



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

March, 2003

President's Message

by Greg Abbruzzese

Society Members:

As we are getting closer to the Memphis conference we are poised to have a very successful couple of days in Memphis! Dennis Campbell and Todd Piepergerdes have provided us with a tentative schedule of events which we hope to be posted on the web site for your review. There will be a welcoming reception on Thursday evening to welcome everyone and new families. Based on the suggestions and feedback from previous conferences, Dennis, Todd, and the Board have tried to incorporate breakout sessions that address a broader spectrum of the needs of both the parents and the children. Such breakout sessions will include: transitional living, jobs programs, sibling workshops, parent panels, augmentative communication, medication, puberty, etc. We are very excited about the full range of topics that will be discussed, especially in this condensed timeframe. Nevertheless, if you miss a session, or are unable to attend the conference all together, we are looking to provide the hand-out and contact information on the Society's web site that you will be able to download.

As we are once again poised to take the Society to the next level, fundraising is a key component to help bring awareness of the syndrome to the public, as well as to be able to offer assistance to families searching for answers. Renee Eickmeier and her husband have put together a wonderful CD Rom/VHS fundraising tool which outlines what the syndrome is and the goals of the Society. This tool should

be available at the Memphis conference should you like to view it and potentially use it for solicitations. Some additional elements of fundraising that have been highly successful for the Society are: the employee matching program, the Sanger's golf tournament in Rochester, NY, Dennis Campbell's solicitation of the Ronald McDonald House, the Winslow's Dinner Cruise, our calendar, etc. We are always on the lookout for potential grant opportunities or suggestions on how to help improve our efforts. With the help of these fundraising efforts, we are able to offer family assistance to help defray the costs of attending the conference. We have allocated \$2,500 against conference fees and hotel costs for families who apply. Unfortunately, the Board received no inquiries for assistance. Please contact any member of the Board if you would like to apply for assistance.

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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- Rocks Memphis

Time is fast approaching for the 5p- Society to Rock Memphis!! We are looking forward to a really great time and lots of wonderful information. We have lined up superb speakers on topics that cover the lifespan. Of course, no one will tell you what sessions you can and can't attend. We have broken them into age ranges to help you choose. This is one time when you will want to gather as much information as possible, so it is a wise decision for couples to divide and go to different sessions.

We are kicking off the festivities earlier Thursday so you will want to plan to arrive in Memphis in the afternoon, check-in is 3:00 p.m.. The registration and reception begin at 5:00. The reception is new this year. We are planning heavy hors d'oeuvres to help defray the expense of food to our families, and of course everything will be "kid friendly" and casual.

First time families will definitely want to take advantage of the New Family Orientation on Thursday evening. This year we have planned many sibling activities to help them enjoy the weekend. Sibs will want to take time out on Thursday evening for their own mixer. After all, this is a "family" conference.

Friday morning the Siblings will head off to Jillian's downtown in Peabody Place for a morning of bowling. Our sessions will begin with the annual Cri-du-Chat general information on the syndrome, "CDC 101"; Problem Behaviors and Supported Living. There will be other breakouts until lunch including a Grandparent Workshop.

Friday afternoon will be the "Family Outing" with a twist as this year we will have a "Family Inning"! That's right, we will stay in the beautiful Adam's Mark and have a Carnival of Fun for all ages, ending with a great Magic Show provided by Shelby Bryant's Uncle Rocky and Aunt Lori! Your whole family will enjoy the Smoke and Mirrors Magic Extravaganza! That will end the planned activities for the day and you are free to explore Memphis or just hang out in the Hospitality Suite or at the pool.

Saturday will start early with more breakout sessions through the afternoon. Take it all in but don't get too tired because you surely won't want to miss the Annual Banquet and Family Dance! It will take you back to earlier times...when things weren't so rushed...to a sock hop!! Feel free to dress the part and make the most of this party!! The children really enjoy this evening and it promises to be a really big hit!! Did someone say Elvis was in the room??

The Adam's Mark is a beautiful hotel in a lovely area of town. They have met Amy and Shelby and are eager to meet ya!!! They have been very accomodating to us and we feel certain that their hospitality will continue. The city of Memphis has a lot to offer in case you are planning a vacation around the conference. So, as you can see, plans are well on the way now and we are ready to show you a great time as the 5p- Society Rocks Memphis!! Ya'll join us as we show you the true meaning of "Southern Hospitality".

- Your Host Families,
- Jim and Deanna Bryant
- Dennis and Shari Campbell
- Todd and Lora Piepergerdes
- Ken and Heather Robison



President's Message Continued . . .

Our Philadelphia meetings went very smoothly and we are anxiously awaiting the final hotel arrangements and calendar of regional activities for the children. Thanks Holly! Furthermore, the Memphis template looks like it will help enhance what we are trying to accomplish in both Philadelphia next year and St. Louis for 2005! Good Luck Renee!!!

Finally, the Board of Directors would like to extend a special thanks to Cisiah Armstrong for all of her dedication and support with the Board and the Society over the years. Her efforts in making the Cincinnati conference run smoothly, the groundwork that she established with the Professional Advisory Board, her design and execution of our inaugural fundraising calendar, coupled with commitment as Conference Coordinator has raised the level of the Society as a whole. Cisiah is stepping down as a Board member, however will remain active in the Society. We owe her a great sense of gratitude!

Please call/e-mail me with any suggestions or concerns that you may have.

5p- Rocks *Memphis* - 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.

Samera Baird, PhD is a Professor of Special Education at Auburn University and Director of Project ECLIPPS. ECLIPPS stands for Early Childhood Low Incidence Personnel Preparation System. She is a licensed speech language pathologist. Her expertise is in infant-parent interaction. Dr. Baird has been involved with the 5p Minus Society for many years and serves on our Professional Advisory Board.

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.

Sandy Cooley, OTR/L is an Occupational Therapist for the Auburn City and Lee County School Systems. She has presented workshops on addressing sensory issues in the regular education classroom and is Mother to Hannah.

Cari Dunn, PhD is an Associate Professor in Special Education at Auburn University in Auburn, AL. Dr. Dunn's area of expertise is transition from school to work and community. Auburn University is a nationally recognized leader in the area of transition. She serves as the advisor to the "Best Buddies Program".

Carol Greenwald, PhD has her background in Early Childhood Special Education. Dr. Greenwald was most recently at the Boling Center for Developmental Disabilities which is the University Affiliated Program for the State of Tennessee. She and her son will share their story with us.

John Halloran is a licensed speech pathologist and represents the Prentke Romich Co. He is an expert in augmentative communication systems and comes to us from Little Rock, AR.

Rebecca Ingram, PhD is currently the Coordinator of Option I, Project ECLIPPS which offers online instruction in early intervention at Auburn University in Auburn, AL. Dr. Ingram is a speech language pathologist and has participated in research projects on young children with Cri-du-Chat. She received her PhD in Early Childhood Special Education at Auburn University.

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.

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.

Jane Sneed, MD is a pediatrician that has worked with many children with developmental disabilities including cri-du-chat. Dr. Sneed has her practice in Jonesboro, AR.

Geoff Towers, MD is a practicing gynecologist and parent to Taylor. Dr. Towers has agreed to speak to us on the inevitable body changes that will occur. He did an awesome presentation last year and we are grateful that he will be presenting again.

5p- Rocks *Memphis* - Proposed Schedule of Events

Thursday, August 7, 2003

Evening

- 5:00 – 10:00 **Registration** Begins — As soon as registration is complete, you may go to the **Opening Reception**. Heavy hors d'oeuvres will be served during this time to save families from having to find a meal when they get in. The evening will be informal and “Kid Friendly”.
- 7:00 – 8:30 **New Family Orientation** — Learn how to get the most out of the weekend.
- 7:00 – 8:30 **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”.
- 7:00 – 11:00 **Hospitality Suite** will be open for socializing.

Friday, August 8, 2003

Morning

- 7:00 **Continental Breakfast**
- 7:30 **Childcare opens**
- 8:00 – 8:30 **Opening Session**
- 8:30 – 10:00 **Sibling Outing** — Siblings gather and leave by bus for a morning of bowling at Jillian's which is located in Peabody Place, downtown Memphis. They will return for lunch.
- 8:30 – 10:00 **Breakout Sessions**
- | | <i>Infant/Toddler</i> | <i>Grade School</i> | <i>High School/Adult</i> |
|---------------|--|---------------------------------------|--|
| | CDC 101 | Problem Behaviors | Supported Living |
| 10:15 – 12:15 | Maximizing Your Infant & Toddler's Potential | Basics of Sensory Integration Therapy | What Every Family Needs to Know About Supported Employment |
- 10:15 – 12:15 **Grandparent Session** — This is special time for Grandparents to share their stories and discuss issues that pertain to them.
- Afternoon and Evening
- 12:30 – 1:30 **Lunch Family “Inning”**
- 1:30 – 3:00 **Carnival**
- 3:00 – 4:00 **Smoke and Mirrors Magic Extravaganza!!** You won't believe your eyes!!
- Dinner on your Own** — Enjoy Memphis!! Sights and Dining packet will be available.
- 7:00 – 11:00 **Hospitality Suite** will be open.

Saturday, August 9, 2003

Morning

- 7:00 **Continental Breakfast**
- 7:30 **Childcare opens**
- 8:00 – 9:00 **Opening Session**
- 8:00 – 12:30 **Sibshop**
- 9:15 – 11:00 **Parent Panels** — We will break into 3 groups; Infant/Preschool (Birth to 5), Elementary/Jr. High and High School/Adult.
- 11:15 – 12:30 **Breakout Sessions**
- | | Sensory Integration & Brainstorming | Augmentative Communication | Commonly Used Medications |
|--------------|--|----------------------------|--|
| 12:30 – 2:00 | Lunch on your own | | |
| | Afternoon and Evening | | |
| 2:00 – 3:30 | Including Our Kids in General Education Curriculum | Puberty and Adolescence | Transition from School to Work & Community |
- 5:00 **Cash Bar, Reception and Photos** (bring your camera!)
- 6:00 **Banquet and Family Dance**
- 8:00 – 11:00 **Hospitality Suite** Open

Sunday, August 10, 2003

Morning

- 9:00 – 11:00 **General Question and Answer**, what did you forget to ask??

Other News

The 5p- Society is the recipient of a \$10,000.00 grant awarded by Ronald McDonald Charties. The grant is to be used to offset 2003 conference costs. A **BIG BIG** thank you to Dale Huffman (Shari Campbell's dad) and to Herb Lotman of Keystone Foods, Inc. for helping us submit for and fine tune the grant to meet the needs of both Ronald McDonald's criteria and still meet the needs of the Society.

Many thanks to Pat Strong, of Iowa, for her commitment to the Society and for the Discovery Toys online fundraiser that she did for Christmas. The 5p- Society has received \$200.00 for this fundraiser.

The **5p- 2004 calendar** is in the works. We would like to have it available at the Memphis Conference but we need your help to make it happen. The 2004 calendar will feature a different collage of our children for each month. We would like pictures that may lend themselves toward different seasons, but any candids will have a place. Sponsors are still needed for various months. Although each month will picture many children there will be a special thank you on each page to the family that made it possible. We are trying this format so more families can be involved so please send your pictures to Cathy Vaden, 8606 Timber Bush, San Antonio, TX 78250. 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 is scheduled for Monday, July 14, 2003. For more information go to the website www.marksanger.org or contact Keith or Claudia Sanger at (585) 586-3888. The Sangers are looking for interested families that can assist with obtaining donations for the door prizes and auction items. If you work for a company that can donate a substantial item (i.e. winery, clothing company, sporting goods company, national chain restaurant, or hotel company) please contact the Sangers right away.

Financial Assistance Program for Memphis

Once again, the 5p- Society will be offering five (5) 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- Rocks Memphis 2003 Annual Conference.

(1) Fill out the Registration form on page 7 and return that to the 5p- Society office.

(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 7th through 10th**. 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 fifteen minutes away from the Memphis International Airport and they do provide complimentary shuttle to and from the airport. Please note that the shuttles are not wheelchair accessible. The address of the Adam's Mark is 939 Ridge Lake Blvd., Memphis, TN 38120.

Please let the hotel know if you need a refrigerator, 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 2003. 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, 2003. After that the room rates will be honored on a space-availability basis.

5p- 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.

This issue of the **5P- NEWS** is brought to you courtesy of a \$1000.00 donation by Chun-yi Chen and Ming-Hsing Tsou of San Diego, California. Thank you!!!

Parent Report - Summer Camp

by Joan Steele parent of 19-year-old Kevin Steele



Kevin's favorite thing to do all year is go to camp. We live in southern Illinois in a university town. Fifty years ago, Camp Little Giant was started through Southern Illinois University. It is an accredited residential summer camp for people with various abilities and disabilities. Kevin enjoys swimming at the beach, boating, campfires, music, sports and games, horseback riding, and special events the most. There are other activities such as arts and crafts, drama, nature study and all the usual summer camp things. An excellent director was hired three years ago, and the quality of the experience has definitely improved. Most camps are six days, but Kevin wanted to stay for 12 days last year. We were somewhat surprised as that is the only time he has been away from us. He had previously been to camp the two years prior for the six day sessions and really loved it. I was involved in staff orientation last summer and was so impressed by the quality of staff. I had a difficult time getting Kevin to come home when camp was over. He had taken on a new persona—Batman. The good-byes from other campers and staff lasted an hour. I can't say enough good things about this experience for

Kevin. In the past, he has had very limited social experiences. The only time he went places was when his family was with him. This experience gave him more self-confidence, fun, and friendships than anything we could have done.

I would be happy to talk to anyone who is interested in the camp about Kevin's experience. The camp has sessions for people ages 8-21 and ages 21 and over. Nursing staff is on duty 24 hours a day. My email is jsteele@accessus.net and you can find me in the family listing. For information on Camp Little Giant contact Randy Osborn, SIUC Touch of Nature Environmental Center, Mailcode 6888, Carbondale IL 62901-6888. The phone number is (618) 453-1121 ext. 231. Email: randyo@pso.siu.edu

The website at <http://www.tonec.siu.edu/> gives a lot of information about the camp. Click on Camp Little Giant.

Joan Steele

Editor's Note: If you know of camps in your area please contact the 5p- Society. I know they fill up fast. It would be great to have a resource for families to share in this great experience that Kevin has enjoyed.

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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 ___ cribs (\$15.00 per stay) ___ refrigerators (\$25.00 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.

Infant/Toddler Size	Quantity		Child Size	Quantity	
	Pink	Blue		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.