

5p- NEWS

The Family Support Group for Children with Cri du Chat Syndrome

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

Conference Time is here again! We are gearing up for a fantastic conference in Dallas this summer. The conference each year is something that we look forward to. My boys are sad to miss it if for some reason we can't go that year. It has become a summer tradition that we all enjoy. A time to spend with friends that know how we are feeling and understand the frustrations and the excitement we deal with on a regular basis.

My daughter just turned thirteen and I have been thinking about how things have changed for the Society over the years. I asked one of the long time board members, Eileen Sherman to share her story:

Nearly thirty years ago my daughter was born and diagnosed with Cri du Chat syndrome. We were told she would be a vegetable and we would be better off leaving her at the hospital where she would surely die within the first year. I guess the doctors were wrong because she is happy, healthy and the world is a bowl of cherries. Don't get me wrong it has not been easy. The hardest part was not having anywhere to go for support. We enrolled her in infant stimulation 0-3 programs and anything I could find for children with disabilities. Of course once I gave the agencies her diagnosis everyone thought I was speaking Greek. A colleague of

Louise Wilkins, was the supervisor for a student we knew at University of Wisconsin. Through her connection, we became part of the first study on children with Cri du Chat syndrome that were raised in their homes.

We had no contact with any other family until Heather was 5-years-old and a worker in her summer program said there was a girl in his church who could pass for Heather's twin. He inquired and found that she also had Cri du Chat syndrome. He gave the mother our name and phone number and I spent a lot of time talking with this mother who knew exactly what I was going through. She told me of a group of families she knew

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Benefit Concert in New York

Barbara Cornell Chavez, of New York City, is planning a benefit concert for her 4-year-old son, Jude. The band is English Beat.

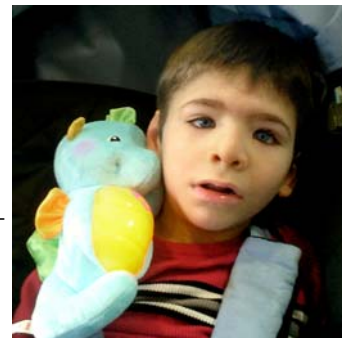
The concert is scheduled for May 13, 2009 at 7:00 PM at Maxwell's in Hoboken, NJ.

If anyone would like more infor-

mation about the concert or would like to attend, please contact Barbara at

Barbara@BarbaraChavez.net

Proceeds to assist the 5p- Society's outreach programs.



Our Story—Mia Fine,

47,XX,del(5)(p15.1p15.3);del(4)(qter-),+r

Our daughter, Mia Fine, has a twin brother, Vincent; they are 19 months old and are inseparable. Mia also has Cri-du-Chat Syndrome. She is missing a section of her 5th chromosome. As you can see from her karyotype, she also has a terminal deletion on chromosome number 4 (which we later found out is hereditary and apparently not a concern) as well as a mysterious ringed chromosome, which the doctors now think may not be chromosome material. Most people we talk to have never heard of her syndrome, since it affects 1 in 50,000 people, I always say “who knows 50,000 people?” That’s why it’s so nice to have avenues like this, where maybe the syndromes aren’t the same, but the experiences are very similar. Here is our story:



After a normal twin pregnancy, our twins were born at 37 weeks. Vincent came out crying and Mia took a little while before we could hear her. They whisked them off to the nursery, and I kept asking upstairs or down. Upstairs meant the NICU and downstairs meant the regular nursery. They went down, yeah! The first few months were great, busy, but great! It wasn’t until about three months, when we really started noticing developmental differences between the two. Vincent seemed right on schedule and Mia was a little behind. We just figured she was smaller, and sometimes the second, smaller twin takes a bit to catch up. Then, Mia spent nine days in the hospital with bronchiolitis and apneic spells. She was also diagnosed with laryngomalacia (an underdeveloped larynx). We went home on an apnea monitor, later to find out that she had a cyst on her larynx. This was removed two weeks later (another night in the hospital), and things seemed to be going well.

At each regular checkup with our pediatrician, we noticed that Mia had a small head, but then again so do my husband and I. However, when her head size growth declined, our doctor sent us through a number of tests: X-ray, CAT scan, and MRI. She thought maybe Mia’s sutures were closing early, but the tests all came back fine. A pediatric neurologist visit was to be next, when she recommended the chromosome analysis. It was then we learned the whole story of Mia’s throat and lung illnesses, developmental delays, and small head. I was driving home from work when our doctor called us. I tried to remember what I could and went home and typed furiously on the computer. We came across the CDC syndrome and just checked off symptoms like they were describing Mia. It was the craziest revelation I’ve ever had.

Okay, at least we know what we are dealing with, now what do we do? We visited a University genetics office where they confirmed what we already knew and were very mechanical with the situation – telling us that she would only be in special education classes and wouldn’t go to college, etc. We left there devastated. How could they tell me what my precious 6-month old daughter was going to be and how she was going act?

We spent the next months lining up therapy, and a battery of tests. Luckily, everything came back normal and Mia doesn’t have any of the major medical issues that normally go along with CDC syndrome. She does have acid reflux, which is controlled with Prevacid.

Mia was diagnosed at 6 months old, just over a year ago. The past year has been awesome! She went from barely moving, to pushing a walker around. She is army crawling, but mostly rolls where ever she wants to go (she’s the fastest roller I know!) She went from barely eating baby food, to picking up puffs and feeding herself. Right now, the feeding issues tend to be the most stressful. Mia is on strictly baby food, with a few bites of crackers here and there. She gets most of her liquids from bottles, but is starting to master the sippy cup. She gags very easily and often vomits in the middle of the night. She tends to have coughing spells, but so far this winter, no diagnosis of bronchiolitis or ear infections (she had PE tubes last summer). We do breathing treatments nightly to help with her coughing.

Now we are trying to educate those around us. I look back at the first few months, and I could tell Mia was “different”, but I didn’t know why or what. I just pushed away thoughts and tried to experience every little thing they did. However, I’m so glad our pediatrician was thorough and willing to try different tests, instead of just chalking it up as “smaller twin, she’ll catch up later.” By finding out when we did, we were able to start Mia in therapies that otherwise would have gone untapped.

As I look at the both of them, I can appreciate them for who they are. Vincent is the best big brother, always bringing Mia her toys, hair ties and even her nebulizer mask. He even loves to try to feed her! He can’t go anywhere with out her, always crying out for “Beepie!” I hope they stay good friends, and that he can appreciate her for all of her giggles and smiles and those she brings to others.

Thank you,

Kevin and Michelle Fine

Limebug4me@yahoo.com

Thank you for your Support!!!

You guys are unbelievable!!

Last month using GoodSearch, to benefit the 5p- Society, we raised \$69.20. This was a record month for us. We beat our previous record of \$49.50 by \$19.70. Thank you so much for stepping up to the plate to help us out. In the tough economic times we are facing, non-profit agencies are suffering. This is one way that we can help just by doing something we do everyday, surfing the net. If you have not been able to visit GoodSearch, it is simple. Just go to <http://www.goodsearch.com>, and enter the 5p- Society as your charity. Every search you make gives a penny back to the society. If you use the good shop tab, a percentage of every purchase you make goes back to the society. These purchases are made at one of the several hundred online retailers on the good shop list. Just last month we made \$43.09 from people who used good shop, and the good news is that they didn't pay anymore for their order than if they ordered straight from the online retailer's website.

Thanks again everyone, and if you haven't had a chance to try GoodSearch, just give it a try. It is simple, and it helps a good cause.

Nick and Angie Wallace

Minnesota Special Olympics with Honor Red Wing's Chalmers

By Jon Swedien
jswedien@republican-
eagle.com

(reprinted with permission)

As an athlete, a coach and an ambassador there is little more Special Olympics Minnesota can ask of James Chalmers.

Likewise, the 36-year-old Red Wing native has benefited greatly from all the organization has offered him.

Chalmers was born with Cri du Chat Syndrome, a rare disease that hampers cognitive development. He's overcome many of his limitations, in part because of Special Olympics, which offers year-

round athletic opportunities to people with intellectual disabilities.

Chalmers is also active in the organization's athlete leadership program. The program consists of a series of classes that help athletes become better coaches, public speakers and organizers.

Special Olympics will present Chalmers with its Outstanding ALPs athlete award today during the organization's distinguished service awards banquet.

"It's inspiring, I'm honored," Chalmers said about the award.

But his involvement with Special Olympics isn't about seeking attention.

"I don't do this for awards," Chalmers said. "That's celebrities — that's their lifestyle."

Rather, Special Olympics is dear to Chalmers because of the lasting friendships he's forged through its athletic contests. The award is good too though, Chalmers said, because it shows people care about his efforts.

Karen Chalmers, James' mother, said the award is well deserved. She also recognizes just how important Special Olympics has been to her son.

"When we have a purpose in life, then we're full of enthusiasm and it really makes life worth living," Karen Chalmers said. "And I think in

Special Olympics Jim really found his purpose."

Chalmers acknowledged as much.

"It's made my life complete," he said.

Dave Glover introduced Chalmers to Special Olympics in 1992.

Glover, a special education teacher at Red Wing High School, asked Chalmers to help coach. Since then Chalmers has been active in the organization as both a coach and an athlete.

"Jim is a mild-mannered, well thought of young man," Glover said. "He's interested in helping people."

However, Chalmers' pursuits in athletics as both a

James Chalmers honored continued



coach and athlete extend beyond Special Olympics.

He's been an assistant coach for the Red Wing High School football and track and field teams. Also he's run several marathons, including the 2007 Twin Cities Marathon that he finished in three hours and 19 minutes.

Chalmers, however, doesn't simply run in marathons. He uses his efforts to raise money and to promote Special Olympics.

In making the rounds between local businesses and organizations for one fundraising effort, he raised \$4,200. It was exactly the type of thing Chalmers would learn about in his ALPs classes.

Glover said Chalmers has been active both locally — speaking to Kiwanis groups and appearing on local radio — and across the state in promoting Special Olympics.

However, coaching is where Chalmers excels.

Those who know him say he has an ability to connect with athletes. Glover said Chalmers is especially adept at coaching athletes who are struggling.

Karen Chalmers said her son's success as a coach is born out of his goodwill.

"As much as he enjoys competing and the honors, I think that he is much more concerned about others," she said.

Chalmers said he's also appreciative of his hometown.

"It's just an upstanding, outstanding town," he said of Red Wing.

He's also thankful to his employer, Red Wing Shoe Co.

The company, Chalmers said, has allowed him to stay active in Special Olympics. And of course there are all the friends he's made.

"If I left this town it would be hard because I feel like a big tree with roots that run deep."

Chalmers said.

Welcome to the 5p- Society – Jacob Graham

Hi. I am a parent of a son with Cri-du-Chat Syndrome or 5p-. My son's name is Jacob and he is now 9 years old. He is not walking completely on his own yet but getting very close. Still not toilet trained, although we are trying very hard. Can hold a cup and have a drink but still does not get that he has to put the cup back down nicely on the table, instead of throwing it across the room. Does not feed himself, but if we put the food on a fork and hand it to him, he will put the fork in his mouth. Jacob has 3 older siblings, 23,20, and 12. The older two do not live at home. We live in a rural community so Jacob's resources are limited. There is no speech therapist or occupational therapist. He gets physiotherapy once a month at school. Jacob can say a limited amount of words and can mimic sounds very good. He is highly sensitive to music and often will hum songs note for note. Our biggest hurdle for us to accomplish right now is the toileting. If anyone has suggestions they can contact us at jnlgraham@hotmail.com. My name is Leah and my husband's name is James.



Special Condolences to a few of our friends

The 5p- Society would like to say farewell to two of our teens who recently passed away; both due to complications with pneumonia. The Society would like to thank the families who were active participants for all their support. We pray that with this difficult time ahead they will be able to grieve and heal and know that the special time they had with their child brought you to this family.

Sarah DePaola, Lava Hot Springs, Idaho, August 3, 1995—October 30, 2008, survived by her mom Debbie DePaola

Shelby Bryant, Jonesboro, Arkansas, February 20, 1992 — February 19, 2009, survived by her parents Jim & Deanna Bryant and her sister Abigail

Hailey's Haggin Oaks Classic Golf Tournament to benefit 5p- Society



Want to Play:

Please contact the 5p- Society or Todd Winslow for registration form. All checks for participants and lunch must be made to Todd Winslow, Tournament Director. Email Todd at haileyshaggi-noaksclassic@hotmail.com.

Saturday, June 20, 2009

**Haggin Oaks Golf Course
Sacramento, California**

7:30 am – 4:00 pm

Registration fee \$99.00 per player
\$375 per Foursome

Registration fees include warm-up, range, coffee and coffee cake, 18 holes with cart, shot gun start, contests, tee prizes, complimentary beverage carts, name on score card and lunch reception.

Not a golfer? Only \$18.00 for lunch and auction

Sponsorships

Lunch Sponsor—\$2500 (please call for more info)
Tee prize sponsor—\$750
Coffee sponsor—\$500
Beverage cart sponsor—\$350
Longest drive/closest to pin—\$250
Hole sponsor—\$185
Raffle prizes

Please contact Todd Winslow for Sponsorships At (916) 396-1907. All sponsorships are tax deductible. Please make out checks to the 5p- Society and indicate Hailey's Oaks Classic on the check.

President's Message *continued*

were getting together one weekend. Unfortunately, I was pregnant and due to deliver around the same time. I kept in contact with this family, but because we lived so far away getting together was hard to achieve. The following summer, the get together was going to be in a suburb of Chicago and we were able to attend. It was amazing and mind blowing to be able to meet other families with children Cri du Chat.

You probably are wondering why I am going through this story, but because of the 5p- Society, new parents do not have to wait six years to meet another family. They are able to have a website that provides information, an annual conference and get-together once a year where families can network and renew friendships, and meet professionals who can give ideas on how to cope with different difficult situations our children face. We also provide scholarships for families in order that they can attend a conference. In this time when the economy is so bad, we all know people who have been laid off, had services cut and are struggling to make ends meet. Because of these economic changes, the Society has seen a loss of donations that were previously forthcoming.

The Board of Directors of the 5p- Society is making an appeal to its families and friends to help keep the Society available to you. One of our members has asked each family member to donate \$10 and then asked each one of them to ask someone to donate \$10. If everyone getting this newsletter did something similar, we would be able to raise monies to help keep the Society running.

I have made lasting friendships with many families across the U.S. and my daughter loves to see her friends at the conference each year. I ask every one reading this article to think what it would feel like to be totally in the dark for six years and have no one to share your cares and concerns.

I was lucky that I did not have to be in the dark for six years. However, thirteen years ago, the internet was not what it is today. I did not have internet at my home to go to for a resource. I had to wait for a booklet to be sent to me. I was able to call Laura Castillo and I also talked to Deanna Bryant the regional representative for my area and they were both fantastic and helping me. We went to our first conference when Taylor was 17 months old and we have gone to most of the conferences since that time. What a blessing it is to have that connection with other families who truly understand.

I am doing a fundraiser next month at a local restaurant. The restaurants here do fundraisers for our schools all the time. I started thinking they would do one for the 5p- society as well. I want to do my part to help the Society, so the Society can be there now and in the future.

We look forward to the conference in Dallas and I hope to see many of you there.



Faces to Love: From top Left: Abigail, "King" Allan, Daniela, Special Olympic Gold Medal Cody, Tommy with Alligator, Kailey and Allie

5p- Society Annual Conference and Get Together Information

Location: Sheraton Grand Hotel, at the Dallas-Fort Worth Airport, 4440 West John Carpenter Freeway, Irving, Texas 75063; (214) 747-3000.

Dates: July 30 through August 2, 2009

Room Rates: The 5p- Society has secured a great rate of \$109.00 per night at the hotel. There are a few suites available at \$149.00 per night. To make your room reservations please contact (800) 345-5251. Let the hotel operator know that you are with the 5p- Society. If you run into any problems making your room reservations, please contact the 5p- Society at (888) 970-0777 and ask for Laura. Room rate is guaranteed until July 1, 2009, after that date the room rate will be honored if space is available — book early!!! Check in is 3:00 and Check out is 12 noon. Room rate is guaranteed for up to three days before and three days after the event for those of you who wish to come early or leave late.

Conference Registration: Registration form for the 5p- Society conference is attached to this newsletter. Fees for members are \$150.00 for up to 2 adults and 2 children; each additional adult is \$50.00; each additional child is \$25.00. This fee pays for your banquet dinner on Saturday evening. There may be additional costs for Friday afternoon-evening event. Sibling event has not been confirmed but there will be a nominal cost to this event for each sibling that attends.

Neat stuff to know: There is a complimentary shuttle to the hotel from the DFW airport. The hotel also offers a complimentary shuttle to the Grapevine Mills Mall.

Proposed Schedule, subject to change

Thursday, July 30, 2009

5:00—10:00 PM	Registration/Check-in
7:00—9:00 PM	New Family Orientation
7:00—9:00 PM	Sibling Mixer
5:00—11:00 PM	Hospitality Suite Open

Sunday, August 2, 2009

10:00—12:00 PM	Closing Session
	Say Farewell
	Picture Session

Friday, July 31, 2009

8:00— 9:00 AM	Child Care Check-in
9:00—12:00 Noon	Child Care
9:00—12:00 Noon	Morning Sessions
9:30 —11:30 AM	Sibling Workshop
1:00—3:00 PM	Friday Fun Event (time subject to change to evening)
4:00—6:00 PM	Grandparent's Workshop
7:00—11:00 PM	Hospitality Suite Open
8:00—10:00 PM	Board of Directors Meeting

Saturday, August 1, 2009

8:00—9:00 AM	Child Care Check-in
9:00—12:00 Noon	Child Care
9:00—4:00 PM	Sibling Outing
9:00—12:00 Noon	Morning Sessions
12:00—2:00 PM	Lunch—on your own
2:00—5:00 PM	Child Care
2:00—5:00 PM	Afternoon Sessions
6:00— 7:00 PM	Picture Session
7:00—10:00 PM	Banquet/Annual Meeting of the Membership
	Family Dance
8:30—11:00 PM	Hospitality Suite Open

*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.*



2009 Annual Conference
and Get Together
Dallas/Fort Worth, Texas

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 _____

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

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

5P- Society

Po Box 268
Lakewood, CA 90714

Return Address Requested

Conference Info Inside

Conference T-Shirt Order Form



Texas Longhorn 5p- Society Conference T-shirt Presale orders now being taken. Please fill out and return with your payment of \$10.00 per t-shirt to: 5p- Society, PO Box 268, Lakewood, CA 90714. Volunteers will have a contrasting colored shirt. Pre-order accepted until June 25, 2009. Limited number of shirts available at the conference.

	Conference Attendees	Conference Volunteers
YS	_____	_____
YM	_____	_____
YL	_____	_____
YXL	_____	_____
AS	_____	_____
AM	_____	_____
AL	_____	_____
AXL	_____	_____
AXXL	_____	_____

I'm not attending the conference, please send my t-shirts to: Name: _____ Address: _____ _____ Phone Number: _____ Email Address: _____
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of Orders _____ x \$10.00 each = _____

Shipping \$5.00 for every 3 t-shirts (non-attendees only); attendees will receive their shirts at the conference
