

5P- News

5P- Society, PO Box 268, Lakewood, CA 90714-0268, (888) 970-0777— fax (562) 920-5240

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

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Fall 2008

President's Message by Jolene Towers

Special

Condolences

The 5p- Society would like to send its condolences to the Families of Hope, Emily and Lindsey Orwick.

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The 5p- Society would like to send its condolences to the family of Stephanie Gibbs.

My husband often tells people that life with our daughter is an adventure. I look back at all the funny and some of the not so funny things we go through with her and I have to agree, it IS an adventure. Lately I have felt like we just keep having one adventure after another.

This is Taylor's first year in middle school and we have had a bumpy transition. To me, it seems like we have had more issues in the past two months than we have had in the previous four years put together. Hopefully, this is not a sign of similar adventures to come. Though my friends here are great, they cannot understand completely what we go through with Taylor — the joys, the frustrations, the triumphs.

But all of you can.

Each year, as we attend conferences, I take in so much information from all of the speakers. Still, my favorite aspect of these get-togethers is the interaction with other families, sharing that understanding and camaraderie unique to families with special needs children. I love building friendships with new families, as well as renewing ties with old friends.

My boys also enjoy being with the other siblings. It has been wonderful for them to see that they are not the only ones out there sharing in the adventures attendant with having a Cri du Chat sibling. Indeed, the conference is a highlight of their year.

I'm especially grateful to

the host families who put forth so much effort to make each conference fantastic. Thank you once again to the Blount and Zettlemoyer families for their wonderful job in Virginia Beach, both with the itinerary and curriculum, as well as with fundraising. Thank You for Everything!! Thank you to the Texas Committee for hosting the conference for 2009 in Dallas. We look forward to the many wonderful events that are planned.

Though we don't like to emphasize the financial aspect of our conferences, many of the events we enjoy are made possible solely through the generosity of multiple donors, and the extraordinary

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Virginia Conference Big Success

Norfolk Waterside Marriott in Norfolk Virginia was the site of the 5p- Society's 23rd Annual Conference and Get-Together. The location was in the heart of Norfolk's business district and had a lot of eateries (everyone's favorite d'egg), a mall within walking distance, Nautilus Museum,

and close to the Atlantic Ocean. Equally as impressive as the location were the two host families and their organization and execution of the event. Bill & Christy Blount and Dave & Anne Zettlemoyer and their many friends and families did a fantastic job.

Highlights of the conference: The Jensen family of Minnesota and the Abbruzzese family from New Jersey share their highlights on pages 2, 3 and 4, 5.

The Dancing Heads, a video production using green screens and music

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Family Stories: Our Conference Experience

By Kate Jensen, mom to Janine, age 6

I wanted to write down some things we got from our recent trip to the 5P- Conference in Virginia before I forget. We have never attempted to fly with Janine, or be in a hotel for such a long stay (6 nights) before, so much of it was new to her!

At the airport Janine followed the instructions of the security people very well - "take your shoes off", "walk through here", etc. She had also done well in this way with the technician from the medical equipment company last week - "scoot back", "lift up your arms", "cross your leg over", as he was fitting some equipment for her. I could cite several other examples, but to summarize, we see many instances of Janine rising to the expectations, but also of her trying to see just exactly how little she can get away with doing, if she has a familiarity and comfort level with a person. If she is motivated and sees that it is in her best interest (more fun, or cool new experiences), she will perform. Boredom/frustration has the opposite effect... she will shut down and go into herself (and that's when we see some self-injurious behaviors as well). It is so hard to undo this. And if her relationship with a particular person has gone this way, or she has gotten used to responding at a certain level, it tends to stay like that. On the other hand, we have seen Janine respond very well to a lively, animated approach, not necessarily loud, but with a respect for what she knows and can do.

She was very fond of the moving sidewalks at MSP, and seemed to think of reasons to get back on, signing "potty" (and she stayed dry and used the toilet properly!) and later "eat", and pointing to that moving sidewalk. She was very patient

when our flight was delayed 2 hrs. She loved the takeoff and landing, and smiled and slept most of the flight. She was excited to be on a real airplane, and wanted us to sign it for her and help her make the sign. At the hotel, she went right to sleep in her little pop-up tent that we use for traveling.

We heard an increase from the usual repertoire of sounds and words on this trip. Janine has been giving us the ending sound of many more words ("k" for "shark", "p" for "cup", "t" for "little bit", etc. -



new ones daily). She has been saying, "done" and "down" fairly consistently, starting to say "no", and learning new signs. One of her favorites is "dolphin"! She is still working on "shark". There is so much that she wants to say to us, if we are interested. Sometimes she gets really excited to find a picture in a magazine (photo or drawing) to express what she wants to say, and nods her head when we elaborate

on the picture or ASL signs she is doing, i.e., "Oh, you are thinking of the boat ride, when you saw ...", or, "You want to tell Daddy about going swimming today", or, "You are remembering the farm where we picked strawberries. That looks just like the tractor that pulled our wagon, huh?" or, "The toboggan run looks a lot like a bridge, doesn't it?" If we don't get it right, she often perseveres in getting her idea across, with other signs, pictures, or words, and is very pleased when she is successful.

One of the wonderful experiences of going to a conference such as ours is the opportunity to interact with the other families. One thing that struck me this year was the outgoing, sociable nature of many of the kids. So many of them would walk up to me and ask what Janine's name was in sign, point to their own name tag to show me their name, and then do the ASL sign for "mom" or "dad" and point to their mom or dad. We had a hospitality suite in the evenings, where the older kids with 5P- would be asking us in sign where our littler kids were. We would have to sign back, "Upstairs, in bed", or, "At the pool" as we spoke the words. Some brought their photo albums to show what they have been doing this year. Some kids were very understandable talkers, and many could read well (quite a few teens and adults were at the 5th grade level, one high schooler was almost at grade level). Handwriting was universally difficult, with even the highest-functioning kids having preschool-like handwriting (large, wobbly letters). Test-taking was an issue that was brought up, as accommodations such as oral testing and touch-screen computer use showed a more accurate measure of the material learned. This seems im-

portant to know now, so we can work on building the foundations.

One afternoon we had Parent Panels, in which we parents broke off into our kids' age groups. I felt fortunate that ours (Ages 5-9) was among the largest, and also that we were on the younger side of our group. We got to list all our issues on a board at the front, and we went through all of them, starting with the most concerning. One of the first was "Communication", and I am happy to report that we are addressing Janine's communication needs in the way that has been most popular and effective for the families in our Panel, namely, the Total Communication approach. Our discussion revealed that all of the modes of communication (verbal, picture communication boards, symbols, PECS, dynamic talker, ASL, written words) are necessary to introduce and practice with, and it turns out that elements of each may be in use simultaneously for a given child. Most of our kids do not use each "system" in the classical or "correct" way (especially the picture-exchange... not fast enough for the kids with a higher cognitive ability than it looks like, and/or with attention problems and sensory-seeking compulsions), but it is important to the child to know that they have options in getting their ideas across. ASL is very widely used amongst our kids, and even though the fine motor skills of a child may impact the understandability of their signs (as oral-motor development is an issue with verbal clarity), this

may be the easiest, fastest, and most often first-chosen mode unless and until the verbal ability catches up. It is important to have teachers and therapists who are skilled in ASL, at least to the point of staying ahead of the child. I have to say that I have had to work diligently to try to stay ahead of Janine in signing. It is also not just about her ability to sign something to me, but about the help that signs are (along with verbal words, written words, symbols and photographs) in learning new concepts and in categorizing. There is also a perceptible comfort level that comes when Janine sees that someone knows sign language.

Here are a couple of online ASL dictionaries that I have bookmarked and use regularly: <http://commtechlab.msu.edu/sites/aslweb/browser.htm> and <http://www.aslpro.com>. These have video clips of people doing the signs that can be played over and over. I also have some books (ESL dictionary and some children's signing dictionaries), as well as the first set of Signing Time Videos, which have been the most fun for our entire family. We are planning to start collecting the 2nd set for a certain 6th birthday coming up in September.

Another thing that I thought I should mention was the progress I noted in Janine's eating skills from last year's conference to this year. I know I should be noting the progress all along, but I couldn't help but be impressed that Janine was

able to actually eat the "Kids' Meal" at the concluding banquet this year without a lot of chopping and mashing or substituting with a baby food jar! And she even signed "more chicken" and was able to take her own bites of chicken strips without choking! She was also able to handle peanut butter sandwiches, grilled cheese sandwiches, and french fries this year, which was somewhat emotional for me. I remember seeing kids at previous conferences being able to eat these things, and thinking to myself that Janine would never be able to. This whole issue makes me more hopeful for what other things Janine may be able to accomplish in the next year.

Speaking of the Banquet, the highlight is always the dance! What a joy. This year Janine RAN to the dance floor every chance she got. She got people to pick her up and dance with her! Next year she may be too big for that. No matter, she will dance every dance in her own way. She danced until she could dance no more. She wasn't the only one. The dance floor was full from beginning to end, and on the elevator up to our room, there were kids asleep on their feet!

There is much more that I could say. I know we will be using all we have learned in the coming year and hope that we can get together with you all soon again next year.

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Highlights of Protect Tomorrows Presentation

By Laurel Daniels Abbruzzese, EdD, PT

The most impactful presentation that I attended at the 5P- conference this year was the series of presentations given by Mary Anne Ehlert, financial professional with a sister born with cerebral palsy. She is the founder of Protected Tomorrows

www.protectedtomorrows.com, and was able to share invaluable information about planning for the future of a child with a disability. I could never do her presentation justice in a short newsletter article, but I'll try to share the highlights.

First and foremost, she recommended establishing a third party (discretionary) Special Needs Trust for your child. The Special Needs Trust is a specialized legal document that allows an individual with a disability to be the beneficiary of an unlimited amount of assets, held in trust, without those assets interfering with qualification for certain governmental benefits. The trust is managed by trustees, and does not actually belong to the beneficiary. This trust must be irrevocable but amendable to stay compliant with the law. It can be set up by anyone except the individual that will be the beneficiary. The trust document should be written by someone knowledgeable about special needs trusts, Social Security regulations, etc. The trust does not need to be funded right away, but ultimately money in the trust will be used for supplemental and extra care over and above what potential government resources will pay for.

You will want to avoid having gifts inheritances directed to your child with a disability or left to another family member with an "understanding." Needs-based entitlements like SSI and Medicaid have income and asset rules. Currently, an individual must spend

down all assets above \$2,000 before becoming eligible for government resources. Services can also be lost if money is left to your child as an adult. For example, an unexpected inheritance can cause an individual to lose subsidized residential services. By establishing a Special Needs Trust NOW, all relatives that may want to leave something to your child can piggy-back off of the established trust, and today's laws can be grandfathered in.

Ms. Ehlert reminded us to check all of our documents regarding beneficiaries. In addition to our wills, many of us have 401K's, insurance policies through work, etc., that may include all dependents as beneficiaries. You will want to specify that the portion that would go to your child with a disability be directed to the special needs trust.

Ms. Ehlert gave sound advice on ways to reduce the expense of establishing the trust. The first step is to discuss all of the details in advance of meeting with a lawyer. Determine guardians for your child. Pick the charity that will benefit from the trust when your child dies. Choose trustees for the trust that are good at managing money and ensuring that the money will last as long as possible. If desired, you can create a team of trustees that will make decisions together, and they need not be the same as the guardians.

In addition to planning for the financial future of our children with disabilities, Ms. Ehlert recommended creating an "Operation Manual." What does your child enjoy doing (swimming, dancing, horseback riding?) what is the contact information for all of the key people in your child's life? Where are your child's favorite places to go?

Organize all medical records, IEP's, attorneys, contacts, guardianship documents, now. If your child is still young, you may take for granted that you have easy access to your child's records. Be sure to request copies of all documents within the month before your child turns 18 to make the guardianship process much smoother. Until and unless you apply for guardianship at age 18, you will not be able to request any medical or school records once your child is considered an adult.

Ms. Ehlert suggested that we each set at least one goal that we would accomplish within the next 3 months with regard to planning for the future. My goal was to find a local lawyer that specializes in Special Needs Trusts. Right now our trust instructions are buried in our will, which won't serve our daughter until we die. I have also added visiting various residential programs in our area within the year. Options are limited and waiting lists are long. I'd rather be proactive and create options for the future than cross my fingers and hope that someone will work something out after I'm gone.

Just thinking about the future can get emotional and overwhelming at times. Many of us may have found it easier to procrastinate and avoid dealing with the issues. Others of us may have gotten bad advice. My best advice is to be your own advocate. Learn as much as you can, attend local seminars, and begin the process now. It's never too soon to start planning for the future. Thank you to Ms. Ehlert for such an informative and provocative presentation.

2008 Conference Highlights

By Laurel Daniels Abbruzzese, EdD, PT

Hats off to the Blount & Zettlemoyer families and to our Executive Director, Laura Castillo, for pulling off yet another hugely successful conference and get together in Norfolk this summer. Kudos should also be extended to president Jolene Towers and the rest of the Board for the work that they do on behalf of the society. Our family has been attending these conferences for the past ten years. Every year I am able to meet someone new that I am able to help and learn something new that will help me to be a stronger advocate for my daughter. Another highlight of every conference is the chance to have fun with other families that understand what it's like to raise a family that includes a child with Cri du Chat syndrome. This conference did all of that yet again. When I look back at the roster of families that were in attendance, however, I am reminded that the families that were able to make it to Norfolk this year are only a sampling of those dealing with the challenges of 5P- Syndrome. It is my hope that by contributing to the newsletter, even more families can benefit from some of what I learned at the conference this year.

First, I'd like to highlight some of the points made by Dr. AmySue Reilly, Associate Professor of Early Childhood Special Education at Auburn University. She gave a talk on "Behavior Applications" to a packed audience. Managing challenging behaviors is always a hot-button issue at our conferences. Most parents with young children are still perplexed. Over and over again you hear a mom or dad say, "He just pulled her hair for NO REASON," or "She pinches her sister without any provocation." How can we fix the problem if we can't make any sense out of what's going on? Well, according to Dr. Reilly, assessing the problem is one of the first steps every family should take. We often want to jump right in with solutions. However, in order to be able to systematically replace unacceptable behaviors with acceptable behaviors, Dr. Reilly recommends that you conduct a functional behavior assessment (FBA).

The Functional Behavior Assessment includes collecting behavior data from multiple sources including interviews and observation. You will want to define the behaviors that are deemed unacceptable and keep track of how frequently the behaviors occur and under what circumstances. What activities or conditions typically precede the problem behavior (the antecedent)? What activities or conditions typically follow the problem (the consequence)? An individual experienced in collecting and analyzing behavior data may be able to help your family determine the function of the problem behaviors so that you are able to replace them with behaviors that serve the same functions.

Collecting baseline data is also an essential component of monitoring the effectiveness of a positive behavior intervention plan. Dr. Reilly pointed out that if you are documenting a behavior plan for a school setting, you will want weekly objectives to be monitored, not the typical quarterly or yearly objectives that are often included in the IEP. "How many weeks do you want to go by before you realize that the intervention is not helping Johnny?" If you have data regarding the frequency and duration of a problem behavior, you will be able to quantify progress. Dr. Reilly warned, however, that you won't always want to abandon a strategy just because problem behaviors temporarily become more frequent. Often things get worse before they get better.

You should also have realistic expectations. You can not expect 100% extinction of every problem behavior. The goal is to end up with a small percentage of residual behaviors that you can live with. You SHOULD have higher expectations for the behavior of your children. Things can get better with focus and consistency. Just don't expect perfection.

This brings me to my last big take-home message from Dr. Reilly... "CONSISTENCY!" Once the behavior data has been analyzed, and the behavior plan is implemented, EVERYONE has to be on board. Everyone who interacts with your child needs to be educated on how to reinforce positive behaviors. This includes grandmas, siblings, teachers, therapists, babysitters, etc. It can't always be mom or dad that jumps in when problem behaviors emerge. Everyone needs to be empowered with the plan, and consistency is KEY.

In summary, the highlights of Dr. Reilly's presentation were 1. Approach your behavioral challenges systematically. A functional behavior assessment can help you understand the circumstances under which problem behaviors are more likely to occur, and can help you to identify appropriate replacement behaviors. 2. Monitor the behavior data regularly. Charting frequency and recording ABC information (antecedent-behavior-consequence) can aid in determining whether or not your intervention strategies are working. 3. Be consistent. Positive Behavior Interventions will be most effective when implemented consistently by all individuals that interact with your child. It may take a while to get everyone on board. It certainly takes hard work and commitment, but consistency will be the key to your success. Whether you are new to these challenges or just want a little refresher, I also recommend the Center for Effective Collaboration and Practice website: <http://cecp.air.org/fba/> as a useful resource for learning more about the FBA and what it may entail.

2008 Ohio Gathering

By Tammy Boring

Continuing the tradition begun by Nick and Angie Wallace, Bellefontaine, Ohio, in 2007, the 2nd annual Ohio Gathering was held October 3-5, 2008, Columbus, Ohio. It was hosted by Bob and Tammy Boring who have a 5 year old daughter, Abigail, with 5p Minus. The Borings first came into contact with the Wallaces the Summer of 2007 after contacting the National Society trying to find someone to talk to regarding their daughter's diagnosis in 2006 at the age of 2. The Boring family went to the 1st Ohio Gathering in 2007 and were so touched by the work that the Wallace's had done and impacted by the other families who attended that they decided to host the 2008 Ohio Gathering. This was exactly the spark the Wallace's hoped to ignite.

To fund the event, Tammy sent out letters to select businesses and individuals requesting donations. Friends organized a golf outing in July. Enough monies were raised to pay for the entire weekend's festivities, including the hotel stay of all registrants.

Friday, 10/3, was the first evening of the event and the Drury Inn, Grove City, donated the use of the conference room, as well as gave a discounted room rate. During registration, all of the families received a 5p Minus of Ohio tote filled with goodies for the children and more gifts were on the registration table for the taking. Carroll Baker, a local Columbus Magician, provided a wonderful show for the families as the after-dinner entertainment, which included a very popular bunny and dove. The McCoy family won an autographed pennant donated by the Columbus Bluejackets' hockey team. The Boring family donated toys to all of the children and each child made their selection as their names were called. It was

a great time of food, fun and fellowship.



Saturday, 10/4, began the day at Easter Seals, the brand new therapy facility in Hilliard. While the parents received free instruction regarding estate planning from Worthington Attorney, Valerie Carlson, and information on supplements and enzymes from Sally Wiersema with Whole Foods, 13 OSU therapy and education students donated their time to play with and watch over the children. The students were excited to be a part of the event and to be with children with the rare genetic disorder. Lunch was donated by Bob Evans' Restaurant. From Easter Seals the group headed to downtown Columbus to COSI (Center of Science and Industry) where the children received some wonderful sensory input from the many hands-on exhibits. Dinner was then held at the Spaghetti Warehouse where the

group received a discounted rate. The day wasn't over yet as everyone made the trek to Worthington for a great evening at SuperGames. There were 16 OSU students volunteering their time to help the children and their parents with safe play on the many HUGE inflatables, the rock climbing wall and video games. Every kid had a great time and every parent became a kid.

Sunday, 10/5, regrettably marked the final day of the gathering and the group went to Dublin for a visit to the Columbus Zoo and Aquarium. The Zoo donated parking passes, admission to the Zoo and the use of the Pavilion. Jacks' Landing, a new edition to the Zoo in 2008, provided 14 amusement park rides for the families. Lunch was held in the Water's Edge Pavilion. As a surprise, there was a special animal presentation for the group, which included an alligator, clouded leopard and the most popular visitor, Mango, the albino python.

During the closing remarks, Tiffany Townsend told the group that her family would be hosting the 3rd Annual Ohio Gathering in 2009 in Toledo. Thanks Tiffany – you are carrying on the tradition!

Tammy, Bob and Abigail Boring are still talking about the event and are so thankful to have been a part in making the kids just feel like, well, kids. They are grateful to all who donated their time, talents, monies and resources to make this year's gathering a success and a source of great memories for years to come.



Virginia Beach Conference Report *continued*

videos provided lots of fun by the kids and the adults of the group. The food was fantastic and plentiful. Thanks to all the siblings who helped out with the games. Childcare was awesome with the assistance of the many friends and family of the Blount and Zettlemoyer families. As usual the hospitality suite was well attended and a great way to relax after a long day.

We had a record breaking year for new family attendees. We hope that you all were able to learn, network and relax a little during your stay.

Our Board of Directors now has an international member; Hayden Nanton from the country of Trinidad and Tobago has joined the board — Welcome!

We have also incorporated a Fundraising Committee and we'd like to invite you to be part of this committee. If you have the knack for fundraising, have any ideas or would like to assist please contact Gloria Griffin at flyinggigi@insightbb.com or by calling (502) 895-9729.



2008 Virginia Beach Conference Hosts — Christy Blount, Cassidy Blount, Zoey Zettlemoyer and Anne Zettlemoyer

President's message, *continued*

Fundraising efforts of many of our members. Thank you to everyone for helping us to keep the registration costs low so that more families can afford to participate! The Society is always looking for extra help with any of our events. If anyone would like to help with fundraising or with the conference in any way, please let us know. We would love to have you!

Fundraising opportunities:

Get great custom clothes for your child and/or children through Mini Miracles; the 5p- Society will get 10% of all sales. Go to <http://www.minimiracles.ca/index.htm>.

Jewelry by Raeann— Order specially made bracelets by 10 year old Raeann, who has a sibling with Cri du Chat Syndrome, contact the 5p- Society for an order form.

2009 Conference Info:

Planning for the 2009 conference in Dallas, Texas is underway. The Texas Conference Committee recently met and have already come up with a t-shirt design — it's got a Longhorn Bull on it, and site for the Friday Family Event — Austin Ranch. If you'd like to assist with the planning and preparation of the conference please contact Jessica Gomez at (469) 834-7262 or Julie & Mark McGough at (972) 312-9899. Childcare volunteers will be needed for the event. The committee is looking for ways to raise monies to help offset some of the costs. If you have any ideas or would like to host a fundraising event please contact the 5p- Society office.

The dates for the 2009 conference are July 30 through August 2 and will be held at the Sheraton Grand DFW Airport Hotel in Irving, Texas. Courtesy shuttle is available from the DFW Airport. If driving to the event, the property has free onsite parking.

5P- Society

PO Box 268
Lakewood, CA 90714-0268

Return Service Requested

THE HOLIDAY SHOPPING SEASON

By Nick Wallace

Well, it is hard to believe that the holiday shopping season is approaching. It seems like the annual conference was just a couple weeks ago. Where has the time gone? As we start thinking about the holidays, we start thinking about what gifts we are going to be getting for others and what great bargains we are going to find. I like the bargains where you spend a certain amount and then get a gift card that you can use or give to someone else. If you are like me, I usually add it to someone else's gift. What if I tell you that I know a place where you can get the same deal?

If you visit <http://www.goodsearch.com/goodshop.aspx>, and enter the 5p-Society as your charity, and choose one of their more than 700 stores,

the store will give a portion of your purchase to the society. They also offer coupons to the store you choose, for greater discounts. For, an example, if you click on the BestBuy.com link, and you purchase an item from them, they will give .5 - 1.5% back to the society. They also have a coupon for [10% - 25% off select GPS receivers, plus free shipping at BestBuy.com](#). Some of the other stores are Dell, Nike, Apple, Amazon, iTunes, Macy's, and several more.

This is a great method to shop, especially with the price of gas, and the hustle and bustle of the crowds. You can just visit the website, add the society, and click on the store you want to shop at. There is no sign up required for Good Search/Shop, no price in-

creases to offset the donation. You get the same deals that you would if you visited the site directly. Don't forget to use <http://www.goodsearch.com> as your search engine, because every search you make, a penny is donated to the society.

So, during the holiday shopping season, don't forget to use Good Shop as your portal to the retailer of your choice. By doing this, you will make someone's holiday a little bit brighter, while helping the 5p- Society. Thank you, in advance for your help, and from our family to yours, "Have a Happy Holidays and a Joyous and Prosperous New Year."