



NEWS

The Family Support Group for Children with Cri du Chat Syndrome

JUNE, 2002

"HOW THE WEST WAS FUN"

Only a few weeks remain before our Annual Conference and Get-together. We look forward to seeing all our old friends and meeting all the new families. Remember, we won't be coming back to the West for about four years. We'd like to see more families from California, Oregon, Washington, Nevada, Arizona, New Mexico, Idaho, Montana, Wyoming, Colorado, Utah, Western/Central Canada and Mexico attend.

Airlines have great prices right now. Check out <http://www.cheaptickets.com> for some great buys online. The Hilton Downtown is looking forward to serving us. There are lots of shopping and eateries nearby. If you plan a driving trip to Salt Lake City, don't forget to stop by the beautiful National Parks on the way.

Many families make the conference their yearly vacation. It is comforting seeing friendly faces, catching up on yearly events and sharing educational accomplishments. In addition to the sharing of educational accomplishments, this year we plan on having a "What Works" table in the hospitality suite. We want to know what items or ideas have worked for you, in the subjects of safety, toys, language development, fine and gross motor skills, and clothing. Even if you cannot attend the conference you can contribute to the table. We'd like to have as many items as possible to share with the families. Submit your ideas or items to the 5p- Society. You can send them to the 5p- Society office, PO Box 268, Lakewood, CA 90714-0268, email them to lc5pminusociety@aol.com or to the Richeys at porgierichey@hotmail.com.

The Friday outing guarantees to be a fun history lesson. Learn about Utah's history at This Is The Place Heritage Park. This Is The Place Heritage Park is the home of Old Deseret Village, a living community that has been recreated to represent Utah's past. All of its historic buildings are carefully restored or recreated homes, stores, churches and other structures essential to a bustling pioneer community. The town is filled with actual "citizens" who demonstrate everyday pioneer life and make you a part of it.

The townspeople of Old Deseret Village wear pioneer bonnets and shawls. Discover what life was like before all modern conveniences -- what would we do without cell phones? Observe the villagers in action and you'll soon appreciate the hard-working, yet fun-loving, Utah pioneers.

In case you've misplaced your registration form for the conference, another is attached to this newsletter. If you have any questions, please contact the 5p- Society office.

Preorders are now being taken for conference T-shirts? The cost is \$8.00 each. Contact the 5p- Society office for an order form.

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 (562) 804-4506 or (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.



Speaker Update

A few new speakers have been added to our lineup for the 2002 conference:

Sally Jones is a Child Life Specialist at the Women's Center, McKay Dee Hospital in Ogden, Utah. Ms. Jones topic will be "Wit & Wisdom."

Dr. Brent Blaisdell is a young psychologist who helps to put fresh perspective on helping families focus on what is working. The topic of his presentation is "Panning for Gold." He is from Farmington, Utah.

Our Grandparents Supportshop will be lead by Jim and Fran Bodle (grandparents of Katie Castillo) and Art & Pat Strong (grandparents of Maxwell Strong).

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A Professional Photographer has graciously agreed to donate her time during the Saturday night banquet to take portraits of your family as a fundraiser for the Society. The cost for 5x7 pictures will \$8.00. What a great opportunity for your holiday picture!!!

Website

We have a new webmaster, Todd Winslow of Sacramento, California. He is the father of 9 month old Hailey. Todd is a Graphic Designer and has designed many websites. Todd has given our website a whole new, refreshing look. A new feature to the website is a place for homepages. If you would like to include your homepage, visit our site at <http://www.fivepminus.org> and follow the directions.

Todd has also redesigned our brochure. Our new brochure is now available thanks to a \$1,000.00 donation from Dale and JoAnn Huffman, grandparents of Amy Campbell of Jonesboro, Arkansas. A heartfelt thank you to Dale and JoAnn for their continued support of the Society, and a special thank you to Todd, for volunteering his time and sharing his expertise.

Please make changes to your email address book. Due to a large amount of unwanted spam being received by the email address laura5p@aol.com, it has been changed to lc5pminussociety@aol.com. It would be greatly appreciated if this new email address is only used for business purposes. The email address laura5p@aol.com will slowly be phased out.

More Changes

Beginning August 1, 2002, the 5p- Society will no longer be affiliated with Mail Boxes Etc. The office will be moved to Laura Castillo's home in Lakewood. The toll free number will remain the same. The new phone number for the Society will be (562) 804-4506.

Also the Society still receives mail at the 7108 Katella Ave address. Again, beginning August 1, 2002 all mail sent to that address will not reach us. All mail should be sent to the PO Box 268, Lakewood, CA 90714-0268.

Please be sure to make the changes in your address book.

Fundraising

Mark Sanger/5p-Society Charity Golf Tournament

The charity golf tournament is almost here and the Sangers have been hard at work soliciting donations for the silent auction. One item they received is an autographed picture of Doug Flutie (football player for Boston College and the Buffalo Bills).

The tournament will be held on July 15, 2002 at the Greystone Golf Course in Rochester, NY. If you love to golf and need an excuse for a trip to New York, come join the fun.

Many of you have received a letter from the Sangers requesting a picture and a short bio/story about your child. They would like to create awareness and understanding of the syndrome for the golfers by placing the picture/bio in the golf carts. They are very pleased with the responses they have received and the many wonderful pictures and stories. They want your story too!! A \$25.00 donation is requested to sponsor the golf cart, but any donation will be accepted, and if you can't send in a donation, but you would like to send in your child's information, we will gladly use it. **All proceeds come right back to the 5p- Society.**

Send the picture/bio and your donation to the *5p-Society Charity Golf Tournament* and mail to:

Dr. Keith Sanger
8 Persimmon Dr
Penfield, NY 14526
(585) 586-3888

2002-2003 Calendar

Many thanks to all the families that submitted photos for the Calendar. All photos that were submitted will be used. There are still some months available for sponsorship. This makes a great opportunity for extended family members to contribute to. On the coupon below you can see which months are available. Know another family? Maybe the two of you can co-sponsor a month. Or better yet, ask your boss if s/he would like to sponsor a page. All sponsorships must be received by July 15, 2002 to be considered for the 2002-2003 calendar due to printing requirements.

Send your sponsorship with the attached coupon to 5p- Society, PO Box 268, Lakewood, CA 90814.

Calendar 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.

Every once in a while I'll get a little down, as I'm sure most of you do. This was given to me by a friend -- I hope it helps! -- Laura Castillo

Steps to Happiness Everbody Knows:

You can't be all things to all people.
You can't be all things at once.
You can't do all things equally well.
You can't do all things better than everyone else.
Your humanity is showing just like everyone else's.

So:

You have to find out who you are, and be that.
You have to decide what comes first, and do that.
You have to discover your strengths, and use them.
You have to learn not to compete with others,
Because no one else is in the contest of "being you".

Then:

You will have learned to accept your own uniqueness.
You will have learned to set priorities and make decisions.
You will have learned to live with your limitations.
You will have learned to give yourself the respect that is due.
And you'll be a most vital mortal.

Dare to Believe:

That you are a wonderful, unique person.
That you are a once-in-all-history event.
That it's more than a right, it's your duty, to be who you are.
That life is not a problem to solve, but a gift to cherish.
And you'll be able to stay one up on what used to get you down.

- Author Unknown



2002 Hotel Booking

To make your hotel reservations for the conference please contact the Hilton Salt Lake City Center at (800) HILTONS or direct at (801) 328-2000. Please make sure you tell them that your with the 5p- Society conference for the reduced rate of \$99.00 per night.

WE ARE WAIVING THE INCREASED FEE FOR LATE REGISTRATION !!!!

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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) waived

\$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:

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

any questions (888) 970-0777 or (714) 901-1544
 (562) 804-4506



Return Service Requested

P.O. Box 268
Lakewood, CA 90714



Would you like to help keep the cost down for mailing the newsletter? Would you like to receive future newsletters electronically in pdf format? If so, please send an email to lc5pminussociety@aol.com.

(Only two were received last time)