

# 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)

### President's Message *by Greg Abbruzzese*

#### Dear Five P Minus Society

Thank you all for your continued support of the Society. As we continue to grow, we are providing greater services, resources, and support for new (and developing) families with the Syndrome.

In an attempt to take the Society to the next level, we are looking for input from our members to what they would like to see from the Society going forward. Some suggestions have been to engage in a more interactive component to the site. Specifically, suggestions range from having "professional hours", where medical professionals, social workers, educators, behavioral specialists, attorneys, etc. would make themselves available during certain hours of a month to answer real-time questions on the site. Members would be able to log in and hopefully answer some of their lingering questions about every day life. Just food for thought... Let me know your thoughts on this idea, as well as any others, to help improve the services that we provide our children and family members - [gab-bruzzese@converse.com](mailto:gab-bruzzese@converse.com)

Several of our members have inquired about the status of our on-line video link from the last conference... where we stand is that we are still awaiting the content from the San

Jose conference. It will then be reviewed by Dr. Dennis Campbell, who will then pass it on to our web guru Mr. Vaden. Again, we hope to have the test up and running by March. Hopefully, this process will get easier going forward.

Looking ahead to the 2007 conference, Paul Bakken has made a great deal of headway on his own securing sites, negotiating with the hotel, and gathering daycare volunteers. With all of that said, we are still looking for additional regional support to assist with Paul's undaunted task. If you are in/near the Minneapolis, MN area, Paul (and the Society) would welcome any assistance! Please feel free to contact Paul, or any Board member if you can help out. In addition, we are still accepting room sponsorships/ donations that will help defray the cost of the Minnesota conference.

The 2008 and the VA Beach conference, which is being run by Christy Blount and Anne Zettlemoyer, is still going strong. They continue to fundraise and are well ahead of their target to date. As always, we can use additional assistance in that area. If you wish to assist Christy and Anne with the VA Beach conference, please contact any Board member as

we will pass it along.

Looking further ahead to 2009, we are looking to have the conference in the Dallas/Fort Worth, Texas area. The Board will be scouting sites within the next few months to settle on a location that will meet all of our needs. I would like to again thank the Board for all of their efforts as they make a tremendous amount of personal and financial commitment on the Society's behalf.

Bless you all this holiday season!

Greg Abbruzzese

#### 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://comtechlab.msu.edu/sites/aslweb/browser.htm>
- Signing Videos and DVDs: <http://twolittlehands.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/](http://www.schoolspecialtyonline.net)
- Identification bracelets: <http://www.stickj.com>  
<http://www.mypreciouskid.com>  
<http://www.911destiny.com>  
<http://www.laurenshope.com>

#### Inside this issue:

President's Message	1
Managing Behaviors	2
Grandparents Corner	4

YOU CAN NOW MAKE  
YOUR  
TAX-DEDUCTIBLE  
DONATION ONLINE  
VISIT  
[WWW.FIVEPMINUS.ORG](http://WWW.FIVEPMINUS.ORG)  
FOR THE LINK

## Managing Challenging Behaviors *by Laurel Daniels Abbruzzese, EdD, PT*

Does your child ever have trouble getting along with peers or siblings?

Is your child ever noncompliant with adult requests?

Does your child ever hit, pinch, bite or pull hair when frustrated, anxious, or in need of more attention?

Does your child ever drop to the floor to avoid going somewhere or avoid doing something?

Do you sometimes feel like you need to be within arm's length of your child because you're not sure what he or she may do next?

If any of this sounds familiar to you, read on.

For me, one of the most stressful aspects of parenting a child with Cri du Chat syndrome has been dealing with her maladaptive behaviors. When my daughter was a toddler, she was fairly docile. She wasn't really mobile until age three. At about age three we started experiencing pinching, hitting, biting, grabbing glasses off of people's faces, grabbing scrunchies, pulling hair. Her frustration tolerance was low. Her communication skills were really poor. She had a new baby sister and had to share attention. She seemed to need more and more attention from adults. Her behavior was impulsive, and at the time seemed "unpredictable". Even though she was really little and really cute...**it hurt**. I knew then that we needed help addressing the problem, but it took a while before we got it.

**The bad news:** Things got worse before they got better. When difficult behaviors arise, it can be very frustrating for teachers and caregivers and can cause a lot of stress.

**The good news:** There are resources and professionals that can help you understand difficult behavior and implement a positive behavior strategy that works. It may take time. It will definitely take a lot of work, but things can get better. Things have gotten much better for our family and we're still moving in a positive direction.

There are a number of factors that have led to improvements in our ability to increase appropriate behaviors and eliminate (for the most part) aggressive behaviors. The first resource that has had a huge influence on our lives is **Dr. Amy-Sue Reilly**. AmySue Reilly, Ph.D. is an Associate Professor of Early Childhood Special Education at Auburn University. We have been privileged to have Dr. Reilly present workshops on behavior strategies at our last four (if not more) 5P Minus conferences. Her approach is child-centered and emphasizes a **guidance-approach to positive discipline**. Adults learn strategies for anticipating problematic situations, and are prepared with positive reinforcers. I learned that "discipline" is not the same as "punishment." "Discipline" helps teach appropriate behaviors. Dr. Reilly shared techniques including humor, nonverbal techniques, brevity, and being direct. Attending her workshops did not make us experts, but got us started in the right direction. Rather than focusing on what I wanted my daughter to "stop doing," I got better at focusing on what I wanted my daughter "to do." For example, instead of saying, "Don't put your feet on the couch," you would say, "Keep your shoes on the floor." If you aren't conscientious about the language that you use, using **positive language** is one of the first things that you can start working on right away. You can read more about the **Guidance Approach to Discipline** at the following websites:

<http://www.ag.ndsu.edu/pubs/yf/famsci/fs468.pdf>

<http://www.humsci.auburn.edu/~abellel/beeprogram/links/resourceupdates/guidedis/guidedis.htm>

Another important factor that has led to improved behaviors in our home is the realization that behaviors have functions. We were struggling to understand "why" she just hit someone for "no apparent reason." Our success at teaching appropriate replacement behaviors did not evolve until we were better at understanding "why" the behavior occurred in the first place. You can figure out the "why" by conducting a **functional behavior assessment (FBA)**. An FBA involves collecting data on the target problem behaviors and analyzing patterns. First it is important to define the behaviors that you want to reduce or eliminate. Behavior is something that someone says or does that can be observed. Emotions, feelings, and thoughts are not observable behaviors. An **FBA** will look at the **ABCs**. The "B" in ABC stands for "behavior." The "A" stands for "antecedent," or what happened before the behavior occurred. The "C" in ABC stands for "consequences," or what happened after the behavior occurred. Looking at frequency and duration of problem behaviors, and the environmental factors that contribute to or reinforce problem behaviors can help determine the function of the behavior. There are four "function" categories: 1) **to get** (attention or a tangible) 2) **to avoid** (something difficult or boring or undesirable) 3) **both** (to escape and gain attention) and 4) **to communicate**. A useful resource for understanding and conducting functional behavior assessments is provided by the **Center for Effective Collaboration and Practice** at:

<http://cecp.air.org/fba/default.asp>

Understanding the functions of the maladaptive behaviors is only the first step. It still takes skill to effectively eliminate and replace the problem behaviors. We were ultimately able to work with a behavior specialist from the Rutgers **Natural Setting Therapeutic Management** project. <http://www.rci.rutgers.edu/~nstm/index.html>

We were on the waiting list for this program for two years through the Division of Developmental Disabilities under the New Jersey Department of Human Services. They are a clearinghouse agency for disability support and resources throughout the state. <http://www.state.nj.us/humanservices/ddd/famsupp.html> It is definitely worth it to get support. Check your own state for available resources.

A professional with expertise in behavior modification may be able to assist you in:

1. Analyzing the functions of challenging behaviors
2. Establishing house rules and structure
3. Learning to praise appropriate behaviors (at least 5xs as often as bad behavior is criticized) and ignore inappropriate behaviors (choose your battles)
4. Use appropriate commands
5. Using "when...then" contingencies
6. Planning ahead and working with children in public places
7. Knowing when and how to use time out from positive reinforcement
8. Daily charts- Point/token systems with rewards and consequences
9. School-home note system for rewarding behavior at school

The above list is a modification of the proposed parent training program described at:

<http://128.205.76.10/PsychosocialFactSheet.pdf>

Lastly, I think it is important to mention our experience with medications. Our daughter is currently taking 15mg/day of Adderall XR, a stimulant medication prescribed for her symptoms of ADHD (decreased attention, impulsivity, and hyperactivity). I believe strongly that there is NO MAGIC PILL. Do not expect to find a medication that will solve all of your problems without a companion behavior modification program. For us, the meds better enable our daughter to respond to the behavioral strategies. Every once in a while we are reminded of the therapeutic effects of the meds when we accidentally miss a dose. On those days, she has difficulty staying still, and may just take food off of a stranger's plate. She's very quick and much more challenging to supervise.

You will hear different reports from parents about the pros and cons of different medications. All of our children have disturbed neurological systems. It is unlikely that they will respond in the same way to various medications. Finding the right medicine and the right dosage sometimes takes trial and error. My advice to you, however, is to use a systematic, data-driven approach to achieving the right medicine dose. This is the advice that I received from an expert in the field of Attention Deficit Hyperactivity Disorder, **Dr. William E. Pelham, Jr.**, Director and Professor of Psychology, Pediatrics, and Psychology at The Center for Children and Families, University at Buffalo, The State University of New York. At Buffalo they run an award-winning summer treatment program providing behavior modification interventions to children with ADHD. I highly recommend the medication information sheet and the guidelines for establishing a daily report card that can be downloaded from the **Center for Children and Families** website:

<http://128.205.76.10/download.html>

There are also some other useful resources that can be downloaded regarding parent behavior management practices and teacher behavior practices.

There is actually a lot more out there that might help you deal with your child's challenging behaviors. These are just a few of the resources that have made a significant impact on our lives. Be your own advocate. Learn as much as you can. Engage in discussions with other parents. You are not alone. Attend conferences and workshops. If you can't make it to the 5P- conference, check out programs offered for families of children with ADHD, autism, or other developmental disabilities. Positive Behavior Support is appropriate for anyone with challenging behaviors. Borrow or buy books on behavior. Knowledge is power. Visit on-line resources. Things can and will get better for you and your family. You just have to connect with the right resources. I hope that these suggestions help get you started.

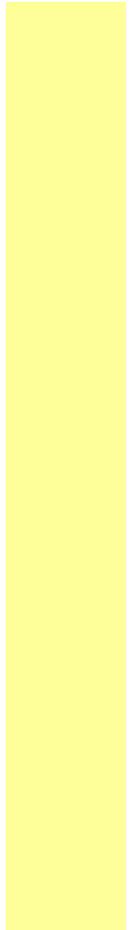
"They say that time changes things, but you actually have to change them yourself." – Andy Warhol

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Return Service Requested



5p- Society families and friends . . .

We need more input from you to make a more comprehensive newsletter. Please submit articles, ideas, questions and pictures. Next newsletter will highlight information about the 2007 conference and include the registration form. Thank you to Dr. Laurel Abbruzzese for her article on Managing Behaviors in this issue.

Thank you, Laura Castillo

## **Grandparent's Corner**

New email address for Art and Pat Strong: [odah@iowatelecom.net](mailto:odah@iowatelecom.net).