

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, Lakeview, 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 Members,
I hope everyone is gearing up for the trip to Santa Clara for this year's conference! The Santa Clara Marriott is quickly filling up so make sure that you have signed up for the conference and reserved your rooms accordingly. I am pleased to announce that things are ahead of schedule as the following speakers/sessions have confirmed attendance: Dr. Dennis Campbell, Dr. Amy Sue Reilly, Dr. Joan Henley, Dr. Monica Bessler, Dr. Rafael Pelayo from Stanford's Sleep Center (special thanks to Denise Lansford for the referral and her support), Dr. Pam Richardson will address sensory issues, S.N.A.P will once again discuss estate planning and medical insurance. We have scheduled a nutritionist, a grandparent workshop, and a reading specialist who will also be presenting as well. Unfortunately, Jennifer

Rosinia, Sarah Rosenfeld Johnson, and Kim Cornish will not be in attendance this year. Nevertheless, this should be a very productive conference.

As I had mentioned in previous newsletters, the cost of running the Society and these conferences has grown exponentially over the years. We have received several substantial donations over the past few months that have helped significantly with the day-to-day operations of the Society and conference preparation for this year. For that we are extremely grateful. Thank you all for your continued support!

Although we are making gains in certain development areas, we are still lacking in others. I encourage more continuous feedback to the Society's Board members. Based on our last Board meeting, Kent Nicholls, is investigating what it would take

to set up Web Casts of sessions from the conference for those who could not attend. We hope to have something up and running by the Minneapolis conference. Kent is looking in to what back-end support we would need and the cost. In addition, we are looking to expand the family scholarship offerings and working with several national banks on setting up online membership/donation capabilities. Lastly, there are still members who have not signed up for

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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>

See pages 4 & 5 for more resources

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Surf'n California Style!!

The 2006 Annual Conference is upon us and your host families have been working hard to bring you a fabulous conference. In this newsletter you will find a registration form, hotel information, t-shirt orders and more.

Welcome to the beautiful and sunny climate of the Silicon

Valley, San Francisco Bay area of Santa Clara, California. Here you will find yourself only 30 minutes from the Pacific Ocean, 45 minutes from San Francisco and 2 minutes away from the Great America Amusement Park.

The Conference will begin on Thursday evening with a New

Family Orientation and Sibling Mixer. Friday Family Fun event will be a Luau-like pool party complete with a barbeque lunch, courtesy of the Lansford family (Filice Lansford Development Corp and Vela Corporation).

Continued on page 6

New to this issue Resource Lists, tried, true or referred to the 5p- Society by parents like you.

Parent Kristen Clark has compiled a list of resources for us to share with you.

See page 4

Parent's Page— Titer test (pneumococcal antibody panel)

By Christy Blount

Does your child suffer from frequent upper respiratory and ear infections? My name is Christy Blount. My daughter is now three years old. Her name is Cassidy Blount and she has a twin brother, Davis. When Cassidy was 19 months old, we were referred to an Infectious Disease doctor because of reoccurring upper respiratory and ear infections.

They ordered a titer test (pneumococcal antibody panel) to check her levels. Her results came back very poor/low. They told me that if her levels did not increase, we would have to possibly come back to the hospital once a month to inject Cassidy with antibodies.

This would help her body fight off the upper respiratory infections (along with others), since her body did not make them herself according to the results. During more research, the Infectious Disease doctor realized Cassidy had missed one of the vaccines given to all children called Prevnar. Prevnar is usually given at 2mo, 4mo, 6mo, and again at 15-18 months. She was not given the 15-18 month shot because there was a national shortage.

The doctor immediately gave Cassidy the Prevnar shot and we went back 1 month later to find her titer test came back within expected levels.

She seemed to have less frequent upper respiratory and ear infections following the last shot. Now that she is older, they are even less frequent (thank the Lord)! At the advice of the Infectious Disease doctor, Cassidy will get extra Prevnar shots in August 2006 and then again in September 2008. At some point, we will also retest the titer test to check her levels.

If you would like more information about vaccines, please visit www.aap.org. Feel free to contact me with additional questions at bill3125@dlba.hrcoxmail.com.



Cassidy age 3

Her Name is Montel by Casey Evans



Montel age 12

My name is Casey Evans and I would like to briefly share with you some of the reasons I had for writing my recently published book, *Her Name is Montel* (Montel is the name of my daughter with CDCS). First though, let me apologize up front if some of my forthcoming observations and comments about books in the special needs genre are obsolete and inaccurate. Probably like many of you, when my daughter was very young there was approximately a 2 – 3 year window when I read nothing but books dealing with special needs children, parenthood, sibling relationships, etc. My daughter is now 12 years old however, and I must confess it has been several years since I have read any special-needs type books.

Anyway, back when I was immersed in reading children with special needs books I noticed none of them were from a male perspective. Actually there was one, but the author was speaking more as a professional psychologist than as a parent (he had a boy with autism). I thought it was important to

write a book about having a child with special needs from a father's perspective.

Another common theme I noticed with the books I read was how the parents were always immediately heroes and advocates for their child. Regrettably that was not the case for me. I really struggled to accept Montel and I found it difficult to believe that I was the only person in the world with such apprehension. I thought it was important for me to tell the story of how I changed. I wanted to let others know that if they are struggling with acceptance of their son or daughter they are not the only ones to have done so, and that it is perfectly okay, they will get through it. But perhaps more importantly than how I changed, I wanted to document who was able to change me. It was the power of the pure and loving spirit of my own daughter, Montel. I am hoping that new parents someday may be able to gain from my experience and realize that while it may not feel like it at the time, their own son or daughter with Cri du Chat

truly is a very special human being, and quite possibly one of the greatest blessings they will ever receive in their lives.

You may obtain the 88 page book by going to www.outskirtspress.com/montel and following the links, or by going to Barnes and Noble (www.barnesandnoble.com) or Amazon (www.amazon.com) and searching for the title, *Her Name is Montel*. In addition, for those of you attending the conference this summer in Santa Clara I will be bringing copies of the book for sale as well. Finally, I want to let everyone know that in addition to getting what is hopefully a good book, a portion of the proceeds from the sale of each book benefit the 5p- Society.

Casey Evans
casey.m.evans@pacbell.net

President's Message *continued . . .*

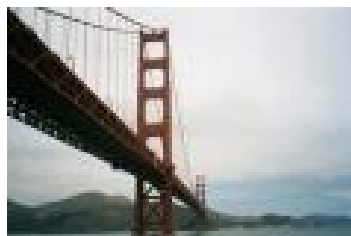
the \$25 dollar membership fee. To date, *only* 263 out of 900 members have paid their membership fees. If you have not signed up yet, please send your membership fee in at your earliest convenience.

As we are confident that the California conference will go off without a hitch, we are equally confident that Paul Bakken and friends are laying a strong foundation in Minneapolis for the 2007 conference. Paul is investigating fundraising options and plans to give a more in-depth report post the CA conference. The 2008 conference being run by Christy Blount and Anne Zettlemoyer is off to a very fast start. At our recent Board meeting in VA Beach, we were graciously hosted by Christy and Anne who brought us to several locations, but we narrowed the choice to a hotel right downtown. This location is central to

convenient dining, the beach, as well as a host of other activities for the families. Our VA host families have begun fundraising as they are negotiating a golf tournament and a 10K race. We would also like to thank both Christy and her husband Bill for generously hosting us for dinner during the last night of our Board visit. Looking at 2010, we are investigating either Dallas or Indianapolis at this time.

One last thing... we are still accepting nominations for "Grandparent of the Year" for those special people who go beyond the call of duty to help out. Please contact Laura or any other Board member at your convenience. Well, that's all for now. Please keep your suggestions coming...

Greg



2005 St. Louis Conference

Three presentations from the 2005 St. Louis Conference are now available on CD format. Each CD is \$5.00. If you are interested in purchasing any of these CD's please send a check to the 5p- Society, PO Box 268, Lakewood, CA 90714.

Available:

Cri du Chat 101
Behavior Applications
Adults with CDC

Thank you to Joe Eickmeier for making these CD's available and possible.

Tert Gene Research Report from 2005 St. Louis Conference

During the Annual Conference of the 5p- Society held in St. Louis last year, Dr. Monica Bessler and her colleagues at Washington University School of Medicine in St. Louis conducted a study on the health effects of **TERT** deficiency in individuals with 5p-. We are grateful to every family who participated in the study. We wish to share information with you about our progress.

TERT is encoded by a gene found on the tip of the short arm of chromosome 5 (**5p15.33**). Since chromosomal deletions often include the tip of the short arm of chromosome 5, individuals with 5p- often have only one copy (instead of two) of the **TERT** gene. **TERT** is part of a protein complex, known as the **telomerase complex**. The **telomerase complex** maintains and repairs the length and structure of the

chromosome ends as the cell grows and divides. If the chromosome ends are damaged or shortened, the chromosome cannot properly share information with the cell. Individuals with shortened chromosomes may have problems with blood cell production and show signs of premature aging. Examining how well telomerase functions may provide additional clues on the long-term health effects for children with 5p-.

Last summer 34 families with family members who have 5p- participated in our study. Due to the limited amount of blood obtained, not all tests could be performed for each person who participated. However, preliminary results from our study show individuals with 5p- have some signs resembling premature aging such as premature graying of the hair, atrophic skin of the hands, and changes in

the circulating blood cells. One important question is, whether the changes observed are due to the missing **TERT** gene, or rather are caused by the deletion of other genes located on chromosome 5p. To answer this question, we wish to invite additional families to participate in this study.

All individuals with 5p- (regardless of the size of the deletion), 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, and providing a sample of blood. Your doctor may draw the blood and ship it to us with the study materials we provide you.

Participation does not provide treatment, however, participation may help to better understand the underlying cause of the symptoms associated with 5p-. All study related materials can be mailed to you and there will be no cost to you or your family. The confidentiality of all study related materials will be maintained in accordance with State and Federal laws.

Contact Chrissie Kamp, our study coordinator to learn more about the study and how you can help contribute to this important area of medicine. Chrissie may be reached at 314-454-5112, or by email at kampc@ccadmin.wustl.edu.

Again we are most grateful for your support and enthusiasm. We will continue our ongoing work and will keep you apprised of our progress.

Resources For Our Special Angels of All Ages by Kristen Clark

SENSORY

http://brighttots.com/sensory_integration.html - Sensory integration - symptoms of sensory integration disorder. Bright Tots educational toy store offering baby toys toddler toys games & videos.

<http://www.iidc.indiana.edu/irca/Sensory/sensoryIntegrate.html> - sensory integration ideas and “map” to success.

<http://www.sensorysmarts.com/diet.html> - describes the components of a sensory diet.

EQUIPMENT

http://www.patinsproject.com/Southwest/new_equipment_sw.htm - communication items.

http://www.flaghouse.com/cat_req.asp - catalog of therapy equipment for schools and home use.

<http://www.playawaytoy.com/index2.ivnu> - indoor swing that fits the doorway (sold at St. Louis conference) highly recommended by editor Kristen Clark.

<http://www.rifton.com/> - adaptive equipment

<http://www.danmarproducts.com/index.cfm?pageSRC=relatedWebsites> - equipment

<http://myweightedblankets.com> – weighted blankets

<http://www.pfot.com/> - therapy tools that can “fit in your pocket”

<http://www.tfhusa.com/products.asp> - great website for toys for our little ones

www.dragonflytoys.com - great “toys” to help you little one achieve more through play

www.comfyland.com/new/index.html - computer keyboards and software designed with the developmental delayed child in mind.

www.pedicraft.com/canopybeds.html - enclosed canopy bed/crib

www.plument.com – soft helmets

<http://www.zevex.com/therapeutics/pumps/infinity.cfm> - Infinity pump (tube feeding)

www.hatchbacksfootwear.com – footwear that fits over AFO's.

www.knitrite.com – socks to wear with AFO's.

SPEECH

<http://www.speechfun.com/> - Check out this site for help with speech and communication.

www.dynavoxsys.com/ - assistive communication devices

<http://www.speakingofspeech.com/generic7.html> - get ideas and pictures for FREE updated and changed often for new words/pictures and ideas

www.signingtimekids.org and www.signingtime.com – Printouts and activities for signing with your children; also has very useful DVD's to assist you with sign language

<http://www.rmlearning.com/auditoryprocessing.htm> - listening program to improve auditory processing

NUTRITIAN

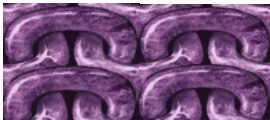
<http://www.all-natural.com/herbnuetr.html> - if you are interested in “natural” “healing” you can use the herbs vitamins and minerals and this site will help decide what you need (example ginger root helps with motion sickness, papaya helps with heartburn etc.)

http://www.4girls.gov/nutrition/eating_essentials.htm - this is also a great one to use to get the most of vitamins and minerals out of foods (example too much calcium will hurt the absorption of iron, vitamin c etc...)

<http://www.ebinfo.homestead.com/recipesdrinks.html> - great recipes for the child that is just coming off g-tube feeds and is very texturally defensive.

http://www.add-adhd-help-center.com/recipes/ADHD_shake.htm - recipe to help attention (not yet tried by editor)

<http://www.leichtman.org/tni.shtml> -- Dr. Leichtman's website – supplements



“To become one chain we must work together, one chain is a family of caring love, and total support.”
Kristen Clark

Resources of Children, continued

REFERENCES/RESOURCES/others

<http://www.familyvoices.org/> - speaking on the behalf of children and youth with special health care needs
<http://dpi.wi.gov/dlsea/> - Wisconsin Department of Public Instruction gives current laws and rights for children
<http://www.nolo.com/> - The Complete Guide to the IEP Process – and other books and laws to help you get what you need and advice
<http://concordspedpac.org/DisabilitiesOrgs.htm> - State resources
www.barnesandnoble.com - editor's favorite site for books of all kinds.
<http://www.mch-hotlines.org> - Wisconsin first step for help is a website for those just starting to need help and continued help with a child with special health care needs
http://www.webmd.com/diseases_and_conditions - look up any kind of disease, condition and symptom checker (very helpful)
<http://ldonline.learningstore.org/index.html> - great online store to help children with all needs
<http://www.loveandlearning.com/> - site where you can read stories of other children with special needs and buy things you may need/want to get to help you/your child out
<http://www.social-security-disability-claims.org/index.html> - government assistive program if you/your child qualify (goes off household income).
<http://www.telusplanet.net/public/nremus/communication.htm> - article to help figure out if your child actually communicates but you just might not know it yet
http://www.php.com/include/resources/iep_prepare.html - GREAT PREP TOOL for the IEP, helps make sure you have all your ducks in a row
<http://www.motherswithattitude.com/links/si.html> - site that shows what other "mothers" have put together to help special angels like ours
<http://www.devdelay.org/> - find articles and ideas that support a child that is "delayed"
<http://colorincolorado.org/home/funways.php> - tip sheets in English and Spanish on "Fun and Effective Ways to Read with Children."
<http://www.copecaredeal.org/> - MindZone a mental health website for teenagers
www.ochealthcare.org – online information source for individuals, families and agencies concerned with health care (Orange County, California)
www.iscoliosis.com/articles-meet-smith.htm - Dr. Smith, Utah, orthopedic surgeon, has worked with children with CDCS with scoliosis.
<http://www.specialchildexchange.org/> - equipment exchange group

To assist Kristen and the 5p– Society become one chain, please forward all resources that you have had positive feedback with to Kristen at krislynn0002@yahoo.com. Our plan is to improve and increase this list of resources for the newsletter and website for you. Also, we would like to list resources for various states/counties in the United States and Canada. Please forward the email addresses for the programs in your area that were of greatest assistance. All of your input will be greatly appreciated!!!

Grandparents' Corner

Nominations are now being accepted for the 2006 Grandparent of the Year Award. Please submit the name of the Grandparent'(s) and why you feel their contributions to the Society earn them the award.

Cookbooks are now available. The Grandparents of the 5p– Society have gathered and published their first cookbook. They are now available through Pat Strong at odah@gmtel.net or by phone at (563) 659-9530.

Surf'n California Style!!

Conference Scholarships Available

We are pleased to announce that we have received some generous donations for the conference and are able to offer five (5) scholarships. These scholarships are for hotel accommodations for three nights at the Santa Clara Marriott hotel and for the basic registration fee (\$150.00) for up to two adults and two children. Applications are now available and are being accepted. You may obtain an application by contacting the 5p- Society at director@fivepminus.org, or by phone (888) 970-0777 (toll free), or (562) 804-4506. We'd like to thank Paul & Terri Arango, Robert & Mary Dennis and Bobby & Mila Zlatnov for sponsorships.

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 Zlatnov
- 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

If you or your company or someone you know would like to help sponsor the 2006 conference, please contact the 5p- Society office at director@fivepminus.org or (888) 970-0777. Thank you!!!

Hotel reservations can now be made at the Santa Clara Marriott. The 5p- Society has secured a rate of \$89.00 per night (+appropriate taxes). Please contact the Marriott at 800-228-9290. You can also make your reservations on line by going to www.fivepminus.org, click on the button that says Annual Conference and scroll down until you see "Reserve a Room" link. If you have any problems making your reservations please contact the 5p- Society office.

The following speakers are now confirmed:

- Dr. Dennis Campbell— Cri du Chat Syndrome 101
- Dr. AmySue Reilly—Behavior Considerations
- Dr. Joan Henley—IEP SNAP—
- Dr. Pelayo—Sleep Disorders
- Dr. Pam Richardson—Sensory Integration

Thursday evening registration begins at 5:00 PM; New Family Orientation at 7:00 and Sibling Mixer at 7:00. We are hoping to get a donation to assist in having a Welcome Reception.

Friday events include 1/2 day sessions; Family Fun Event poolside for a "Luau." Hawaiian dancers are planned for this event and the kids will even get a hula lesson.

Saturday events include full day sessions; banquet and dance.

Sunday event will be our wrap up session.

2007 Calendar

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 September 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 sponsors are now being accepted. Reduced price of \$50.00 per month for sponsorship. Months will be reserved on a first come, first serve basis. Any questions please contact director@fivepminus.org.

Photo Release: I authorize the 5p- Society to reproduce the attached photo of my child for the purpose of the 5p- Society's 2007 Calendar and Photo Yearbook.

Name: _____ Child's Name: _____
Address: _____

Signature Date

I'd like to sponsor the month of _____. Enclosed is my check for \$50.00

Please return form to 5p- Society office at:
5p- Society
PO Box 268
Lakewood, CA 90714-0268



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

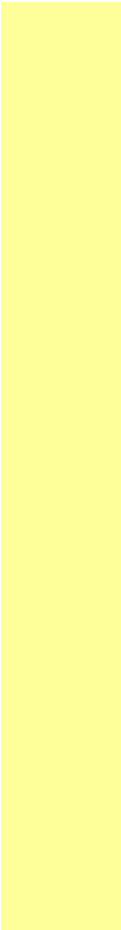
Date

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 (which is still being designed). All conference and 5p- Society volunteers including the host families, welcome committee members, board of directors and child care provider's T-shirt 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. **DEADLINE FOR PRE-ORDERS JULY 1, 2006.**

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 _____