

5P- News

Family Support Group for Children with Cri du Chat Syndrome

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.

5p- Society, PO Box 268, Lakewood, CA 90714-0268 (562) 804-4506 toll free (888) 970-0777 fax: (562) 920-5240

President's Message *by Greg Abbruzzese*

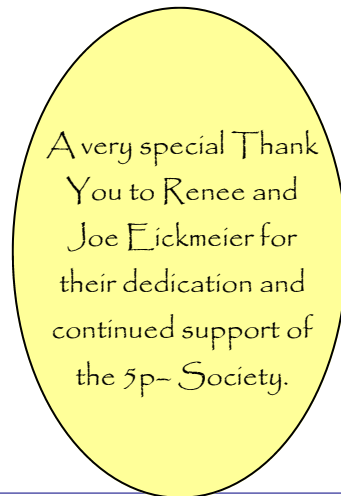
Dear Five P Minus Society

We are just a few weeks away from the Santa Clara conference and everything seems to be going very smoothly. We have one last slot open for speakers, however, not to worry, as we will most likely just have one of the speakers double up a session. Again, for your reference, this list of confirmed speakers is as follows: Monica Bessler, Speech Therapist, Dr. Rafael Pelayo from Stanford's Sleep Center, Dr. Pam Richardson will address sensory issues, S.N.A.P will discuss estate planning, Cri du Chat 101 by Dr. Dennis Campbell, Educational issues of children with Cri du Chat Syndrome by Dr. AmySue Reilly, Dr. Campbell and Dr. Joan Henley. Dr. Henley and Dr. Reilly will also present on IDEA and IEP's and behavior modification. We have scheduled a grandparent workshop, and possibly a reading

specialist. This is an impressive line-up of speakers that should address a great deal of concerns expressed by the Society. I would encourage any family member that would like to see a different type of speaker (advocacy speakers, special needs attorney, etc) to come forth and see if that is something that you would like to hear at the next, or up coming conferences. We are very open-minded when it comes to what issues you would like to hear at these conferences. Please contact any Board members and we can address it at the next Board meeting. In addition to the fine list of speakers, the Day Care volunteers are all lined up. As usual, we can always use the extra help in the children's room. If you would like to volunteer for one session, it would be tremendously helpful!!! Make sure that you sign up your children as early as possible for the entire weekend so that we can coordinate the

appropriate coverage. Regarding the playroom and local activities, we are still seeking local donations (or to borrow) additional age appropriate toys to keep the kids occupied. Again, please contact any Board member or Laura if you can help out. Feel free to browse the link and plan your getaways accordingly.

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Resources

- Message board: Post a message or respond to another parent's questions at http://groups.yahoo.com/group/Cri-Du-Chat_Syndrome/ Need to join group to participate. New members joining this active group daily.
- Clothing: <http://www.special-clothes.com/>
- Patient Travel <http://www.patienttravel.org>
- Signing Videos and DVDs: <http://twolittlehands.com>
- Speech/Language and Feeding tools: <http://talktoolstm.com>
- Specialty toys – Abilitations: <http://www.schoolspecialtyonline.net/>
- Identification bracelets: <http://www.stickj.com>
<http://www.mypreciouskid.com>
<http://www.911destiny.com>
<http://www.laurenshope.com>

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Surf'n California Style!!

It's not too late to sign up for the 2006 Conference and Get Together in Santa Clara, California. With hotel rates as low as \$89.00 a night, it's the deal of the century.

Be prepared to dance the Hula!! A Hawaiian dance troupe will entertain us during the Friday

Family fun event at the pool. Other activities include *ring the octopus*, *ring the dolphin*, and *bubbles*. Make sure you wear your best Hawaiian shirt and bring your grass skirt; don't forget the flip-flops; it's going to be a great event. The event is being sponsored by the Lans-

ford family and their family business. The Lansford's have a 16-year-old son, Jason, with the syndrome.

Our grandparents have developed their own support system and will be meeting on Friday afternoon to talk and share about their special grandchild.

Parent's Page—

Dear 5p- Society families, my daughter, Kendra, is 11-years-old, and I just took her to a chiropractor to get her adjusted. The doctor took x-rays and saw some defects. Are there any common or known skeletal anomalies or defects, primarily in the pelvic, lumbar and femur head that are seen on plain x-ray film? Any advise or suggestions would be greatly welcomed. Thank you.

Dana Gonzales—954-443-9538
or whateverd@aol.com

Dear 5p- Society families, my 17-year-old daughter, Tessa, is having problems with her knees. Her knees luxate and she falls to the ground with pain. The last time she chipped her kneecap. We have had x-rays and MRI and have seen three orthopedic specialists, they say nothing can be done. Has anyone else come across this and what did you do? Any assistance would be greatly appreciated. Thank you.

Tanya Stevensen—
tanyatess@aol.com

Congratulations to Cody Palma for winning two medals at the Special Olympics in May. He received a Gold Medal in track and a Silver Medal in the Softball throw.

I know there are a lot more kids out there that participated in the Special Olympics in your area. Please send a picture and share a story!!



The Grand Marshal of the Day by Sue McDaniel

Congratulations to the McDaniel Family for being chosen to lead the Parade of Dreams at Disneyland on New Year's Day.

We had a terrific day in the park, full of extra special treatment. We had to be in the park at 10:30 a.m. on New Year's Day to meet with a cast member. She gave us instructions for the parade along with reserved seating to watch a show at the Golden Horseshoe, that afternoon. We also received reserved seating after the parade was over and reserved seating for the Christmas parade that evening.

It was such a special day . . . One we will never forget! We rode in a 1928

American LaFrance Firetruck decorated with Mickey balloons, our name on a sign on each side of the truck, and a set of Golden Ears for each of us. Jared of

course wore his for only a few seconds and Erica wanted to wear her princess tiara instead. Dad and I wore ours though, after all it was the 50th Anniversary of Disneyland parade!!!, which they called the Parade of Dreams. Our driver was off, and with a big welcome by the Disneyland Mayor and several characters the music started and the Mayor with a cordless microphone proceeded to announce to the lined Main Street people "Happy New Year!, please join

me in welcoming our Grand Marshals of the day . . . THE MCDANIEL FAMILY!!" It was a half hour of smiles and waves to people we didn't know but worth a lifetime of joy watching Jared enjoy himself. He was full of smiles, rocking his head as if he was on a great ride. At the parades end he politely signed, "more please." If only he

could go to the Happiest Place on Earth every day!! It was a fantastic way to start 2006!!!



President's Message *continued . . .*

We have received a few generous donations in the recent months that have helped guide the Society through another conference, thank you all for your support!!! However, we are still coming up a bit short when it comes to running the day-to-day operations for the remainder of the year. Please don't forget that membership dues are due and we still have a few hundred people that have not sent in their dues. To date, we have received fewer than 300 dues and we have over 900 members. These dues are a critical part of allowing the Society to grow. Laura Castillo does a great job on a shoestring budget, but we are running out of laces. Keeping that in mind, our fundraising efforts have increased significantly. For example, Gloria Griffin has continued her tireless efforts on behalf of the Society raising several thousands of dollars. Georgia Richie came up with a

great idea that we ALL can participate in from a local level. Apparently, each Wal-Mart has discretionary funds to assist charities in raising money for their cause. All you have to do is approach the Manager and fill out a form. It's that simple! I would encourage all members to at least give it a try. It only takes a few minutes and any monies collected will go a long way. In addition, Micah Hoernig has done a great job soliciting his employer for \$750 dollars. Lastly, a special thanks to the Lansfords for their substantial donation that has allowed us to underwrite a great deal of this year's conference. For that we are truly grateful!

We are gradually taking the next steps to improve the Society with putting a link of the conference to the web. This is a critical step forward for the Society to improve communication for those who will be unable to attend some of the con-

ferences. Kent Nichols will be our on-site videographer; thanks Kent!!! I warn you that it may take a while to work out the kinks of the sessions (audio – questions from the audience, filming the speakers, etc.) however, Joe Eickmeier has generously agreed to donate his time editing the test session. Please keep in mind that this is an extremely time-consuming task and would cost the Society in the thousands of dollars to execute from an outside technician. Clearly, the Eickmeier's are up for "Family of the Year" between running last year's conference, Joe's excellent child care and his mother's great giveaway bags. They are tremendous friends of the Society.

Not to get ahead of ourselves, but the updates in Minneapolis and VA Beach are going ahead of schedule. Paul Bakken has already sent out local inquires for assistance and started laying the foundation for next year's conference. I would encourage any local or regional families near Minneapolis

to contact Paul Bakken directly. Paul is a Board Member and his contact information is on our web site. The VA Beach 2008 conference being run by Christy Blount and Anne Zettemoyer is already off to a fast start as well. They renegotiated a special parking rate at the Marriott hotel and they have already raised over \$9,000 dollars from their raffle. They have a road race planned and several other events in the mix for the 2008 conference. That said, we are looking for a site in the central part of the country for 2009. If you are interested in hosting a conference, please contact any Board member directly so that we can review your location.

Again, thank you all for your continued support and I look forward to seeing you in Santa Clara.

Greg

2007 Calendar—Pictures Wanted

Pictures for the 2007 Calendar and Picture Yearbook are now being accepted. **Please send your pictures electronic format (jpeg) to ttownsend@buckeye-express.com.**

New for 2007, your Calendar and Picture Yearbook (photos from the conference and those received all year long) will be available in October 2006 in a CD format. You can view the calendar and pictures from your computer, or you can print off the ones you want.

Calendar monthly spon-

sors are now being accepted. A reduced price of \$50.00 per month for sponsorship. Your sponsorship will help with the development and copying of the pictures onto disks. Your child's picture will be showcased for the month of your choice. You need not be a sponsor for your child's picture to be included. All pictures received will be included. Months will be reserved on a first come, first serve basis.

Costs of the picture CD will depend on how many sponsors are received.

Any questions please contact director@fivepminus.org.

Please send in your pictures and attached permission slip no later than **August 31, 2006**.

Please fill out the form to the right and return it and any sponsorship monies to:

Attn: 2007 Calendar
5p- Society
PO Box 268
Lakewood, CA 90714

We, the parent of, _____, give the 5p- Society permission to publish our child's picture(s) in the 2007 Calendar and Picture Yearbook.


____ Yes, we'd like to sponsor the month of _____ for the Calendar. Enclosed is our check for \$50.00 made payable to the 5p- Society.

____ Sorry, we can't sponsor a month at this time, but please include our child's picture(s) in the Calendar and Picture Yearbook.

Parent's Signature

Date

Family Fundraising



Raeann's Creations

What began as a hobby for a year old Raeann has turned into a way to earn money for organizations involved with helping her brother Derek, who has Cri du Chat Syndrome along with PDD... They include: The 5p- Society, NAAR (National Alliance for Autism Research), and Clavian Heights School.

Raeann became interested in making bracelets at 6 years old and quickly grew more creative designing several different specialty bracelets including: Faith, Autism, Special Needs and Celtic Rosary. The bracelets are made using different colored beads and charms that represent the type of bracelet. Each bracelet is accompanied by a unique card that describes the meaning of the color of beads which are used. The price of each bracelet is \$10.00 and it comes in a cute little bag which makes it perfect for gift giving. \$3.00 from each bracelet purchased will be donated to the 5p- Society!

Orders will be accepted by email (sleith11227@msn.com), phone (724-861-5655) or by mailing the form below to Raeann or Johnna Sleith 11227 Pershing Dr. N. Huntingdon, PA 15642

5p- Name: _____

Address: _____

Phone: _____ E-Mail: _____

____ Faith ____ Autism ____ Special Needs ____ Celtic Rosary
(Indicate number of bracelets needed in the space provided)

Children sizes are available for children under 10 years old upon request.

Total number of bracelets needed ____ Amount enclosed: \$ _____

We'd like to thank Raeann who has already raised over \$200 for the 5p- Society through her jewelry sales. If you'd like to order a bracelet(s) please use form at the left.

We'd also like to thank Gloria Griffin for her continued support through her jewelry sales. This year to date she has raised more than \$1400.00 for the 5p- Society.

Memberships continue to come in and we are currently at 319 members. Membership renewal is due August 1st. Many of you have already renewed. A postcard reminder will go out to everyone. If you've paid your membership within the last 6 months please disregard. Thank you for your continued support

A special thank you to all the families who participate in their Employer Matching program and/or deduction contribution program. Participants include:

- Bruce Rambacher
- Robert Davenport
- Andrea Poole
- Nicole Leary
- Alison Bakken
- Stephen Richey
- Casey Evans
- Rhonda Becker
- Kent Nicholls
- Inman family

We also have a few anonymous participants, if you are one of them, thank you!!

Other fundraising ideas:

Pizzeria Uno's—have a party and 20% of the bill will go to the charity of choice. Check out their website at www.unos.com/fund.html

Wal-Mart—check your local Wal-Mart and ask if they would like to donate to the 5p- Society for a special activity such as the Conference. One family, Kim and Kevin Campbell, has done this and received \$500 for the conference to assist in paying for materials needed for a "Make and Take" special project.

DVD's Available from the 2005 conference in St. Louis, Missouri. Four presentations were videotaped and are now available. The presentations are \$5.00 each and you can order by sending a check to the 5p- Society, PO Box 268, Lakewood, CA 90714.

*Cri du Chat 101—Dr. Dennis Campbell
Behavior Applications—Dr. AmySue Reilly and Dr. Joan Henley
Adults with Cri du Chat Syndrome—Dr. Kim Cornish
Role of Emotions on Child Development—Dr. Jennifer Rosinia*

Center for Disease Control (CDC) 2006 National Health Promotion Conference

You are invited to CDC's 2006 National Health Promotion Conference on Tuesday, September 12 through Thursday, September 14, 2006. The 2006 National Health Promotion Conference is the first joint conference presented by CDC's Coordinating Center for Health Promotion and the National Center for Chronic Disease Prevention and Health Promotion, the National Center on Birth Defects and Developmental Disabilities, and the Office of Genomics and Disease Prevention. For more information please go to <http://guest.cvent.com/i.aspx?1Q,P1,3EEBA81C-829D-42A0-B47A-857D54808E73>

This will be located at the Hilton Atlanta, Atlanta, Georgia.

Family working on a Documentary to do filming at the 5p- Society 2006 Conference in California.

The Tanner family would like to promote awareness of the syndrome so that families do not have to go through the despair that they went through because of the grave prognosis that was given to them about the syndrome when their daughter was diagnosed. The Tanner's along with a New York based filmmaker, will be interviewing families and hope to provide better knowledge of the syndrome to professionals and lay person alike. The 5p- Society looks forward to participating in this needed communication forum.

Grandparent's Corner

New to the Society? Our Grandparents have their own newsletter. Please contact Pat Strong at odah@gtmel.com to be added to their own mailing list. Grandparent's support group will be held on Friday, 4-6 PM at the Annual Conference in Santa Clara, California. Besides sharing about their grandchild and his or her development, they will be talking about fundraising opportunities and ways to help the Society.

Thank you and congratulations to all the grandparents who were nominated for The Grandparent of the Year award. We will announce the recipients in the September newsletter.

Surf'n California Style!!

We'd like to thank our Conference Sponsors to date:

Mr. and Mrs. Ming– Hsiang Tsou
 Mr. Robert Wright
 Mr. and Mrs. Robert Dennis
 Mr. and Mrs. Paul Arango
 Mr. and Mrs. Bobby Zlatanov
 Vela Corporation
 Filice Lansford Development Corp
 Lan Associates
 Fabco Generators
 Mrs. Gloria Griffin
 Mr. and Mrs. James Bodle
 Mr. and Mrs. Damien Hillseth
 Mr. Masoud Foudeh
 Microsoft Corporation
 Wal-Mart
 Mr. and Mrs. Micah Hoering
 Ms. Andrea Blum and Mr. Kenneth Leeser
 Mrs. Jennie Tanaka
 Mrs. Gloria Johnson
 Mr. and Mrs. Cedrick Wong
 Safeway
 Dr. Reza Neil
 Ms. Nina Rivkind and Mrs. Steven Shatz

Speakers and Topics:

Dr. Dennis Campbell— Cri du Chat Syndrome 101
 Dr. AmySue Reilly—Behavior Considerations
 Dr. Joan Henley—IDEA and the IEP

Melvin Honda of Metlife—Estate Planning for the Special Needs Child
 Dr. Pelayo—Sleep Disorders
 Dr. Pam Richardson—Sensory Integration
 Dr. Campbell, Dr. Reilly and Dr. Henley will be talking about their Educational Research project, and will be interviewing more families for the research project
 Dr. Monica Bessler will discuss the status of her Tert Gene Research and will be taking more samples for the study.
 Parents Helping Parents of Santa Clara—Sibling workshop
 Parent Panels—Breakout session for different ages
 Parent Panels—Breakout session for Moms and Dads
 Judith Gomoll— Transition to Adult Living— Strategies and Resources
 Dr. Hardan—Psychiatrist

Make and Take Special Project by Kim Campbell. Make a sensory toy for your child and take it home with you. A sewing project scheduled for Friday evening.

Host families:

Don Hille and Laura Ballance
 Dawn Ward
 Bobby & Mila Zlatanov
 Diane Ekhoff
 Kristi Dasher
 Merrill & Joanne Bobele
 Al Hakam

Thank you for the many hours that you have given — it's almost here!!! Laura

Board of Directors

Would you like to participate on the 5p– Society Board of Directors? We are currently looking for new members. If you are interested please contact any of the current board members or contact the 5p– Society office. Our next board meeting will be on Friday evening, July 28, 2006 at the Santa Clara Marriott. All members are welcome to attend the board meetings.

Coming up . . .

2007—Annual Conference and Get Together: July 26-29—Sheraton Bloomington South, Minneapolis, Minnesota, host family Paul and Alison Bakken

2008 — Annual Conference and Get Together: July 30-August 3 — Norfolk Marriott, Norfolk, Virginia, host families Bill & Christy Blount and David & Anne Zettlemoyer.

2009 — We are currently looking for families interested in hosting the 2009 conference. Moving the conference around the country, the mid-south would be a great place to be — any interest?



Surf'n California Style

5p- Society Annual Conference Santa Clara
July 27-30, 2006

Conference Registration form

Yes, I will be attending the 5p- Society Annual Conference and Get together, scheduled for July 27-30

Basic Registration fee—Member — \$150.00 USD for up to two adults and two children.

Non-Members— \$200.00 USD for up to two adults and two children

Each Additional Adult - \$50.00 USD each

Each Additional Child — \$25.00 USD each

No, I am unable to attend, please accept our donation. Please apply the donation to the following:

Name: _____

Phone Number: _____

Address: _____

City/State/Zip: _____

Email address: _____

Names of Adults who will be attending the conference

Relationship to 5p- Syndrome Child/Adult

Names of Children who will be attending the conference

Relationship to 5p- Syndrome Child/Adult

Age

Childcare
Y/N

Items requested directly from Hotel: Refrigerators _____

Cribs _____

roll-a-way _____

Photo Release:

I/We give(s) the 5p- Society authorization and/or permission to use any photograph and/or video tape of our immediate family who attends the 2006 5p- Society Annual Conference and Get-Together in Santa Clara, California for the purpose of promoting the 5p- Society or explaining Cri du Chat Syndrome. The 5p- Society will have ownership of the photographs and/or video tape and will not be used for any other purpose other than to promote the Society or educate the general population. Photographs will also be used in the 2007 Photo Yearbook.

Signature

Date

Signature

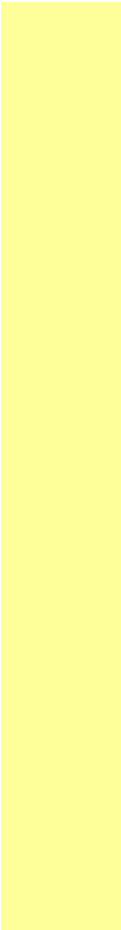
Date

Fill out and return form to 5p- Society, PO Box 268, Lakewood, CA 90714-0268



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

Return Service Requested



2006 Conference T-Shirts

Surf'n California Style t-shirts will be in all white with the conference logo. All conference and 5p- Society volunteers including the host families, welcome committee members, board of directors and child care provider's T-shirts will be in a contrasting color. Please indicate below the quantities and size that you would like. T-shirts are \$10.00 each. Please make checks payable to the 5p- Society and send your order form and money to the 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. **Pre-order deadline has passed, but we will fill orders with overflow on first come first served basis.**

Sizes	Quantity		
	White	Volunteer	
Youth Small	_____	_____	Name: _____
Youth Medium	_____	_____	Address: _____
Youth Large	_____	_____	_____
Youth XL	_____	_____	Phone: _____
Adult Small	_____	_____	No. Shirts _____ x \$10.00 = _____
Adult Medium	_____	_____	
Adult Large	_____	_____	Add for shipping: _____
Adult XL	_____	_____	(if not attending conference)
Adult XXL	_____	_____	Total Enclosed _____