



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

June 2003

President's Message

by Greg Abbruzzese

As the 2003 conference draws closer there is tremendous excitement brewing in Memphis! Both Todd Piepergerdes and Kent Nicholls assure us that everything is going on track and they are proclaiming that this will be the BEST conference ever! The genre for this year's meeting is a carnival theme from which Tracy Copeland has graciously donated t-shirts for the occasion, thank you Tracy! I hope everyone has their registration information in **early** this year!!! We wouldn't want you to miss such a wonderful event!

Looking ahead to the 2004 and 2005 conferences, it looks like we are leaning toward the Adam's Mark Hotel right on the outskirts of Philadelphia. The location offers easy access from airport locations and all major highways. Holly Gattone has been doing a great job leading the charge with this conference. In addition, Sesame Place is only about 20-25 minutes away from the hotel, along with other local historical attractions in the immediate Philadelphia area. Now on to St. Louis for 2005... With the Eickmeiers as our host, we can all expect an exceptional conference in St. Louis as well! We all look forward to some wholesome St. Louis barbeque and we have no doubt that this will be an equally successful conference going forward.

As always, it is our hope to help defray the cost of all of these conferences as much as we can. Once again, we have a great fundraising tool at our disposal. The Eickmeiers have graciously donated a wonderful fundraising tool for the Society, a CD Rom/video that outlines who we are, what the Syndrome is all about, and our goals going forward. It truly is heartwarming. This CD Rom alone

has already generated a great deal of enthusiasm from the people who have viewed it. We plan on showing it at the conference and it will be available for distribution as well. Furthermore, I encourage any friends or members of the Society to contact me regarding any fundraising opportunities going forward.

On a more personal note, both Laura (Castillo) and I have received numerous calls from new families inquiring about speaking with parents who have shared similar experiences. Unfortunately, some of these new families have met with resistance from parents to talk about their children. I completely understand if families want to remain guarded of their children, it's just that I hope that we can all try to open our hearts to these new families and guide them along the path.

continue on page 2

In this Issue . . .

- **5p- Rocks Memphis**
 - Hotel Name Change2
 - What Works Table4
 - Registration form 7
 - T-shirt Order form8
- **Parent Report**
 - College Girl6
- **Other News**
 - Recreation Resources 3
 - PECS Training Schedule 5
 - Families Supporting the Society 5

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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LC5PMINUSSOCIETY@aol.com

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- Rocks Memphis

Hello from the sunny south. We have been working diligently to assure everyone of a fun, invigorating and informative family get together. We believe we have activities and presentations that will be beneficial to all. Knowing how sunny it gets in Memphis in August we are finishing preparations for the Friday afternoon inning. Friday evening you can either explore Memphis or kick back at the Park Vista. Beale St. is a popular stop in Memphis. Early in the evening you will see families enjoying some of the street musicians and fine dining. Later at night Beale St. gets really rocking with rock and roll, blues and jazz. At the Peabody Place (one block from Beale St.) you have movies, neon putt putt golf, bowling, shopping and of course more restaurants.

If you arrive early to Memphis or stay after the conference you might want to check out the zoo (yes we have pandas), Pink Palace Museum, take in a ball game at Autozone Park, see the famous Peabody ducks, the casinos at Tunica, or a trip down the Mississippi on the Delta Queen. Memphis is a great place for families to visit. Those of you flying in should get your reservations early. Little Rock, AR is about two hours from Memphis. You might check it for available flights since Southwest does not serve Memphis.

Additional presenters since the last newsletter include:

Brian Dion who will present information on supportive living issues. Brian, among other experiences, is currently the State Director of Residential Supports and Provider Development for the Tennessee Division of Mental Retardation Services, Dept. of Finance and Administration. Over the past 25 years, he has worked as a volunteer, direct support staff, agency director, and National Quality Assurance and Development director for various organizations supporting children and adults with developmental disabilities, autism, mental illness and acquired brain disorders in six states.

Carolyn Graff, PhD, RN has agreed to lead a sibshop on Saturday. She facilitated Sibshops for 7 years while living in Kansas City.

Caroline Gomez will be co-presenting with Drs. Baird and Ingram. Some of you met Caroline in Miami when she assisted with a research project.



President's Message continued . . .

Lastly, we are working on creating a bilingual (Spanish) segment of our web site. In addition, we are trying to collect a list of Spanish speaking families with whom new parents of Latin/Spanish children can speak to about issues. If you would like to assist, please contact either Laura or myself.

See you all in Memphis!

Greg

From the Executive Director . . .

Many of you have moved and I don't have updated information on you. Look at your label. if your phone number is incorrect please contact me by fax (562) 920-5240, phone (888) 970-0777 or (562) 804-4506 or email lc5pminussociety@aol.com. **Thank you.**

Hotel Name Change

The hotel, Adam's Mark, was recently acquired by the Hilton chain of hotels. The new name for the Adam's Mark in Memphis is now Park Vista Hotel. The phone number for the Park Vista Hotel is (901) 684-6664. Several families have had difficulty making their reservation with the new hotel chain. We have tried to remedy these difficulties. However, there may be a few more of you that are having some difficulty with the new hotel and you may be thinking that you cannot come because of these new changes. Please know that if you encounter any difficulty in obtaining reservations from the hotel please contact Laura at the 5p-Society office. It is possible that she can assist in "fixing" the problem with the hotel. When making your reservations and asking for a King Size bed and a roll-a-way, just say you have two people in the room instead of three or four. If you are getting double/double rooms tell them you only have four people in your room - even if you have more. Remember to make your hotel reservations by July 5th to guarantee the \$99.00 room rate.

WHAT WORKS TABLE

WANTED: Creative or unconventional ideas and resources that have helped you solve a problem. We will have a WHAT WORKS TABLE at the Memphis conference to showcase ways that you have created materials, modified your house or added to existing resources to help your child in an innovative way. For example, so that our daughter did not flop around in her bathup ring, we took water noodle foam (and put a slit in one side) and covered the bath ring with it. If you have a picture of your idea, please bring it with a description to the conference or send to Cathy Vaden (8606 Timber Bush, San Antonio, TX 78250 or email to redtwin@satx.rr.com).

Website Resources on Recreation

With summer here you will need to keep the kids busy. Here are some websites and resources that may assist you with Recreational Activities.

Afterschool Alliance. "Afterschool and Students with Special Needs." www.afterschoolalliance.org/issue_needs.cfm.

Brookes newsletter Archive. "Including Children with Disabilities in Community Recreation Activities." www.pbrokes.com/email/archive/august02/august02D1.htm

Educational Equity Concepts. "Playtime is Science for Children with Disabilities." www.edequity.org/text/playdisab1.htm

Research Connections in Special Education. "Homework Practices that Support Students with Disabilities." <http://ericec.org/osep/recon8/re8sec3.html>.

Other Recreation Resources

AGH Associates, Inc. (1994). Managing Inclusive Programs: How to Set Up and Run Inclusive Extended Year Programming. AGH Associates, Inc., Box 130 Hampton, NC 03843

Caroll, M.E. (1990). Focus on Ability/Serving Girls with Special Needs. To order, contact Girl Scouts of U.S.A. at 420 Fifth Ave, New York, NY 10018-2702

Center for Recreation and Disability Studies and Recreation Administration. [Videotape]. Learning to Play, Playing to Learn; Recreation as a Related Service. University of North Carolina at Chapel Hill, CB#8145, 730 Airport Road, Suite 204, Chapel Hill, NC 27514-8145. Call (919) 962-0534.

Greenstein, D. (1993) Backyards and Butterflies; Ways to Include Children with Disabilities in Outdoor Activities. Brookline Books.

Kasser, S.L. (1995). Inclusive Games: Movement Fun for Everyone! Champaign, IL; Human Kinetics.

Komissar, C., Hart, D., Friedlander, R., Tufts, S., & Paiewonsky, M. (1997) Don't Forget the Fun: Developing Inclusive Recreation. Boston: Children's Hospital, Institute for Community Inclusion, University of Massachusetts Center for Excellence in Disabilities.

Moon, M.S. (1994) Making School and Community Recreation Fun for Everyone/Places and Ways to Integrate. Baltimore: Paul H. Brookes Publishing Company.

Morris, G.S.D., & Stiehl, J. (1989) Changing Kids' Games. Champaign, IL: Human Kinetics Books

Schleien, S.J., McAvoy, L.H., Lais, G.J., & Rynders, J.E. (1993) Integrated Outdoor Education and Adventure Programs. Champaign, IL: Sagamore.

Schleien, S.J., & others (Editors, 1995). Powerful Partnerships. Order from University of Minnesota, 110 Cooke Hall, 1900 University Ave SE, Minneapolis, MN 55455. Call (612) 625-7583

PECS Training Workshops

PECS is the Picture Exchange Communication System, a language training package, used to teach communication skills rapidly to those with limited functional speech. PECS promotes communication within a social context, and there is no lengthy prerequisite training. Training in PECS begins by teaching a spontaneous request, and goes on to teach additional communicative functions such as responding to questions and commenting. An added attraction for preschool children with autism and related disabilities is the high proportion of children who acquire independent speech. Some of our children with Cri du Chat Syndrome are using the PECS program with much success. Please keep in mind that this is just one of many different programs that are available to you with regard to speech and language.

Pyramid Educational Consultants, Inc. Services provides workshops and trainings for PECS. Remaining training workshops for 2003 are as follows:

July 14 -15, 2003 - Indianapolis, Indiana
July 21-22, 2003 - Hartford, Connecticut
July 24-25, 2003 Salt Lake City, Utah
July 24-25, 2003 - Rosemont, Illinois
August 5-6, 2003 - San Diego, California
August 11-12, 2003 - Romulus/Detroit, Michigan
August 21-22, 2003 - Bloomington, Minnesota
August 21-22, 2003 - Norfolk, Virginia
September 22-23 - Essington, Pennsylvania
September 22-23 - San Francisco, California
September 29-30, 2003 - Dedham, Massachusetts
October 6-7, 2003 - Oklahoma City, Oklahoma
October 27-28, 2003 - Eau Claire, Wisconsin
November 17-18, 2003 - St. Louis, Missouri
December 15-16, 2003 - Towson, Maryland
December 15-16, 2003 - Pittsburgh, Pennsylvania

For more information about PECS please check the web at www.pecs.com.

5p- Society Rocks Memphis T-Shirts

Don't forget to order your T-shirts early this year! Why? We will have two colors to choose from so order early to get what you want. The color choices are: a sporty pink cadillac color or the beautiful aquamarine 57 Chevy! YUP, pink and aqua!! So you choose! You can pre-order your T-shirts on page 8 of the newsletter. Even if you are not attending the conference you can order a T-shirt. Children and Adult sizes will be \$8.00 each. This year infant/toddler sizes will be available at \$5.00 each. Please indicate your color choice and sizes. Pre-orders will be taken until July 1, 2003. T-shirts will be available at the conference, for the same price, however your color choices may be limited.

Grandparents Newsletter

A newsletter just for grandparents is in the process of being completed. If any interested grandparent would like to receive the newsletter, please contact Patricia Strong, by email at odah@clinton.net or by phone at (563) 659-9530. Thanks Pat for putting your time into this endeavor.

At this time it would be appropriate to recognize a few Grandparents who we have loss in the past few months. These grandparents have been active members of the 5p- Society and will be greatly missed. Many of the families for these wonderful people have requested that donations be sent to the Society in their names: Jean Berry (Lora Piepergerdes' mom), Harvey Wilfred (Joyce Harwell's dad), Eilene Sakston (Janine Palma's mom) and Theresa Frayn (Jim Frayn's mom).

FAMILIES SUPPORTING THE SOCIETY

5p- 2004 calendar -- The 2004 Calendar will be available at the Memphis Conference for \$10.00 each. Sponsorships for all twelve months have been received. The 5p- Society wishes to thank new family member Tiffany Frezza from Carrollton, Texas for obtaining the JC Penney Company's printing department for donating the cost of printing the calendars. With the generous donation we should be able to use the contributions received for the calendar to help pay for general costs for the Society, including copying, postage and offices supplies. The 5p- Society would also like to thank Cathy Vaden for organizing this fundraiser, Cisiah Armstrong for initiating the "Calendar" idea, the family of Tiffany Frezza for the layout, design and printing of the calendar. If you have any questions or comments please call Cathy at 210-681-2317 or email at redtwin@satx.rr.com.



The 2nd Mark Sanger/5p- Society Golf Tournament, scheduled for Monday, July 14, 2003, at the Greystone Country Club and Golf Course. The Sanger family is looking for families that would like to "spread awareness of the syndrome" to their golfers and the community by sending in your picture and a little bio about your child for the golf carts. Last year we asked for a \$25.00 fee to accompany your child's picture and story. This year, we will accept any amount to accompany your picture and story (even if you cannot send any monetary donation, we'd gladly accept your picture and bio for the golf carts). Please send all pictures and donations to: Mark Sanger/5p- Golf Tournament, 8 Persimmon Drive, Penfield, NY 14526-2800. Don't be shy!! It's a great way to promote the Society and the Syndrome. For more information go to the website www.marksanger.org or contact Keith or Claudia Sanger at (585) 586-3888. The Sangers would like to thank the families that were able to help with donations for the tournament. The 5p- Society would like to thank the Sangers for all their hard work and determination. We wish you the best of luck and great weather!!

5p- Society Benefit Golf Scramble -- If you can't make it to Rochester, New York in July, how about Louisville, Kentucky in August? Chris and Hope Orwick are putting together their first fundraiser for the 5p- Society. The event will take place on August 2, 2003 at the Shawnee Golf Course with a 8:00 AM shotgun start. Chris and Hope are parents of 2 1/2 year old Lindsey. For more information about this event please contact Chris Orwick at (502) 368-2905.

5p- Society Softball Tournament -- Ray and GERALYN Maurer of West Bend, Wisconsin are planning a Softball Tournament in September. The tournament is still in the planning stages. Ray and GERALYN are parents of 5-year-old Anna. If you would like more information about the Softball Tournament please contact Ray and GERALYN at (262)338-3745.

5p- Society Annual Quilt Raffle -- Each year at the Annual Conference and Get Together a beautiful and unique quilt is raffled off. Tickets to acquire such a beautiful and unique quilt are \$1.00 each. What makes the quilt so unique? We are fortunate to have a wonderful volunteer parent, Carolina Kretschmar, who brings to each conference a box full of markers and fabric squares. She summons as many kids with Cri du Chat Syndrome as she can (parent's permission of course) and lets each child "draw" whatever he or she wants on one of the squares. After she has collected all the mini Picasso pictures from the conference, she takes them home and with the assistance of her sister, puts the squares together with colorful material to make the quilt. That newly designed quilt is then raffled off at the next year's conference. In Memphis, we will be raffling off our 6th Quilt made from the kids at the Salt Lake City Conference. If you are interested in purchasing quilt raffle tickets, please contact the 5p- Society office at (888)970-0777 or by email at LC5PMINUSSOCIETY@aol.com. The winning ticket will be chosen at the Family Dance. We'd like to thank Carolina and her sister for all their hard work.

5p- Society 2nd Annual Sunset Dinner Cruise -- Todd and Andrea Winslow of Sacramento, California will be having this 2nd Annual Event for their daughter Hailey. The event will take place in Sausalito, California, on Saturday, August 9, 2003 at 5:00 PM. For a \$100 donation guests will cruise aboard the magnificent Avalon through Bay and Delta Charters. Guests will dine aboard the 70 foot yacht complete with living room, dining room, 4 state rooms and a cash bar. If anyone is interested in attending this event, please contact Todd or Andrea at (916)524-3535 or (916)396-1907. Seating is limited.

Christmas in August -- This year the 5p- Society will be offering Holiday Ornaments as a fundraiser. These dated ornaments will be a blue glass ball ornament with the 5p- Society logo and the greeting of "Happy Holidays to you and your family." These ornaments will be available for \$10.00 and we will have them at the Memphis conference. The ornaments will make a great gift for your child's teachers, therapists, family and friends. The Society will receive approximately \$5.00 for each ornament sold. If you are not attending the conference but would be interested in assisting in this fundraiser please contact Renee Eickmeier, our coordinator, for information on ordering and shipping at (636)227-9811. Thank you Renee.

Parent Report - College Girl

by Lori Passerelli, mom to 20-year-old Briana



My youngest daughter Briana is twenty years old. When she was fifteen, the director of the Orange County school program approached me and asked if I would like Bri to attend one of the two community colleges in the county offering an intense vocational program for people with developmental disabilities. I was, to say the least, elated at the prospect. Briana, she said, would be a prime candidate because of her strong family support, her sociable personality and because of her ability to achieve up to her potential. This was quite an honor and compliment to Briana. It is a small program and she is not high functioning yet they chose her! That night at home I told Briana how proud I was of her!

For the next few years she was primed for the class. One obstacle was her inability to make it to the toilet on time and her general lackadaisical attitude about whether she did or not. This would not be acceptable at college we were warned. Since she was three years old I had been trying to get her to use the toilet. Suddenly the ball was in her court. She was told, "If you want to go to

college, use the toilet!" To my amazement she began to try harder. She wanted to go to college. Her face beamed with pride at every mention of it.

From afar Briana looks like any other student on a college campus. Her pre-maturely gray hair is dyed dark burgundy and cut in shag, she is clad in dark gray 'dickeys' and a t-shirt with a retro Snoopy carrying a surfboard over his head. She is laughing with a group of kids. The crowd disperses and suddenly she stands out like a sore thumb. It is her gait and shuffle that first gives her away. Then her long arms reach out to touch anyone that passes by. She is a student here and everyone knows her. She makes sure of it.

She began the program about a year and a half ago. During the transition she began wetting again. I worried that her teacher, Christa, would dismiss her from the class permanently. We spoke on the phone a lot. I was relieved to find Christa to be a relaxed and flexible teacher. Within a few weeks Briana began using the toilet again. She settled into the class and everyone accepted her as a classmate. Soon everyone was calling her by her pet name, 'Breezy'. Her class is composed of seven students of varying disabilities. Briana is academically below them all. She has trouble keeping her hands to herself. We are working very hard both at home and school to teach her not to touch people. A personal aide has been assigned to her. Presently a young man barely out of college himself, Rob, alternates with Dolores a middle-aged woman Briana adores both of them.

The classroom is situated in the middle of the campus. Briana gets off the bus with another student whom along with other problems is blind. The two of them amble together to their class, Briana saying "hello" to everyone that passes by. The morning consists of reading, writing and arithmetic according to one's ability. The computer is used a lot. Then it's off to work via the citywide bus. Vocational exploration is emphasized. It is hoped that Briana will have some say in her future employment after graduating. As a result she is being trained in several different jobs. Mondays, it's off to the Laundromat where she helps with sorting, measuring detergent, turning dials, pushing buttons and folding. Tuesdays, she becomes a real asset to the community as a volunteer with the 'Adopt A Beach' organization. After cleaning up the beach, it's a fun walk on the pier and a trip to a restaurant for lunch. Briana is encouraged to order and pay for her own lunch. Wednesday she works at the Huntington Beach library, stamping books and assisting with other tasks as needed. Thursdays she works at a restaurant folding napkins. Fridays is fun day. The class does various activities such as bowling, golfing, going to the mall, etc. followed by lunch at a fast food restaurant.

Briana has her own student I.D. card and attends many events on campus with the regular ed college students such as assemblies, rallies, entertainment and picnics. Christa gets them involved whenever something is going on. Tuesdays and Thursdays Briana has PE. Currently she goes to the weight room where she and her fellow college pals lift weights and run on the treadmill.

Twenty years ago, I would have looked cross-eyed at a person had they suggested Briana would one day attend college. But that is exactly what she has been doing for the past year and a half and my eyes are looking straight into a promising future for her. She is a person whom despite many obstacles and difficulties has shown us what true success looks like. My husband Chris and I are enormously proud of our daughter, Briana, whose name means 'strong' appropriately so.

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**2003 North American Annual Conference
and Get-Together - August 7-10th - Memphis**

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)

\$30.00 for each additional adult _____

\$15.00 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 (\$10.00) ___ cribs ___ refrigerators (\$10.00 per stay)

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

2003 Conference Registration
5p- Society
PO Box 268
Lakewood, CA 90714-0268

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

2003 Conference Registration Enclosed

Return Service Requested

P.O. Box 268
Lakewood, CA 90714



T-Shirt Order form

The design's a surprise, but we do know they will be offered in two colors "Cadillac Pink" and "57 Chevy Aquamarine." Please choose your color and size and return to the 5p- Society, PO Box 268, Lakewood, CA 90714, as soon as possible. **Must be returned by July 1, 2003 to guarantee size and color.**

<table border="0"> <tr> <th style="text-align: left;">Infant/Toddler Size</th> <th colspan="2" style="text-align: center;">Quantity</th> </tr> <tr> <td></td> <th style="text-align: center;">Pink</th> <th style="text-align: center;">Blue</th> </tr> </table>	Infant/Toddler Size	Quantity			Pink	Blue	<table border="0"> <tr> <th style="text-align: left;">Child Size</th> <th colspan="2" style="text-align: center;">Quantity</th> </tr> <tr> <td></td> <th style="text-align: center;">Pink</th> <th style="text-align: center;">Aqua</th> </tr> </table>	Child Size	Quantity			Pink	Aqua	Name: _____ Address: _____ _____ Phone: _____
Infant/Toddler Size	Quantity													
	Pink	Blue												
Child Size	Quantity													
	Pink	Aqua												
0-3 mo	___	___	2-4 (small)	___	___									
3-6 mo	___	___	6-8 (med)	___	___									
6-12 mo	___	___	10-12 (lrg)	___	___									
18 mo	___	___	14-16 (xlrg)	___	___									
24 mo	___	___												

Adult Size	Quantity	
	Pink	Aqua
small	___	___
medium	___	___
large	___	___
x-large	___	___
xx-large	___	___

Total Infant/toddler ordered _____ x \$5.00 USD = _____
 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 shipping.