

# 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/](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://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/>

Yellow Pages for Kids with Disabilities—State by State resource for therapists and other services. [www.yellowpagesforkids.com](http://www.yellowpagesforkids.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

5p- Society Flower Shop— 8% of each sale goes to 5p- Society [www.fivepminusflowers.com](http://www.fivepminusflowers.com) or [www.5pminusflowers.com](http://www.5pminusflowers.com)

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)

## MAGIC OF ORLANDO, CONFERENCE 2010 WRAP

The 2010 5p- Society conference was held July 29-August 1, at the Orlando Airport Marriott with great success. Many families took advantage of the vacation hot spot by spending some extra time visiting Disney-world, Universal Studios, Sea World, and Cape Canaveral.

Many thanks to all the many individuals involved in the overall success of the event, especially the two host families, David & Jacqui Galvagni and Rob & Cathy Vaden. Both families along with their extended families and friends brought experience, fresh ideas, and organizational skills to deliver an informative and fun weekend.

The Board of Directors, Professional Advisory Board members, and Speakers helped with the flow of the event, filled in where needed and provided us with ideas to help us become better

parents to our children with Cri du Chat Syndrome.

Thank you to our many siblings, cousins, and friends who assisted with the Friday Fun Event — Pirates & Princesses— helped with child care and the sibling events.

Seventy-five families attended the conference. Of those seventy-five families there were nine new families . It was great to see all the families support each other, ask and answer questions, being relaxed and having fun.

The conference would not have been a success without the assistance of some very special people who held fundraising events to help offset the cost of the conference. Thank you to the family of Sophie Deleon, for her birthday fundraiser that helped pay for the sibling outing; Matt & Rachel Stanford and David & Amy Ratcliff for the Wine & Cheese fundraising event

that helped pay for the Family Fun Event; the Galvagni family for their yard sale and other fundraising events to help with the hospitality suite. Rob & Cathy Vaden for their donation for the bags and badge holders, Geoff & Jolene Towers for their yard sale to help pay for the conference booklets. The Oliver Fund through the Dade Community Foundation to help offset general conference expenses. The Harms family for their donation that assisted with some of the child care costs. The friends and family of the Vaden's who donated items for child care. Gloria Griffin for her many jewelry sales that help offset costs of copying. Jim & Fran Bodle for the use of their vehicle trekking many items cross-country to and from the conference. Terry & Pat Offerle, Steve & Kristi Furnari, and Art & Pat Strong for their donations to help with the Family Assistance Program.

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## 5P- SOCIETY FLOWER SHOP

That's right, the 5p- Society now has it's own online flower shop. If you need flowers for any occasion, please consider using our flower shop. 8% of each sale will come right back to the 5p- Society. Check out all the great arrangements at [www.5p-flowers.com](http://www.5p-flowers.com).

## In the eyes of... by Jannie Boulanger



Hi, my name is well it doesn't really matter. People stare at me and I wonder how they have the nerve to. I can't do anything without somebody staring at me. It's frustrating when I have something I want and it's not on my communication system. When it's not on my communication system, I have to either try to sign it or go find it myself. Usually it's not something I can sign. If it is one of the few things I can sign, nobody is in the room and sometimes it's one of those times that nobody even knows I'm up. That's because I get up too early. In conclusion then, I must be independent and find whatever it is

I need. When I look for what I need it usually ends up in a mess. I mean well, but I just don't have the coordination like everybody else to look for things any differently. By the time I find what I'm looking for, I just don't have the patience to clean up the mess I accidentally made. It's not any easy task to clean up a mess being uncoordinated and having no patience. I do end up forgetting about the mess. I'm only human, humans have the natural tendency to forget at least once in a while. When people remind me of the mess, I'm just angry that I left a mess for so long and I'm sorry. My anger usually comes out before my apology. I was born the way I am. If there were some magical way to change this I would. Sometimes I wonder why this happened. "Why can everyone else function normally and I can't?" Why am I different? Why can't somebody else be different? Sometimes I want to cry. When I have a dream I want to share, I can't. I can't communicate it to others. I can only communicate through a communication system and if I want to say something that isn't on there, then I can't tell my dream. There are so many other things that make my life ruff, but I won't bore you with those. I try being happy and not think of all of those things I can't do. All I want to say I guess is that maybe one should think before they say my life is easy and that maybe I may look and act different, but I'm human too, so don't laugh or stare at me. I can't help that I act younger than I am. I don't try to .It's just something I was born with. Like I said before, if I could change it I would. In conclusion one should think before they stare or make any harsh comments about me.

Jannie M. Boulanger

This was written from the eyes of a child that has 5p minus syndrome.

## BIKING FOR 5P- SOCIETY

Hello 5p- Society Supporters,

During the first week in October, I am biking over 150 miles along the Katy Trail in Missouri to raise money for the 5p- society, a support group for families with children with cri du chat (5p-) syndrome. The Katy Trail is the longest rails to trails path in the United States. The trail follows the Missouri River from Boonville to St. Charles for a little over 150 miles.

It is a long road for parents with children with disabilities to find the right resources for their children. One reason our daughter, Rosalie, is doing so well developmentally is due to the support that Tina and I received during our first 5p- conference. We found out just 2 weeks before the 2007 5p- conference that Rosalie had Cri du chat syndrome. At the conference we found out that good experienced therapists are worth their weight in gold and not to limit our expectations of Rosalie.

After the conference, we switched from our inexperienced general early education therapist to a group of very experienced specialty therapists. Rosalie started responding immediately. Since then, Rosalie has become the poster child of early intervention. We also got to know Vincent Hutchinson, another child with Cri du chat syndrome in the Denver area, and his family. They have been a great support to us and now we are hosting the 2012 5p- Society conference with them.

Please help us raise \$5,000 for the Denver 2012 5p- Society conference Family Outing, Sibling Outing, and Banquet by donating with a credit card via the ChipIn! Link that says "150 miles for 5p-" on the 5p- society website, <http://www.fivepminus.org/>, or sending a check made out to the 5p- society to:

Mike Brewer  
2304 South Ogden Street  
Denver, CO 80210

No donation is too small and all donations are 100% tax deductible (5p- Society 501(c)3 number is 48-1022202). Please consider forwarding this e-mail to 5 friends to help children with 5p- syndrome.

Thank you for making the 2012 5p- Society conference a success,

Mike, Tina, and Rosalie Brewer

## Fundraising Events for 5p- Society

80/20 Raffle—Thank you to all members, families and friends of the 5p- Society for your support of our 80/20 raffle. The Society fell short of its 500 ticket sale goal. Only 262 tickets were sold; the winner VANESSA MORTIZ of Forest Park, Illinois. Vanessa, parent of Zena Flagg who passed away March of 2000. We are very happy for Vanessa she has been a big supporter of the 5p- Society for many years. The winner of the vacation condo stay is grandparent JEAN LINDBERG of Missouri. Thank you to Bagety Elien for the donation of the vacation condo.

Little Edmund Piccuito turns One and his family has a Birthday Brunch and Softball game fundraiser on Saturday, September 23rd. The first time event for Elizabeth & Vincent Piccuito has raised close to \$20,000.00. Congratulations on the success of your event.

Golf Tournaments:

Third Annual Hailey's Haggin Oaks Classic was held in early August and the Winslow family raised over \$4,000. Todd and his committee is already planning the fourth golf tourney for May of 2011 in Sacramento, California. Hope you can make it.

Two golf tournaments for the 2011 Ohio Conference were recently held; the Townsend family of Sylvania, Ohio raised over \$5,000.00; The Hammond family of Ontario, Canada also raised over \$5,000 Canadian dollars.



**CdCS Motor Skills Study**  
Columbia University  
Program in Physical Therapy



Dear CdCS parents,

My name is Dr. Laurel Daniels Abbruzzese. I am a professor at Columbia University in the Program in Physical Therapy. I am conducting an investigational research study examining motor skills in children with Cri du Chat Syndrome (CdCS). We are interested in learning how individuals with CdCS walk and perform functional activities. We are inviting you to be a part of this study because you have a child with CdCS. Participants should be between 3 and 19 years of age, and be able to walk at least 25 meters.

If you and your child want to be a part of this study, we will ask you to do some tests. These tests involve activities that your child would usually do at home or at school. You do not have to do all of the tests. We will first measure your child's height, weight, and heart rate. We will ask your child to walk for six minutes. We will assess your child's strength, coordination and balance. We may also ask your child to bounce a ball, draw shapes, and run a short distance. We will also ask you to help answer questions about what activities your child with CdCS does at home and at school and what activities are difficult for them to perform.

If you are interested in participating in this research study and/or have any questions, please call: Laurel Daniels Abbruzzese, EdD, PT at (212)305-3916, or email: [la110@columbia.edu](mailto:la110@columbia.edu).

Sincerely,

Laurel Daniels Abbruzzese, EdD, PT

## Conference Thank You *by Maria-Jose*

We are finally back home, in Argentina, after the lengthiest vacations we've ever had.

I wanted to thank the organizers, Laura, the board of directors and everybody else that participated in the organizations. Congrats to all siblings that attended the conference, I strongly believe that they are special kids too, they are one of a kind, they go beyond any other human being.

We had a wonderful time, I really enjoyed meeting you all and I hope we can stay in touch. It might be a few years 'till we can make it back for another conference, but we are already looking forward to that moment.

Maggie had a great time, specially at the party. She is a party girl!!!

My step son and Maggie's friend expressed that attending the conference was one of the most amazing experiences they've ever had. They had mixed feelings initially but eventually expressed the beauty and kindness that surrounded them, they just felt so relaxed. They appreciated how other folks wouldn't look at Maggie in a strange way, as it usually happens when we go out, they were so happy to be there. In their own way they told us that seeing all the families and kids and their siblings made them understand Maggie a lot better. They even told me that the conference also showed them how to appreciate more what they had and who they were.

We are fortunate to have a wonderful family and group of friends who support us all the way. But, when people ask me what I thought was the best thing of the conference, I just tell them that for the first time in many years I felt relaxed. I felt that I did not need to constantly apologize for my daughter coming up to someone and drooling on them, not having to apologize for her spilling her glass, nor explain why at 15 she still not potty trained, or why at 15 she still likes Hanna Montana. I felt that for 4 days I was a regular mom.

Thanks  
Best Regards  
Maria-Jose



Conference Picture: Katie, Maggie, Tara, Rochelle & their families and David, too.



Kiara meets the Jonas Brothers and Demi Lovato at an autograph session. Just look at that smile!!!



PO Box 268  
Lakewood, CA 90713

Return Service Requested

### *Conference Wrap Up Continued . . .*

We'd also like to thank those members and friends who donated items for our silent auction and raffle; Kent Nicholls for the donation of the Microsoft Products; Carolina & Jerry Kretschmar for the beautiful children's quilt (next year's quilt will be raffled off instead of part of the silent auction); Frances Bodle for her Themed Quilt and Special T-shirt Quilt; Miranda Elien for the beautiful painting by a Haitian artist; Nancy Greenberg for her numbered prints for both the silent auction and raffle; Pat Strong for her continued support and donation of Discovery Toy items; Thomas Brown for his beautiful handcrafted men's jewelry box. Janet Weber for the purses and jewelry, Cathy Vaden for the Ceramic animal set and USL for the jewelry charms.

The presentations and speakers were awesome as usual; thank you to the Furnari family, Nicholls family and Campbell family for allowing us to utilize their projectors for our speakers. Our speakers were predominately parents or a child with Cri du Chat Syndrome with a wealth of information to share. Many thanks to Dr. Dennis Campbell (CDCS 101, Behavioral Strategies, Transition), Dr. AmySue Reilly (CDCS 101, Behavioral Strategies), Sandy Cooley, & Brenda Martin (Sensory Strategies & Coping Strategies), Shanida Mathieu (IEP—Advocacy), Kelly Fox-Galvagni (dental hygiene), Lisa Pugliese (speech & language), Janet Weber (Developing Fine & Gross Motor Skills) Mary Anne Elhert (Planning for the Future) Fundraising Board—Mike Brewer, Gloria Griffin & Jennifer Wong, Kent Nicholls (New Family Orientation); Miranda Elien (Sibling workshop), Jim & Fran Bodle and Gloria Griffin (Grandparent's Workshop).

A preview at the 2011 conference in Columbus, Ohio — Dr. Adam Mezzoff, Gastroenterologist will be joining our awesome speaking panel and Dance Heads are back!! Look for more information in the next newsletter. The conference theme "You Don't Know What You're Missing" has information already up on the website on the conference page. The conference committee has been fundraising and planning for a fantastic event.

Two years from now in 2012 we will be in Denver, Colorado. Conference will be held at the Renaissance Hotel. Mike & Tina Brewer along with David & Carren Hutchinson are currently planning and fundraising for their event (see page 3 for info about Mike's 150 Mile Bike Ride Fundraiser).

2013 conference is now accepting bids from families or a committee of families to host. We have families in the New York/New Jersey area, the DC/Maryland area, and possibly the Indianapolis, Indiana area interest in hosting.