

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
email director@fivepminus.org

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.lifecarestudio.com
- Advocacy — www.protectedtomorrows.com
- Fundraising for the 5p- Society through: www.give.com — online shopping mall and through www.goodsearch.com — search engine that gives .01 per search to the 5p- Society

President's Message *by Jolene Towers*

Dear Friends,

Once again Spring is upon us, that time of year when nature comes alive, and our lives rapidly fill with new obligations and activities. For our family, it's a flurry of soccer games and end-of-school activities, as well as a time to plan for a busy summer. Our boys always look forward to their sports camps, and Taylor looks forward to her camp as well. We are fortunate to have her summer camp run by one of her therapists, and it involves horseback riding, swimming, campfire singing, crafts and lots of games. In fact, Taylor's brothers always get jealous of all the fun things Taylor gets to do without them . . . quite the role reversal!

Of course, what would summer be without vacations. Our usual summer consists of two important ones . . . seeing family and attending the annual 5p- Society Conference. This year's conference promises to be an incredible one, due to the tireless efforts of our host families Bill & Christy Blount and Dave & Anne Zettlemoyer.

We would like to thank them all in advance for their selfless participation. From experience, we know it's no cake-walk! Our family is planning on adding a few extra days to thoroughly enjoy the surf and sand of Virginia Beach. Taylor loves spending the weekend with her many friends and the Boys love the camaraderie and the sibling workshop. For those of you with small children, remember that childcare is provided . . . my young ones have had a great time there in the past, and the volunteers are always top-notch!

For us adults, the highlight is talking with all the families, renewing old friendships and forging new ones. Every year, we learn new things, both from the family members and the speakers. The more we attend, the more we find renewal in just being together with a great group of people . . . people who understand through firsthand experience the unique challenges that our exceptional families face. We sincerely hope that each of you will be able to make the time in your busy

schedules to join us this year.

See you in July!!

Jolene Towers
President
5p- Society

5p- Society offers five scholarships for those wanting to attend the Annual Conference. Deadline is May 15. Please contact the 5p- Society office for more information and an application

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Fundraising News

Fundraising It's Not As Bad As You Think

By: Nick Wallace

Fundraising; don't stop reading because you just read the dreaded word. I know I hated fundraising door to door when I was in school. I was elated when I no longer had to sell cheese and sausage for the high school music department anymore.

What would you say if I told you that you could raise funds for the 5P- Society, without talking to anyone, going door-to-door, selling products and/or services, or spending any money? The society came across a wonderful website that gives the Society money whenever we search the Internet. The website is <http://www.goodsearch.com>. I know it sounds too good to be true, but it is the real deal. There is no sign up, no personal information gathering, and no fee to you or the Society. All you have to do is search like you do on Google, Yahoo (Which powers the search), or any other search engine you may use. Every time you use Good Search as your search engine, with the 5p- Society as your charity, they give a penny, per search, to the Society. The other nice thing about this site is that you don't have to be a member of the Society to raise money. You can have family, friends, co-workers, and anyone else you can think of use Good Search to search and raise money for the Society and for our Kids.

Another feature that Good Search offers is Good Shop. Good Shop consists of several stores from Amazon.com, to Ebay, to iTunes, to Travelocity, and others that offer a donation to the Society if you purchase items from their online store. This process is very simple. You go to Good Search and click on the Good Shop link, find the store you are looking for in their extensive list, and click on the link to that company. The link takes you to their store and you shop just like you would if you visited their site directly. This is all you have to do. There are no extra buttons to click or any special instructions. You purchase your item as usual and they give the percentage back to the Society. I know we are planning on using Good Search's Good Shop to purchase our travel arrangements for the Annual Conference at Virginia Beach on July 31 – Aug. 1, 2008.

So to summarize, **It's Easy!!** I love being able to raise funds for Allie & the Society by doing something I do everyday and not having to pressure anyone into buying or sponsoring me for anything. Just so you know, we earned \$43.27 from Good Search in March. We had a total of 1325 searches and \$30.02 in Good Shop donations. So, give it a try; search, or purchase something like your travel needs for the Virginia Beach Conference, and see how easy it really is. If anyone has any questions regarding Good Search or Good Shop, please email me at wallacefamily04@earthlink.net. Thanks for your support.

GOLF TOURNEY TO SUPPORT SOCIETY



Keep swinging.

Haggin Oaks Golf Complex **Sacramento, Ca**



Hailey's
Haggin Oaks Classic

Save the date
Saturday, May 3, 2008

**A golf tournament to
benefit the 5p- Society.**
\$125.00 per player OR
\$450.00 per foursome

Contact information
Todd Winslow
Tournament Director
e: haileyshagginoaksclassic@hotmail.com



FAMILY STORIES: A Very Special Bar Mitzvah

(*Bar* or *bat mitzvah* is the rite of passage when a Jewish youth assumes the responsibilities of adulthood in the Jewish community)

For several years leading up to his September 2006 *bar mitzvah*, our son Aaron would ask us, “You cry my bar mitzvah?” Aaron has always thought it strange that people cry at happy occasions. Well, the day of his bar mitzvah, was indeed a happy occasion. There was not a dry eye in our synagogue in Lexington, Massachusetts, including our own!

Celebrating Aaron’s bar mitzvah countered one of the greatest fears that came with receiving Aaron’s 5P-minus diagnosis. On that dark winter morning nearly 13 years earlier, we imagined that we had immediately and completely lost many of the simplest, yet central experiences of parenthood. Gone, we expected, was the joy of celebrating our first child’s bar mitzvah.

Needless to say, our family’s journey has been very different from what we anticipated before Aaron’s arrival. But there’s no question, we have found that we all do experience life’s anticipated celebrations. The difference is that that the work required for Aaron to reach these important milestones is intensely challenging, thus the joy is equally magnified.

Fortunately, our temple offers a welcoming environment for people of all backgrounds and abilities. While Aaron attended Hebrew school from the time he was in kindergarten we knew we would need to be creative to design a worship service that reflected Aaron’s love for Judaism, yet not rely upon him to “perform” on command. Our Rabbi gave us his full support to create the type of service that would work for Aaron. Rather than prepare for a typical bar mitzvah celebration, where the child leads the congregation in many prayers and chants from the *Torah* (the first five books of the bible), we worked with Aaron for about a year before he turned 13 to create a special service.

We talked through several of the key prayers and asked Aaron to tell us in his own words what they meant for him. Aaron dictated, for example:

*Listen Israel, there is one God.
I feel God in my heart.
I feel God in school and when I miss somebody.*

We shared Aaron’s interpretations in a booklet distributed to everyone at the bar mitzvah service and asked a few of Aaron’s most special teachers to read them aloud.

We also worked very hard on the recitation of the prayers before and after reading from the Torah, as well as “bar mitzvah behavior” for all stages of the nearly two-hour service. Although Aaron was not able to memorize or read entire prayers, he could repeat them phrase by phrase (with Mom whispering the words in his ears). We and our entire congregation of family and friends will never forget the powerful moment when Aaron finished the first prayer and exclaimed, “I did it!” The floodgates open, the tears of joy flowed profusely.

Knowing that Aaron is fairly good at sharing information when asked familiar questions, we also prepared a Q&A discussion for him and our Rabbi about the meaning of becoming a bar mitzvah and about “his” week’s *Torah* portion from the book of Deuteronomy. We wrote the Q&A out in simple words illustrated with Mayer Johnson pictures and used this to practice with Aaron. We also included the discussion in the booklet to help everyone understand Aaron’s speech – and in the event that he went silent with the Rabbi. We practiced this every morning for about six months.

Aaron’s bar mitzvah experience was life altering for him, for his family and for our entire congregation. As many had told us, life cycle events can unleash hidden or repressed emotions; and this bar mitzvah did just that. But the process of soul searching for the right way to celebrate . this special milestone, and the intense joy it provided have given us great strength to continue on with our journey.

We’d love to hear about your family celebrations and would welcome the opportunity to share more about Aaron’s bar mitzvah or to help you brainstorm creative ways to celebrate your child with 5P-minus. Feel free to contact us at liberwatt@verizon.net

Shalom,
Ruthie Liberman & Danny Watt



“It takes a Village to Raise a Child”

2008 CONFERENCE NEWS

2008 Annual 5p-Society Convention July 31-August 3

The 2008 Annual 5p- Society Convention will be held in Norfolk, Virginia at the Norfolk Marriott Waterside. Visit www.marriott.com. The Blount and Zettlemoyer families are very excited to be hosting this wonderful event! The hotel is located in beautiful downtown Norfolk, VA. This is also only a 20-minute drive directly by interstate to the Virginia Beach oceanfront. For more information about the area, please visit www.vgnet.com and look under Virginia Beach, VA.

The Norfolk Marriott Waterside is centrally located, and within walking distance from many restaurants and shops. It is connected to shopping/eating/entertainment area by an aerial crosswalk from the parking garage attached to the hotel. Also, there is the Macarthur Mall within walking distance. Visit www.macarthurmall.com. We will be having our sibling outing at the Nauticus marine aquarium and then over to Jillian's for some fun and games, both of which are just a matter of a few blocks from the hotel. Visit www.nauticus.org.

If you need help with your travel/flight reservations, please contact Toni at The Travel Pro (757-961-9528). **To reserve your hotel room, please contact The Marriott Norfolk Waterside at 1-800-874-0264.** Please reference that you are with the 5p- Society and they should give you a room rate of \$130.00 per night. If you have any problems making your hotel reservations please contact Laura at the 5p- Society office. Taking a taxi from the airport to the hotel is going to be the cheapest way. There should be cabs waiting at the airport. If not, please call Andy's Cab 757-461-8880 or Beach Taxi 757-486-4304. I was quoted around \$23.00 for the taxi ride. Please verify with the driver. If you do decide to drive please note that there is a \$21.00 daily parking fee.

The Friday Family Event will sport an *Down by the Sea* theme with carnival games, face painter and "Dance Heads," an interactive video production where you become the star of your own video.

Just like previous years we are welcoming volunteers to help out with childcare, the sibling outing and the Friday fun event. Please contact Christy Blount (757-496-5166) or Anne Zettlemoyer (757-431-0903) if you would like to be a volunteer.

For more information about the upcoming conference, please contact the 5p- Society at 888-970-0777 or director@fivepmminus.org.

It's not too late to get your tickets

The 2008 Conference Committee is once again having their raffle for the donated house in Nags Head, North Carolina. The house, "The Painted Lady," is being donated by Atlantic Realty. The cost of the raffle tickets is \$10.00 each, only 1000 tickets will be printed. Get your tickets by sending in your check made payable to the 5p- Society to:

Christy Blount
3125 Sand Pine Rd
Virginia Beach, VA 23451

For more info you can contact Christy at (757)496-5166 or at bill3125@dlba.hrcoxmail.com

Nags Head House

We are raffling off a week at a 5 bedroom house in Nags Head, NC with a pool and Jacuzzi.

Drawing will be held June 4th at Croc's 19th Street Bistro. Do not need to be present to win.

To View the House Online:

Go to: www.atlanticrealty-nc.com

1. Find your Outer Banks vacation rental
2. Choose#3, Advanced Search



2008 Annual Conference
and Get Together
Norfolk, Virginia
July 31 – August 3, 2008

CONFERENCE REGISTRATION FORM

Yes, I plan to attend the 2008 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 _____

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, Zip _____

Names of Adults who will be attending the conference	Relationship to 5p- Syndrome Child/Adult
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Names of Children attending conference	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 this information will not guarantee you a high chair, however for planning purposes we will alert the hotel of the amount of highchairs needed for the event.)

Sibling Outing:

The sibling outing will be at the Nauticus , a temporary museum that uses the natural setting of Norfolk's harbor to showcase global maritime commerce and the world's largest Navy. The Nauticus is within walking distance from the hotel. The event will take place on Saturday, August 2nd. For more information go to www.nauticus.org. Please indicate if your sibling child(ren) will be attending the outing. The host families have secured a donor to cover the cost of the event and lunch. However, you will need to provide your child(ren) with money for spending money at "Jillian's" an indoor arcade. Adult chaperones are needed. If you would like to help chaperone the event please indicate below.

Name of child(ren) to attend _____

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 2008 5p- Society Annual Conference and Get-Together in Norfolk, Virginia 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 it's 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 2008 5p- Society Annual Conference and Get-Together.

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 (562) 756-4123 or direc-

More Conference Info

Dates of Conference: July 31—August 3, 2008

Location: Marriott Norfolk Waterside, 235 East Main Street, Norfolk, VA 23510, (757)627-4200

Room Rates: \$130.00 per night, room rates are good for 3 days before and 3 days after event; make your reservations by calling the hotel at (800)874-0264. If you run into any problems with making your reservation please contact Laura at the 5p- Society office at director@fivepminus.org or (888) 970-0777. Hotel parking is \$21.00 per day (subject to change) per night.

Airport to Hotel service: Taxi—Andy’s cab (757) 461-8880 or Beach Taxi (757) 486-4304 (approximately \$23.00)

Conference Schedule (Subject to Change)

Thursday, July 31, 2008

5—10 PM Registration
 7—9 PM New Family Orientation
 7—9 PM Sibling Mixer
 5—11 PM Hospitality Suite Open

Friday, August 1, 2008

7:30—8:30 AM Childcare Check in
 8:30—9:00 AM Opening Session
 9:00—11:00 AM Sibling Workshop
 9:15—10:45 AM Breakout Session I
 11:00—12:30 PM Breakout Session II
 12:30—3:00 PM Family Fun Event—*Down by the Sea*
 Lunch Provided
 4— 6 PM Grandparents Workshop
 8—11 PM Board of Directors Meeting
 7—11 PM Hospitality Suite Open

Saturday, August 2, 2008

7:30—8:30 AM Childcare Check in
 8:30—9:00 AM Opening Session
 9:00 AM—4:00 PM Sibling Outing—Nautilus and Jillian's
 9:15—10:45 AM Breakout Session I
 11:00—12:30 PM Breakout Session II
 12:30—2:00 PM Lunch—On your Own
 2:00 PM-3:30 PM Breakout Session III
 3:45—5:15 PM Breakout Session IV
 5:30—6:30 PM Family Picture Session
 6:30—10:00 PM Banquet and Family Dance and Raffle
 8:00 PM General Session of the Society
 8:30—11:00 PM Hospitality Suite Open

Sunday, August 3, 2008

10:00 AM—12:00 PM Closing Session and Picture Session
 Time to say Farwell to our friends until 2009
 scheduled for July 30– August 2 in Dallas, Texas

T-Shirt Order Form

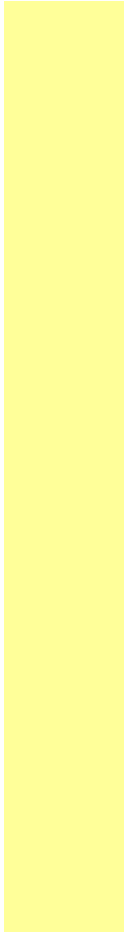
Conference T-shirts will be available by pre-order (recommended) and at the event (sizes not guaranteed). Local Virginia Beach artist, Jack Ryan (Katie Castillo’s uncle) will be designing the T-shirt for the Society. All conference and 5p- Society volunteers including the host families, welcome committee 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 USD 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, 2008.**

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



PO Box 268
Lakewood, CA 90714-0268

Return Service Requested



MEMBERSHIP RENEWAL

Thank you to the many families that renewed your membership. For those of you going to the conference you can renew your membership with your registration. Your membership can be renewed at any time. Not a member? It's not too late, we welcome you to join. Membership dues are \$25.00 per year. Not sure if you've already paid your dues — contact the 5p- Society at (888) 970-0777 or at director@fivepminus.org. Dues can be paid by check, money order or credit card (in US funds).

Please fill out and return with your membership dues:

Name: _____ Child's Name _____

Address: _____ Child's Date of Birth _____

Phone: _____

Email address: _____

Circle one: Check Money Order Credit Card # _____ Exp. _____

Please fill out and return to: 5p- Society, PO Box 268, Lakewood, CA 90714-0268