



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

September 2003

President's Message

by Greg Abbruzzese

Dear 5P Minus Society Members,

We all owe a special thanks and gratitude to Todd and Lora Piepergerdes, Ken and Heather Robison, Jim and Deanna Bryant and Shari and Dennis Campbell for hosting such a wonderful conference in Memphis. My phone is constantly ringing and my e-mail is burning with praise because of this year's event! These families did an exceptional job providing childcare, entertainment, receptions, and good 'ol southern hospitality! In addition to the host families, I would like to extend a special "thanks" to Laura Castillo, who, once again, ran a very professional and family friendly conference. Without her tremendous organizational skills, the conference would have run far less smoothly.

Some specific highlights of this year's event were the "in-ing", with the magic show and carnival games. These events were run through the host families and local volunteers. Most of these events were underwritten by tremendous local fundraising efforts of the host families. In addition, the closing reception and dance proved to be equally successful! There were plenty of poodle skirts, Elvis impersonators, along with dance lessons from Todd Piepergerdes. Watching the children (and adults) dance to the YMCA, Chicken Dance, Bunny Hop, and Hokey-Pokey, was truly a sight that would have made Elvis proud!

As is from every conference, we learned a great deal more from the speakers, parents, peers, and of course, our children. This year's conference proved to be no exception. The Memphis conference covered a wide range of topics for varying aged 5p- children/adults. Topics included: "Sensory Integration", "Early Intervention", "Special Needs Advocacy Groups", "Augmentative Communication", "Employment", "Supportive Living" and "Parent Sessions" just to name a few.

Thanks again go out to Renee and Joe Eickmeier for the wonderful CD Roms that they provided as a fundraising tool (also available to any members who think it would help with any regional fundraising for the Society). In addition, McDonald's Grant secured by the Huffman's, the FoxCor

continue on page 6

In this Issue . . .

- **Annual Conference**
 - 2003 Memphis Wrap Up.2
 - 2004 Philly Style7
- **Parent Report**
 - Conference Follow up3
 - Nutrition4
- **Other News**
 - Parents Helping Parents 3
 - 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.

President Greg Abbruzzese Executive Director Laura Castillo
5P- Society, P.O. Box 268, Lakewood, CA 90714 (562) 804-4506 (888) 970-0777; Fax (562) 920-5240; www.fivepminus.org or www.criduchat.org
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 - Wrap Up

It's official -- we have awesome families in this organization. The Memphis Rocks conference was our second biggest, only a few families shy of the Chicago Conference. Your host families had one big goal in mind and that was true Southern Hospitality and they definitely succeeded. All families involved in the preparation and overseeing of the conference did a "beyond the call of duty" performance. Did you know that none of the host families were from Tennessee? They were from Arkansas, Mississippi and Alabama utilizing Memphis as a central location. It worked!!

In order to have many of the events that the host families wanted they needed to do a lot of fundraising and that they did -- receiving a \$10,000.00 grant from Ronald McDonald Charities -- with the support of Dale and JoAnn Huffman, Dennis and Shari Campbell and Herb Lotman of Keystone Foods. A \$5,000.00 donation was received from FoxCor with the assistance of Todd and Lora Piepergerdes. They also received an additional \$2,000.00 from Rhodes, Lauck and Associates solicited by Jim & Deanna Bryant that was used specifically to assist in speaker expenses for the conference. The Bryant's also received an additional \$1,500.00 in memory of Deanna's father, James Blalock.

Wow, that's a lot of money and you are probably wondering what it was used for -- let me tell you. On Thursday evening members attended a welcome reception -- \$1500.00 was designated for finger foods. The reception also included background music by the Southern Strings that included the children of Jamie and Natalie Gunnells of Ripley, Mississippi. When the reception came to an end, families were able to visit the hospitality suite where Lora Piepergerdes' sister donated a lot of food from Harry & David Gourmet Foods and the extended family members of Jim and Deanna Bryant made a lot of homemade goodies for us to munch on. Some of the beverages were donated by Pepsi, Inc. and D. Canale.

On Friday, Saturday and Sunday morning, there was a "continental" type breakfast for the members -- approximately \$3,000.00. On Friday afternoon the host family members decided to keep the families at the hotel for our "outing" and provided lunch comprised of BBQ Pork sandwiches, chips, and lemonade and ice tea. After lunch the families organized a "Carnival" complete with games and prizes. A fantastic Magic Show, donated by a relative of the Bryant's rounded out the event. This Friday event cost approximately \$11,000.00. Other expenses include \$2000.00 for additional food/beverage for and rental of the hospitality suite, \$600 for audio visual expenses and \$300 for volunteer lunch. You may be wondering about the Saturday evening banquet (\$11,500). That is covered with your registration fees (\$12,800). Other items that your registration fees cover are reproduction costs, and general expenses of the conference (name badge production, etc.)

Now that you see how much money it costs to run a successful conference, you can understand how important it is to the Society to have such awesome families involved. The fundraisers that families do for us keep the organization going so we can bring you these well attended, well organized events.

Let's get to the actual conference. On Thursday evening as mentioned earlier we had a Welcome Reception. Families were able to meet each other and listen to the sounds of the Southern Strings. After the reception, new families met and were given brief introduction to the conference by our founder Kent Nicholls. Siblings were able to meet and play "getting to know you" type games in a separate meeting room. Thanks goes to Joey Castillo and Derek Ward for leading the siblings through these games. This is the second year that we have had the mixer and it is a great opportunity for the kids to meet and find a friend or friends for the rest of the conference -- and possibly find lifelong friends.

Friday began with Jolene Towers singing a beautiful song and a slide presentation. Breakout sessions included the Basics of Cri-du-Chat Syndrome (Dennis Campbell, Ph.D.), an overcrowded and well received Problem Behavior's presentation (see parent report for more information) (AmySue Reilly, Ph.D.) and a talk for our families with adults with Cri du Chat syndrome on Supported Employment. (Dr. Carol Greenwald and her son Keith). Next session included Maximizing your Infant and Toddler's Potential (Dr. Caroline Gomez and Dr. Rebecca Ingram), our ever popular Basics of Sensory Integration Therapy (Jennifer Rosinia) and a well received presentation regarding Supported Living (Brian Dion).

Approximately 50 siblings went bowling at Jillian's located at Peabody Place. Jillian's donated the bowling for the group and the hotel donated the bus to transport the kids. The Hospitality suite was overflowing with Grandparents for their annual supportshop (Dale & JoAnn Huffman, Virginia Bryant and Alice Blalock, facilitators).

On Saturday, the group broke out into age appropriate parent panels -- an informal gathering of the parents to talk about issues that are important to them. Following the parent panel sessions the group broke into the following: Commonly Used Medications (Mary Esther Carlin, MD), Sensory Integration and Brainstorming (Jennifer Rosinia), Augmentative communication devices (John Halloran, Prentke Romich) with the assistance of two of our kids, Tyler Piepergerdes and Amy Campbell. After a well deserved lunch break, our last session of the conference included a presentation on Inclusion (Sandy Cooley, Dr. Campbell, et al), Puberty and Adolescence (Dr. Geoff Towers and Dr. Jane Sneed) and also, Transition from School to Work (Dr. Carri Dunn). In the morning our Siblings attended a workshop with their new friends (Carolyn Graff, facilitator).

Shari Campbell put together a notebook of some of the slides from the different presenters. If anyone is interested in obtaining a copy of the notes, please send \$5.00 to the Society and the office will copy and send the notebook to you.

The pool was the happening place both on Friday and Saturday where the families were able to continue to gather and discuss their kids accomplishments -- I think children with Cri du Chat Syndrome are fish, they sure like to swim. Lots of networking, lots of sharing of information, lots of preparation and a lot of fun.

As you can imagine with 175 kids in attendance, 80 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. Many thanks also goes out to those who put so much time and effort into the preparation of this successful event -- your host families -- Jim & Deanna Bryant, Dennis & Shari Campbell, Todd & Lora Piepergerdes and Ken & Heather Robison.

--Laura Castillo

Parent Report

Conference follow-up

by: Jennifer Barrow - Mom of 6-year-old Valerie

I attended Amy Sue Reilly's, Ph.D. seminar on Implementing Effective Positive Behavior Strategies. She began by laying the foundation of the rights of children, including the principles of respect, normalization, and fairness. Her thoughts that made a difference for how I would change my behavior strategies is giving the children controlled choices or win-win choices. For example, "It is time to take a bath, would you like bubbles or no bubbles". She also emphasized practicing patience. If you do not get the response you want from your child, wait three minutes, and try again. Sometimes by making a small change, for example, by removing the word "OK?" from the end of "It is time to get in the car, OK?" you can get the response you want. It is important to be prepared, with rewards or reinforcers for good behavior and allow sufficient time to get the desired behavior. If the desired behavior has not been achieved in ten days, then the strategy must change. A Positive Intervention Behavior Plan can be included in our child's Individual Education Plan. Included should be a baseline of 3-10 days of the child's particular behavior and determine instructional objectives for behavior change program. By working with a behavior specialist at your school and using a positive behavioral support and functional analysis the teachers and parents will be able to understand why the challenging behavior occurred and its function or purpose for the child.

It has been requested to bring Dr. Reilly back next year to Philadelphia, the host families are looking into bringing her back

Parents Helping Parents

Are there any families in our organization that have set up and run a group home for their adult with Cri-du-Chat Syndrome? Please contact the 5p- Society. We have several families interested in doing this and they would like to talk to other families or find resources to assist them with this issue. Thank you.

Are there any families in our organization who would like to adopt a child with Cri-du-Chat syndrome? Periodically we do get requests from agencies that would like to know if we have a resource or active list of parents who are interested in adopting. If you are interested please contact New Horizon's for more information. Please call Marlys at (800) 314-3370.

At this year's annual conference many families who attended the Assistive Technology presentation were inquiring as to where to start looking for a device or assessing what device would be best for a particular child. There is a website that can help with this information. It is <http://atto.buffalo.edu/>. If you have difficulty with this website or need additional information, please contact Cathy Vaden at (210) 681-2317 or redtwin@satx.rr.com.

Would any families living in the Florida area be interested in hosting the director of the Cri du Chat Syndrome organization from Denmark? She is planning a trip to check on Dolphin Therapy with her son and would love to visit a family from the States. Please contact the 5p- Society office if you are interested and I will pass your information on to her.

Parent Report

Think Quality - Not Quantity for Nutrition

by Susan Donnelly - Mom of one-year-old Hannah
scd1709@aol.com

The Problem

My daughter with CDCS turned one year old in May of 2003. I was helplessly watching her go backwards in her development. Her eating was deteriorating. She could no longer roll and her back arching went from occasionally to all the time during the day.

In January of 2003, Hannah had been able to take a five-ounce bottle at one time four times a day so we began concentrating more on spoon feedings. Under the care of a GI Specialist, we were giving Hannah three different stomach medicines to help her reduce the spitting up that she had had since she was born. As June approached, Hannah could barely take two ounces before either spitting up or vomiting. I called the doctors often to let them know the problems we were having. Many times I was told "On paper, Hannah is following her own growth cart. She is doing fine." In my heart, I could see she was not doing fine. Things were going downhill quickly. I was losing Hannah.

The Solution

In the beginning of July, Hannah's nutritionist met me at a natural food store. We suspected that Hannah might have a soy allergy as she was taking Prosobee baby formula. The nutritionist offered me four different options to try. The last one finally worked! I now make my own formula each morning. Her formula each day consists of 9 ounces of Enriched Vanilla RiceDream, one heaping tablespoon of NutriBiotic Rice Protein and a cooked egg yolk. She also has three to four spoon feedings each day. I then tube some olive oil for additional fat and half a children's vitamin.

The change was dramatic. She began laughing and cooing again, rolling all over the floor, sitting balance improved dramatically, she began to grow hair, a wound on her arm finally began to heal, she made eye contact again, she wanted to eat and was eating more by mouth, etc. She began displaying a new skill every day. I was thrilled with all the changes as well as the therapists, doctors and friends.

Learned Lesson with a Global Solution

The lesson I learned, regardless of Hannah's food allergies, is I wish I had improved the quality of Hannah's food since the day she was born. I would have put protein supplements in Hannah's formula as well as giving her vitamins and additional fat. That way she would have received more nutrition in less time. Before the formula change, I struggled to feed her all day with the requirements that babies need every day. I was worn out every day trying but only meeting bare minimum requirements with only 15-20 ounces of baby formula. I was ready to force the doctor to perform a fundoplication (which was a whole other bag of problems as noted by the surgeon). Surgery is not what Hannah needed. She needed more quality food rather than quantity. Some CDCS children may still need the fundoplication surgery but for other reasons.

The global lesson I think we need to learn is:

- 1) Do not rush and perform a fundoplication - but get a feeding tube;
- 2) We need to rethink how we feed CDCS children or any child who is a poor eater. Don't force them to take large amounts of a gastric intake.
- 3) Let the child be in charge of when they are hungry or full, but give them what they need in smaller quantities.

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.

Families Supporting the Society

5p- 2004 calendar -- The 2004 Calendar is now available. You can get your copy of the calendar by sending a \$10.00 donation per calendar to the 5p- Society. Again we would like to thank Nicholas and Tiffany Frezza, JC Penney Printing Department, Cathy Vaden and Cisiah Armstrong for their continued commitment to the 5p- Society in bringing the calendar to you.

The 2nd Mark Sanger/5p- Society Golf Tournament -- A great time was had by all who attended the Golf Tournament. Keith and Claudia Sanger and their friends and relatives did it again with a very successful event. The 5p- Society has received a check in the amount of \$11,000.00 as proceeds from the Tournament. We are so fortunate to have such a fantastic family in this organization -- Thank you Keith and Claudia.

5p- Society Benefit Golf Scramble -- Louisville, Kentucky was the site of the Golf Scramble hosted by Chris and Hope Orwick. A very successful event for their first fundraiser. The Orwick's presented the 5p- Society with a check in the amount of \$3900.00. The Orwick's had such a good time they are already planning next year's event. Thank you very much.



5p- Society Softball Tournament -- Anna Maurer 5p- Society Softball Tournament was held September 5 and 6, 2003. Ray and GERALYN Maurer of West Bend, Wisconsin hosted an Old Timer's Softball Tournament to benefit the 5p- Society. The teams that participated in the tournament had played in a Sunday Softball league during the 1970's and 1980's. Ray was a batboy for his dad's team and developed friendships with some of the players. Most of them no longer play softball on a regular basis but they decided to play for this great cause. It made for some interesting games. The event was very successful. Over \$6,000.00 was raised and will be donated to the 5p- Society. The money will be used for 5 conference scholarships for the 2004 conference, 5 conference scholarships for the 2005 conference as well as host one of the continental breakfasts at the 2004 conference.. If you would like more information on how to have a successful Softball Tournament please contact Ray and GERALYN at (262)338-3745.

5p- Society Annual Quilt Raffle -- A big thank you goes out to Jerry and Carolina Kretschmar for their continued support of the Society. The proceeds from the Annual Quilt Raffle was \$407.00. Carolina also spent most of her time at the conference getting new pictures for the next quilt to be raffled at the 2004 Conference in Philly. Thank's Carolina for all your hard work.

5p- Society 2nd Annual Sunset Dinner Cruise -- Cruising the bay, having dinner and watching the sunset in Sausalito, California while raising money for the 5p- Society -- could it get any better than that? Thank you to Todd and Andrea Winslow for their continue support of the Society and for your successful dinner cruise. The Winslows have presented the Society with \$3853.00 from the event.

Christmas in September -- You are in luck! There are still some of our 2003 holiday ornaments left. These are beautifully made glass ball ornaments that would make perfect gifts for family members, teachers, therapists, bus drivers, respite providers and friends. The ornaments are \$10.00 each and can be ordered by emailing Renee Eickmeier at Reickmeier@sbcglobal.net or calling her directly at (636)227-9811. There will be a nominal shipping fee based on the number of ornaments ordered. This is a great way to support the Society and promote awareness of Cri-Du-Chat Syndrome. A big response to the ornaments was had at the Memphis Conference.

Conference T-Shirts -- Memphis Rocks T-Shirts were in big demand at the Annual Conference and Get-Together. The shirts were printed by TGI Enterprises. A large portion of the T-shirts was donated by TGI Enterprises and Tracey Copeland. Approximately \$2000.00 was raised by selling the shirts. TGI Enterprises has also developed logowear for the 5p- Society. Polo Shirts for men and women, denim shirts with long sleeves, short sleeves or sleeveless, sweatshirts and baseball caps all with the 5p- Society logo on them were being promoted at the 5p- Society's Annual Conference. If you are interested in prices and ordering information please contact the 5p- Society for an order form. New orders will be taken with a November 1, 2003 deadline. Order now in time for Christmas. These items make great gifts and what better way to promote the 5p- Society and create awareness by wearing your official 5p- logowear.

Bracelets -- We are fortunate to have a brand new grandmother to the organization, Gloria Griffin, from Louisville, Kentucky. Gloria does a lot of fundraising for various organizations in and around her area. Coming to her first conference in Memphis, she felt an immediate need to assist us in raising money. She donated several dozen bracelets to the society that were sold at the conference and were in such demand that she donated a couple more dozen for those who requested them. Gloria also held her first fundraising event for the Society in her hometown and raised \$1,200.00. Thank you so much Gloria -- we look forward to your future assistance. I still have a few bracelets left. They are \$7.00 each. Please contact the 5p- Society if you are interested in purchasing one.

continue on page 8

President's Message continued . . .

donation, the two Golf Outings, run by the Sanger and Orwick families, the 5p- Calendar, the 5p- Ornaments, the 5p- Logowear, conference t-shirts donated by Tracy Copeland, Sunset Dinner Cruise, run by the Winslow family, and the proposed "Vegas Night" being held with new 5p- family the Freeza, all help allow the Society to function more effectively and efficiently. Furthermore, the time and efforts of our "Web Master" Todd Winslow should not go unnoticed. We truly are a family within a family and I (we) cannot thank you enough for your selfless efforts to enhance the Society as a whole.

Looking ahead to Philadelphia, clearly we have a lot to live up to, but Holly Gattone and my wife, Laurel, are embracing the challenge. The conference will be held in Philadelphia, PA, from August 5th through the 8th, 2004. My family just came back from the Sesame Place water park (roughly 20 min. away from the Adams Mark hotel where we will be staying), and I can safely say that everyone will enjoy Big Bird's hugs!

See you all in Philadelphia! 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.

Greg

Congratulations to your New 2003-2004 Board of Directors

President	Greg Abbruzzese	(New Jersey)
Vice President	Jolene Towers	(Washington)
Secretary	Renee Eickmeier	(Missouri)
Treasurer	Eileen Sherman	(Illinois)
At Large	Paul Arango	(Florida)
	Laura Bruns	(Ohio)
	Sandra Cooley	(Alabama)
	Holly Gattone	(Pennsylvania)
	Kent Nicholls	(Kansas)
	Todd Piepergerdes	(Arkansas)
	Georgia Richey	(Utah)
	Ken Robison	(Mississippi)
	Jean Strong	(Iowa)
	Cathy Vaden	(Texas)

Professional Advisory Board Members

Chairman	Dennis Campbell, Ph.D.	(Arkansas)
	Samera Baird, Ph.D.	(Alabama)
	Elizabeth Dykens, Ph.D.	(California)
	Robert Hodapp, Ph.D.	(California)
	Antonie Debra Kline, MD	(Maryland)
	Adam Mezoff, MD	(Ohio)
	Jennifer Rosinia, M.Ed, Otr/L	(Illinois)

The 5p- Society is in the process of reintroducing the Parent Panels listing that was originally developed through the board of directors. This list is comprised of parents who are professionals or experts in a field that would benefit the Cri du Chat Syndrome child and his/her family. For example, Medical field including dental, vision, nutrition, gastrointestinal, cardiology, ENT, gynecology; Developmental including speech-language, physical, occupational, drug and behavior therapies, eating/feeding, toilet training, puberty, sleeping; Education including inclusion, transition, group homes; Also, special needs advocate, lawyer, financial planner. In order to update this list we are asking for all parents who are professionals or experts in a given field to be included in this list. We will then forward this list to your Regional Family Support coordinator who can refer families to appropriate individuals. If you are a parent professional or expert and would like to assist with this endeavor, please contact Georgia Richey, new board member and host of the 2002 Annual Conference in Salt Lake City Utah. You can contact Georgia at (801) 392-2628 or email Georgia@richey.cc.

5P Philly Style

2004 5p- Society Annual Conference August 5-8th Philadelphia, PA Adam's Mark Hotel

City Ave & Monument Rd
Philadelphia, PA 19131
(800)444-2326

Home of the Liberty Bell and American Bandstand, our next conference is sure to inspire the red, white and blue in you! Philly is a great location for a family vacation. Young ones are sure to enjoy nearby Sesame Place, a play escape and water park for kids of all ages. Downtown Philly hosts the famous Franklin Institute, science museum, the Liberty Bell and many other historical sites. Philly is also easy to get to by plane, train or automobile.

Host families, Holly Gattone and Laurel & Greg Abbruzzese are busy planning for speakers and event sponsorships now. They have already secured their first speaker. Sara Rosenfeld-Johnson, an oral motor specialist. You can learn more about her at www.talktoolstm.com. We are always interested in ideas and assistance from other families, so please contact us.

Laurel: LDABBRUZZ@aol.com

Holly: Holmarie@webtv.net

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
 - Red, White & Blue 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 - \$ 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

Return Service Requested

P.O. Box 268
Lakewood, CA 90714




Families Supporting the Society continued . . .


Discovery Toys -- If you are interested in purchasing Discovery Toys for your child and would like to help the Society, please contact Patricia Strong at odah@clinton.net or by phone at (563) 659-9530. Pat has presented the Society with a number of donations derived from proceeds from the sale of Discovery Toys for the Society. Thanks Pat.

iGive.com -- Do you shop online? KB Toys, JC Penney, etc. If you shop through the website www.igive.com and designate the 5p- Society as your organization, then the 5p- Society will get a percentage of your purchase. It's painless and if you are already purchasing items online, it's easy.



A few things to remember . . .

 Change your address for the 5p- Society. We are no longer at 7108 Katella Ave #502, Stanton, California. The correct address is PO Box 268, Lakewood, CA 90714-0268. We are still getting some mail in Stanton.

 You can access the 5p- Society website at either www.fivepminus.org or www.criduchat.org.

 Update your information with us by phone, email or fax.

Thank you