

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

Happy New Year! This is the 25th year of the 5p- Society. What better place to celebrate our 25th year anniversary than in Orlando, Florida? I know my family is already looking forward to the National conference, not to mention a side trip to Disney World. This vacation will be the highlight of our upcoming summer.

The host families, along with the Board, have been working hard to ensure this conference is a success. As you may suspect, our biggest hurdle for the 5p- Society, especially with the current economy, is

fundraising. If you are able to help out in any way with this, please contact a board member. As always, we welcome any and all assistance, and convey our sincere appreciation to those who have been able



to contribute in any way. If anyone has ideas for fundraising that have been successful for them, you are encouraged to share these

with the Board or Society as a whole.

In addition to conference planning, the Board has been working on both long term and short term goals for the Society in many areas. This will help to stabilize the financial situation of the society over the long term, and will greatly assist the Society as a whole moving forward.

I hope many of you will be able to come celebrate Disney-style with us the end of July in Orlando Florida. See you there-

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"Give a Day, Get a Day" at Disneyland or Disney World

If you plan on attending the 5p- Society Annual conference in Orlando this summer and plan on visiting Disney World, you can volunteer a day with a participating organization and get a free ticket to the park. Anyone in the United States can participate. Go to www.disneyworld.com and click on the Give a Day, Get a Day banner. Put in your zip code and look at all the opportunities there are for you to volunteer. A great way to help out your community and get a free ticket to Disney World.

1st Annual Pitch n' Putt for 5p- in Denver *by Mike & Tina Brewer*

Who says you can't play golf in Colorado in October? On October 24th the Brewer and Hutchinson families had the 1st Annual Pitch n' Putt for 5p- and Raffle to raise money for the 2012 annual conference in Denver. Between the entrance fees, hole sponsorships, and the raffle, we raised over \$3,200 for the 5p- Society! We had never organized a golf tournament before and it was quite an experience. We were happy to see over 100 friends and family come out and support the 5p- Society as they played golf, enjoyed a simple lunch of hot dogs, chips and assorted adult and kid-friendly beverages, and entered to win twelve different raffle prizes ranging from restaurant gift certificates to golf lessons.

Everyone had a great time and is looking forward to next year's Pitch n' Putt. One thing we did learn is that we'll have next year's tournament in early September. Although we had great 60 degree weather for the tournament, it snowed 14 inches five days after this year's tournament. We won't take that chance again!

Thinking about organizing an event of your own? What we learned is that organizing a golf tournament is pretty simple. The first step is to figure out a date and place to have the tournament. A golf tournament doesn't have to be at a fancy country club. We had our Pitch n' Putt at a small public Par 3 golf course, which helped keep the costs down and made it accessible to families, not just adults.

Next step is to get the word out about the event. Use advertisement fliers, donation forms, and thank you letters from previous 5p- golf tournaments and modify them for your tournament. Send an email or invite to family, friends and acquaintances to tell them about the event.

Third, ask local businesses for raffle and tournament prizes. Local businesses were eager to donate items such as \$25 restaurant gift certificates, bottles of wine and other local wares and services for the tournament. We learned that the secret to getting stuff for the golf tournament is talking to the manager or owner in person.

Finally, show everyone you're the host with the most by providing plenty of beer, water, soda, hotdogs, chips, and cookies. You may even be able to get local grocery stores or liquor distributors to donate as well. Good luck and have fun!



Vince and Rosalie at Pitch n' Putt for 5p-



Briana, Katie and Julie enjoying girl time
At the 2009 Annual Conference

Judy Beth's Story *by Ainslie Reschke*

Hello, my name is Ainslie Reschke, and I am a Program Development Specialist for the Lake County board of MR/DD, in Mentor, Ohio. I would like to introduce you to Judy Beth, and to share an exciting medical advancement that has proven to be beneficial to Judy Beth.

Judy Beth was born with Cri du Chat Syndrome. While she has encountered many challenges over the years, the blessings she has received, and *especially* those that she has given far surpass the struggles. She is generally always happy, and can put a smile on your face like nobody's business! Not only have I had the opportunity to work closely with Judy over the years, I have had the extreme pleasure of becoming part of her wonderfully devoted family. She is 37 years old and the youngest of 3 girls. She lives with her mom and dad, and receives in home services provided by an Individual Options Waiver.

While Judy is chronologically 37 years old, cognitively and developmentally she tests in the profound range of mental retardation. Developmentally she is approximately at a 2 year level. At times she may appear to be at a higher level, as she is very observant and has a keen sense of humor. She has an uncanny ability to read people and their moods. Her receptive skills are much better than her expressive skills, although, she is always able to get her point across through gestures, signs, and isolated words. Her mom is correct when she says she would be the perfect Wal-Mart greeter!

Judy is very sensitive. While she does understand most words, she counts on body language, facial expressions and the tone of one's voice to help discern what is expected of her. In fact, the tone of one's voice and their body language is almost more important than the words themselves.

Judy and I have a connection that is hard to explain. I can, however, say for certain, that she is good for my soul! I can also declare with conviction that I could not love her more than if she were my own. I am grateful that our paths have crossed, and that her family shares her with me!

Over the past few years, Judy's ability to walk has diminished, to the point that walking, even with help, is limited to a step or two. Her doctors have said that this is, at least in large part, due to spasticity, specifically in her upper thigh/hip area. Spasticity is a movement disorder that is caused by an imbalance between the signals that inhibit or stimulate the spinal cord. This results in hyper excitable stretch reflexes, increased muscle tone, and involuntary movements. Spasticity can cause muscle stiffness and tightness which interferes with voluntary movements. The stiffness can be both bothersome and painful, and interferes with the ability to carry out daily activities. In Judy's case, the ability to take unaided steps has faded away. A total hip replacement was on the table for discussion, as well as other surgical procedures. As you can imagine, it is the hope that any type of surgery can be avoided.

When exploring alternatives to surgery, we discovered Botulinum Toxin Therapy. Botulinum toxin (BT) is a medication derived from a neurotoxin produced by a bacteria (*Clostridium Botulinum*). It works because BT blocks the release of acetylcholine from the nerve to the muscle, therefore, the muscle relaxes. BT is given as an intramuscular injection (into the muscle). The injections are given during an outpatient visit, which lasts about 1 hour. The effect of BT is expected to last between 2 and 6 months, and then gradually wears off. Most often, the injections are repeated every 3 months. In many cases, physical or occupational therapy is needed after the injections to maximize the benefits of BT. In all cases, it is necessary to stretch and exercise daily at home.

A web site that can explain more is: www.wemove.org. The institution that treats Judy is the Cleveland Clinic, Neurological Institute, 1.216.444.8600.

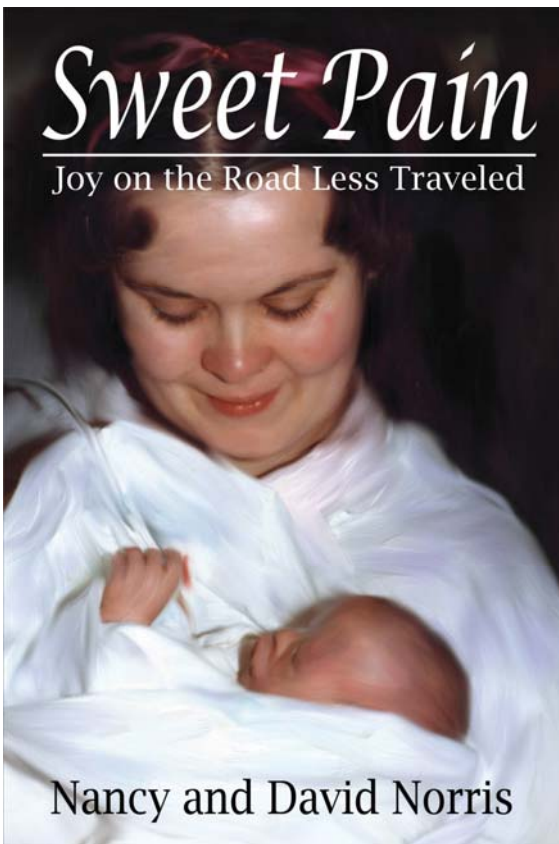
Judy began BT therapy in May of this year. To date, she has had 2 treatments, approximately 3 months in between each treatment. We have clearly seen a significant improvement in her flexibility. When starting the treatments, there was a span of about 6 inches between her knees. Currently she is able to stretch her upper thigh muscles to a span of approximately 13 inches. She moves and transfers herself quicker and seemingly, with less pain.

I have her parent's permission to share her story with the readers of the 5P-News. It our hope that Judy's story may help someone else faced with a similar situation. In addition, I would like to inquire if anyone has explored this treatment, and if so, what have their experiences been.

Please feel free to email me at: ainslie.reschke@lakemrdd.org, or call me at 440.918.1050 x110.



Sweet Pain *by David & Nancy Norris*



When our son, Nathaniel, was born with Cri du Chat syndrome in 1983, there was a lot less information available to parents than there is now. Our geneticist had both good and bad news. First, he told us that though the booklet he gave us offered us a very meager prognosis in terms of our child's health and longevity, this booklet should not be taken as the last word. Because the information from the study had been garnered from children who were institutionalized, Dr. Hermann insisted that the statistics did not accurately reflect what we could expect. And although he did tell us that the deletion that Nathaniel had would put him in the category of those who are most severe among children with Cri du Chat syndrome, he insisted that we should not put limits on what Nathaniel could do, how long he would live, or what life would be like for us. Recently, my husband and I wrote a book about our son's life. It is entitled: *Sweet Pain: Joy on the Road Less Traveled*. It is a fast paced story written that reads like a novel and offers a realistic telling of our experiences; laughter, tears, adventure, and frustration, but most of all, love. Perhaps the dedication of the book says it best: "Dedicated to those with pain so profound it cannot be spoken...dedicated to those whose joy is so deep that it cannot be understood...and dedicated especially to those who live both of these worlds at the same time." Pictures and information about how to purchase the book can be found on the website: nathanielnorris.com.

I can also be contacted through Facebook or by emailing me: nancynorris@gatewaycollege.net
Love and laughter

Editor's note: This is a wonderful book and shares a lot of the feelings and frustrations that we all have gone through. Thank you Nancy and David for sharing your story.

Meet Kim *by Rena Kimbrough*

Here is a picture of my daughter who was diagnosed with Cri Du Chat at 5 months. She is 38 years old and born in Aug of 71.

Kim is very loving. Enjoys playing games on her computer. Loves animals and helping with her Grandmother. Kim went to school at Rise Learning Center. She was a leader with her peers and Cheer leader for their teams. Kim can read and writes poems. She really likes drawing angels and reading her bible. I will never have anyone who adores me the way she does. She always says, "Anything you want, Mama"

I never joined a support group, I ventured my journey alone. There is one thing I know, I have been truly "Blessed" to have her for my daughter.

Have a great day

Rena Kimbrough rena_kimbrough@yahoo.com



Communication Device Opens New Worlds for Minnesota Girl *by Kate & Stephen Jensen*

Janine was born with a rare genetic condition called “Cri du chat” syndrome (French for “Cry of the Cat”, one of the first signs associated with suspicion of this disorder), or, 5P- syndrome. There are several features in common with ataxic cerebral palsy: low muscle tone, poor coordination, and an unsteady gait. Janine also has global developmental delays, the biggest in the area of oral motor development and speech production. Attending clinical speech therapy since infancy, Janine has always made slow but steady progress. Producing a verbal word and uttering it in a clear, understandable, and timely fashion is a great challenge. At age 7, she remains mostly nonverbal, yet has a large receptive language vocabulary.

Phenomenal gains have been made over the last year in Janine’s ability to communicate through the use of assistive communication technology, such as picture symbol boards, picture schedules, gesturing, and American Sign Language. Because of this progress, in February, Janine was introduced to the use of a computerized “talker” (the Vantage Lite by PRC), which can generate audible words for her. After some initial training on the device in the speech clinic, she was given the opportunity by United Cerebral Palsy to “trial” the Vantage Lite in daily life at home and across all her usual settings (school, therapy, doctors’ appointments, and leisure) for several weeks.

Results have been amazing. Teachers and therapists were shocked at the higher level of cognitive understanding that Janine was demonstrating versus her very limited verbal skills. Some of the professionals working with Janine were previously unaware that Janine knew colors, numbers, letters, even sight words, appropriate to her age. Low expectations had often led to a “dumbing down” of her preschool curriculum, which in turn had led Janine to “tune out” or “shut down” when bored, thus perpetuating a false notion that she “obviously” was not capable of understanding more than she was being given credit for.

Janine’s use of the Vantage Lite over several weeks has proven that she is quite capable of navigating the device, expressing her thoughts, needs, emotions, and opinions, often in complete sentences, which she can quickly assemble word by word from her picture keys. A school administrator sat in on a session with Janine’s occupational therapist at lunch time one day to observe the use of this device. The administrator actually cried to see what Janine was able to do: “I __want__eat__more__yogurt__please,” then indicating that she was done, and then asking to go to the bathroom, all with the Vantage Lite. It was a world away from whining, banging, and throwing herself on the floor in frustration. Or having others decide for her.

The Vantage Lite is a VOICE where there was none. Without a voice, it is very difficult and frustrating for Janine to convey what she knows. With a voice, Janine can be more socially engaged with adults and children, be a part of her class, and show what she knows. Having an efficient way to convey the very basic message that she needs help to use the bathroom, or is feeling hot, or cold, or ill, will make a profound difference in the life of this remarkable little girl as she attends kindergarten and beyond.

Janine is currently using a borrowed Vantage Lite from Gillette Children’s Specialty Hospital. As it may be needed at any time for another patient, the family is seeking to purchase its own customized device. The high cost (approximately \$10,000), along with a concurrent need to replace Janine’s outgrown adaptive equipment (supportive task seating, a new car seat, transport chair and adapted tricycle at approximately \$4000) has led to a fundraising initiative to help meet these needs.

An account for specific prescribed equipment has been established at Adaptivemall.com. Find Janine’s web page at www.adaptivemall.com/janinej.html



Janine thanks you!



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Return Service Requested

2009 CONFERENCE PICTURES



Here are some pictures from the 2009 Conference Top from left to right. . . Nisto Martinez, Colton Warren, Faith Cruz, the Miller family—Abby, Greg and Fisk, the Lopez family —Ann, Walker, Lora Piepergerdes and Tony, Tina Britton, and the Registration Desk #1 volunteers Heather Sherman, Grandparent Pat Strong, Board Member Treasurer Eileen Sherman and Grandparent and Board Member Gloria Griffin