

# 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](mailto: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/](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](http://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.lifecareredesignstudio.com](http://www.lifecareredesignstudio.com)
- Advocacy — [www.protectedtomorrows.com](http://www.protectedtomorrows.com)
- Fundraising for the 5p- Society through: [www.igive.com](http://www.igive.com) — online shopping mall and through [www.goodsearch.com](http://www.goodsearch.com) — search engine that gives .01 per search to the 5p- Society

### President's Message *by Jolene Towers*

#### Dear Five P Minus Society

Happy New Year! A time for refreshment and renewal, a time for looking at ourselves and our lives and striving to understand what we can do to improve. I'm sure that many of us, like me, are also thinking of ways to help our children achieve. These goals can be small or large, long term or short, but all have in common the need for perseverance and patience. For some, challenges will be met quickly...for others less so. Where our unique children are concerned, even more patience is required.

For example, toilet training for a typical child may take days, weeks or months. While it's reasonable to expect development of toileting skills from Cri-du-Chat children, placing the same time constraints upon them may result in more frustration than felicity. In our case, with Taylor, the time frame is MUCH longer! Still, over the past 12 years we learned that smaller goals...baby steps...are much easier for Taylor to comprehend and reach, and much less frustrating

for her parents. Most long-term objectives, in fact, can be easily divided into smaller, more manageable ones, allowing for continual stepwise progression.

As a society, it's just as important to have a long-term plan, with manageable goals. Those of you along with the society know that fundraising is a perpetual issue, but one without which we could not function. So, many of you put forth tireless and creative efforts to this end. Thank you for all you do! Some members have a gift for doing big things, and those are frequently detailed in the newsletter. This issue, I want to advocate setting small, easily reachable goals in this area as well. Many corporations, Wal-Mart for example, have funds available each quarter for grants...take your adorable Cri-du-Chat child along and consider applying for these funds in behalf of the society. Remember that many employers offer matching programs for charitable donations. When appropriate, encourage family (i.e. grand-

parents) and friends to donate to the society. Each donation is a huge help toward reaching our larger, long term goals of continuing the society as a forum for support, discussion and information, as well as running our annual conference.

Speaking of the conference, the host families and the Board have an amazing program planned for July. Many top-notch speakers are committed, and the venue is amazing. Please plan to bring the family for a wonderful vacation in Virginia Beach, where we can renew friendships and learn from one another as well as the program.

Thank you to EVERYONE for all your support and efforts! See you in July!

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Welcome to  
the 45 new  
families that  
have Joined  
the  
Society in  
2007

## Virginia Beach 2008

As the year 2007 comes to an end and we are preparing for 2008 we thought we'd give you a preview of what to expect at our 2008 Annual Conference and Get-Together in Norfolk/Virginia Beach, Virginia.

The conference will be held at the Norfolk Waterside Marriott, located at 235 East Main Street, Norfolk, VA 23510. The dates for the conference are July 31-August 3. Room rates are \$130.00 per night (+ tax). You can get these great rates by calling the Hotel Reservation line at 800-874-0264 and telling the operator that you are with the 5p- Society conference. For those of you planning to vacation a little, the room rates are valid for three nights before and three nights after the conference. There is no online reservation system set up for this conference through the hotel.

Your host families for the event are Bill and Christy Blount and Dave and Anne Zettlemoyer. Christy and Anne have worked hard for the past three years raising funds through various fundraising events. The raffle for the one-week stay for the vacation house in Nags Head, North Carolina donated by Myra of Altantic Realty ; the Annual Chesapeake Bay 10k run through Kale Running; and the selling of Zoey's Zinger Gourmet Pretzels made by Zoey Zettlemoyer's grandparents.

Some of the highlights for the conference include the following confirmation of topics:

Hippo Therapy  
 Nutrition  
 Planning for the Future/Transition  
 Cri du Chat 101  
 Education and the IEP  
 Behavior Issues  
 Sign Language/Augmentive Communication



Still waiting for confirmation on:

Sleep Disorders  
 Sensory Integration Therapy

Friday afternoon's event plans to be "carnival-like" with fun ocean/water themed games.

Siblings will enjoy a day at the Nautilus Aquarium that is within walking distance.

Once again the conference committee will be offering five (5) scholarships for families wishing to attend the conference but may find it financially difficult. The conference scholarship will cover the basic registration fee for two adults and two children (\$150.00 value) and will also cover the cost of the hotel rooms for three nights (Thursday, Friday and Saturday). The conference scholarship does not cover travel fees or incidentals. Those interested in receiving a scholarship application need to contact the 5p- Society office at 888-970-0777 or by email at [director@fivepminus.org](mailto:director@fivepminus.org). Deadline for applications will be May 1, 2008.

Registration forms for the conference is available online and will also be available in the Spring Newsletter. If you require additional information please fee free to contact the 5p- Society office at 888-970-0777 or by email at [director@fivepminus.org](mailto:director@fivepminus.org).



Zoey Zettlemoyer and Cassidy Blount are ready to welcome you to sunny Norfolk, Virginia for some Sand and Surf

## 11th Annual Owens Scramble Golf Tournament—August 18, 2007



The day dawned a little chilly and misty, but that’s what you expect at the Oregon Coast . . . In OCTOBER!!! Unfortunately for us, this was mid-August, and it was the day that 80 of our friends and family were planning on taking part in the Eleventh Annual “Owens Open” Golf Tournament. Luckily, these hearty Oregonians that we are proud to call our friends didn’t bat an eyelash and one team after the other teed off for a somewhat wet and chilly 18 holes. What was the story with our not-so-summery-weather in August?? I don’t know. All I can say is “that’s the Pacific Northwest for you!”

The course played well– despite the wet weather, and the scenery was beautiful. The Fifth Hole is the course’s signature hold where golfers tee off a cliff down to the fairway below with Neahkahnne Mountain straight ahead in the distance.

Up until two years ago, we took the proceeds from the golf tournament (greens fees, etc.) and donated it to a local charity. However, two years ago, we received the news that our newborn son, Max, had Cri du Chat Syndrome. As a result, we turned the tournament into a fundraising event for the 5p– Society. We added a silent auction to the two-day event and opened up the tournament to more four-somes. Last year, we donated over \$2,300, and this year, we DOUBLED that—and then some!

We sold Mulligans—”do overs” in golf-speak, which we re-named “Maxigans” - for \$5.00 each. After our expenses were paid (lunch for everyone, prizes, and golf course fees), we added the leftover money to the pot. Then, we held a silent auction which included everything from a couple of bottles of rare wine to a weekend at a coastal beach home. When everything was added up, we had collected \$5,700 for the Society.

The Owens Open has been an event that many of our friends look forward to every year. Our eleventh year was no different. With 20 four-somes and their families in attendance, we had a fantastic day of golf, visiting with friends, and playing at the beach.

And, of course, Max was there to greet everyone as they came off the 18th hole and thanked them for their help and support. We are lucky to have so many people who love and care about Max as much as we do!!



## Fundraising News

Want to make some fast and easy money for the 5p- Society? The 5p- Society has teamed up with Goodsearch.com. Goodsearch.com is a search engine similar to google or yahoo. The only difference is that for every Internet search you do through Goodsearch.com the 5p- Society gets a .01 cent kickback. What you can do is go to [www.goodsearch.com](http://www.goodsearch.com) and in the box that asks what charity you are supporting type in the 5p- Society. You can even add the Goodsearch task bar to your homepage so that your searches are fast and easy. Tell all your friends and family too. Thank you for your continued support of the 5p- Society.

The 2008 Conference Committee is once again having their raffle for the donated house in Nags Head, South 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](mailto: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 4<sup>th</sup> 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](http://www.atlanticrealty-nc.com)

1. Find your Outer Banks vacation rental
2. Choose#3, Advanced Search
3. #368 "The Painted Lady"



## Family Stories

Hi! I've just find 5 P Minus homepage and i want to share with you my sister's story,

She's 30 years old; she was born in Chiapas, Mexico but we're living now in Mexico City. She worked very hard during her first year she had pulmonary and cardiac problems that increased her brain damage which is considerable but thanks God and against every medical prediction she recovered!

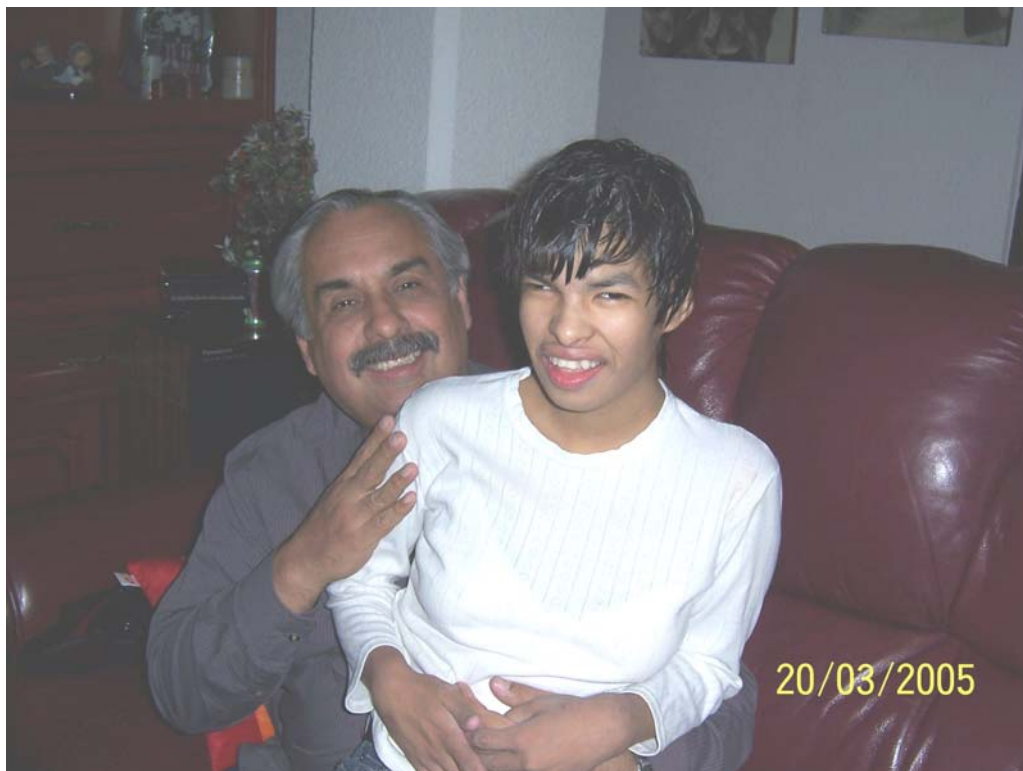
She took about 7 years to walk after intense physical therapies. Intellectually, she didn't had many chances due lack of institutions in Mexico that accepted her so she went for a few years to an special education school but children were so frightened from her because she hauled their hair that teachers told my mother that they weren't able to take care of her even though my mother stayed there.

At that time there were not many institutions dedicated to this kind of problem but now I'm really happy to find a lot of information on internet and specifically one little institution in Mexico owned by a great family who are willing to help everyone who needs it.

We are a 6 member family; Dad, Mom, Arturo who is 31 years old, Annie, Eva who is 20 years old and me, I'm 25 years old.

I'm sure that love, patience, respect and maintaining the family together are the key elements to complement all the medical treatments that Annie had and to contribute with her happiness. She is fan of Disney's movies specially Jungle Book, Alice in Wonderland and Dumbo, she loves animals and having time playing in the parks.

Even though she's now 30 years old she is still a child who laughs a lot, love "quesadillas" (like burritos), chocolate and candies.



I'm really happy to know that there's such an important association like yours dedicated to help families with this syndrome, and hope that eventually you help families in Mexico and Latin America. A good beginning may be is to make contact with Medical Institutions and help them to make an opportune diagnosis to take opportune actions. For example: My sister Eva is studying medicine in a very good university and a professor told her group in a class that any child with Cri du Chat Syndrome doesn't live more than 2-4 years and a lot of wrong information! I dare say that a lot of Doctors in my country especially in governmental institutions are not prepared to recognize the syndrome and to give accurate orientation to the families, and there's a lack of resources which impedes many families to find "a second opinion".

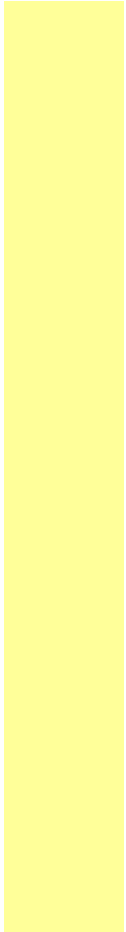
Best Regards!

Silvia Selvas Moreno



PO Box 268  
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Return Service Requested



## MEMBERSHIP RENEWAL

It's time to renew your membership with the 5p- Society. 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](mailto: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