

5P- News

Family Support Group for Children with Cri du Chat Syndrome

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- Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506 toll free (888) 970-0777 fax: (562) 920-5240
email director@fivepminus.org

President's Message *by Greg Abbruzzese*

Dear Five P Minus Society

We owe a special thanks to all of the host families and corporate sponsors for the Santa Clara conference. I have received nothing but compliments about how smoothly the conference was run. In addition to the host families, I would like to thank Laura Castillo and the rest of the 5P- Board Members for their efforts with the conference and their selfless dedication to the Society as a whole. All of the speakers and events went so smoothly that we will be inviting several West Coast speakers to Minneapolis as well.

Looking ahead to 2007, Paul and Alison Bakken are working diligently toward a

successful conference in Minneapolis as well. Paul and Alison have recruited a few families to form a committee in the area. But of course, to have a successful conference and to lighten the load on one or two families, it would be great if any local or regional families interested in lending a hand would please contact Paul, or any of the Board Members, directly. You can reach any Board Member through their address on the 5P- web site. In addition to logistical support, we are also looking for sponsors (of events and/or donations) to help defray the cost of the conference. On average, each conference costs \$20-\$25 thousand dollars to run for the host families. Fundraising efforts and donations thus far are less than ex-

pected, so any support that you can put forth to the conference will help tremendously. As I had mentioned at the closing dinner, I would like to bring to everyone's attention just one very SIMPLE way to help fundraise... All you have to do is go into your local Wal-Mart and follow these three simple steps:

Continue on page 3

Our Deepest Condolences to the family of Cisiah Armstrong. Cisiah was a former Board of Director and Hosted the Cincinnati Conference in 1997

Resources

- Message board: Post a message or respond to another parent's questions at http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/ Need to join group to participate. New members joining this active group daily.
- Clothing: <http://www.special-clothes.com/>
- Supported Living Services www.supportedlife.org
- Sign Language Vocabulary <http://commtechlab.msu.edu/sites/aslweb/brower.htm>
- Signing Videos and DVDs: <http://twolittlehands.com>
- Speech Therapy ideas: <http://www.speechtx.com/index.htm>
- Speech/Language and Feeding tools: <http://talktoolstm.com>
- Specialty toys – Abilitations: <http://www.schoolspecialtyonline.net/>
- Identification bracelets: <http://www.stickj.com>
<http://www.mypreciouskid.com>
<http://www.911destiny.com>
<http://www.laurenshope.com>

Inside this issue:

President's Message	1
Surf'n California Style	1
Parent's Page	2
Grandparent's Corner	2
2007 Calendars	3
Fundraising Ideas	4
Loving Family Wanted	4
Conference Pictures	6

Surf'n California Style!! Wrap up

Whoever said our kids have no rhythm has not been to one of our Annual Conferences. Not only do the kids like to "dance the night away" they also can Hula!!!

Approximately 75 families attended the Get Together in Santa Clara, California. It was a

very nice and relaxing weekend with many activities, superb speakers and great company. There were a lot of new families from as far away as England and Ecuador. Our eldest in attendance this year with Cri du Chat Syndrome was Heidi, 42-years-old from El Granada, Cali-

fornia and our youngest, Lucy, 4 months, from Richmond, Vermont. Many parents took advantage of the hospitality areas to network and share information. Both the parent panels by age and by Moms/Dads proved to be a very important aspect of the conference where lots of networking and sharing occurred.

Continue on page 5

Parent's Page—

Hi Everyone,

This is our sweet daughter, Megan Elise. Megan turned 11 in June and she continues to meet and exceed expectations. When Megan was 6 months old the doctors diagnosed her with microcephaly and failure to thrive. She was unable to sit up on her own or roll over. Megan had intensive physical, occupational, and speech therapy. She was one of the youngest children to ever receive hippo therapy (horseback riding) in Oklahoma. Megan was diagnosed with Cri du chat syndrome at age 2. We attended the Cincinnati Conference in 1997. Megan started walking, one year later, at age 3.



Megan started participating in the Area Special Olympics at age 6. When she first started running in the Special Olympics, she would stop running when she would see Mommy and Daddy. Last April, Megan made it to the State Special Olympics where she won two bronze medals in track and one bronze medal in the softball throw. Megan

has overcome so much and we are so proud of her!

Megan's hobbies are swimming, playing outside, and

watching Rugrats with her little brother, Gage.

Megan's strength and determination has inspired her father, John, to write a children's storybook titled "Lilly Lightbug." This story is for children with special needs. It will teach kids with any limitation that it is ok to learn at your own pace. This wonderful story emphasizes the importance of patience, persistence, and especially love.

15% of proceeds from the sale of this book will go back to various schools and special education departments. TRC Publishing Company will donate an extra 5% back to the 5p- Society for purchases made through the 5p- Society. The cost is \$15.95 and \$3.00 tax and shipping for each book. Total \$18.95. Please email me at trcpublishing@yahoo.com and let me know if you are interested in purchasing this book and how many you would like. This way I will know how many books to print. The money will not be collected until 3 weeks before printing the books.

John, Susan, Megan and Gage Morrow
10026 S Linn Ave
Oklahoma City, OK 73159
(405) 691-4466
trcpublishing@yahoo.com

THERE ARE SEVERAL T-SHIRTS AVAILABLE FROM THE 2006 CONFERENCE AT A REDUCED PRICE OF \$3.00 EACH. SIZES AVAILABLE ARE 3 XXL BLUE SHIRTS; 14 LARGE WHITE SHIRTS; 1 MEDIUM WHITE SHIRT; 12 SMALL WHITE SHIRTS; 4 YOUTH SIZE 14-16 WHITE SHIRTS. SHOW YOUR SUPPORT. INTERESTED? EMAIL DIRECTOR@FIVEPMINUS.ORG AND WE'LL GET THOSE SENT RIGHT OUT TO YOU. THANKS .

Grandparent's Corner

Congratulations to **Valeria Eickmeier** for being named "Grandparent of the Year." Valeria provided all the attendees of the 2005 conference with beautiful tote bags.

There were 21 grandparents at the Grandparent's workshop at the 5p- Society conference—half were brand new. It is a great way to share their grandparent experiences, worries, concerns and joys. Fundraising opportunities were discussed.

Fundraising opportunity: Get your Christmas shopping done early and help support the 5p- Society by contacting Pat Strong for a current Discovery Toy catalog. Order through Pat and she'll donate her commission to the 5p- Society.

Cookbooks are still available for \$10.00 each plus \$2.00 for the updates. You can order through Pat Strong at odah@gmtel.com. Recipes are also being accepted for an additional update.

New to the Society? Our Grandparents have their own newsletter. Please contact Pat Strong at odah@gmtel.com to be added to their own mailing list.

President's Message *continued . . .*

1. Go to your local Walt-Mart and ask for the Operating Manager
2. Request a form for charitable donations
3. Take FIVE MINUTES to fill it out on behalf of the Society and then you are done

The Society could get up to as much as \$500 dollars for the next conference or help defray the general cost of running day-to-day operations for the Society. Again, FIVE MINUTES, that's all we ask... In advance, thank you all for your continued support.

For those of you who could not attend the conference, we have taken the first step toward a virtual conference. We are working with a documentary videographer, who taped Dennis Campbell's "Cri du Chat 101", which we will be setting

up as a link on our web site. In addition, we are requesting that all guest speakers, going forward, provide us with their speaking notes in PDF format so that we can put them up on the web as well. These are just some small steps that the Society is taking to provide all families, educators, and health care professionals with as much up-to-date information that we can.

As we glance toward 2008 and the VA Beach conference, which is being run by Christy Blount and Anne Zettlemoyer, they are doing a GREAT job preparing already. They are ahead of the fundraising curve and they have taken copious notes from both the St. Louis and Santa Clara conferences to make sure that nothing is left out. There are plenty of local and regional activities for families and we plan to have a full list of potential sites and events soon after

Minneapolis. Looking even further ahead to 2009, we are still looking for a host family in the central part of the US. If you would like to host a conference, or contribute in any way, please contact Laura or any of the Board Members.

I would also like to take a moment to offer special thanks to one of our departing Board Members, Gloria Richey. She has decided to step down from the Board so that she can spend more time with her family. We all owe Gloria a special thanks because she has given (and continues to give) so much of her time and energy to the Society. Beyond hosting the Salt Lake City conference with her family, she always maintained a positive disposition with the Board and members of the Society. For that we are truly grateful and she will be missed by all on the Board.

God bless all of you,
Greg Abbruzzese



Lydia Abbruzzese doing the chicken dance at our 2006 Annual Conference

2007 Calendar and Picture Yearbook

2007 Calendar and Picture Yearbook should be available approximately November 1, 2006.

This year your calendar will be on a CD-diskette so all you have to do is print it out.

Pictures that have been sent to the 5p- Society throughout the year will also be on the disk.

Cost for each disk will be \$5.00 that will include shipping and handling.

To order send you check to:

5p- Society
PO Box 268
Lakewood, CA 90714

If you have any questions please contact director@fivepminus.org or call toll free at (888) 970-0777.

You can still get your pictures into the picture yearbook by sending them directly to Tiffany Townsend at ttownsend@buckeye-express.com or on disk to Tiffany at 7207 Ridgeland Rd, Sylvania, OH 43560. Please make sure you include a permission statement to have your child's picture published.

Thank you to all who participate. Thank you to Tiffany for her time and effort in creating such a wonderful work for the families. Because Tiffany so generously donates her time all monies received from the sale of the calendar makes for a great fundraiser.

Thanks again

5p- Society office



The Hall's and the Szabo's getting ready for Picture time at the 2006 Annual Conference.

Looking for Love and a Family to call their own . . .



Royce and Noah are brothers who have been diagnosed with Cri du Chat Syndrome and are currently in the foster care system in Broward County, Florida. Their case is monitored by ChildNet, a foster care and adoption agency that is also in Broward County, Florida. The brothers are available for adoption and are eager to find a home. Royce was born October 1994 and is 11-years-old, and Noah was born July 1998 and is eight-years-old. The brothers fortunately live together at this time and it is imperative that they get adopted together. Most of the lay population is not familiar with Cri du Chat Syndrome, and because of this reason, ChildNet looks for opportunities to recruit families that are familiar with the children's syndrome. The purpose of this article is to create awareness that we have children in the system with this syndrome, and also to possibly recruit a qualified and experienced family that is familiar with this syndrome. The boys are active and happy children. Noah loves watching TV, putting together puzzles, and playing with his action figures. Noah is friendly, talkative and is very affectionate with others. Royce, Noah's brother, enjoys Lego's, children's television, and outdoor activities. Royce is friendly, lovable, happy, and affectionate. Royce and Noah are children that also need constant redirection, structure, and a consistent schedule. Any family

that would be interested in Noah and Royce would have to obtain an approved adoption home study. Depending on the state, a family would normally have to go through some classes specific to adopting children out of the foster care system, and then someone would assess the family and write an assessment, called a home study. Anyone wanting to find out more information can go to the website, www.adoptuskids.org, and this website can link you to an agency in your county or state that can get you started with the process. ChildNet would like to give a special thanks to the 5p- Society for giving us this opportunity to feature Royce and Noah in their newsletter. To find out more about Royce and Noah, please call Lanecia Radcliff, ChildNet Adoption Homefinder, at (954)336-3448. Lanecia is a special recruiter for children who are hard to place and recruits for forever families for these special children. Lanecia can also be emailed at lradcliff@childnet.us.



Board of Directors

New Board for 2006-2007

President—Greg Abbruzzese
 Vice President—Paul Bakken
 Secretary—Jolene Towers
 Treasurer—Eileen Sherman

At Large Members

Paul Arango	Micah Hoernig
Stefanie Batdorff	Kent Nicholls
Laura Bruns	Georgia Richey (retiring)
Renee Eickmeier	Nick Wallace
Jacqueline Galvagni	Anne Zettlemoyer
Gloria Griffin	

Executive Director Laura Castillo

Fundraising

Have a fundraising idea? Please contact the 5p- Society with the information.

Did you know that if you work for Verizon, Kimberly-Clark, Microsoft, Alliance-Bernstein, Abbott Laboratories, Alcon Packaging, Dell Computers, Raytheon, Corbis and many more companies, your donation to the 5p- Society can be matched. Several of our members, families, and friends take advantage of these great programs and double their donation. This year alone over \$3,000 has been matched. A special thank you to all the families who do participate.

lgive.com is another shopping portal that provides a donation to the 5p- Society by purchases made through its shopping mall.

See Grandparents' corner for more fundraising opportunities.

Conference Wrap Up continued from page 1

A special thank you to all our host families who donated their time and talent to making the conference run very smoothly; Don Hille and Laura Ballance for taking on the overall task of seeing that all aspects of the conference were covered; Dawn Ward and her family with hospitality suite; Merrill and Joanne Bobele securing the Hawaiian Dancers; Kristi Dasher and her mom Diane Ek-hoff for coordinating the childcare; Bobby and Mila Zlatanov for assisting with the planning, many hours of volunteerism and toys for childcare at the conference; and Albert Hakam for securing many of the donations to assist with the different events. Many evaluations have come in and overall there has been so much praise. The location was great, the hotel and its staff was superb. Many local families with a child with Cri du Chat Syndrome also volunteered at least 2 hour shifts for childcare — again thank you.

We again would like to thank our speakers, especially those who provide us with such invaluable information year after year; Dr. Dennis Campbell on Cri du Chat 101 and Educational Issues, Dr. AmySue Reilly, Dr. Joan Henley, the duo presenting on Behaviors and Cri du Chat Syndrome and Educational Issues including IEP's, Dr. Monica Bessler on her continued research with Tert gene and Cri du Chat Syndrome; along with newcomers Dr. Rafael Pelayo on Sleep Disorders, Dr. Pamela Richardson on Sensory Integration, Dr. Antonio Hardan on Behaviors and Medications, Melvin Honda from MetLife on the importance of Planning for the Future, and parent Judy Gomoll on Supportive Living Services.

Probably one of the most memorable moments that I had at the conference was watching the dialog between a couple of our Cri du Chat older teens and adults. They were actually carrying on a conversation, about what I don't know, but it was just so awesome to watch — it actually brought tears to my eyes. Another memorable moment was when (oh yeah forgot to mention that we were housed with the entire San Francisco 49er football team as they were preparing for "hell" week) one of our male adult members with Cri du Chat Syndrome, Allan Dawson, waited and waited for a 49er to come out of his lunch break and when he saw one of them jumped up and down, gave the big burly player a hug and got a picture with him. That was great of the 49ers to let us "mingle" with them.

The siblings enjoyed themselves at the movies, the Great America Amusement Park and just hanging around together. A local Family Helping Families chapter provided us with a Sibling workshop. The pool was the favorite spot of all.

The board of directors assisted with many aspects of the conference both behind the scenes and at the registration table. A special thank you to Kent Nicholls for his powerful New Family Orientation that provides all first timers the information they need to make the conference a fantastic experience.

The events for the conference would not have been available without the financial support of many family and friends. The Welcome Committee headed up by the Frayn family and Manhard Consulting Ltd. and the Hakam/Fousad families and Microsoft Corporation. The Hawaiian lunch donated by the Lansford family and Filice Lansford-Vela Corporation. Photographs by John Dasher and Kent Johnson. The Jones family for their donation to the Family Scholarship program, Carolina Kretschmar for her continued support with the Annual Quilt, and all the other wonderful friends and families who so graciously gave monetary assistance.

I do have to thank my family; my Mom for keeping an "eye" on Katie during the conference, my Dad, Husband and sons, Joey and Mikey for transporting from the airport to the hotel, and my daughter Maggie, for all the pre-conference assistance she provides with nametags, collating, etc. I love you guys!!!

Looking forward to next year . . . Laura Castillo, Executive Director



Cody and Abby at the dinner banquet

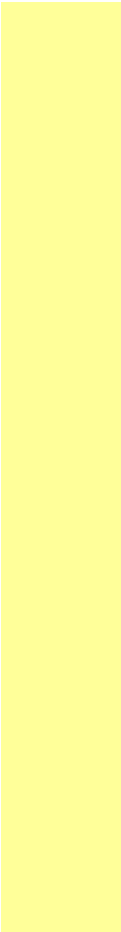


The Jones Family—donors of a Family Scholarship



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

Return Service Requested



CONFERENCE PICTURES



Clockwise from left: The Towers and the Tsou Families smiling pretty for the camera; Kiara and friend dancing the night away; Betty Bedard, Jalean and Weston Blank from Canada; Mary Clare and Anna Garvey and the Galvagni's from Florida showing some love and enjoying the dance.

