

5p- News

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/>
- Supported Living Services www.supportedlife.org
- Sign Language Vocabulary <http://commtechlab.msu.edu/sites/aslweb/brower.htm>
- Signing Videos and DVDs: <http://twolittlehands.com>; <http://www.signingtime.com>
- Speech Therapy ideas: <http://www.speechtx.com/index.htm>
- Speech/Language and Feeding tools: <http://talktoolstm.com>
- Specialty toys — Abilitations: <http://www.schoolspecialtyonline.net/>
- Living Spaces — Architectural www.lifecaredesignstudio.com
- Advocacy — www.protectedtomorrows.com
- Fundraising for the 5p- Society through: www.igive.com — online shopping mall and through www.goodsearch.com — search engine that gives .01 per search to the 5p- Society

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, email director@fivepminus.org

President's Message *by Jolene Towers*

There is not a day that Taylor does not talk about our upcoming trip to Florida or, should I say, Disney. You can ask Taylor when we are going and she will quickly answer "July . . . I can't wait!" Needless to say, our family is looking forward to spending a couple of days at the Disney parks before we attend the conference.

As some of you know, we live in Ohio, the planned location for the 2011 conference. The Ohio planning is well under way, with families busy on conference calls and meeting for dinners to plan. Our fundraising efforts are underway as well. With a fundraising goal of \$40,000 per conference, it's easy to see why every newsletter deals at least in part with this difficult issue. As you may know, the annual conferences are expensive to host. Through our fundraising efforts, however,

we are able to keep the cost down for each family!

To this end, the board has been working on raising the bar. We had a fantastic board meeting in Denver at the end of January, where we evaluated prospective locations for our conference in 2012. Additionally, we focused on three main areas: strategic planning, fundraising and board development. While we have plans for all of these areas, we especially need the Society's help with fundraising. Though this has always been a struggle, it is certainly not any easier given our present economy. If any of you have some expertise or ideas in this area that you could lend to the fundraising committee, please let us know. Most importantly, our heartfelt thanks go out to those who have generously contributed, and continue to

contribute, their time, experience and substance to date!

We currently are looking at dedicating two years to developing a strategic plan for the Society. The first half of our board meeting we had a non-profit specialist and friend of the 5p- Society, PJ D'Amico, who helped us map out our strategic plan. At one point the membership will be involved in the process.

If you are interested in learning more about the roles and responsibilities of a board member, please email me at gnjtowers@aol.com. Each year we do look for several new board members.

We are looking forward to a fabulous conference this year. We hope you will join us as we celebrate the 25th Anniversary of the Society and the Magic of Orlando.

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Discount DisneyWorld Tickets

DisneyWorld has set us up with discounted tickets for the 5p- Society Conference. You can visit the following link to get more information: <http://www.disneyconventionear.com/FPS>

The "Give A Day, Get A Day" program has ended as Disney was able to meet its goal of One Million individuals donating a day to a specific organization.

Fundraising for the 5p- Society

I'm sure everyone is getting excited about the upcoming conference in Orlando, Florida. We will be celebrating the Society's 25th Conference for the families of children with Cri du Chat. In mid February the membership received an opportunity to participate in the 80/20 raffle for the society; our goal is to sell 500 tickets. The winning ticket will be drawn July 31st, the night of the banquet. Thanks to all the people who have already sent in their ticket stubs and money. You can continue to mail them to the 5p- Society office until mid July. GOOD LUCK!!!

We have a fundraising committee in place to help with ideas for the Society in our endeavor to raise funds for our day to day expenses. During the conference we are setting aside time to present a workshop with ideas for members to use in their local fundraising. If you have done a fundraiser, we would like for you to submit a "how to do it" so it can be available for the workshop. If you are interested in joining the Fundraising committee please email me.

The Avon nationwide fundraiser benefiting the 5p- Society went live on March 14 and will run until May 31, 2010. All via the internet...or known as an online event, products are shipped to your home (FREE) and the society would get a % of the sales.

Contact info: <http://robbiesimon.avonrepresentative.com>—Avon's main page will show.

Click online events, then the 5p Minus Society online event will come up. Place your order and you will have the products in a week or so. We hope it will be a win win for the Society.

Gloria Griffin, Fundraising Committee Chairperson
flyinggigi@insightbb.com

80/20 Raffle to Support the Annual Conference

Last month all members of the 5p- Society received two 80/20 Raffle Tickets. The goal of the 5p- Society is to try to sell 500 raffle tickets at \$100 each. If all 500 tickets sell the winning ticket could get up to \$10,000.00 The monies raised from the raffle will be used to help offset the cost of the 25th Annual Conference in Orlando, Florida. We would be grateful to you and your family if you could send in your tax-deductible \$100 donation and one (1) ticket stub no later than July 15th. We understand and realize that times are tough right now and you may not be able to participate, but even if you could try to get four family members to kick in \$25 each for one ticket, then the winning ticket could be split four ways. If you did not receive a ticket and would like to participate, please contact the 5p- Society office at (888)970-0777 or director@fivepminus.org.

We would like to thank everyone who participated in the End of the Year Appeal. With your help we were able to raise \$2,800.00.

I would also like to take this opportunity to thank everyone who participates in Employer Matching programs. In 2009 you raised \$6,500.00 for the Society.

Upcoming Events:

Sounds of WWII—Benefit Concert featuring the music of the World War II era — Wallace Family—Bellefontaine, Ohio— Memorial Day Weekend

Wine & Cheese Event—Stanford and Ratliff families from Houston, Texas.— June 2010

Online Speech Therapy

Online Speech Therapy is an alternative way to provide high-quality speech therapy to children and adults. It is also referred to as telepractice or telehealth. The American Speech-Language and Hearing Association endorses the use of online speech therapy saying that "telepractice is an appropriate model of service delivery for the profession of speech-language pathology." (you can see the full position statement at www.independentspeech.com)

At Independent Speech, each speech therapy session is held in real-time video and audio over a secure internet site. You are able to see, hear and interact with your therapist as if they were sitting across the table. Each session has its own link and requires a unique password to ensure complete security. A web-cam and/or headset is provided for you.

Activities are designed by speech-language pathologists to engage and motivate the students. Each activity is designed to target a specific objective but will be tailored to meet the specific needs of each individual. The activity library houses hundreds of activities and is continuously being updated to ensure there are new, exciting activities to work on during each therapy session. All activities are interactive. You are able to control the activities you see on the screen by using your computer's keyboard and mouse.

Parent, Anna Berrios of Florida, has begun this program with her daughter, and is impressed with the ease of its use. The 5p- Society is looking forward to seeing how well 3-year-old Jacey does on the program. Anna keep us posted. For more information call Independent Speech at 1-877-480-7913 .

Welcome to Florida—MAGIC OF ORLANDO

Hello, we are the Galvagni and Vaden families, your host families for the 2010 conference. We are so excited for this year's 25th anniversary conference in Orlando. *Magic in Orlando* is going to be a conference to remember. We have many events planned to keep everyone busy during their stay with us in Orlando.

On Thursday, Friday and Saturday evening the hospitality suite will be open for meeting, reconnecting, networking, sharing and relaxing. The Barrios and Asman families will be your hospitality hosts.

On Friday, the event for the Family Fun Day is the Pirate and Princess pool party. We will have both Pirates and Princesses as our special guests. We will also have a bounce house there for the kids to have fun. There is an outdoor sand volleyball pit for you sports enthusiasts, and the pool is HUGE. Kids can also be transformed into anything they want with our face painters. We will have the ever so popular hair coloring station too!! Please remember to bring your sunscreen!! A lunch will be available for purchase and you will get more information about the lunch in your confirmation packet. Friday evening will also be movie night by the pool, sponsored by the Marriott.

On Saturday, our Banquet theme is "Magic Under the Stars Ball." A photographer will be available for families to take family portraits. To enhance the theme, formal-wear is encouraged, but not required. Our famous family dance will follow dinner. It should be a fun evening.

Siblings have their own agenda. On Thursday night they will have a mixer meet and greet with games. On Friday morning there will be a Sibshop, to talk and discuss with other siblings their experiences. On Saturday they will go to the Fun Spot on International Drive. There they will be able to drive all the go-carts they want and have unlimited rides and arcade games. We could use some volunteers to accompany the sibs.

The Vaden family is working on putting together the child care rooms. Child care is offered at no cost to the attendees. Both children with Cri du Chat Syndrome and their siblings are welcome. Most child care volunteer workers are family members, friends, or professionals of children with Cri du Chat Syndrome and are compassionate, caring individuals. If you have family members who live in the Orlando area that would like to give a few hours of their day on Friday morning or Saturday morning or afternoon to volunteer for child care, please have them contact Cathy Vaden at redtwin@knology.net.

As for speakers, the Galvagni family has secured Bella's speech therapist, behaviorist, hippotherapist and dental hygienist to present for the group. The Vaden family has secured family members who are professional occupational and physical therapists to provide us with hands on ideas. We also have our favorites coming back to engage us, teach us and interact with us about the syndrome, including Dr. Dennis Campbell (CDCS 101 and Transition), Dr. AmySue Reilly (Behavioral Applications), Shanida Mathieu (IEP and the Planning Process), Sandy Cooley and Brenda Martin (Sensory Integration Therapy and Coping Skills). We also have Mary Anne Elhert from Protected Tomorrows coming to talk with us about Planning for the Future.

We would like to thank those of you who have already participated in the 80/20 raffle. Your participation will assist us with these events. Help us reach our goal of 500 tickets!! We received a donation for a time share called Verde Trail in Orlando, so we will have a second chance drawing with your 80/20 tickets for the time share!!!

There will be a separate raffle for our Annual Conference Quilt, Themed Quilt, donated Discovery toys and other awesome donated items.

We hope to see you in July, we look forward to seeing all our old friends and meeting some new ones!!! If you have any questions please email us or call us.

Your Host Families

David & Jacqui Galvagni & Family
Jacqui@comcast.net
(561) 432-2138

Rob & Cathy Vaden & Family
redtwin@knology.net
(850) 215-3364

THE MAGIC OF ORLANDO

Location: The 25th Annual conference of the 5p- Society will be located at the Orlando Airport Marriott, 7499 Augusta National Drive, Orlando, Florida 32822. Hotel phone number (407) 851-9000. The 5p- Society's group rate is \$109.00 per night. You can make your reservations by calling the hotel's toll free reservation line at (800)380-6751 or online at <http://www.marriott.com/hotels/travel/mcoap?groupCode=pmspsmsa&app=resvlink&fromDate=&toDate=> (you can also access this reservation link on our conference page on our website at www.fivepminus.org/annconfX.htm) Make sure you indicate that you are with the 5p- Society. **IF YOU RUN INTO ANY PROBLEMS MAKING YOUR RESERVATIONS, PLEASE CONTACT LAURA AT THE 5P- SOCIETY OR ON HER CELL PHONE AT (562)756-4123.**

Transportation: The Orlando Airport Marriott offers a complimentary shuttle from the airport to the hotel. There is also a Hertz car rental onsite at the Marriott.

Conference Registration: Registration is now open. Please fill out the form on pages 6 and 7 of this newsletter, or you can download a copy of the Registration form at the 5p- Society website at www.fivepminus.org/annconfX.htm. The Members Registration fee is \$150.00 for up to two adults and two children; each additional adult is \$50 and each additional child is \$25 (non-member fee is \$200.00). Please note that these costs only include the dinner banquet on Saturday night. We are looking for sponsors to help offset the cost of the other events, including, Friday's Family Fun Event, Hospitality Suite, Sibling Event, and possibly continental breakfast and/or welcome reception.

Volunteers Needed: Volunteers are needed for our complimentary child care that is offered during the Friday and Saturday break out and panel sessions. If you have an extra adult that will be accompanying you or teenager that loves to baby sit, then please contact Cathy Vaden at (850)215-3364 or redtwin@knology.net. Volunteers will be given a complimentary lunch on Saturday afternoon.

Conference Scholarships: The Board of Directors of the 5p- Society has approved three (3) scholarships to be funded for the conference. If you are interested in obtaining an Application for the scholarship, please send an email to Laura Castillo at director@fivepminus.org. The scholarship will pay for three nights at the Orlando Marriott Hotel and also for the basic registration fee of \$150.00 for up to two adults and two children. Deadline to submit your scholarship application will be May 1st.

Speakers: The following speakers and topics have been confirmed:

Dr. Dennis Campbell—(1) Cri du chat 101 (2) Transition

Dr. AmySue Reilly—Behavior Applications

Sandy Cooley (OT) and Brenda Martin (OT)—(1) Sensory Integration Therapy; (2) Coping Skills

Janet Weber (PT) and Kierstin Weber (OT)- Developing Fine & Gross Motor Skills

Mary Anne Elhert, Protected Tomorrows—Planning for the Future

Mike Brewer—Fundraising 101

Lisa Pugliese—Speech Therapy

Shanida Mathieu—The IEP Process

Vinceromos—Therapeutic Riding—HIPPO Therapy

Kelly Galvagni—Dental Hygiene

Kevin McCormick— Behavior in the School System

Conference Schedule

Thursday, July 29, 2010

5:00 PM to 10:00 PM	Registration
7:00 PM to 9:00 PM	New Family Orientation
7:00 PM to 8:00 PM	Sibling Mixer
5:00 PM to 11:00 PM	Hospitality Suite Open

Friday, July 30, 2010

7:30 AM to 9:00 AM	Child-care Check-in
8:30 AM to 9:00 AM	Welcome Session
9:00 AM to 10:30 AM	1st Break Out Session—3 tracks running
10:30 AM to 12:00 PM	2nd Break Out Session—3 tracks running
9:00 AM to 11:30 AM	Sibling Supportshop
12:00 PM	Child-care Check-out
12:00 PM to 3:00 PM	Family Fun Event—Pirates & Princess Pool Party* (at this time we are still looking for a Sponsor to cover lunch for this event—if we do not get a sponsor then we will have a boxed lunch available for purchase at the pool)
4:00 PM to 6:00 PM	Grandparents Supportshop
8:00 PM to 10:00 PM	Board of Directors Meeting
7:00 PM to 11:00 PM	Hospitality Suite Open

(The hotel may be offering a movie by the pool for the evening. More information will be available closer to the event)

Saturday, July 31, 2010

7:30 AM to 9:00 AM	Child-care Check-in
8:30 AM to 9:00 AM	General Session
9:00 AM to 10:30 AM	1st Break Out Session—3 tracks running
10:30 AM to 12:00 PM	2nd Break Out Session—3 tracks running
12:00 PM	Child-care Check-out
12:30 PM—1:30 PM	Volunteer Lunch (all conference volunteers are treated to lunch in the Hospitality Suite)
12:15 PM—1:45 PM	Professional Advisory Board Lunch
12:00 PM—2:00 PM	Lunch on your own
1:30 PM—2:00 PM	Child-care Check-in
2:00 PM—3:30 PM	Parent Panels
3:30 PM—5:00 PM	Professional Panel
5:00 PM	Child-care Check-out
5:30 PM to 6:30 PM	Family Photographs
6:30 PM to 10:30 PM	“Magic Under the Stars” **- Banquet, Family Dance, General Meeting of the Membership and Raffle
9:00 PM to 11:00 PM	Hospitality Suite Open

Sunday, August 1, 2010

10:00 AM to 12:00 PM	Closing Session, Picture Session Time to Say Goodbye and Talk about 2011 in Columbus, Ohio
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* Pirates & Princess Pool Party—You will be responsible for supervising your children at the event

***“Magic Under the Stars,” girls are encouraged to wear their “Prom” dresses and boys their “Suits and Ties”



2010 Annual Conference and Get Together
 Orlando, Florida
 July 29 – August 1, 2010
"The Magic of Orlando"

CONFERENCE REGISTRATION FORM

Yes, I plan to attend the 2009 Annual Conference and Get Together

Members — registration fee \$150.00 USD (two adults and two children) _____

Non-members — registration fee \$200 USD (two adults and two children) _____

Each Additional Adult — \$50.00 USD each _____

Each Additional Child — \$25.00 USD each _____

***** If you are not staying at the Orlando Airport Marriott please add \$100.00 to your registration fee** _____

No, I am unable to attend, please accept my donation in lieu of attendance _____

Please renew my annual membership at this time \$25.00 _____

Total Enclosed _____

Name _____ Phone No. _____

Address _____ Email Address _____

City _____ State/Province _____ Zip _____

Country _____

Names of All Adults who will be attending the conference

Relationship to 5p– Syndrome Child/Adult

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Names of All Children attending conference (even your child with CDCS)

Relationship to 5p– Syndrome Child/Adult

Age

Childcare

Sibling Event

_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Please let the **hotel** know if you need specific items such as cribs, roll-a-ways or refrigerators. There will be an additional cost for the roll-a-ways and refrigerators.

Items requested directly from hotel: Refrigerators ____ Cribs ____ Roll-a-way _____

Will you be needing a high chair for the banquet? Y N

(providing us with the above information will not guarantee you the item, however for planning purposes we will alert the hotel of the amount of highchairs, cribs, roll-a-ways and refrigerators needed for the event.)

Sibling Event:

The Siblings are planning a trip on Saturday, July 31 to the Fun Spot Action Park in Orlando (<http://www.funspot.tutengraphics.com/index.php?mypage=Groups>). The cost to attend will be \$25.00 per child (in addition to the registration fee). We are looking for sponsors to help cover the cost of the bus (\$399) and lunch (\$7.00 pp). Please indicate on the registration form if you are planning on having your child attend the event. If you would like to supervise a group of siblings, please list your name and number where we can reach you: _____

Photo Release:

I/We give the 5p- Society authorization and/or permission to use any photograph and/or video tape of our immediate family who attends the 2010 5p- Society Annual Conference and Get-Together in Orlando, Florida 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 and its educational goals.

Signature date

Signature date

Two ways to pay:

Check: USD funds made payable to 5p- Society

Credit Card: Type Mastercard or Visa

Card No. _____ Exp. Date _____

Name on Card _____

I agree to charge my credit card, number listed above, in the amount of \$ _____ USD for registration fees for the 2010 5p- Society Annual Conference and Get-Together (T-shirt fee can be added here too).

Signature date

Please fill out and return both pages of this form to:

5p- Society
PO Box 268
Lakewood, CA 90714

Any questions? Please contact the 5p- Society office (888) 970-0777 or director@fivepminus.org.

If paying by credit card you can fax the form to (562) 920-5240.



PO Box 268
Lakewood, CA 90713

Return Service Requested

COMMEMORATIVE 2010 CONFERENCE T-SHIRT

Celebrate the 25th Annual Conference with a Commemorative T-Shirt. The T-shirt will be Black with Silver writing and will list all the years and sites of the past twenty-five conferences on the back. The front will have the "Magic in Orlando" Sorcerers' Hat and Wand. T-shirts will be \$10 each. To guarantee your size please pre-order your t-shirts no later than June 25th. Payment does not have to accompany your pre-order but is appreciated. Payment can be made at the time of pick up. The Society will have a limited number of shirts to sell at the conference. If you are not attending the conference and would like to purchase a shirt please make sure you add in the shipping cost to your order (shipped T-shirts will have to be paid upon order). All other shirts will be available for pick up at registration. Volunteer T-shirts will be Gray with Black writing. Please indicate if you need a volunteer or attendee shirt. If you have any questions, please send an email to director@fivepminus.org.

SIZES	QUANTITY		Name: _____
	Attendee	Volunteer	
YS	_____	_____	Address: _____
YM	_____	_____	
YL	_____	_____	Phone No. _____ Email _____
YXL	_____	_____	Total # of Shirts _____ x \$10.00 each = _____
AS	_____	_____	Shipping fee (add \$5.00 for each 3 shirts) = _____
AM	_____	_____	Total Amount Enclosed: _____
AL	_____	_____	Paid by ___ check ___ credit card ___ pay at conference
AXL	_____	_____	
AXXL	_____	_____	Credit Card Information: _____
Total:	_____	_____	Expiration Date: _____ Total Amt Charged: _____