \$10,000.00 (Event Underwriter)  
Platinum Sponsor - \$ 5,000.00  
Gold Sponsor - \$ 2,000.00  
Silver Sponsor - \$ 1,000.00  
Friend/Exhibitor - \$ 500.00

Contact the host families or the 5p- Society for a list of the benefits to each sponsorship level. To become a sponsor, make check payable to 5p- Society, PO Box 268, Lakewood, CA 90714-0268



P.O. Box 268  
Lakewood, CA 90714

Return Service Requested

2005 Calendar

The color 2005 Calendars are now 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 = \$1.29    2 - 7 calendars = 3.85    8 - 15 calendars = \$8.00    16 and more please call Society for amount