



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

March, 2004

President's Message

by Greg Abbruzzese

As August draws closer, we are getting excited about our upcoming 5P- conference and get-together in Philadelphia. Last week, Laura Castillo, Holly Gattone, Laurel Abbruzzese, and Carin Conner did some on-site reconnaissance at the Adam's Mark Hotel to coordinate the weekend events. In addition, Tiffany Frezza has been securing initial conference sponsors, and Linda Magin has begun coordinating childcare for the event.

The following is a recap by Laura and Laurel of how the plans for the upcoming conference are evolving...

The theme this year is "5P- Philly Style". Since Philadelphia is rich in American history, our t-shirts and banquet will be inspired by patriotic themes and lots of red, white and blue. Philadelphia is also known for its cheese steak sandwiches, soft pretzels, and Italian ices. We plan to serve these local delicacies at the Friday indoor picnic. Since 2004 is also an Olympic year, we are planning a 5P- Philly Olympics for Friday afternoon. There will be lots of fun activities and competitions for kids of all ages, and chances to win prizes and medals. We hope that the picnic/Olympics and banquet will be fun gatherings for our entire group.

In addition to opportunities to interact with other families, one of the highlights of the conference each year is the line-up of professional speakers. This year we have invited over 20 professionals to speak to our group on topics of interest to CDC families. Special attention was given to include presentations that would appeal to special needs across the

lifespan. Some of the topics will include: a genetic overview of Cri Du Chat Syndrome, oral-motor strategies for feeding and speech, augmentative communication, sensory integration, positive behavior strategies, dental care, guardianship and trust planning, self determination, housing for individuals with disabilities and special education, to name a few. Our final session on Saturday afternoon will include a professional panel including researchers, therapists, and health professionals that have expertise with 5P-, so get your questions ready!

We are also pleased to be able to offer a grandparents' workshop, a fathers' workshop and a sibshop at this year's conference. Parents and grandparents of children with special needs often recognize the benefit of knowing other parents in a similar situation. As advocates for our children, we actively seek out peer support, information, and validation. Opportunities for siblings of children with special needs often need more facilitation.

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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.

President's Message continued . . .

The ARC's sibling support project points out that the brothers and sisters will often have the longest-lasting relationships with individuals with disabilities. The sibshop is an opportunity for peer support and education within a recreational context. According to ARC, "Sibshops acknowledge that being a brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many somewhere in between." The annual conference and get together offers a unique opportunity for siblings to interact with peers with similar issues and experiences. In addition to the Sibshop, we will have a sibling mixer on Thursday evening, and a sibling outing on Friday morning.

In concert with our fundraising efforts, we are planning on having a vendor exhibition area on Saturday. We are soliciting vendors that sell special education resources, augmentative communication devices, and pharmaceuticals. We have only begun our efforts in this area. Securing sponsorship and fundraising dollars are still critical to having a successful event. The registration fee that is paid only covers the cost of the Saturday night banquet. All other conference expenses are supported by fundraising dollars. We are woefully short of our goal for this year's conference. We still need to raise money to cover the expense of the welcome reception, continental breakfast, conference programs, and rental of speaker equipment. These are just a few of the additional expenses. I would encourage any member that can help, or has heard of any potential grants to contact me directly so that we can investigate additional donations and/or sponsorship.

We are also hoping to recruit assistance from more of the 5P- families in Philadelphia and surrounding areas. We are in need of food donations for the hospitality suite, toys and equipment for the childcare rooms, and more childcare volunteers.

We understand that traveling with a family can often be cost prohibitive, yet the experience can be such a valuable one. Again this year we have set aside money for five conference scholarships. I encourage families that may need some financial assistance to please apply. Please send your inquiry directly to Laura Castillo at the Society's web site.

Moving on to St. Louis... (site of the 2005 conference) the 5P- Board of Directors had a wonderful visit hosted by Renee Eickmeier. Thank you Renee! We narrowed down the hotels to two locations and decided on the Hyatt Regency Union Station. This is a GREAT location with direct access to public transportation (trains, busses, etc), along with a plethora of dining options ranging from food courts to fine dining. In addition to the centralized location, there are several historical sites, along with kids' entertainment a stone's throw away from the hotel.

I must add that Renee has already begun her fundraising for 2005! She and her family sponsored "*Mouse Races*"... yes, you read correctly, she raced mice (in a humane way)! The mice races raised over \$11,000 dollars for the event!!! Outstanding effort Renee!!!

Looking ahead to 2006, we have heard from several Northern California families that have expressed interest in hosting the 2006 conference. We're mostly looking in the Oakland and San Jose areas.

Although we focus a great deal on the annual conference each year, we are always looking for ways to share the wealth of information that is out there with more of our members across the country. The mission of the 5P- society is "To encourage and facilitate communication among families having a child with 5P- syndrome and to spread awareness and education of the syndrome to these families and their service providers." In keeping with the society's mission, my wife, Laurel, will be compiling a Resource Manual for families and service providers of children with 5P- syndrome. Along with the conference materials, you will find a short questionnaire that can be copied and distributed to all of the professionals that have worked with your kids. Current therapists, teachers, and medical professionals will be the obvious first targets. Please also consider contacting individuals that have worked with your child in the past. It would also be helpful if each parent offered their own insights regarding the challenges and successful strategies implemented with your children. Depending on the response, this project can hopefully be completed by August 2004. It will depend in large part on the active participation of our members. No one knows as much about 5P- as the parents and individuals working with our kids. Please take advantage of this opportunity to share this expertise with other families.

That's all for now... I look forward to seeing you all in Philadelphia!!!

Greg Abbruzzese

5p- Philly Style - Look Who's Talking

The following presenters are confirmed at this time and we are looking forward to hearing from others, so stay tuned! We feel like we have some really great experts in the fields they represent and are certain they will offer very valuable information to our 5p- families.

Dionne L. Beaman is the Associate Director of In-Home and Community Based Services of the Philadelphia Developmental Disabilities Corporation. She is responsible for developing and implementing individualized programs for children and adults with developmental disabilities within the home and community setting. She provides training in life skills and community based activities to staff and families. Dionne also works extensively in Recreation Therapy for various organizations in Philadelphia.

Dennis Campbell, PhD is an Assistant Professor of Special Education at Arkansas State University. Dr. Campbell directs the Early Childhood Special Education Program. He is an advocate for families and inclusion in the least restrictive environment. He is father to Amy and also chairs the Professional Advisory Board of the Society.

Cynthia Cohen, MS, CCC/SLP is a speech and language pathologist/AAC specialist at the Teachers College-Columbia University. Cynthia will be giving us an overview of augmentative and alternative communication.

Kim Cornish, PhD has done extensive research on Cri du Chat syndrome with the Cri du Chat Support Group in the United Kingdom. She has recently relocated to McGill University in Canada. Currently she is interested in studying the Adults with Cri du Chat syndrome. We welcome Dr. Cornish and her wealth of information.

Antonie D. Kline, MD, Director of Pediatric Genetics, Harvey Institute for Human Genetics, Greater Baltimore Medical Center. Dr. Kline is on our Professional Advisory Board and will be available for families for one-to-one talks with parents on Saturday.

Wanda Poole is the Director of Advocacy and Family Services at the ARC of Philadelphia. Wanda is responsible for insuring that the rights of individuals with disabilities are protected and supported by promoting education, resources and supports as they relate to the consumer and their families. She also is responsible for developing specific programs such as GED, housing facilitator, representative payee and volunteer.

AmySue Reilly, PhD is an Associate Professor at Auburn University in Auburn, AL. She teaches Early Childhood Special Education and is the Director of the Friends for Life family support group. Dr. Reilly has expertise in working with families and with individuals having challenging behaviors.

Sara Rosenfeld-Johnson, MS, CCC/SLP has more than 30 years experience as a speech and language pathologist. She has spent the last 20 years perfecting her unique brand of oral-motor speech therapy with a high degree of success, even where traditional speech therapy has failed. Now she is devoted to teaching others the methods so they can help their clients with difficult-to-remedy articulation problems.

Jennifer Rossinia, MEd, OTR/L is a registered Occupational Therapist and has her Master's Degree in Early Childhood Education from the Erikson Institute in Chicago, IL where she is completing her Doctoral studies. She is the president of KidLinks Unlimited, Inc., whose company mission is to link theory to practice, parents with professionals and kids with their optimal potential. Jennifer is also a member of our Professional Advisory Board.

Maria Smith, Vice President and Director of The Family Trust of Achieva (ARC) in Pittsburgh, PA.

Angela M. Stout, DMD, MPH is a pediatric dentist in private practice in Erdeneheim, PA as well as a Clinical Assistant Professor of Pediatric Dentistry at Temple University School of Dentistry. Dr. Stout is the Liason for Temple University and the Special Olympics, Special Smiles Events along with participation in and consultation for several other special needs organizations.

5p- Philly Style - Proposed Schedule of Events

Thursday, August 5, 2004

Registration

Welcome Reception Meet, Greet, Reacquaint families in a relaxed environment

New Family Orientation — Learn how to get the most out of the weekend.

Sibling Mixer — This is an important time for our typical siblings to be able to make new friends and renew old friendships. This will be the kick-off for all the Sibling activities during the weekend and will serve as the “ice-breaker”.

Hospitality Suite will be open for socializing.

Friday, August 6, 2004

Opening Session/Child Care check in

Sibling Outing — Siblings gather and leave by bus for a morning of miniature golf, batting cages or regular golf. They will return for lunch.

Morning Sessions

	A	B	C	D
1	CDC 101	IDEA and the IEP	Dental Care	Housing for Individuals with Disabilities
2	Early Intervention and the IFSP	Transition from School to Adulthood	Guardianship/Trust Planning	Intro to Sign Language

Family Event Lunch and “Philly Olympics”

Grandparents’ Workshop -A time for the Grandparents to get together and share

Dinner on your own

Board of Directors’ Annual Meeting

Hospitality Suite

Saturday, August 7, 2004

Opening Session/Child Care check in

Sibshop and Fathers’ Workshop

Vendor Displays

Morning Sessions

	A	B	C
1	Improving Feeding and Speaking	Sensory Integration	Self Determination
2	Medical Insurance Empowerment	Behavior Strategies	Understanding Medicaid & SSI

Lunch on your Own

Afternoon Sessions

	A	B	C
1	Augumentative	Research Update - Children	Research Update - Adults
2	Question and Answer Session with the Professionals		

Cash Bar/ Photo session

Banquet and Family Dance - General Meeting of the membership, photo opportunities

Hospitality Suite

Sunday, August 8, 2004

General Question and Answer, what did you forget to ask??

Other News

Tiffany Frezza of Texas has secured two donations for our 2004 conference. Mead/Johnson Company will be donating \$150 and Braintree Laboratories (makers of Miralax) will be donating \$500.00. The donations will assist in offsetting some of the costs of the conference.

Grandparent Gloria Griffin of Louisville, Kentucky, continues to raise hundreds of dollars through the sale of jewelry at various local events for the 5p- Society. A large amount of the contributions will be used to assist with offsetting some of the costs of the conference.

An aunt, Marty Nash, of Dallas, Texas will be having Denim Days at work on April 23rd. Co-workers that want to wear denim to work on that day will be making a donation to the 5p- Society. Fun idea and easy, too. Thanks Marty.

Financial Assistance Program for Philly

Once again, the 5p- Society will be offering five (5) scholarships, The Anna Maurer Family Scholarships, for families that would like to attend the conference. The scholarships assist in paying for your Registration Fee of \$125.00 for up to two adults and two children for the conference and will pay for three nights stay at the Adam's Mark Hotel (Thursday, Friday and Saturday nights). The scholarship does not assist in travel or incidentals. If you are interested in more information about the scholarship program and would like an application, please contact the 5p- Society office at (888) 970-0777 or you can email Laura at lc5pminussociety@aol.com.

More Conference Info . . .

There are two things that you will need to do to register for the 5p- Philly Style 2004 Annual Conference.

- (1) Fill out the Registration form on page 7 and return that to the 5p- Society office with your registration fee.
- (2) Contact the Adam's Mark Hotel and make your hotel reservations. Call the Adam's Mark Hotel at their toll free reservation number (800) 444-Adam. Room rates for the conference are \$99.00 per night. Please make sure that you mention that you are with the 5p- Society in order to get the \$99.00 per night rate. The dates of the conference are **August 5th through 8th**. Room rates will be honored for a short time before and after the conference. If you have any questions, please contact Laura at the 5p- Society office at (888) 970-0777 or (562) 804-4506. You can also email Laura at lc5pminussociety@aol.com.

The Adam's Mark is approximately 12 miles Northwest of the Philadelphia International Airport via the Schuylkill Expressway (I-76) to City Avenue exit. There is no complimentary shuttle. There are several ways you can get to the hotel. One option is a shuttle service called Lady Liberty. They have passenger vans to transport your family. The cost for these shuttles is \$12 per adult, \$4 for children (7-12 years) and children 6 and under are free. At the airport baggage claim you would dial #27 at the Ground Transport Center and you will be directed as to where to wait for your van to the Adam's Mark Hotel. They run from 5:30 AM to Midnight. On your return to the airport, you would need to let the concierge at the hotel know one day in advance when you would need transportation. The vans are not wheelchair accessible. Please contact the Philadelphia International Airport for wheelchair accessible transportation.

Please let the hotel know if you need a refrigerator (\$15.00 per day), crib or roll-a-way at time of making reservation. Indicate on your registration form on page 7 of this newsletter what items you requested. Marking these items on page 7 does not mean you'll get them. You do need to make those requests **directly** with the hotel.

Confirmation packets will be sent out in mid-June 2004. Registration for the conference will be accepted at the door. However to get the great room rates please make your hotel reservations prior to July 6, 2004. After that the room rates will be honored on a space-availability basis.

5p- Philly Style - T-Shirts



Don't forget to order your T-shirts early this year! Why? Because last year we ran out of shirts and we want to make sure you get one. Pre-orders will be taken until July 1, 2004. T-shirts will be available at the conference, for the same price, however your choices may be limited. T-shirts will be \$8.00 each. You may order your shirts in either white or blue. You can pick up your shirts at the registration table. See order form on page 8. If you would like a T-shirt but cannot attend the conference please add \$5.00 for shipping (up to 5 shirts, \$10.00 up to 10 shirts).

Parent Reports

If you're looking for a good resource publication go to <http://www.thearc.org/publications/futureplanninghandbook.doc> -- information provided by Genetic Alliance

Several families have found the "magic" in discipline and managing behavior issues with Dr. Thomas Phelan's [1-2-3 Magic Book](#). This best-selling book provides easy-to-learn discipline techniques for parents of children ages 2-12. For more info go to <http://www.parent-magic.com>. Information on this technique provided by the Palma family.

Summer Camps. Now's the time to start thinking about your summer camp plans for your child. One family in El Granada, California has told us about Camping Unlimited. This year round program has both weekend and day trips and during the summer runs 6 to 12 day sessions from their base camp in Boulder Creek (near Santa Cruz). They have a main camp, outdoor camp and travel camp program. For more info about Camping Unlimited write to them at PO Box 20774, El Sobrante, CA 94820. Information provided by Joanne Bobele, mom to 39-year-old Heidi.

Eniva Water Soluble Minerals and other vitamins, including Ensure may be claimed on your income tax if they are written as a prescription by your physician or pediatrician. For more information about the Eniva products contact parent Linda Mischley at mischley@northwood.edu.

Do you have a successful summer camp, behavior technique, resource or anything that we should all know about? If so, please send a note either by email, fax or mail to the 5p- Society for publication in a future newsletter. Families supporting families is the best type of networking.

Photo Opportunity

We are now in the process of putting together the 5p- Society 2005 fundraising calendar so it will be finished in time and available to buy at the Philly conference. We are in need of picturees to create a collage of our children for each month. Twelve monthly sponsors are now being accepted (actually two have already been received) Don't wait too long and miss getting your favorite month. Your \$100 sponsorship assists us in the production of the calendar. This \$100 can be split between two families. Please submit your sponsorship amount with a picture or pictures of your child. We will need a release form from you to publish your child's picture. Please send sponsorships to the 5p- Society office and indicate on your check that it is for the 2005 Calendar. Please send your pictures to Cathy Vaden, 4708 Park Blvd, Parker, FL 32404, along with your release form. If space permits we will be able to publish non-sponsorship pictures of Cri du Chat syndrome children in the calendar. If you are interested in having your child's picture placed anywhere in the Calendar send your photos with a release form. Note that the photos become the property of the 5p- Society, may be used in different publications of the 5p- Society and cannot be returned. The Calendar committee is also looking for talented individuals that have a background in Graphic Arts that would like to assist in designing this year's calendar. If you are interested please contact Cathy Vaden at redtwin@knology.net or (850) 215-3364.

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**2004 North American Annual Conference
and Get-Together - August 5-8th - Philadelphia**

Yes, I/We plan to attend the conference.

Registration fees

\$125.00 for up to two adults and two children *in the same family* _____
(\$150.00 After July 1, 2003)

\$35.00 for each additional adult _____

\$20.00 for each additional child _____

Total Enclosed _____

No, I/We are unable to attend. Please accept
our donation. _____

Name: _____
Address: _____
City: _____ State/Province: _____
Country: _____ Zip/Postal Code: _____
Telephone: (____) _____

Please list **all** adults attending (list additional names on separate page):

Name	Relationship to child with Cri du Chat
_____	_____
_____	_____
_____	_____

Child care will be available for all children. Please indicate below if you will require child care and your child's age(s).

Please list **all** children attending (including your child with Cri du Chat Syndrome)

Name	Relationship to child with Cri du Chat	Child Care	Age
_____	_____	y n	_____
_____	_____	y n	_____
_____	_____	y n	_____
_____	_____	y n	_____

Please indicate how many items you are requesting directly from the hotel:

___ roll-a-way beds ___ cribs ___ refrigerators (\$15.00 per day)

**Return this completed registration form with your check or money order (US funds only)
to:**

2004 Conference Registration
5p- Society
PO Box 268
Lakewood, CA 90714-0268

any questions (888) 970-0777 or (562) 804-4506



Resource Manual

Please contribute to the 5p- Society Resource Manual for families and service providers of children with 5p- Syndrome.

If you have experience working with an individual with Cri du Chat (5p-) syndrome, we need your input. Our goal is to compile the information provided on these questionnaires into a resource manual. We would like to have all forms back by May 1, 2004.

Please fill out the form below and mail it to Laurel Abbruzzese, 521 Palisade Ave. Teaneck, NJ 07666; fax (201) 287-1871 or email the same information to LDABBRUZZ@aol.com. Many thanks for taking the time and being willing to help out.

Name:			
Address:			
Phone: (day)		E-Mail:	
Workplace:		Occupation:	

Are you willing to be contacted by other professionals _____ Y _____ N parents _____ Y _____ N

How many months experience do you have working with a child with 5p- Syndrome? _____

How old was the child at the time? _____

What were the child's biggest challenges?

- 1 _____
- 2 _____
- 3 _____

What were your two primary goals?

- 1 _____
- 2 _____

Home much time did you give to meet the above goals? _____

What were the effective strategies used when treating this child? (explain)

Suggested Resources: _____

2004 Conference Registration Enclosed
Return Service Requested

P.O. Box 268
Lakewood, CA 90714



T-Shirt Order form

The front logo is found on page 6. The back is still being prepared. Please choose your color and size and return to the 5p- Society, PO Box 268, Lakewood, CA 90714, as soon as possible.

Child Size	Quantity	
	White	Blue
small	___	___
medium	___	___
large	___	___
x-large	___	___

** Please note that volunteers for the conference, board members, and Welcoming Committee members t-shirts will be ordered in Red so that they can be identified by the conference attendees. If you are a volunteer please indicate your size and place a * next to it.**

Adult Size	Quantity	
	White	Blue
small	___	___
medium	___	___
large	___	___
x-large	___	___
xx-large	___	___

Name: _____
 Address: _____
 Phone Number: _____

Total Child/Adult ordered _____ x \$8.00 USD = _____
 Total amount due: _____ USD

If you are not attending the conference and would like these shipped, please add \$5.00 for every five shirts ordered for shipping.