



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

March 2005

President's Message *by Greg Abbruzzese*

Hello again everyone! As the St. Louis conference draws closer, we are finalizing everything at the St. Louis Hyatt Union Station. The Eickmeier family has prepared an excellent agenda of events throughout the weekend. Once again, even though the Eickmeier's are the host family this year in St. Louis, we are still taking on volunteers to help with day care, room/event sponsorship, and donations (toys, welcoming room, etc.). If you are interested in helping out, please contact Renee directly at: reickmeier@sbcglobal.net, or one of the other Board members (e-mail addresses available online at www.fivepminus.org). In addition, we still have several family assistance scholarships available for the conference that I encourage families to apply for through the Society.

We have finalized the list of speakers for St. Louis, and, per the suggestions from the Philadelphia conference, we have confirmed that some speakers will provide dual sessions (to avoid conflicting sessions). In addition, we have confirmed that we will have a dietician, and an orthodontia specialist, and a grief counselor at the conference this year. Some additional offerings that we would like to present and are in the process of finalizing are: a traveling sensory team that visits the child care rooms throughout the conference, an augmentative communication workshop and a message board at the conference for families to send notes to re-connect with past conference friends. Lastly, we are working on the final stages of the sibling outing and the grandparents' workshops that we hope to complete within the next few months.

The children can look forward to several key events throughout the weekend. We are all excited about the "A Day at the Fair" inning with hot dogs, hamburgers, potato salad, chips, popcorn, cotton candy, ice cream with waffle cones and cups. There will also be ball pools, a bounce dome, an inflatable slide, and an obstacle course that will hopefully tire everyone out! We are still hopeful for a clown and jugglers as well as a DJ to entertain the kids.

Regarding the 2006 conference, the Board has decided on the host city of Santa Clara, CA, and the Santa Clara Marriott as the site location!!! The Santa Clara Marriott is conveniently located just a few miles from the San Jose airport and approximately 45 minutes from the San Francisco airport. There are several entertainment sites, restaurants, along with an amusement park right next door to the hotel so there are plenty of activities for one and all. Looking at 2007, we are confident in targeting Minneapolis, MN, with Paul Bakken and his family as the host family. For 2008, we are looking at the Northern Virginia/Washington D.C. area.

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5P- NEWS, published four times a year, is a publication of the 5P- Society, the national support group for families who have children with Cri du Chat Syndrome also known as Cat's Cry Syndrome or 5P- Syndrome.

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Mission Statement: To encourage and facilitate communication among families with a member who has 5P- Syndrome and to spread awareness and education about the syndrome to these families and their service providers.

President's message continued

As we grow as a Society, the general costs to run this type of organization grow exponentially. After continuous fund raising efforts, the demands of maintaining the Society's web site, the newsletter, running cost-effective conferences, an Executive Director, etc., the Society is at a financial crossroad. Although we continue to solicit grants, encourage matching gifts from employers, and receive donations from friends and families of the Society, it appears that we must now consider annual dues as part of membership to the Society to help defray some of these growing costs. We are considering implementing this annual membership fee starting in 2006. We are targeting a cost of \$25 dollars per immediate family and will finalize this proposal at the conference in St. Louis. As always, if families cannot afford this fee, we will consider waiver requests sent directly to the Society. It is important that we receive your feedback regarding this new direction so that we can gauge the sentiments of the Society. We can only improve as a Society if we hear from you!

Lastly, there have been several recommendations presented to the Board since the last conference on how to improve the Society's immediate communication and where we would like to see the society go within the next five to ten years. Some great suggestions were to make video conferencing available on the Web for those who cannot attend the conference, make the conference workbooks available on-line in PDF format, have links on our site to past conference speakers' notes, provide a parent message board to facilitate communication between parents, etc. All of these ideas take the Society in a new direction and are great ideas for the future. We are working toward making these investments going forward. Again, we encourage open dialog on how to best improve the Society and we would like to hear from you directly. Please contact me at: gabbruzzese@converse.com, or any other Board member, with any thoughts or suggestions for the Society.

Thank you all for your continued support of the Society.

Greg Abbruzzese

2006 5p- Society Color Calendar

Sponsors and pictures are now being accepted for the 2006 5p- Society calendar. Kinko's/Fed Ex has agreed to give us another great deal on the COLOR calendars. Month sponsors are needed and the cost is \$100. Co-sponsorships are also available. If you would like to sponsor/co-sponsor a month (May 1st deadline), please contact Tiffany Townsend by email at Ttownsend@buckeye-express.com or by telephone at (419) 824-8496. Pictures are also now being accepted. This year, pictures will need to be sent via email only and they need to be in jpg format. If you do not know how to do this, or do not have access to email, your local Kinko's/Fed Ex, Office Max, or library should be able to help you. All pictures and sponsorship information/questions should be sent by June 1st to Tiffany Townsend at Ttownsend@buckeye-express.com. All sponsorship checks should be sent to the 5p- Society office at PO Box 268, Lakewood, CA 90714-0126. Thanks and hope to see all of those adorable pictures soon!

A limited number of 2005 5p- Society Color Calendars are still available. Please contact the 5p- Society for more information at director@fivepminus.org or (888) 970-0777. These beautiful calendars are \$15.00 each (plus shipping) and showcase many children with Cri du Chat syndrome.

Fundraising Opportunity

My name is Kim Truesdell and I am a parent of a child with 5p-. Josh is now 4-years-old and he is doing great. I am doing a fundraiser for the Society. I will be contacting some of you to help. I will send a catalog and order form for Cookie Lee Fine Fashion Jewelry. I am hoping you will help me get a few orders. There are some really cute things for Mother's day, birthdays and just to wear. I will be donating 20% of all sales to the Society; also I will not charge for shipping. If you are willing to look at a catalog and take a few orders from close friends or family, please contact me at (801)794-0112 or my email address is jptkim@hotmail.com. Thank you for your support in this endeavor. I am hoping this goes really well and I will be able to do this twice a year. Once in Spring and again in Fall.

Research program sponsored at summer conference:

Chromosome Ends in 5p-

Jennifer Ivanovich, Honyang Du, Philip J. Mason, Joshua J Fields, Alison Whelan, David Wilson, and Monica Bessler
Washington University School of Medicine St. Louis MO

Dr. Monica Bessler and her colleagues at Washington University School of Medicine in St. Louis are studying the health effects of shortened chromosome telomeres. **Telomere** is the name used to describe the ends (or caps) of each chromosome. Telomeres are critical in maintaining the structure and function of the chromosome. If the telomeres are damaged or shortened, the chromosome cannot properly share information with the cell.

Telomerase is a complex protein that maintains the length and structure of the chromosome ends. Telomerase is composed of two components. One subunit is **TERC** encoded by a gene on chromosome 3, the other is **TERT** encoded by a gene found on chromosome **5p15.33**. **TERC and TERT** act as a unit to actively build and repair the chromosome ends as the cell grows and divides.

Individuals with short chromosome ends caused by a defect in TERC have a decreased blood cell production and signs of early aging such as, early graying of the hair, wrinkling of the skin, and immune deficiency. We do not know what happens if one copy of the other component of telomerase, TERT, is missing. Individuals with the 5p- syndrome, also known as the Cri du Chat syndrome, have a deletion in chromosome 5p, exactly where the TERT gene is located. Short telomeres in individuals with the 5p- syndrome might explain some of the problems individuals with this condition might have or might develop as they get older. We wish to understand whether all individuals with the 5p- syndrome are missing one copy of TERT, to learn if a deletion of TERT always causes short telomeres, and to determine if the telomeres are short at a very young age.

Please join us during the summer conference in St. Louis to participate in this important study. Examining how well telomerase functions may provide additional clues on the long-term health effects for children with 5p-. All individuals with 5p-, their parents, and their siblings are invited to participate. Participation includes signing a consent form indicating your desire to participate, completing a short medical and family history questionnaire, undergoing a short physical examination, and submitting a blood sample. Your participation may help us to better understand the underlying cause of the symptoms associated with 5p-, and hopefully in the future, lead to better therapies for people with 5p-. There will be no cost to participate and the confidentiality of all study related materials are maintained in accordance with State and Federal laws.

Contact Dr. Bessler to learn more about the study and how you can help contribute to this important area of medicine. Dr. Bessler may be reached at 314-362-8807

Parent Reports, Resources and Announcements

Congratulations to new family Chad and Kyla Chandler, parents of Merrick Chandler, for being named The March of Dimes Ambassador Family for Princeton County, Indiana.

Old reading series brought back in publication. The Dick & Jane reading series has been reintroduced and some of our parents are using these books to help our children with reading. Angela Richey of Ogden, Utah started to read the books that have large print and is becoming quite the reader. She has gone from a Kindergarten to a second grade level in just a few short months. Visit www.tagnwag.com to learn more information about these books.

Sports for our kids. The Middletons of Cincinnati, Ohio have recommended a soccer program that their son is involved in. It is called TopSoccer. For more information and a brochure on TopSoccer go to <http://usyouthsoccer.org/downloads/topsoccer/topsoccerbrochure.pdf>. AYSO soccer organization also has a soccer program called VIP Soccer. For more information please visit the AYSO website at <http://soccer.org/Programs/VIP/>.

If it's baseball you'd like to see your child play, the Little League organization has its Challenger League. Check the Little League website at www.littleleague.org/programs/challenger.asp for more information on Challenger Leagues.

Meet Us in St. Louis -- Conference news

Family Assistance Program

Once again, Ray & GERALYN MAURER have designated their softball fundraiser to assist five (5) families to attend this year's Annual Conference and Get Together. Scholarships are designed to pay for the basic registration fee for the conference for two adults and two children (\$125.00) and for hotel accommodations for three nights at the hotel (3 x \$110.00). It does not cover travel, meals or incidentals. Applications are now being accepted. To obtain an application please contact the 5p- Society either by phone at (888) 970-0777 and leave your name and number or by email at director@fivepminus.org. Deadline for applications is May 1st. Applicants need to show good faith in attempting to get funding from an outside local source before submitting their application. The Family Assistance Program committee will review and make their decisions by May 15th.

Exhibitors

We will have an Exhibitors' area for Saturday, July 30. If you know a company that might be interested in exhibiting at our conference please contact conference host Renee Eickmeier at reickmeier@sbcglobal.net or the 5p- Society office for an Exhibitor's Application.

Speakers

This year's conference brings back many dynamic speakers and topics but also some new speakers on topics of interest to the members of the Society.

Dr. Dennis Campbell	Cri du Chat 101 -- For new attendees to find out more about the syndrome
Dr. AmySue Reilly	Behavior Applications
Dr. Jennifer Rosinia	Sensory Integration 101
Dr. Jennifer Rosinia	The Role of Emotions and the Stress Response System on Child Development
Sara Rosenfeld-Johnson	What Can I do to Improve my Child's Speech
Sara Rosenfeld-Johnson	What Can I do to Improve my Child's Feeding
Dr. Kim Cornish	Results of Adult Study
Dr. Kirt Simmons	Orthodontia
Cathy Ranney	Dietary Needs of Cri du Chat Syndrome
Ashley Nanny	Supportive Employment
Christine Schneider	Augmentative Communication in the Classroom
Dr. Monica Bressler	Current research (see page 3 of newsletter)
Dr. Jeff Bradstreet	Recovery of the Unrecoverable: Hope through Advanced Nutritional Biochemistry and Beyond

Other Events

Parent Panels - Parents break out into different groups based on age and discuss, brainstorm, network issues and ideas relating to your child with other parents.

Grandparents' Workshop - A time for all the grandparents of our group to network and discuss issues important to them. The Grandparents' group is planning to put together a Recipe Book to sell at the conference. Interested in submitting a recipe? Please contact Pat Strong at odah@gmtel.net or send to Pat at 809 9th Ave, DeWitt, IA 52642.

Sibling Events:

Workshop - A structured event for siblings to learn more about what it's like to be a sibling of a child with a disability.

Mixer - A fun event for siblings to meet and greet and make long lasting friendships.

Outings - Off site events for the siblings during session time to have some fun with their new friends (without their brother or sister with Cri du Chat). On Friday to Gateway Arch and on Saturday to Glow Putt Putt. Any interested teen or adult siblings that would be interested in assisting as a chaperone please contact Renee Eickmeier or 5p- Society.

Professional Panels - Many of our speakers will come together and answer frequently asked questions about our children. Some will also explain the results of their studies that have been conducted in the past few years.

Conference 2005 -- Friday Family Event "A Day at the Fair"

Come join us as we relive the World's Fair at the 5p- Society conference. Games, inflatable bouncers, obstacle course, small ball pools and possibly a juggler will entertain us. For lunch, plan on traditional foods that you would find at a Fair such as hot dogs, hamburgers, potato salad, pork n beans, potato chips, ice cream in waffle cups or cones, and coffee or iced tea.

Renee and Joe Eickmeier have been working to bring this unforgettable experience to you. Thanks to the Erin Eickmeier Foundation for supporting this event.



More conference news

Don't forget to submit your stories to our own version of "Chicken Soup for the Cri du Chat Families' Souls" to conference host Renee Eickmeier at reickmeier@sbcglobal.net. Your story will be published in our Conference book.

Sponsors for this year's conference are:

The Maurer Family (Family Assistance Program)
The Sanger Family (continental breakfast - Friday)
Erin Eickmeier Foundation (Friday outing, overall conference)
Kohler Printing (conference book printing)
Valeria Eickmeier (tote bags)
The Krestchmar Family (Annual Quilt Raffle)

Have you considered sponsoring an event at the conference or know someone who might? Even if you are unable to attend you can assist. On the Registration form there is an area to sponsor an event. Please circle the event you are interested in assisting and attach your donation. Your name will be added to our list of sponsors in our Conference Book.

NEW THIS YEAR!! Professional fee. Do you have a professional that would like to attend the conference meetings but not all the family events (Friday "Inning", banquet, etc.) We are initiating a Professional Fee of \$50.00 to attend. However, and this is the best part . . . this fee can be waived if the professional will donate some of his or her time at the conference working in our child care. Child care shifts are 1 1/2 hours long on Friday and Saturday. If this is of interest please contact Renee Eickmeier at reickmeier@sbcglobal.net or (636) 227-9811 or contact the 5p- Society office at (888) 970-0777 or director@fivepminus.org.

What Works Table -- Bring or send your ideas that work to the conference. We will display these in the Exhibit area for all to see. It can be a toy, a therapy, a discovery, foods, anything that works for you might just work for someone else. Not attending the conference but would like to share your ideas, please submit to the 5p- Society office. Written ideas can be submitted for the Conference Book.

Quilt Raffle - Drawings made by our children with Cri du Chat Syndrome at the 2004 Philadelphia conference will be pieced together by Carolina Krestschmar and her sister-in-law to create a one-of-a-kind quilt. Chances for the quilt will be a \$1.00 donation. Raffle tickets can be purchased beforehand or at the time of the conference.

Thank you to Gloria Griffin, grandmother and board of director for her continued fundraising efforts. Some of you know that Gloria sells mostly bracelets and necklaces (and other items) to assist in supporting the 5p- Society. In the year 2004 Gloria raised over \$13,000 for the Society and this year has raised over \$1,800. You're the best!!!

Many thanks to Tiffany Frezza for assisting in obtaining many donations for our 2004 Conference in Philadelphia.



All members of the 5p- Society, extended families and professionals are invited to our Annual Conference and Get Together scheduled for July 28-31, 2005 at the Hyatt Regency St. Louis at Union Station in St. Louis, Missouri. Registration application is on page 7 of this newsletter.

Site: Hyatt Regency at Union Station, One St. Louis Union Station, St. Louis, MO 63103.

Room Rate: A reduced rate for 5p- Society members is \$110.00 per night. To make your hotel reservations please call (314) 231-1234 or (800) 233-1234 and tell the operator that you are with the 5p- Society to get your reduced rate. If you encounter any problems when making reservations please contact Laura at the 5p- Society office at (888) 970-0777 or director@fivepminus.org. All suites are currently occupied.

Transportation: The hotel is just 20 minutes from the Lambert St. Louis International Airport. There is a MetroLink Light Rail that can take you from the Airport to the Hotel for less than \$3.00 each. The MetroLink can also take you from the Hotel to many attractions including the Gateway Arch. Trans Express provides transportation to and from the airport and the Hyatt Regency every 25 minutes for \$13.00 per person one-way or \$21.00 per person roundtrip. If you are driving to the conference please contact the hotel for directions or go to the hotel's website at www.stlouis.hyatt.com.

Area Attractions: Gateway Arch, America's Center, St. Louis Zoo, Anheuser Busch Brewery, Missouri Botanical Gardens, Laclede's Landing, riverboat cruises, St. Louis Science Center.

Child Care: Complimentary child care will be available during meeting times. Please indicate on your registration form if you will be needing childcare. Thank you to Susan Donnelly for heading up this part of the conference

T-Shirts: T-shirts will be white and have the St. Louis Conference Logo above. They are \$8.00 each. Please pre-order your T-shirts (recommended) on the order form on page 8 of this newsletter. A limited amount of shirts will be available at the conference. All volunteers of the conference, including child care, board of directors and welcome committee please order your shirts in pastel yellow (on order form).

Thursday July 28, 2005

5-10 PM Registration
 7-8:30 PM New Family Orientation
 7-8:30 PM Sibling Mixer

Friday July 29, 2005

8 AM Child Care Check-in
 7:30-8:30 AM Continental Breakfast
 9 - 9:30 AM General Session
 9:30 AM - 12:30 PM Break Out Sessions
 1 -3 PM Friday Family Social
 3-4:30 PM Grandparents' Session
 7 - 11 PM Hospitality Room
 8 - 11 PM Board of Director's Meeting

Saturday July 30, 2005

8 AM Child Care Check-in
 7:30 - 8:30 AM Continental Breakfast
 9 - 12 PM Morning Sessions
 12 - 2 PM Lunch on your own
 2 - 5 PM Afternoon Sessions
 6 - 7 PM Cash Bar
 7 - 8 PM Dinner Banquet
 8 - 11 PM Family Dance
 9 - 11 PM Hospitality Room

Sunday July 31, 2005

9 - 11 AM Wrap up session



Registration Form

\$125.00 Two adults/two children same family _____
 (after July 1st \$150.00)
 35.00 Additional adult _____
 25.00 Additional child _____
 50.00 Professional fee - *professionals only* **not** attending family events _____
 (see page 5 for more information on how you can waive this Professional fee)

Sponsorship Opportunity -- Please consider a donation to assist in sponsoring one of the following events:

Continental Breakfast, Welcome Reception, Sibling Outing, Volunteer Lunch, Friday "Inning" *World's Fair Carnival*, Speaker Expenses _____

Total Enclosed _____

Names of all Adults attending	Relationship to Cri du Chat Child/Adult
_____	_____
_____	_____
_____	_____
_____	_____

use additional page for more than four adults

Names of all Children attending	Relationship to Cri du Chat Child	Daycare Y/N	Age
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

use additional page for more than four children

Requesting directly from the hotel:

Cribs ____ Rollaways ____ Refrigerators ____ Will you need a high chair for the banquet y n

Please attach your check or money order (in US funds only), fill out and return this form to:

5p- Society
 2005 Conference
 PO Box 268
 Lakewood, CA 90714

Any questions please call (888) 970-0777



P.O. Box 268
Lakewood, CA 90714

Return Service Requested

T-Shirt Order Form

This year's T-Shirts will have the **Meet Us In St. Louis** logo on the back and 5p- Society logo on the front left pocket area. T-Shirts will be in white. All conference and 5p- Society volunteers including host families, welcome committee members, board of directors and child care provider's T-Shirts will be in pastel yellow. Please indicate below the quantities and sizes that you would like. T-Shirts are \$8.00 each. Please make checks payable to the 5p- Society and send your order form and money to 5p- Society, PO Box 268, Lakewood, CA 90714-0268. If you are not planning on attending the conference but would still like a T-Shirt (pre-orders only) please add \$5.00 for shipping up to 3 shirts (\$5.00 for each additional 3 shirts). There will be a limited number of T-shirts available at the conference. Pre-ordering will guarantee your shirts. Any questions please contact the 5p- Society office at 888-970-0777.

Sizes	Quantity	
	White	Yellow (volunteers only)

Youth Small	_____	_____
Youth Medium	_____	_____
Youth Large	_____	_____
Youth XL	_____	_____

Adult Small	_____	_____
Adult Medium	_____	_____
Adult Large	_____	_____
Adult XL	_____	_____
Adult XXL	_____	_____

Name: _____

Address: _____

Phone: _____

No. Shirts _____ x \$8.00 = _____

Add for shipping: _____

(if not attending conference)

Total Enclosed: _____