



# NEWS

*The Family Support Group for Children with Cri du Chat Syndrome*

September, 2002

## President's Message

by Greg Abbruzzese



It is with great pride that I take over the position of President of the 5P- Society. My hope is to build on the strong foundation that Laura Bruns has laid and to help the Society grow to reach new highs. I would like to thank Laura for her dedication to the Society and her leadership over the past two years.

In addition to extending my many thanks to Laura, I would like to thank all of the Salt Lake City families who helped prepare for the 2002 Conference in Utah. Specifically, I would like to extend our great appreciation to the Richey family for coordinating all of the events, facilitating the logistical hotel and sightseeing information, and of course, leading us in song. In addition, I would like to thank Jolene Towers for her exemplary daycare provisions. And finally, I offer a special thanks to Laura Castillo for all of her hard work making the conference run so smoothly. The Salt Lake City conference proved to be a tremendous success!

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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.

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

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.

# Family Sponsored Events

The 5p- Society would like to thank the many families who have dedicated themselves to the 5p- Society by sponsoring events that increase awareness about the syndrome.

## Mark Sanger/5p- Society Golf Tournament

The Golf Tournament was held on July 15, 2002. Hosting this event was Keith and Claudia Sanger of Rochester, New York. The successful event brought in over \$13,000.00 and the Sangers gladly present the 5p- Society with a check for this amount. Keith and Claudia put many man-hours into the event and enjoyed every minute of it. They're already talking about making this an annual event and already have the next date, Monday July 14, 2003. It is their hope that more 5p- Society families can attend (even if you don't golf) to spread more awareness about the syndrome.

Besides the golf tournament, there were other events, such as a Chinese Raffle, Silent Auction and hole-in-one contest, longest drive and closest to the pin. The favorite part of the event was the many pictures and stories that were sent in by you for the Cart Sponsorships. Many individuals went home knowing more about Cri du Chat Syndrome and the families and children that the 5p- Society supports.

## Sunset Dinner Cruise

A Sunset Dinner Cruise was held on August 31, 2002 in Sacramento, California. Todd & Andrea Winslow hosted this very successful event. Andrea's father owns a boat, she pitched the idea to him and he was glad to provide the transportation. The dinner cruise raised over \$5,000.00. There were a lot of raffle items including dinners at local restaurants and hotel stays. Todd & Andrea put a lot of work into the event and it is their hope to make this an annual event.

The monies raised for both the Golf Tournament and the Dinner Cruise were put into our General Fund account and assisted with the Annual Conference Costs.

## Discovery Toys Online/Phone In Fundraising

Grandparent, Pat Strong of Iowa, is a Discovery Toys representative and has pledged to donate her proceeds from purchases made online or via the 24 hour Customer Connection line between September 3 and December 25, 2002.

Discovery Toys have long been a favorite among families for tactile and fine motor improvement. They make excellent gifts.

Check out the website at: [www.discoverytoyslink.com/patstrong](http://www.discoverytoyslink.com/patstrong) (just click on the shopping cart at the top of the page) or you can phone 1-800-341-TOYS (8697) anytime day or night. When calling by phone please indicate the sales representative as Patricia K. Strong EC STR906.

Need a catalog? Contact Pat directly at [odah@clinton.net](mailto:odah@clinton.net) or (563) 659-9530

## Annual Quilt

For the past 5 years we have been truly blessed with a parent who brings her talent to the Annual conference. Carolina Kretschmar, from New Hampshire, doesn't like to miss a conference. She comes to the conferences with a box full of markers and squares and summons the kids with Cri du Chat syndrome to draw a picture for the Annual Quilt. She takes home the samples from the conference and works with her sister to stitch the quilt together for the next year's conference. The Quilt is then raffled off at the Banquet Dinner. This year, the lucky winner received not only a quilt but a wall hanging because of the over-whelming samples that were done in Toronto.

The raffle contributes approximately \$300-500 depending on the location. If you plan on attending next year's conference make sure you see Carolina for the next 2004 quilt!!

## **Bicycle Racing Team**

Rob Vaden  
San Antonio, Texas



Recently the bicycle racing team that I ride with redesigned our uniforms. We decided that since we were an amateur team we would place the names of our favorite charitable organizations on the uniforms vs. the usual gear sponsors. The 5p- Society was one of the organizations we used on the jerseys. The 5p- emblem was placed on the right side of the jersey so as to be visible to as many spectators as possible. The hope is to increase awareness of the organization and the syndrome.

I have learned that everyone needs a release, and thanks to my very supportive family, cycling has become my release. It has mirrored my life, and life in general, and has brought me closer to my family. Cycling's comparison to all of our lives can be summed up in one ride I recently took on the way to the Salt Lake City annual conference. We stopped in Albuquerque to rest and see the sites. I couldn't visit Albuquerque without riding up the Sandia Crest, a 13 mile climb of steep switchback roads starting at 5500 and climbing up to over 10,600 feet. As I reached the first mile I began to feel a little overwhelmed with the task at hand. I passed the first mile marker and thought to myself "Boy! That was a long mile!" I still had 12 miles of fun to go. By the second mile marker I was beginning to doubt whether or not I would ever get to the top. The altitude was starting to get to me, I had a long drive the day before . . . Had I eaten too much breakfast? By the third mile, I was beginning to realize that these were all excuses. I just needed to stop looking at this ride as climbing a mountain and just focus on completing each mile, one at a time. That worked . . . until about the fourth mile. By this time my lungs were burning, my legs felt like concrete, and the top was nowhere in sight. I then resorted to what I have done only on the steepest of climbs, I broke the ride down to one pedal stroke at a time. I just had to keep the pedals turning; one side, then the other. I did the last nine miles of the mountain one pedal at a time. The closer I got to the top, the harder it got, and the harder I pedaled. Sometimes it got easier, sometimes tougher. But the closer I got to the top, the more I began to appreciate the easier parts, and the view was certainly improving.

The exhilaration of reaching the top of any mountain under your own power can never fully be explained in words, but in that climb I realized that we all have our mountains to climb. Each of us are at different points of the climb; some have the first mile jitters, others are finding excuses at the second mile, while others are simply climbing, one pedal at a time, taking the good with the bad, and enjoying the view along the way. Good luck on your life climbs, each pedal stroke is worth double the effort.

## President's Message

Attending the various conference sessions and networking with families from the Society each year has been an invaluable experience for our family. Our daughter, Lydia, turned four this year, and each year has offered new challenges. Each September we feel empowered and better prepared to meet our daughter's needs, thanks to what we learned that August. One of my goals as President is to help the Society serve as a greater resource to families unable to attend the annual conferences. We will continue to work on ways to disseminate resource information to all of our members via the newsletter, the website, and perhaps, regional gatherings. My wife, Laurel, has joined the Society's Professional Board, and is interested in preparing informational segments for the newsletter. Other members of the Professional Board have already been preparing "fact sheets" regarding various topics of interest to families of children with Cri du Chat syndrome.

We know that the society can have a very important support role for new families with young children, but we also want to be sure that we continue to address the needs of families of children of all ages. The two main goals in our mission statement include sharing information and offering support. In addition, I'd like to see our organization facilitate new research that will assist families of children with 5p-.

In order for these goals to be achieved, our fundraising efforts will continue to be a major focus each year. I am very receptive to any and all ideas regarding the society and fundraising. Our hope is to build on ideas that have worked so well, and to continue to improve in areas that our members feel require growth. I encourage any family to call or email me directly if I can be of any assistance to their needs: 201-287-1871, greg.abbruzzese@newbalance.com. I look forward to working with you in the years to come.

--Greg

## 5p- Society Awarded its First Grant

With the combined efforts of parents Greg Abbruzzese and Stephen Richey, the 5p- Society was awarded its first grant by New York Life Foundation. Two actual grants were awarded -- TeamGrant and Local Volunteer Grant totalling \$2,500.00. These grants could not have been awarded if we didn't have the volunteering of several employees of New York Life Insurance Company, at the annual conference including Stephen Richey, his son, Craig, and another parent of the 5p- Society, Gary Thompson.

If you have an employer that provides for grants please contact the 5p- Society office. We'd also like to thank those of you who do employer matching programs and United Way designated donations to the 5p- Society.

## Meet Your 2002-2003 Board of Directors

### President

Greg Abbruzzese 201-287-1871  
New Jersey greg.abbruzzese@newbalance.com

### Vice President

Paul Arango 305-662-1194  
Florida paul.arango@csfb.com

### Secretary

Renee Eickmeier 636-227-9811  
Missouri eickmeierr@aol.com

### Treasurer

Eileen Sherman 847-674-6815  
Illinois eilsher@aol.com

### Members at Large

Cisiah Armstrong 937-865-9581  
Ohio vikingsongbird@prodigy.net

Laura Bruns 419-678-8207  
Ohio duane-n-laura@bright.net

Holly Gattone 570-345-1173  
Pennsylvania holmarie@webtv.net

Kent Nicholls 913-851-0922  
Kansas kent\_nicholls@hotmail.com

Todd Piepergerdes 501-221-7987  
Arkansas tpiepergerdes@foxcor.com

Cynthia Rambacher 717-949-2844  
Pennsylvania bcjkn@email.com

Dawn Sadler 907-474-0956  
Alaska d.n.sadler@worldnet.att.net

Jean Strong 515-292-3848  
Iowa rjstrong@mcleadusa.net

Jolene Towers 253-840-2228  
Washington gnjltowers@aol.com

Cathy Vaden 201-681-2317  
Texas redtwin@satx.rr.com

### Professional Board Liaison

Dr. Dennis Campbell 870-934-9472  
Arkansas djcshc@cox-internet.com



## How the West Was Fun! Annual Conference Post Report

Laura Castillo  
Executive Director

The Salt Lake City Annual Conference and Get Together was a huge success. Only 60 families attended but because most of the families brought extended family members it seemed a lot bigger.

The conference began with the reciting of the Pledge of Allegiance led by two of our Cri du Chat kids, Angela Richey and Carrie Snoddy. Both girls were fortunate enough to be torch bearers at the 2002 Para-Olympic games in Salt Lake City in February. They donned their torch bearer uniforms and did a fantastic job. A very well done slide show that the Richey family put together followed, along with music and song. Many thanks go out to the entire Richey family. Stephen & Georgia have been blessed with the most talented family.

Siblings were able to meet earlier in the conference with the hopes of forming friendships that will go beyond just three days. Joey Castillo, Rebecca Sherman and her cousin Beth Messer led about 20 siblings in games and events to promote friendship. I can tell you that my kids each met someone their own age that they hung out with the rest of the conference. Of course, they all talked about seeing each other in Memphis so I hope you all know you're coming back!!!

Parents were able to divide themselves up on Friday and Saturday between well done presentations on various subjects. With the most sought after having to do with puberty, given by parent Dr. Geoff Towers, Sensory Integration therapy by Jennifer Rosinia, Orthopedic considerations given by Dr. John Smith, new speech and language techniques by Lillian Clark and both presentations by Dr. Dennis Campbell, schooling issues and Cri du Chat 101. All presentations were well received and we want to thank all the speakers for giving their time to us.

I personally would like to thank Laura Bruns and Eileen Sherman for assisting at the front desk. They have assisted me so much in the past couple of years and I am truly grateful (and of course Paul Demorett for bringing us some humor and stress release).

Most of the families thanked us for having the Continental breakfast in the morning, so I guess we'll have to budget for it in the future. But, seriously, the most positive feedback that was received from the parents who attended, and many who attended for the first time, was the family support, the warmth, the feeling that you are not alone that we all experience at the conferences. I'd like to thank the host families, the Richeys, the Towers, the Turners, the Thompsons, the Wright-Downs, the Campbells, the McNaughtans, the Peery's, the Truesdells, the welcoming committee and the old-timers for making the first-timers feel good to be there.

Several handouts were provided by the speakers. I didn't get handouts from all the speakers, but one in particular that was very popular was "Toilet Training for Children with Mental Retardation" put together by The Arc of Utah. If you would like a copy of this handout, please send a stamped self address envelope and I can provide you with one. Please contact me if you want any additional handouts.

### 5p- Society *ROCKS* Memphis in 2003

Dates and locations have been set for the 2003 Annual conference. We will be rocking Memphis August 7-10. We will be staying at the Adam's Mark Hotel. The family dinner dance will be a sock hop. The current plan is to have concurrent sessions focusing on cri-du-chat through the ages. More information will be provided in the December/January issue of the newsletter.

Your host families for the event are Jim and Deanna Bryant, Dennis and Shari Campbell and Todd and Lora Piepergerdes. If you live in the surrounding area and would like to give these fine families a hand in the preparation of the conference or if you're able to assist at the conference please contact the 5p-Society office and we will put you in touch with them.

### Pennsylvania in 2004

The site for the 2004 conference has been voted on and we will be going to Philadelphia, Pennsylvania. Holly Gattone will host the event with help from Greg and Laurel Abbruzzese and Henry and Carolyn Ansell. In February/March the Board of Directors will meet with Holly in Philadelphia for it's mid-year board meeting. If there are any families in the area that would be willing to assist and be on the conference committee, please contact the 5p- Society office and we will provide you with additional information.

Has it been a while since you received a listing of the members of the Society? We update the listing approximately three times a year. A member that has a \* on their mailing label is not included in the listing. We do need to have a release from you before putting you on that list. How can you get that \* removed from your mailing label? On the last page of this newsletter is a Basic Membership form. Please fill it out and return it and your \* will be removed. Other members have asked that they not be listed, and we respect that request. If at any time you choose to change your mind and would like to be listed please resubmit a Basic Membership form.

If it's been a while and you'd like a new listing, please send a donation for the envelope and postage, approximately \$2.00 (continental US) (overseas is extra), and I'll get it out to you.

Thanks to all of you who responded that you'd prefer your newsletter to come to you via the internet. If you are interested in receiving it as an email attachment in pdf file format please send an email to lc5pminussociety@aol.com.

# Parent Report

2002 Annual Conference Speech & Language Presentation

Cathy Vaden



Since most 5p- children have speech issues, I was excited to see a speech therapist on the conference schedule this year. My daughter, Abigail does not talk (she has about 8 words that anyone could understand). Speech, in addition to being her weakest area, is also the domain she is making the least amount of progress. This year, my husband, Rob, and I decided to make Abigail's speech program our main focus. In April, I found a speech therapist that specializes in oral motor. She explained how oral motor differs from speech therapy. The program she follows is Sara Johnson Rosenfeld's. Imagine my surprise when I found out that Lillian Clark, a speech and language pathologist from Payson, Utah, was speaking about Sara Johnson Rosenfeld's program. Her presentation was called: "Using Oral Motor Exercises to Improve Speech Clarity." I thought that she did a great job summarizing the program in an hour and a half. Before I describe the program for those who could not attend let me say that I always have had the idea that if Abby was not doing certain things by the ages of 5, 7 and definitely 10, that she would never do them. I was encouraged to hear Lillian Clark began working with a 5p- child at the age of 13. The child is now 16 and in those three years has learned many new speech skills and fine tuned others. This shows that many of the reasons our children are not speaking or not speaking very well is not that they are not capable or do not have the cognitive ability, rather that their oral muscles need to be specifically trained to build

patterns of movement. This program is not only for speech but feeding and therefore could be used with children as young as one year.

There are many factors that contribute to our children's feeding and speech issues. There are abnormal types of sensitivity: Hypersensitivity, Hyposensitivity, Mixed-sensitivity and Fluctuating sensitivity. There are issues such as low tone and high tone and other factors such as positioning, inability to close mouth, sensory strength and swallowing. Sara Johnson Rosenfeld's program has 6 goals: 1) Increase awareness of the oral motor mechanism, 2) Normalize oral tactile sensitivity, 3) Teach more normal movement patterns, 4) Increase differentiation of oral motor movements (Dissociation, Grading, and Fixing a muscle) 5) Improve feeding skills and nutritional intake and 6) Improve speech sound production to maximize intelligibility. I can say as a parent that the exercises are easy to understand and do. They take only 10-15 minutes and use common and inexpensive materials. Abigail's exercises include sensory stimulation, bubble blowing, horn blowing, jaw exercises, straw drinking, lip exercises, and tongue exercises. Abby usually has three exercises per session that are very specific, but the instructions on how to do them are easy. I encourage you to request copies of the handout from Karolyn Peery (801) 465-8128 get on Sara Rosenfeld's website at <http://www.talktoolsstm.com>, or find a therapist in your area who has been trained.

Feel free to email me at [redtwin@satx.rr.com](mailto:redtwin@satx.rr.com) with any questions you have about this program or our experiences with Abigail.

In the recent newsletter from the Cri du Chat Support Group of Australia, Inc., they introduce a different type of communication program called the Hanen Approach, for more information please visit their website at [www.hanen.org](http://www.hanen.org). Another Speech and Language site they listed in their newsletter is <http://www.new-vis.com/index.htm>.

FYI: The Cri du Chat Support Group of Australia, Inc has changed it's address: 104 Yarralumla Drive, Langwarrin, VIC 3910, phone/fax: (03) 9775 9962, website address:<http://www.criduchat.asn.au> email: [info@criduchat.asn.au](mailto:info@criduchat.asn.au)

**Basic Membership Information**  
Parent, Professionals, Relatives and Other

**General Information** (*please print*)

Name(s): \_\_\_\_\_

Organization (if applicable): \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_

Zip/Postal Code: \_\_\_\_\_ Country: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

E-Mail: \_\_\_\_\_ Prefer Newsletter by email (pdf file format):  yes  no

Language(s) spoken: \_\_\_\_\_

(please check one) Parents  Professional  Relative  Other (please state how affiliated) \_\_\_\_\_

**Child Information, if applicable**

Child's full name: \_\_\_\_\_ Birth date: \_\_\_\_\_

Sex: Male  Female  Child is: biological  adopted  foster

Chromosome abnormality: deletion  translocation  other (state type) \_\_\_\_\_

Child lives with: both parents  mother  father  relative (state who) \_\_\_\_\_

group home (less than 12 residents)  other (state type) \_\_\_\_\_

Ethnic/Racial Origin (Optional): White/non-Hispanic  Hispanic  African American

Native American  Asian  Other

**Release**

*Parents only*, please state your level of interest in the society.

\_\_\_\_\_ I/We want to receive all mailings from the society. I/We also agree to let the information stated above be made available to other parents. I/We would be willing to be contacted by professionals whose research projects are approved by the 5p-Society. Participation in any project would be optional.

\_\_\_\_\_ I/We agree to let the information stated above be made available to other parents as well as receive all mailings from the society. I/We am not interested in being contacted by any professionals or participating in any research efforts.

\_\_\_\_\_ Newsletter only please. I/We do not want to be contacted by other families or professionals.

*All others*, please state your level of interest in the society.

\_\_\_\_\_ All mailings from the Society

\_\_\_\_\_ Newsletter only please

\_\_\_\_\_ signature

\_\_\_\_\_ date

\_\_\_\_\_ signature

\_\_\_\_\_ date

Please accept the enclosed donation (donation not necessary to become member).

\$10  \$25  \$50  \$100  Other: \$ \_\_\_\_\_

Return this form to:

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

Return Service Requested

P.O. Box 268  
Lakewood, CA 90714



## **GET YOUR 2003 CALENDARS!!!**

The 2003 Calendar was put together with pictures that were sent earlier in the year and is now ready for distribution. The calendars will cost \$10.00 US each. We were able to get the printing of the calendars at a really good price (this is a fundraiser for the Society, we will get approximately \$5.00 for each calendar). These will make great gifts for family members, teachers, therapists, doctors and friends.

This was our first attempt at putting a calendar together and although we know that there are things we will be doing differently in years to come, we are very excited to be able to provide you with our FIRST calendar.

If you are interested in ordering calendars, please send a check made payable to the 5p- Society for the amount of the calendars that you would like. If you would like to order more than 5 calendars, please add \$5.00 for mailing. If you order more than 20 calendars, please add \$10.00 for mailing. If you order more than 40 calendars, please contact the office to see how much extra to send for shipping.

We would like to thank Cisiah Armstrong for her idea of the calendar and for spearheading this endeavor.

Want to sponsor a month in the 2004 Calendar? Please contact the 5p- Society for more information. Calendar sponsors are \$100.00 for the month indicated and are now being taken for the 2004 calendar.