



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

June, 2004

President's Message

by Greg Abbruzzese

Hello again Society members. We are just a few weeks away until the Philadelphia conference. As the conference draws closer, we are still trying to nail down several key elements to help make the event one of the best conferences ever! We are still looking for assistance with childcare volunteers for incremental 1 hour shifts (Fri. 7:00-12:00, and Saturday 7:00-5:00). Linda Magin has been securing volunteers in the area, however, more are still needed. Hopefully, some area families and/or attendees will be willing to lend a hand. See the Volunteer application enclosed.

Again, we are very excited about the list of speakers that we have, as well as the various age groups and fields that the topics will range from. Infant, school-age, and adult topics will be addressed. We are also planning to have a sponsor exhibit room on Saturday, August 7th. For details regarding exhibition space, please contact me at: gabbruzzese@converse.com. Furthermore we are investigating ways to put some of the lecture notes/highlights on the web for those of you who cannot attend the conference. Again, that was a concern for those who could not travel such great distances

We are very grateful for those of you who have graciously donated to the Society and have earmarked funds for the Philadelphia conference. Since the conference is being held in a major city this year, our expenses have increased exponentially. Hopefully, within the next few weeks or so we will hear from some of the proposals that we sent out, but we welcome any late grants that you (or your company) can help provide. Again, please contact me, or any other board member to help with those requests. In addition, Laurel had a great response to the *Resource Manual Questionnaire*, please continue to send those in!

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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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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.

President's Message continued . . .

Looking ahead to St. Louis, Renee Eickmeier and family are well on their way in the planning and development stages for the 2005 conference. Going forward to 2006, it looks like we are headed to San Jose, California. There are several families in the San Jose area that have expressed an interest in hosting the event

Lastly, in an attempt to broaden the scope of the newsletter, we would like to start a parent question and answer section that might be of help to parents. Basically, we are looking to parents to e-mail the Society and ask questions they have about medication, potty training, behavioral problems, or whatever. It is our hope that we will be able to help parents experiencing similar concerns.

That's all for now... I look forward to seeing you all in Philadelphia!!!

Greg Abbruzzese

2005 Calendar

The 5p- Society would like to put the final touches on the 2005 calendar so that it is ready for the Philadelphia conference, but we still have three more months available for sponsorship. If you would like to showcase your beautiful child on a page of the calendar, please feel free to contact the 5p- Society office. The following months are still available for sponsorship: January, September, and December. The sponsorship fee is \$100.00. (You can split this fee with a friend). This fee helps us to defray the cost of printing the calendar. Please send your \$100.00 sponsorship fee to the 5p- Society office at PO Box 268, Lakewood, CA 90713 and indicate what month you would like. Your pictures can be emailed to Tiffany Townsend at TSquared417@aol.com, or you can send them to her at 7207 Ridgeland Road, Sylvania, OH 43560. When you send your pictures, please make sure that you send a signed note that says you agree to the publishing of your child's picture by the 5p- Society. **We need all kinds of pictures.** Even if you can't sponsor a month, your child's picture can still make the calendar. Email or send your picture to Tiffany as stated above, with a release form.

Did you say you wanted the calendar in color? Guess what? It will be!! Thanks to some determined committee members and a national printing chain the calendar will be in color. Deadline for pictures to be published in our first color calendar is July 1, 2004. **Remember, you don't have to sponsor a month for your child's picture to be in the calendar, we need all kinds of pictures.** Please note that pictures submitted to the 5p- Society become the property of the 5p- Society for future use. If you need the picture returned please indicate this with submission.

The 5p- Society would like to thank Tiffany Townsend, who has agreed to volunteer with the layout and printing of the calendar. Thank you also to Donald Vey and Jack Parish Therapy Group for their donations to assist in offsetting the cost of the printing of the calendar. We would also like to thank Cathy Vaden for all her hard work.

Family History Questionnaires

In 1999 the 5p- Society sent out Family History Questionnaires to assist with a research request. The Family History Questionnaire has assisted the 5p- Society office by putting families together when a request for a specific ailment has occurred. For example, a mom called about her child's newly diagnosed scoliosis and wanted to talk to other families who had experienced scoliosis. The office was able to put that mom in touch with several other families to get information. A student may ask "How many children have a simian crease?" I can run through the data and tell them that a specific percentage of the children in our Society have them. We'd like those of you who filled out a Family History Questionnaire to update them. In the next few weeks Family History Questionnaires will be sent out. You will either receive a printout of your previous responses for updating, or you will receive a brand new form. Please take the time to fill this information out and return it. The information provided can be utilized in so many ways. Every five years, we'd like to make sure that the information is updated.

Parent Fundraising Reports

AND THEY'RE OFF MOUSE RACING IN ST. LOUIS by Renee Eickmeier

Mouse racing? Yes, you heard correctly. The hottest thing in fundraising in the Midwest is Mouse Races. The Erin Eickmeier foundation hosted its first fundraiser February 20 and we made over \$11,000.00

Now that I have you hooked, let me back up a little. My husband, Joe, and I started a nonprofit foundation in November of last year. It is under a "parent" foundation, the National Heritage Foundation. In a nutshell, they take a small percentage of all our donations, and in turn, manage all the money for us. It is so easy to set up, and they are very helpful at National Heritage. We have found that it is easier to raise money as a foundation rather than just "nice people wanting to help." Now we are able to make donations to any other 501(c)(3) organizations, like the 5p- Society.

For our first fundraiser, we were in search of something unique and fun and mouse races seemed to be a good fit. We were lucky enough to find a good "mouse guy", who was very helpful in assisting us with the event set-up. It was honestly one of the funniest things that I have ever seen. Six mice raced at a time, and there were 7 races. Your guests bet on a mouse of their choosing with chips that they get in exchange for cash. Some mice don't even move. Some go fast out of the gate, only to turn around halfway down the track and go back to where they started. The crowd goes nuts!

In between races, we had Mouse Roulette. The winner from the previous race got the honors to be paced on a very large roulette wheel, where people placed tickets that they had purchased in the cubby holes around the edge. The wheel was spun, ever so slowly, and whichever cubby the mouse ran into, the person with the matching ticket won \$120.00.

Throughout the evening, we had a silent auction going, with items donated from friends and relatives. We had sports memorabilia, toys, gift certificates, and all sorts of good stuff. We were lucky to get food donated as well. It was such an enjoyable evening. People are already asking us when we will do it again.

If you are interested in learning more about Mouse Races or setting up a nonprofit foundation, please email me at Reickmeier@sbcglobal.net.

Next up for the Erin Eickmeier Foundation Erin Eickmeier Golf Tournament

The golf tournament is scheduled for July 17, 2004 at 1:00 PM at the Mid Rivers Golf Links in St. Peters, Missouri. Cost is \$75.00 per golfer and includes 18 holes of golf, cart, dinner and beverages on the course. If you cannot attend but would like to sponsor a hole the sponsorship fee is \$100.00. For more information regarding the golf tournament please contact Joe or Renee Eickmeier at (636)227-9811 or reickmeier@sbcglobal.net.

Other fundraising news:

Thank you for Marty Nash and her crew at K&L Law firm in Dallas, Texas. Denim Day brought in \$400.00.

Thank you to the family of Austin Hoover for their combined donations of \$603.00 from Mary Kay sales and the Toboso United Methodist Church.

Conference Contributions

Tiffany Frezza of Texas has secured another donation for our 2004 conference. Ross Laboratories will be donating \$400.00.

The KONE Elevator Company has also committed to a donation to assist with the 2004 conference. A big thank you to Randy Strong, an employee at KONE Elevator Co. for laying the groundwork for this donation.

Other conference sponsors:

Erin Eickmeier Foundation
Rob & Cathy Vaden
Mike & Vicki Perry
Greek Ladies Philoptochos
Braintree Laboratories
Bruce & Cynthia Rambacher
Bart & Chris Harms
Kevin Gattone

John Kenee
Gary Valko
Maurer Family
Eileen Abbruzzese
Holly Gattone
Henry & Carolyn Ansell
Gloria Johnson

Many continued thanks to Gloria Griffin for her jewelry profits and to Carolina Kretschmar for the 2004 Quilt that will be raffled at the Philly conference.

Financial Assistance Program for Philly

The 5p- Society would like to thank all the families that submitted applications for the Anna Maurer Scholarship fund for financial assistance to the upcoming Philly conference. More than the allotted five scholarship applications were received. The committee had a difficult task of picking the recipients. We encourage those of you who did not receive a scholarship to reapply for next year -- look in the March 2005 newsletter for more information.

More Conference Info . . .

There are two things that you will need to do to register for the 5p- Philly Style 2004 Annual Conference.

- (1) Fill out the Registration form on page 7 and return that to the 5p- Society office with your registration fee.
- (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 5th through 8th**. 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.

Updated conference schedule . . .

We have confirmed the Father's Workshop speaker. Dr. Bob Handfinger will be meeting with the dads to discuss specific issues. A brief description of his presentation:

"A Boy Named Sue": A Father's Predicament

Fatherhood is a responsibility complicated by challenges, value, dilemmas and difficult decisions. Fatherhood, for a father with a special needs child with severe impairments can be extremely trying without guidance and support. This workshop will attempt to do just that. Through the use of popular music and film and over 30 years of professional experience, Dr. Bob Handfinger will attempt to lead as many fathers as possible to a position with more "savvy" in the role of a father.

5p- Philly Style - T-Shirts



Don't forget to order your T-shirts early this year! Why? Because last year we ran out of shirts and we want to make sure you get one. Pre-orders will be taken until July 1, 2004. T-shirts will be available at the conference, for the same price, however your choices may be limited. T-shirts will be \$8.00 each. You may order your shirts in either white or blue. You can pick up your shirts at the registration table. See order form on page 8. If you would like a T-shirt but cannot attend the conference please add \$5.00 for shipping (up to 5 shirts, \$10.00 up to 10 shirts).

Help Wanted

Childcare Volunteers: We are in great need of volunteers to work the childcare at the conference. If anyone of you have relatives or friends that can give a couple of hours of their time at the conference it would be greatly appreciated. Or if any of you know of community service groups in the Philadelphia area that can help with childcare this would be also very helpful. Volunteers can work in shifts on Friday from 7 AM to 12:30 PM and on Saturday from 7 AM to 5:00 PM. Please contact the 5p- Society office at (888) 970-0777.

Board of Directors: We will be in need of several new board of directors to replace those current board members whose term expires. If you are interested in becoming a board member or would like more information regarding the volunteer position with the Society, please contact the 5p- Society office.

Newsletter Assistance: Many families contact the 5p- Society about needing and wanting more parental guided information, using this forum to assist with issues, etc. This can't be done however, without your participation. Make this your newsletter by contributing, either with an article about an issue of interest to you and your family/child, or by sending in requests that possibly other families can help answer. You could also send in an article about your child's development, the good days and the bad days. Make this your newsletter, share a little. You may have a very important issue that needs to be dealt with that possibly one or more of the over 1000 families in the Society can assist with. I look forward to a mountain of responses to this!!!! You can email the requests or articles to Laura, or send them via fax at (562) 920-5240, or by mail at the 5p- Society address. Whatever you do please don't be shy and MAKE THIS YOUR NEWSLETTER.

Updated Library of Abstracts and Articles

The 5p- Society has recently updated it's Library of Abstracts and Articles with new entries from 2002-2004. Due to new technology the Society is able to send these new articles electronically. If you are interested in seeing what new articles have been ascertained, please contact the 5p- Society office for an updated listing. There is a \$2.00 per article charge. The listing is done as a word document for those who would like to have it emailed to them. The listing can also be mailed. Please forward a self-addressed stamped envelope to the 5p- Society and ask for the updated listing.

Parent Support

Do you remember the first time you were told that your child was diagnosed with Cri du Chat Syndrome? The grief that you encountered? The information that you received and how it would be great to talk to another mom or dad with the same feelings? Experiences? Your Regional Family Support Coordinators are there to help you and provide you with additional support. We'd like to provide the Regional Family Support Coordinators with additional names and numbers of parent professionals that they can refer families to for additional information on specific issues. Several parent professionals answered the call in our September 2003 newsletter. We know there are more "parent professionals" out there that can be available to our members. If you have knowledge in any area that our family members can contact you about, please let us know. Board member Georgia Richey will be maintaining and updating this listing. You can contact Georgia at georgia@richey.cc or by phone at (801) 392-2628.

We'd also like to take this a little further. Did you feel overwhelmed at the beginning and not feel comfortable calling another parent? Many of us do. One member, Micah Hoernig, of Monroe, NY, has suggested that on your Basic Membership form, *you let us know* if you want to be contacted by another family. The Basic Membership form will reflect a new area that asks you the above question and you will need to circle the yes or the no. There will also be an area that asks if you would be willing to contact a newly diagnosed family if your Regional Family Support Coordinator needed you. Future Basic Membership forms will be forwarded to the Regional Family Support Coordinator for their specific area.

If you are interested in changing your current Basic Membership form to reflect these two new areas please contact the 5p- Society for a new form. The new Basic Membership form will be posted to the internet in a few weeks. Please keep in mind that the 5p- Society will not provide any other member with your information unless we have a Basic Membership form on file that specifically states that your information can be forwarded or included in our printed database. Many of you have not filled out the Basic Membership form and are only on our database to receive information, but not to receive phone calls. If you are unsure about your status, please contact the 5p- Society either by email at director@fivepminus.org or by calling our toll free number (888) 970-0777.

Your current Regional Family Support Coordinators

East Coast	Ruthie Liberman	(781) 861-3962
Midwest	Joan Steele	(618) 687-3006
Southeast	Deanna Bryant	(870) 802-2193
Plains States	Crystal Marshall	(316) 669-8367
Rocky Mountain States	Kathy Phelps	(970) 259-3588
West Coast	Dawn Sadler	(907) 474-0956
Eastern Canada	Julie Deyell	(705) 887-4770
Western Canada	Patricial Wheatley	(403) 251-9855

A special thank you to these individuals who have dedicated their time to helping other families.

**WE NEED YOUR CHILD'S PICTURES FOR THE 2005 CALENDAR
SEND THEM IN NOW . . . SEE PAGE 2 FORM MORE INFORMATION**

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**2004 North American Annual Conference
and Get-Together - August 5-8th - Philadelphia**

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, 2004)

\$35.00 for each additional adult _____

\$20.00 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 ___ refrigerators (\$15.00 per day)

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

2004 Conference Registration
5p- Society
PO Box 268
Lakewood, CA 90714-0268

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



Childcare Volunteer Application

Be a Part of the 5p- Annual Conference in Philadelphia, August 6-7, 2004

The Philadelphia Conference Host Families are seeking volunteers to assist with childcare on Friday AM and all day Saturday, so that parents may attend educational meetings. If you are interested, please fill out the form below and mail it to Laurel Abbruzzese 521 Palisade Ave, Teaneck, NJ 07666; fax (201) 287-1871, or email the same information to LDABBRUZZ@aol.com. Many thanks for taking the time and being willing to help out.

Name:			
Address:			
Phone: (day)		E-Mail:	
Workplace:		Occupation:	

How did you find out about our conference? _____

Area of Interest (check all that apply_

- | | |
|--|--|
| <input type="checkbox"/> Infants (6 weeks to 18 mos) | <input type="checkbox"/> Toddlers (18 months to 3 years) |
| <input type="checkbox"/> Age 4 --7 | <input type="checkbox"/> Age 8--13 |
| <input type="checkbox"/> Adults 13 and up | <input type="checkbox"/> Sibling Outing |

Availability

- Friday, August 6, 2004, 7:30 AM - 12:30 PM (5 hours)
 Saturday, August 7, 2004, 7:30 AM - 12:30 PM (5 hours)
 Saturday, August 7, 2004, 1:30 PM - 5:00 PM (3.5 hours)
 Other: _____
 Not sure yet

Shoe size _____ (___ Male, ___ Female, ___ kids)

T-Shirt Size: ___ Adult Small ___ Adult Medium ___ Adult Large ___ Adult XLarge ___ Adult XXL



Resource Manual

Please contribute to the 5p- Society Resource Manual for families and service providers of children with 5p- Syndrome.

If you have experience working with an individual with Cri du Chat (5p-) syndrome, we need your input. Our goal is to compile the information provided on these questionnaires into a resource manual. We would like to have all forms back by May 1, 2004.

Please fill out the form below and mail it to Laurel Abbruzzese, 521 Palisade Ave. Teaneck, NJ 07666; fax (201) 287-1871 or email the same information to LDABBRUZZ@aol.com. Many thanks for taking the time and being willing to help out.

Name:			
Address:			
Phone: (day)		E-Mail:	
Workplace:		Occupation:	

Are you willing to be contacted by other professionals ____ Y ____ N parents ____ Y ____ N

How many months experience do you have working with a child with 5p- Syndrome? _____

How old was the child at the time? _____

What were the child's biggest challenges?

- 1 _____
- 2 _____
- 3 _____

What were your two primary goals?

- 1 _____
- 2 _____

How much time did you give to meet the above goals? _____

What were the effective strategies used when treating this child? (explain)

Suggested Resources: _____

2004 Conference Registration Enclosed
 Return Service Requested

P.O. Box 268
 Lakewood, CA 90714



T-Shirt Order form

Please choose your color and size and return to the 5p- Society, PO Box 268, Lakewood, CA 90714, as soon as possible.

Child Size	Quantity	
	White	Blue
small	___	___
medium	___	___
large	___	___
x-large	___	___

** Please note that volunteers for the conference, board members, and Welcoming Committee members t-shirts will be ordered in Red so that they can be identified by the conference attendees. If you are a volunteer please indicate your size and place a * next to it.**

Adult Size	Quantity	
	White	Blue
small	___	___
medium	___	___
large	___	___
x-large	___	___
xx-large	___	___

Name: _____
 Address: _____

 Phone Number: _____

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 every five shirts ordered for shipping.