

The Post CARD

A Publication of the Center for Autism and Related Disabilities
at the University of Florida/ Gainesville

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Dear Families and Friends of CARD,

I am very excited to send you this issue of the PostCARD. Over the past several months, since our Autism Awareness Activities in April, we have been collecting stories and articles written by or about families from our region. Thanks to the efforts of some parents of individuals with autism, the Palatka Daily News, the Ocala Star Banner, the Citrus County Chronicle and the Gainesville Sun have all printed articles about autism. Furthermore, several parents have sent us pieces that they just felt inspired to write about their children and families. It seemed only natural to compile and publish these stories in our newsletter so we can share them with all of you. Therefore, each article in this edition of the PostCARD (with the exception of my letter and our SibShop Update) was "penned by parents." A few of the articles were solicited by us as we saw individuals in our communities involved in "newsworthy" activities. Others were sent to us by parents who just wanted to write about and share their feelings and experiences. We feel confident that you will appreciate what they have to say and hopefully identify with some of their stories. The articles include pieces on discipline, the Marion County Parents Helping Parents support group, autism awareness, the CARD Parent Partners program, a moms' theater group, and an inspiring reflection on parenting a child with autism.

We hope to make "penned by parents" a regular feature in our PostCARD so please keep us in mind when you feel inspired to write about your experiences and send us your thoughts to share.

Sincerely,



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CARD UF/Gainesville News

The Mountain

by Wendy Baugh

There is a mountain. It is a huge mountain, covered with snow and ice, with many cliffs and deep ravines. At the top of this mountain is a beautiful summit, where my child can dwell and function in a typical society. My goal is to get my child up this mountain as quickly and easily as possible. I see a long line of other mothers with their children. Why of course! They are waiting to get on the ski-lift - obviously the fastest way to the top. I take my child and we get our tickets at the ticket booth. We stand in the long line for the ski-lift and wait our turn. We are excited about the fun ride up. We watch the other moms and children give their tickets to the man at the gate, and then go on their merry way.



Our turn comes.

The man looks at my ticket and says "Go ahead." However, when he sees my son's ticket, he tells me that my son can't take the ski-lift. "Why not?" I ask. "Because his ticket is stamped with the word AUTISM."

Well, needless to say I am so angry with this man. "It's not fair!" I cry. "All the other children get to ride the ski-lift!" "Sorry, says the man. Children with AUTISM may not ride the ski-lift." "Why not?" I scream. "It's just the way things are," he replies. I am extremely upset. I try bargaining. "I'll give you all my worldly possessions, if you just let him ride the lift." "Can't do it", he says staunchly.

I resort to begging. "Please have mercy on us!" I am on my knees. Again his reply is an even firmer "No!" "How in the world do you expect me to get my son up this gigantic mountain?" I ask. "That's your problem. Now get out of here, you're holding up the line!"

So, I take my son, whom I love more than anything on this earth, and we start climbing. The mountain is cold and steep. It's even covered in slick ice at certain spots. It seems like it takes forever just to go a half a mile.

I look up at the other moms and their children on the ski-lift. Some wave and shout, "You can do it!" Some even cry and yell, "I wish I could help!" Others actually point and laugh at us. I throw snowballs at them.

I am so tired and so discouraged on this dreadful mountain. It wouldn't be so bad if it was just me that had to climb it. But every day I have to prod, push, and coax my child up. Sometimes I even have to carry him. I am unbelievably lonely.

Then one day, lo and behold, I see another mom with her child climbing on this very same mountain. We

wave and shout to each other. We make our way across the land and meet. We embrace and we cry-both tears of joy and of sorrow. For I know that I'm not alone anymore, but I also know her pain. We talk for hours, and we agree to climb this awful mountain together. We share our equipment, and try to map out the best paths. We share one another's burdens. Most of all, we share our love for our children. Sometimes one of our children falls into a deep ravine. We help each other to pull him out. Sometimes they make great progress, and we rejoice together. And there are times when it seems that our children are stuck in a snow bank, or days when they make no progress at all. Sometimes they even fall a long way down. We still help each other. And we remind each other that we are a lot farther up the mountain than when we first started.

We encourage one another, and always, always, keep hope alive. And we realize that even though the ski-lift sure would have been a whole lot easier, there is a strength of character, and a resolve inside of us that we never would have known if not for this mountain. Sometimes we even find precious jewels in the darkest caves. So, we continue to climb, with the strength, comfort, and support of each other. And together we marvel at our amazing and beloved children.

Wendy Baugh is the mother of Sam, age 6. She lives in Marion County where she is active in God's Exceptional Moms (GEMS) parent support group. Sam was featured in Autism Awareness posters (see below) that were displayed in several businesses in Marion and Alachua Counties during April.

April is Autism Awareness Month!



Sam - 6 years old

Autism is a lifelong developmental disability resulting from a neurological disorder that affects brain functioning.

Usually occurs during the first 3 years of life.

Two of every 1,000 births affected.

Interferes with speech, learning, and social development.

Symptoms can range from mild to severe.

More common in boys than girls.

Facts used with permission of the Autism Society of America
1-800-3AUTISM

Autism Awareness

by Carol Paullin

The other day I was at the grocery store and was in line wanting to get home and was just generally impatient with the situation. While standing there I became aware of the other people and how impatient they were and then sort of smiled to myself and thought what a world, nobody wants to be where they are and are not shy in showing their impatience.

Then I noticed the young man bagging groceries. He seems oblivious to all the glares aimed at him and the loud sighs aimed at him. He was a little on the slow side but very careful and doing a very good job no one seemed to care about.

I began to wonder if these people knew how hard it was each day for this young man to try and fit himself into the round slot when he maybe was a little on the rectangle side. Maybe they would have more appreciation of his effort if they knew how hard he was working at doing the best he could.

One woman asked him if he could speed it up and he stopped doing what he was doing and said he didn't want to injure her groceries that she had to work so hard to get. She said just never mind and impatiently waited and he resumed his job just as before.

I knew he felt the rudeness of others even if he wasn't showing it at the time because he is a human just like us so when I got up for my turn I told him he was the best person I had ever had to bag my groceries. I said thank you and made sure I said all of this loud enough so the others behind me would get the message.

I feel I need to do these things when the opportunity arises because my son has autism and I know how hard he works to fit in to a society that doesn't understand his battle to be a part of something, to belong as the rest of us want for ourselves. He is different but when did different mean not a good thing. I think different is a good thing. It makes us grow and learn and love and be kinder, more understanding people. Different is a challenge. Would you be up to that challenge every day?

Autism is a lifelong developmental disability resulting from a neurological disorder that affects

the way the brain functions. People with autism have difficulties interacting with others, behaving in a socially appropriate ways, using language and communicating. Not being able to read social cues. Misreading facial and other cues if at all.

They tend to develop narrow interests, repetitive behaviors, and intense attachments to routines, they can seem too sensitive to sights, sounds, smells, or physical contact - or not sensitive enough.

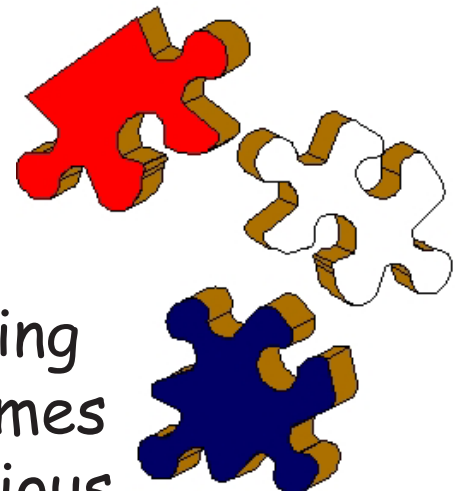
The Autism Society of America estimates that as many as 1 in every 500 children is born with autism. It affects more people than Down's Syndrome, Muscular Dystrophy, or Multiple Sclerosis. Autism is more common in boys than in girls. Autism affects people of all races, religions, ethnicities and social backgrounds. Autism differs in its severity from person to person.

Everyone needs a little patience. I think it is not too much to expect.

Carol is the mother of a young adult with autism. She wrote this piece for Autism Awareness Month. Carol also promoted Autism Awareness within her local law enforcement community by meeting with Citrus County Sheriff Jeff Dawsey and presenting him with a copy of Denis Debaudt's book "Autism, Advocates, and Law Enforcement Professionals".

Carol and her family recently moved out of Florida. We are sorry to have lost such a great advocate and Constituency Board member and wish her, Scott, & their family all the best.

Always
Unique
Totally
Intriguing
Sometimes
Mysterious



The Art of Discipline

by Pam Beville

The greatest challenge I have encountered, thus far, as a parent of a child with Autism is how to discipline him. My son, Jonah was formally diagnosed at the age of two years and seven months. At that time, he had minimal language development and vocabulary, which made it very hard to communicate with him. I didn't know any parents personally who had children on the spectrum and there weren't any support groups available either. Obviously, this is before "Parents Helping Parents" was in existence. Jonah wasn't enrolled in any early intervention program and had not started any therapies yet. We were on the necessary waiting lists for speech and language therapy and he wasn't able to start in the Pre-K public school program until after he was three years old. Needless to say, I was very confused and frustrated and everyone close to me did not understand what I was going through. Time outs only worked sometimes but not without a fight. I wanted to avoid "the fight". I honestly have to admit that sometimes "I lost it". I yelled and screamed and even resorted to spanking occasionally. I knew neither of these tactics was effective and I immediately felt guilty and full of shame. I didn't know for sure if he understood half of what I said to him, which made it very difficult if not impossible to reason with him. I needed help and guidance fast!

The very first conference I attended was the annual CARD Conference and I immediately felt at home. I started asking everyone and anyone who would listen to me. I even waited in line to ask Temple Grandin, an adult author with Autism, what worked for her parents. She told me that her parents used rewards for good behavior and they let her watch her favorite television show as a reward. All the professionals I approached said the same thing: Positive Reinforcement.



I knew Jonah was very visually perceptive, so I decided to build on this exceptional skill of his. I was already using sequence boards for help with his schedule. His sequence board consisted of pictures for getting ready for school, going to bed, etc. I had learned this from Cathy Zenko, our CARD representative. Instead of fighting with him in the morning to get dressed or eat breakfast, I would guide him to the wall where his schedule was located and ask him, "What do we do first"? He would then tell me according to the picture "Put on my clothes" or whatever came next. I also learned about an internet site, www.do2learn.com, where you can make free picture cards and schedules. I found a weekly schedule that I can print so I made a weekly behavior schedule. The behaviors I included on his chart are: Putting on his clothes, brushing his teeth, eating, taking a bath, going to the bathroom and listening. He received a sticker by every task or behavior he accomplished daily. This worked remarkably! In no time, all I had to do for positive reinforcement was tell him he wouldn't get a sticker if he didn't listen, put on his clothes, etc.

Presently, Jonah is five years old and is attending a Pre-K Program at an elementary public school. His language and communication skills have progressed remarkably. I still use his positive behavior chart. I have had to add new behaviors and pictures to it accordingly, but it still works most of the time. I also use his videos as a reinforcer now. When he gets off of the school bus, the first thing he tells me is "I was a good listener and I get a movie" or "I didn't listen so I don't get a movie". He always tells the truth which is so cute.

Thank God for all the people we have in our life who have helped me and Jonah. I feel very blessed and I am grateful that I went searching for the answers to the questions I had. I know this is an on-going process but I know I will never be afraid to ask.

Pam is the mother of Jonah, age 5. She is one of the founding partners of Parents Helping Parents of Florida (PHPF) in Marion County and is currently taking the Partners in Policymaking course so she can be an even more informed resource for her son and other families.

Parent Partners

by Cheryl Brenner

The Parent Partners Program at the CARD in Gainesville was established in March, 2002.

As a Parent Partner my job is to:

- ◆ provide information and training to other parents based on the individualized needs of the family
- ◆ help the families see beyond the disability and renew their sense of hope
- ◆ share information on community resources
- ◆ create networks of support for the families
- ◆ team with CARD staff in difficult family situations
- ◆ encourage and assist the families in attending workshops and training given by CARD staff and others
- ◆ assess the training needs of the families
- ◆ collect additional information on service providers available in my community
- ◆ promote autism awareness in my community

Above all, I feel the most important thing that I can do is to listen to families and be there for emotional support. When your child is diagnosed with autism, you feel all alone. You have questions that need to be answered. I try to help families by sharing my own experiences. Being a Parent Partner has been very rewarding for me. Because I have a 12 year old daughter with autism I understand what other parents are experiencing. When I meet families I immediately feel a connection with them because they are going through some of the same things that I experienced with my daughter, Hillary. I feel that I have been very fortunate to be a Parent Partner because I have had the pleasure of meeting some wonderful parents and some very special children.

A lot of the children are being diagnosed at an earlier age because there is more awareness about autism. I look at these kids who are so special and I see brighter futures for them. If I can make a difference, even in some small way, then I am happy.

Cheryl Brenner is a Parent Partner for CARD in Putnam County. She is the mother of Hillary Brenner, age 12.

Hi Mom: The Play

by Carole Polefko

Many parents of children with autism spectrum disorder feel a great sorrow that they often cannot connect with their children. A Gainesville mother, Susan Thiele, has created a play, *Hi Mom*, with the help of other mothers that will express their feelings of sorrow and frustration, but also feelings of joy and incredible strength. Planning for the play started with informal dinners and story-telling at Susan's house. These sessions involved laughter, tears, and stories that would help weave the play. The dinners were very important to the mothers because they were able to connect with others who shared a bond that most people wouldn't understand.

Susan, a mother of a child with Down Syndrome and ASD, is also a certified psycho-dramatist. She received a degree in Theatre from Northwestern University and has worked with teens with alcohol and drug addictions and their parents in creating therapeutic plays that toured high schools. *Hi Mom* was created because Susan and the other mothers want to help other people, like their children's teachers and school administrators, gain a better understanding of what their lives are like.

The group hopes to receive a Robert Wood Johnson Grant to help with production costs and perhaps develop a video and training manual that could be used by other support groups around the country to help them create their own therapeutic plays. The Across Town Repertory Theatre has agreed to host the play in the Fall and there are plans to bring the play to other venues and disability conferences.

Susan has solicited help from people already working within the disability community. For example, a Behavior Specialist she knows will do the lighting and a teacher will create a Power Point presentation that will be incorporated into the play. She hopes that others will come forward to share their talents. She is also looking for more mothers interested in being performers. Since there are plans for touring and she knows how busy mothers are, she will need a few groups of actors.

If you are interested in helping out or want more information please contact Susan by phone at 352/376-9706 or by email at susan_thiele@hotmail.com.

Susan is the mother of Jacob, 10, and Jonah, 5. She is a licensed psycho-therapist and an active advocate for children with ASD.

Parents Helping Parents of Florida, Inc.

By Sylvia Miller

My name is Sylvia Miller and I am the very proud mom of three children--two sons aged seven and nine and an eleven-year-old daughter. I first became involved with CARD back in 1996-97 when after much research on my part and several evaluations on the part of the "system" it was announced that I had been blessed with a (then three year old) son with autism. I was devastated, to say the least, but not for the reasons most people would think. I was devastated because Dad and I had scolded, punished and on occasion even spanked our son thinking him stubborn. You see, all his traits only became visible the day I returned home from the hospital with his baby brother. I had feared that going away to have a baby would somehow affect him (I mean this was the first time I had ever left him for an extended period of time) and I honestly believed that his odd behaviors were just a form of the "sibling thing" that even patience had not managed to quell. I had no idea of the changes that were really taking place. My son, Kibby, spoke fluent sentences and could count to seventy consecutively. He knew the alphabet, the colors, and the days of the week. He had a very extensive vocabulary and had begun to learn addition and subtraction. He was an expert at putting puzzles together, loved to play and sing and we understood just about every word he ever said, all before age two and then everything changed. By the time his baby brother, Shukiy, had turned six months old, Kibby no longer spoke, no longer ate, no longer played. He seemed lost in himself most of the time and would totally destroy the home, throwing things all over the place. I wondered at first if it was the trauma of my leaving him for five days that had brought this baffling behavior into existence. Needless to say, I learned that nothing I had done had caused any of this behavior to happen.

Dad had a difficult time accepting that there was something different about his son and I had a difficult time accepting that he just couldn't see it. So, I had come to Florida that year without Dad seeking the support of my mom. Hearing that I was moving to Florida, only days after the evaluation, one of the therapists who evaluated Kibby had directed me to CARD and Emily Savarese was the person who came to our home and worked with him. She explained to me in detail what autism was and the research that had been done thus far. She taught me ways to begin working with him and was the first person to introduce me to the Picture Exchange System. We worked very closely together to find methods that would help him to communicate his needs and she prepared lesson plans to teach him to do chores and participate in everyday activities without too much anxiety on both our parts. It was an extremely lonely time for me, being new to the area with no friends, Dad seventeen hours away and my mom not being able to cope with the nighttime screaming and behaviors. She felt my son should be institutionalized. Though the support from CARD was great and Kibby's Med-waiver support coordinator had found us an incredible speech therapist here in Ocala, I tired very quickly and after only a year, returned to New York and Dad. It was then that the real learning began.

Dad was now more accepting of his son's behaviors and we became an awesome team. Not a moment too soon I might add, because six short weeks after my return to New York we lost our oldest daughter to a tragic and untimely death and shortly thereafter found out that our youngest son also had autism. There was no time to mourn on either account. We still had a six-year old daughter who had to grow up very quickly as a result of the pressures brought on by the death of an older sister and living in a household with two baby brothers she could not communicate with. Our lifestyle was completely different from anyone we knew and caused her to have peer problems and social issues to contend with. We had to find a way to help her with the challenges of being an older sibling to two brothers with autism and had two sons to learn about, work with and advocate for. We were blessed with the strength to do it all and teachers, staff and a school that provided all of us with much needed education, training and support. We became knowledgeable of ABA, TEACCH, and the Miller Method and even began working with basic American Sign Language. Then while Dad extended his research of herbal alternatives and diets (neither of our sons have ever taken medication, no matter how many doctors recommended it), I took many lessons in patience and tolerance. Now, let me add a little something to the mix right here. I am an avid believer that everything happens to us for a reason and just about everything is a lesson in life for something we are put here by a Higher Power to do. We don't always know why things happen, but given time, we do find out. Well, I found myself back in Florida, only this time with Dad, and we quickly became accustomed to the tremendous differences between Florida and New York. We immediately contacted CARD and were blessed with Jennifer Nye Flanagan as our support specialist. She visited our boys in school, came to our home and got to know each member of our family. We immediately bonded and became the perfect support team for our boys--blending her vast knowledge of autism with our knowledge of our boys, and we knew they were on their way to a successful future.

Once again I felt blessed and very thankful for the "tests" that had been given to me, and there were many more--too many and too extreme to write about here. Anyhow, being the mother of children with autism had given me a passion for all "special" children, and being blessed with a partner whose gentle nature balanced out our lives so well that the challenges seemed effortless, it's no wonder that I wanted to share my peace of mind with as many parents as possible. So four months after moving to the area, realizing that there was no support program for parents or siblings, I decided to start support groups at Maplewood Elementary, the school attended by both my sons. Our principal, Carol Bard, was very supportive and once again CARD (this time Cathy Zenko) put me in touch with a mother who helped me to put it all together and is by my side to this day. Parents and siblings longed for a place to be with their peers for much needed emotional support and just to share experiences and know that they were not alone.

At about the same time the groups began, Jennifer approached me with an application for the Florida Partners in Policymaking program (a program funded by the Florida Developmental Disabilities Council) and encouraged me to apply. I knew very little about Florida, let alone the "Partners" program, but I followed her suggestion, applied and was accepted. I committed myself to one weekend per month for six months of extensive training in everything from "soup to nuts" about the disability movement and any and all issues that relate to persons of all ages with disabilities of any kind. I graduated from "Partners" in November of 2002 and it was one of the most incredible experiences I have ever had. The only thing that the FDDC asked in return was that we take what we learned back to our communities and put it to use, giving them an update from time to time. Well, you can believe I came home with a confidence like never before and an eagerness to advocate for every child and empower every parent that crossed my path, and Partners in Policymaking had provided me with the tools and the contacts to do just that.

I became actively involved with as many committees as possible that would assist me in my mission to bring about awareness and make change: ESE Parent Advisory Committee (where I met another CARD mom, Amparo Perales, who works alongside me and is instrumental in my successes), Superintendent's Advisory Council, the Marion Area Transition Team (MATT) and our School Advisory Council (which I am proud to Chair with Mrs. Perales as my Chair Elect this year). Then, I became an active school volunteer and PTO member working hard alongside parents of "typical" children forming bonds that I hoped would bridge the gap between ESE and Regular Education parents and students. I created 'The Fountain', a newsletter that I put together each month during the school year that is packed with information and articles contributed by parents and siblings. The April 2002 issue was distributed to approximately 8,000 homes

by our ESE Department and it is our hope to raise funds to enable us to place our newsletter in that many homes on a regular basis.

By the end of the "Partners" program my support group had become Parents Helping Parents of Florida, Inc. (PHPF), a full-fledged organization that not only provides emotional support to parents, but, through its partnership with agencies and service providers gives direction to valuable resources and services by educating parents about available services thus eliminating their frustration as they look for assistance for their "special needs" children. PHPF also provides trained parent advocates to assist parents with the educational system and any issues relating to a child with a disability. We have formed a working relationship with our school district that is bringing about positive change in our educational system and as a part of MATT we are working diligently to help make the process of transitioning students from high school to the workforce easier and more successful. Last, but by no means least, I am working on a website that will be available on the world wide web this coming June, making PHPF accessible to parents every day of the year.

PHPF continues to grow and I have surrounded myself with hardworking, dedicated parents who share my passion, not just for our own children with autism, but for any child with a special quality, need or behavior. As for me, I no longer ask myself "what is this thing that has my children locked away and has left me without a key?" I now know that this "thing" has opened a door for me, giving me reason to celebrate the smallest accomplishments as the greatest achievements and has given my life purpose.

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Sibshop Update

by Karin Marsh

Since the last newsletter, we have had two sibshops and are currently planning the next one.

On March 29th, 5 siblings (ages 12-16) joined us for an entertaining sibshop at Skate Station. Here we enjoyed many silly games. One game involved testing our senses and gaining a new perspective about how our brothers and sisters might sense the world differently. We soon discovered that some of us might need skating lessons, but we all had a blast.



On May 31st, 5 siblings (ages 8-12) attended a sibshop at Victory Riding Stables in Alachua. We had a great time riding horses, going on a hayride, and playing games. It was very hot that day and one of the favorites for all was water balloon volleyball. Thanks to the stables for hosting this event and giving us a generous discount. Also, a big thanks to the Gainesville Boston Market who kindly donated boxed lunches for all participants and helpers.

The next sibshop will be held on September 13, 2003 for 5-8 year olds. As always if you have any suggestions, don't hesitate to contact me. Thanks! Karin Marsh 352/392-4171

The Centers for Autism and Related Disabilities and the Florida Outreach Project for Individuals with Deaf-Blindness are excited to announce their

11TH ANNUAL STATEWIDE CONFERENCE

"Moving Ahead: From Promise to Practice"

Supporting the Needs of People with Autism Spectrum Disorder, Deaf-Blindness, or Cognitive Disabilities with a Vision or Hearing Loss

Pre-Conference Teacher Day & Pre-Conference Focusing on Adult Services

January 23rd, 2004

Conference Registration Fee
\$95.00 before 12/19/2003
\$120.00 after 12/19/2003

Eleventh Annual CARD Conference
January 24th & 25th, 2004

Hilton Miami Airport
5101 Blue Lagoon Drive
Miami, FL 33126
1-800-HILTONS / 305-262-1000
Fax: 305-267-0038

If you have any questions about the conference, please contact:
Donna Casella -813-974-6168 or dcasella@fmhi.usf.edu or
Alessandra Carrieri -305-284-5263 or acarrieri@miami.edu

Keynote Speakers:
Temple Grandin, Ph.D.
Karen Erickson, Ph.D.
Wendy Stone, Ph.D.
Serena Wieder, Ph.D.

When calling to make reservations, remember to ask for the CARD Conference. Room rate is \$125 per night for single/double.

The Post CARD

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Go to

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for information about:

- *current news about autism and related disabilities
- *support groups
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