



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

MARCH, 2002

President's Message

Help wanted: Family members willing to share their time and talent for the good of the 5P- Society as a member of its Board of Directors. Must have personal experience in the life of a person with cri-du-chat syndrome. Willingness to travel to annual conferences and mid-year meetings a must. Compensation will be awarded through the smiles and laughter of the attendees at the annual conferences.

Many men and women have answered this ad since the beginning years of the 5P- Society, and have served the society with dedication and hard work. Our organization would not be the same without these selfless people building it into what it is today. But I think that I can speak for the current and past members when I say that we are just ordinary people who happen to believe that the 5P- Society is something special and important to our lives, important enough to offer something of ourselves for its continuation and growth.

My "advertisement" may be a little on the corny side, but the invitation is real. The board will be in need of a few new members at the annual conference in August. If you have ever considered becoming a member, now may be the right time to come aboard. Read on and I'll try to explain what the board does and how it does it.

The 5P- Society Board of Directors has four meetings a year. We meet twice in person: at the annual conference, and sometime mid-year, usually in February or March, in the city of the following year's conference. We also have two telephone conferences, usually in the spring and fall.

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"How the West was Fun"

The families of Utah are excited to invite YOU to our CONFERENCE 2002 -- "HOW THE WEST WAS FUN!!". The eyes of the world have been on Utah and we hope you have enjoyed watching some of the Winter Olympics. The Conference will be held in downtown Salt Lake at the Hilton Hotel, just 3 blocks from the Winter Olympic Venues and Medal Plaza. The Hilton is beautiful and the staff are anxious to host our group. They met Angela and are excited to meet your children. And yes, there is a great indoor pool and whirlpool, etc.

The daily room rate is \$99.00 for single, double, triple, or quad occupancy. There are cribs available for \$15.00 per stay and refrigerators for \$25.00 per stay on a first come first serve basis. Transportation to and from the airport is \$6.00 each way as it is only 12 minutes from the Salt Lake International Airport. We encourage those who can to drive, as there are five beautiful canyons within a day's drive from the hotel that are a must to see. The web site is www.saltlakecitycenter.hilton.com. To make your reservations call 1-800 HILTONS or direct 1-801-328-2000. Outside the US and Canada call Hilton Reservations Worldwide nearest you. Please make sure that you tell them you are with the 5p- Society conference when booking your stay for the great room rate.

We have arranged for a sibling outing that is a short walk from the hotel to the Hansen Planetarium. This would be for school-age siblings and will be delightful. The childcare will be provided for us by Geoff and Jolene Towers and their extended families. We appreciate their volunteering for this assignment. Your children will be in very good hands. _____continue on page 4

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 Laura Bruns Executive Director Laura Castillo
5P- Society, P.O. Box 268, Lakewood, CA 90714 (714) 901-1544; (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.

Grieving

This subject reminds me of the 1993 5p- Society conference in Irvine, California. A speaker came to talk to us about loss and grieving. When one thinks of grieving it's usually due to death to someone close to you, but we also experience it when our hopes and dreams for our child and his or her future is suddenly taken from us due to illness, injury or disability. She explained to us the stages of grief -- shock, denial, guilt, anger, depression, sadness, objectivity and maintenance -- and provided a handout that explains these stages. Over the past few years I've sent this handout to parents who have felt this exact loss.

Recently, however, this handout was sent to a parent because of a loss of a family member. The parent's 15-year-old daughter with Cri du Chat Syndrome is having difficulty coping with the loss of her grandfather. The grandfather was very ill and the parent was taking care of him throughout his illness in her home. The child with Cri du Chat Syndrome had also become his caregiver -- visiting him daily and "reading" books to him -- just being close to him.

The parent of the child doesn't know what to do. Her daughter goes into her grandfather's room, points up to the sky and tells her mom she's angry, mad because her grandpa is gone. Behavior problems have begun to emerge that weren't there before.

What suggestions do you have? One parent who recently lost her daughter with Cri du Chat syndrome due to choking, suggested that the child keep a memory box. The child can then put special items into the box that remind her of her grandfather and she can go to it when she is thinking about him. It would be very helpful if you will tell us about your experience that you may have had with a loss of a family member (or even an animal) that was close to your child with Cri du Chat Syndrome. Your response will not only be helpful to this parent, but to many of us who may experience this same situation in the near future.

Responses will be greatly appreciated and some of them will be published in the next newsletter. If we get enough responses we may be able to put together our own pamphlet on the subject of loss and grieving and the child with Cri du Chat Syndrome. You may submit your response in writing and send it to the 5p- Society office, by fax at (562) 920-5240 or by email to laura5p@aol.com.

Do you have an issue that you would like to get some help with? Remember we are the experts when it comes to certain issues with children with Cri du Chat Syndrome and you may be able to help another parent. Please submit any questions to the 5p- Society office.

Website Down

Many of you have been trying to access our website www.fivepminus.org with no luck. The 5p- Society office learned that at the end of 2001 our current host filed for bankruptcy and failed to transfer our files before shutting down their servers. Fortunately we have found a new host. We are in the process of reconfiguring the site and making appropriate changes and soon it will be up and running (hopefully by the time you get this newsletter, it will be up). When it does come back up you should be able to access it through www.fivepminus.org or www.criduchat.org. Thank you for your patience in this matter.

Library Abstract Update

We have added a new article to our Library Abstract & Article listing:

98. **Young Children with Cri-du-Chat: Genetic, Developmental and Behavioral Profiles**, Baird, Samera M, et al. *Infant-Toddler Intervention* (2001, Vol 11, No. 1, pp 1-14).

If you would like a copy of this article, please send \$2.00 with a self-addressed stamped envelope to the 5p- Society office

Wanted: Host Families!

The Annual Conference Committee is currently looking for host families in the Washington DC or Philadelphia area for the 2004 conference. Yes, 2004. A year from now the Board of Directors will be visiting hotels in the chosen metropolitan area, thus leaving some lucky family or families 18 months to put the conference together. This area is desirable because it meets our goal of reaching as many families as possible throughout the country and it has been a number of years since we last visited this region (Boston 95' and Cincinnati 97').

The host families are required to assist in finding speakers, volunteers for childcare, ideas for our Friday outing and more. Because the commitment and responsibilities are so involved we often encourage 2-3 families to join forces so the load can be shared. Many of our host families speak of how challenging and rewarding it has been to host a conference. So please give this some thought and if you do not live in this area don't worry we are coming to your area soon enough.

Please e-mail Todd Piepergerdes at tpiepergerdes@foxcor.com or Laura Castillo, our Executive Director at laura5p@aol.com if you are interested or need more information about hosting an Annual Conference.

Fundraising

FYI

Do you know what the Society spends yearly on the Newsletter/Internet, Annual Conference, Executive Director, etc.? Many of us have not given it a thought, yet we spend approximately \$40,000 - \$45,000. How do we cover these expenses? We cover them with donations from people like you.

There are many ways to raise money. Some have included a Pancake Breakfast or Spaghetti Dinner through a local church or civic organization, a golf tournament or a raffle for a "Special" quilt. If you give to the United Way you may be able to direct your contribution to the Society. Today many employers will often match the contributions employees make to a qualified organization. These are just a few of the ways you can give to the Society.

We know that last year has not been easy with the economy and the events of September 11, but the Society would greatly appreciate your donation no matter the size.

Remember that the Society is a 501C(3) non-profit organization and your donation is tax deductible. Please call or e-mail our Executive Director Laura Castillo for more information.

Photo Opportunity!!

The 5p- Society Board of Directors will be putting together a calendar of pictures of our 5p- Society children and selling the calendar as a fundraiser.

Board member Cisiah Armstrong and her son Andy have agreed to take on this project with the hopes of having it completed by our next conference on August 15th in Salt Lake City, Utah. The all color 2002-2003 calendar will be a 16 month calendar and will include all the US and Canadian Holidays. It will also include certain facts about the 5p- Society, the syndrome and upcoming conferences.

We need pictures of your kids -- CANDID SHOTS ONLY PLEASE. Must be original photographs --no negatives. Due to copyright infringements we cannot accept any pictures that have copyright information on the back of the picture. **Deadline** for the pictures for the 2002-2003 calendar is **May 1, 2002, no exceptions.** We'll need pictures of all the Holidays so make sure to include them (family, individual, friends and pictures with a favorite animal are encouraged). Your pictures will not be returned, please make sure you keep copies of them. We will **try** to use all pictures submitted. If we don't use your picture for this calendar we will use it for a future calendar. Please write the name(s) and age(s) of the individuals in the picture.

Sponsors are also needed for the Calendar. You or your family can sponsor a month for \$100.00 Cut out and return the sponsorship form at the bottom of this page. Sponsorships are needed to help offset the cost of the calendar. If you know of any corporate, business or employer that would like to sponsor the calendar we have three levels of sponsorship, Gold for \$250.00, Silver for \$200.00 and Bronze \$150.00. Gold Sponsorship includes a full page advertisement in the calendar, Silver Sponsorship 1/2 page and Bronze Sponsorship business card size. Corporate sponsorship letters are available through Cisiah and the deadline to request a sponsorship letter is April 15th. All sponsors will receive a complimentary calendar and an acknowledgement in a future newsletter.

This will be an annual fundraiser. If you cannot participate this year there's always next year.

Order forms and the price of the calendar will be available in the next newsletter. We'd like to have a preliminary idea of how many calendars to order. Please contact the 5p- Society by fax, email or message and let us know if you are interested.

Please send your pictures by May 1st to:

Cisiah Armstrong
673 So. Riverview Ave
Miamisburg, OH 45342
(937) 865-9581

2002-2003 5p- Society Calendar FAMILY SPONSORSHIP

Yes, we would like to sponsor a month in the 5p- Society 2002-2003 Calendar. Please find enclosed \$100.00 US made payable to 5p- Society, PO Box 268, Lakewood, CA 90714.

Months preferred (indicate 1st-3rd choice)

Jan Feb Mar Apr May June July Aug Sep Oct Nov Dec

Inscription: (example -- The Month of June Proudly Sponsored by the Castillo Family or Grandparents of Katie Castillo)

We give permission to use our child's picture in the 2002-2003 5p- Society Calendar.

_____()_____
Signature Date Phone

**Monthly sponsors will be awarded on a first come first serve basis. If your 1st three choices are taken we will contact you for the next available. If we receive more than 12 responses, your sponsorship will be forwarded to the 2003-2004 Calendar.

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"HOW THE WEST WAS FUN!!"

For guest speakers, we will be privileged to hear Dr. Geoff Towers, a parent and Gynecologist who will speak on Puberty and Body Changes. Dennis Campbell, Associate Professor at Arkansas State University and a parent, has graciously accepted to update us on the syndrome, research, etc. as well as an overview of the special education process, goals, etc. Jennifer Rosinia, who did a great job in Miami and Canada, has agreed to speak to us on Sensory Integration and have a Brain Storming session. Dr. John Smith, Associate Professor at the University of Utah in the Department of Orthopedics has agreed to speak on orthopedic problems in children that are developmentally delayed. He specializes in scoliosis. Dr. Julien Smith, Director of Pediatric Neuropsychology Services at Primary Children's Medical Center, will present on the Neuropsychological Patterns in Cri-du-Chat syndrome.

We will have a great parent panel from some of the parents from Utah that are able to join. We are waiting confirmation on several other outstanding speakers who we know you will find very informative. The Friday outing is in the planning -- we have several great choices to pick from. Plans are underway for a great banquet and dance. We encourage western attire for the Saturday event. It will be fantastic!! Ya'll come and enjoy "HOW THE WEST WAS FUN!!"

Your Host Family, Georgia and Stephen Richey
1-801-392-2628 -- porgierichey@hotmail.com

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President's Message

During these meetings we discuss funding, public awareness, the website, upcoming conferences, the professional advisory board, and other business. At our mid-year meeting we also meet with the host families and tour prospective sites for the conference in that city and make a decision where the conference will be held.

During our recent meeting in Memphis, Tennessee, we also discussed producing a video highlighting the society for fund-raising purposes, and the development of a calendar featuring kids with cri-du-chat syndrome.

Please feel free to e-mail me if you have any questions or if you are interested in joining the board. My e-mail address is duane-n-laura@bright.net.

Enclosed in this newsletter is your registration for the annual get-together in Salt Lake City, Utah. The Richey family is hard at work planning a fun and informative conference, and I hope many of our families can attend.

Laura Bruns
President

Mark Sanger/5p-Society Charity Golf Tournament"

The Sanger family along with their good friend Keith Gerhard of Maximilian's Deli are planning to have their first annual golf tournament to support 5p- Society. It will be held at the Greystone Golf Course in Rochester, NY, July 15, 2002. We are looking to have children with Cri du Chat Syndrome profiled to create awareness and understanding of the syndrome. For a \$25.00 golf cart sponsorship you can have your child profiled at the tournament. A picture of your child along with 2-5 lines of information about your child will be placed facing toward the golfers while they ride in their carts. **All proceeds come right back to the 5p- Society.**

If you would like to participate in this fundraiser, please send a small picture and on a separate piece of paper your child's name, age, hometown, any specific likes/dislikes/ abilities.

Send the above and a check for \$25.00 to *5p- Society Charity Golf Tournament* and mail to:

Dr. Keith Sanger
6 Woodfiled Drive
Webster, NY 14580

More about the golf tournament . . .

Lunch will be served from 11:00 - 1:00. A silent auction will held at this time. Shot Gun starts at 1:00 PM. There will be a 50/50 raffle -- \$5.00 entry for shot put contest where the individuals participating will get 1/2 the money and the 5p- Society will get the other 1/2. Corporate sponsorship are also being pursued. Looking for a minimum of 110 golfers . . . interested please contact Dr. Keith Sanger at (716) 787-1174.

October 2001 Texas Gathering

The 5p- Family Gathering in Texas last October was a success. Ten families came including three sets of grandparents. The most rewarding part was the time to mingle and get to know one another by sharing information. There were all kinds of activities available at the retreat center plus we had a jumping castle donated for the day. Dr. Carlin and Dr. Millay came and made themselves available to the families. In addition, Dr. Carlin held a discussion about her latest research. We took a field trip down the road to a horse therapy ranch for a great presentation and the opportunity for the kids to pet a horse. Seven families stayed overnight. We look forward to having another gathering like this every year and hope even more families will come. We had enough sponsors and donations so it was a free event for all. If you would like to see pictures they are posted on Abby's website at <http://home.satx.rr.com/redtwin/abby.html>.



How the West Was Fun!

About the Speakers

Jennifer Rosinia, M.Ed., OTR/L -- Jennifer is a Registered Occupational Therapist with over 20 years experience in pediatrics. A specialist in serving the needs of children birth to age three and their families, she also has extensive experience working with children ages three to twenty one. Jennifer has her Masters degree in Early Childhood Education from the Erikson Institute in Chicago, Illinois, where she is completing her doctoral studies. A master clinician and a gifted teacher, Jennifer describes herself as having a dual identity working as a clinician serving infants, toddlers and their families as well as a graduate instructor teaching a variety of Infant Studies and Early Childhood courses at the Erikson Institute. With a growing national reputation as a powerful speaker and consultant, Jennifer brings a healthy balance of humor, passion and expertise to all of her presentations. She is the president of Kid Links Unlimited, Incorporated a company whose mission is to link theory to practice, parents with professionals and kids with their optimal potential.

This will be Jennifer's third conference with the 5p- Society speaking about Sensory Integration. This year we are adding a second presentation with Jennifer for brain storming and hands on approach to Sensory Integration.

John Smith, MD -- Dr. Smith is an Associate Professor in the Department of Orthopedics at the University of Utah's Primary Children's Medical Center. Dr. Smith has cared for several patients with Cri-du-Chat syndrome, including our host family's daughter, Angela. All aspects of orthopedic problems will be discussed during his presentation. He has given presentations all over the country, has authored many books, publications, electronic publications and abstracts and teaches a variety of courses relating to Orthopedic problems, procedures and research.

Dr. Smith will be presenting for the 5p- Society is "An Approach to Orthopedic Deformities in Children with Developmental Disabilities: One Physician's preceptive.

Julien Teresa Smith, Ph.D. -- Dr. Smith is the Director, Pediatric Neuropsychology Service, Clinical Coordinator Medical-Psychiatry Service, Psychology Discipline Chief at Primary Children's Medical Center, Department of Psychiatry, Neuropsychology Service and Adjunct Professor, at the University of Utah. Dr. Smith has presented all over the country on Pediatric Pain Management, Behavior Management, Neuropsychological Assessments and Coping with Chronic Illness.

Dr. Smith's presentation will be the "Neuropsychological Patterns in Cri-du-Chat syndrome."

Dr. Claudia Eliason -- A professor at WSU will be presenting on Creativity and Children.

Lillian Clark -- will be presenting on Oral Motor Speech Therapy Program.

We have the privilege of having two parents of children with Cri-du-Chat Syndrome who will be speaking on their area of expertise.

Geoff Towers, MD -- A practicing gynecologist, will provide us with some insight on puberty and body changes. This will be a great opportunity to ask questions about your teen and his/her changes.

Geoff and his wife Jolene and their extended family will provide childcare at the Salt Lake City conference.

Dennis Campbell -- Assistant Professor, Department of Educational Leadership Curriculum and Special Education, Arkansas State University will provide us with two presentations. His first will be Cri-du-Chat, review of the literature, current research and what it all means; and Monitoring your child's progress. An overview of the Special Education Process, Goals and Objectives.

Dennis has presented at the last four conferences and continues to provide the Society with much needed up-to-date information about the syndrome. In addition, Dennis, his wife Sheri will serve as one of our host families for the 2003 Memphis conference.



Family Assistance Program

The 5p- Society is once again offering five (5) scholarships for families who would like to attend the Annual Conference and Get-Together in Salt Lake City, Utah.

The scholarships help families by covering the following expenses:

- One guest room for three nights (August 15, 16 & 17)
- Basic registration fee of \$125.00 for two adults and two children

The scholarship does not pay for travel fees or incidentals.

For an application please contact the 5p- Society at (888) 970-0777 or (714) 901-1544 and leave a message for Laura Castillo.

To be considered for a scholarship your application and conference registration form must be received by May 15, 2002.

"HOW THE WEST WAS FUN!!"

Dates: August 15-18, 2002

Location: Hilton Salt Lake City Center, 255 South West Temple, Salt Lake City Utah 84101

Room Rate: \$99.00 for single, double, triple and quad occupancy per night. Cribs available for \$15.00 per stay, refrigerators available for \$25.00 per stay. Book these directly through the Hilton Salt Lake City Center (800) HILTONS or direct at (801) 328-2000. Make sure you mention that you are with the **5p- Society conference**. You cannot get the great daily room rate through internet booking.

Transportation: Hilton Salt Lake City Center is only 12 minutes from the Salt Lake City International Airport. From the airport you can take the Express Shuttle, (800) 397-0773, that you can take for \$6.00 per person each way to the hotel. Once there you can walk to many famous sites including Salt Palace Convention Center, Historic Temple Square (home of the Mormon Tabernacle Choir), world's largest genealogy library, two malls, museums and a planetarium. If you drive or rent a car you can visit a botanical garden, arboretum, a zoo, amusement parks, Kennecott Copper Mine, the Great Salt Lake and 10 national parks (all within a days drive).



Tentative Schedule

Thursday, August 15, 2002

5:00 - 10:00 PM Registration
 7:00 - 8:00 PM New Family Orientation
 6:00 - 11:00 PM Hospitality Suite Open

Friday, August 16, 2002

7:30 - 8:30 AM Childcare Check-in
 7:30 - 8:30 AM Registration
 8:30 - 9:00 AM Welcome, Introductions, Announcements
 9:00 - 10:30 AM Parent Panels
 10:45 - 12:30 AM (1) Puberty and Body Changes
 (2) Neuropsychology and Cri du Chat Syndrome
 (3) Grandparents Supportshop
 1:00 - 5:00 PM Family Outing - TBD
 6:00 - 11:00 PM Hospitality Suite Open
 8:00 - 10:00 PM Annual Board Meeting

Saturday, August 17, 2002

7:30 - 8:30 AM Childcare Check-in
 8:30 - 9:00 AM Announcements
 9:00 - 10:30 AM (1) Orthopedic Deformities in Children with Developmental Disabilities
 (2) Monitoring your Child's Progress. An Overview of the Special Ed Process
 10:45 - 12:30PM (1) Sensory Integration 101
 (2) Creativity and Children
 11:00 - 12:30 PM Sibling Outing to Hansen Planetarium
 12:30 - 2:00 PM Lunch on Your Own
 2:00 - 3:30 PM (1) Oral Motor Speech Therapy
 (2) Cri du Chat Syndrome -- Review of Literature, Current Research
 3:45 - 5:15 PM (1) Sensory Integration and Brain Storming
 7:00 - 11:00 PM Banquet and Family Dance

Sunday, August 18, 2002

9:30 - 11:00 AM Picture Session, Open Forum, Conference 2003 in Memphis

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2002 North American Annual Conference and Get-Together

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, 2002)

\$30.00 for each additional adult _____

\$15.00 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 (\$15.00 per stay) ___ refrigerators (\$25.00 per stay) ___ highchairs

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

2002 Conference Registration
 5p- Society
 PO Box 268
 Lakewood, CA 90714-0268

any questions (888) 970-0777 or (714) 901-1544



"How the West was Fun"
2002 Annual Conference and Get Together
Salt Lake City, Utah
August 15-18, 2002

Conference Registration Enclosed

Return Service Requested

P.O. Box 268
Lakewood, CA 90714



Would you like to receive future newsletters electronically in pdf format? If so, please send an email to laura5p@aol.com