

The Sun The Voice of Autism in Delaware

Detachable Monthly Calendar

May/June 2008

Autism Society of Delaware			(302) 472-2638		www.delautism.org	
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
May				1	2	3
4	5	6	7 Chapter Meeting 7 pm	8	9	10 ASD Day at the Blue Rocks
11	12	13 Parent Coffee Hour 9am	14 Bowling 5:30pm	15	16 Teen Game Night 6:15pm	17 Mom's Night Out 5 pm
18	19	20 Kent Support Group	21 Bowling 5:30pm	22	23	24
25	26 Office Closed	27	28 Bowling 5:30pm	29 The Drive for Autism	30 Office Closed	31
June						
1	2	3	4 Bowling 5:30pm	5	6	7
8	9	10 Parent Coffee Hour 9am ———— Dad's Night	11 Bowling 5:30pm	12	13	14
15	16	17 N.C.C. Support Group	18 Bowling 5:30pm	19	20	21
22 29	23 30	24	25 Bowling 5:30pm	26	27	28



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July/August 2008

Autism Society of Delaware			(302) 472-2638		www.delautism.org	
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
July		1	2 Bowling 5:30pm	3	4 Office Closed	5
6	7	8 Parent Coffee Hour 9am	9 Bowling 5:30pm	10	11	12
13	14	15	16 Bowling 5:30pm	17	18	19 Mom's Night Out
20	21	22	23 Bowling 5:30pm	24	25	26
27	28	29	30 Bowling 5:30pm	31 Office Closed		
August					1 ASD Office Move/Closed	2
3	4 Office Closed	5	6 Bowling 5:30pm	7	8	9
10	11	12 Parent Coffee Hour 9 am	13 Bowling 5:30pm	14	15	16
ASD Beach Picnic 10 am-4 pm	18	19 N.C.C. Support Group	20 Bowling 5:30pm	21	22	23
24 31	25	26	27 Bowling 5:30pm	28	29	30



Putting The Pieces Together The Sun

The Autism Society of Delaware Newsletter

www.delautism.org

May/August 2008

By: Cheryl Frampton

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Our Mission

The Autism Society of Delaware are people with autism, their family members and friends, and professionals who work in the autism field.

Our mission is to improve the lives of people with autism and their families. We will educate, advocate and raise public awareness in order to promote lifelong opportunity and acceptance for people with autism in their communities.

We serve the entire state of Delaware.

I Want To Go Out!

"I want to go out and have fun with my family and child who has autism. But we are always stuck home because of his behaviors. I am afraid of what people will think or say. Not to mention the looks we get when he has a meltdown. There is nowhere to go and nothing to do."

Unfortunately, this is how many parents feel, particularly the ones with younger children. You are so busy trying to adjust to this new world of autism that you don't have much time to dig around at the possibilities around you. You are just trying to survive a basic trip to the grocery store. It's overwhelming; at times heart breaking and most of the time you feel like you are fighting a losing battle. I know, I have been there myself.

After a while, you stop caring about what others say or think. As a matter of fact many of us learn to educate those in the public who question our children. I certainly never see the stares anymore; I just don't have time to worry about them. I am too busy trying to find ways for my family and me to have fun, despite the fact that I have a 14 year old with severe autism who cannot talk, who is taller than I am, and he certainly can outrun me as well.

This is where ASD comes in. ASD has spent years creating a social calendar for our families to meet the needs for just about every age group and functioning level. You will find social opportunities for both parents and children with autism and their siblings in the pages of this newsletter. We try hard to make our events as comfortable, safe and autism friendly as possible. You do not have to worry about your child having a melt

(Continued on page 3)



Summer Fun in the Sun!

ASD's will hold it's 10th Annual Summer Picnic at Cape Henlopen State Park, Lewes, DE.

August 17th 10am-4pm, Rain or Shine

Lots of Food, Games, food, swimming, food, sand, and did we mention, FOOD? We'll provide hot dogs, hamburgers and rolls. You bring a side dish to share, beach towels, chairs, drinks, OH...and the kids, too! Plenty of fun activities for the kids. This is one of our most popular events so don't miss out on a great day of fun at the beach!

Due to the popularity of this event, we ask that only immediate families come (including grandparents) to this event. We are limited to 220 participants at the pavilion and have filled to capacity the past two years, even turning down a few families. Get your reservations in early and please call if you cannot make it so we can remove you from the list.

Please RSVP by August 13th, so we can have enough food. Email: delautism@delautism.org or call (302) 472-2638.

Funding for this newsletter provided by:





The Sun

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Thoughts From Rob

A.K.A. Rob's Ramblings

By: Rob Gilsdorf, President, ASD

Each of us have days where we think, "Man, I just can't take this anymore..." or "Why can't my

child get what he needs from the educational system here in Delaware" or "What will happen next or when my little guy gets older?". The Autism Society of Delaware's membership of parents, grandparents, sisters, brothers, friends and others face these questions from time to time and they can feel daunting. They should be... but please know that you are not alone.... And, that as an organization we are working diligently to address all these questions and many more.

Last evening, I had the pleasure of presiding over ASD's volunteer recognition celebration. We honored some very special mothers, fathers, husbands, wives and students for their contributions over the past year. Many of these folks are working directly with our talented professional staff on a daily basis to search out and identify answers and solutions to the difficult questions we face. Some of them have worked with you or will be teaching your child shortly. It was an uplifting moment not only for myself, but also for our entire board and staff to recognize such wonderful people and their contributions.

And yet, we also recognize that there are many unsung heroes amongst us. I want to take a moment to thank all of you as well for your contributions this year. Whether it was that time you had a little more patience than normal with your autistic son or daughter, whether it was the time you shared an interesting article with a friend affected by autism or maybe that time you offered to watch your friends' autistic child so he, she or they could get away for a few hours by themselves. Thank you! You make our world that much better. It is often the little things as well as the big things that change the world we live in... never discount that one small gesture you make as insignificant... it may very well be the one saving moment in a person's day, week, month or year.

Once again I would like to invite you to continue to work us as we work together for our future. I hope to see you at the next meeting, recreational event, fund-raiser... or maybe at the park, the bowling alley, or the grocery store. If you ever need a hand or want to offer one, please give us a call.

In the meantime, enjoy the warming weather and promises of a great year ahead.



A Service of the Autism Society of Delaware

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I Want To Go Out

(Continued from Cover)

down at ANY ASD events. Believe me, we have seen it all and nothing will surprise us. That is why we are here, and, when you attend an ASD event, you will be around other families going through the same exact thing.

Being part of the autism community is critical. We are very fortunate to live in a state small enough to get folks together with relative ease. We are also fortunate to have active parent groups or PAC's through the statewide Delaware Autism Program that provide and the Lower Delaware Autism Foundation provides bike and swimming camps. There is so much to do, my calendar is usually very full and yours can be too!

Get Connected!



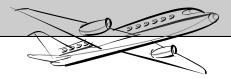
Join ASD's On-Line Support eGroup

This group is for parents, guardians or any family member who has a care-taking role of an individual with autism, Asperger's Syndrome or PDD-NOS living in the State of Delaware. This will be a place to safely share your experiences and concerns. This group is set on private and only members can read and post to the group.

To join the group send Cheryl your request with your full name, your child's name, age, diagnosis, day time phone number and email address to:

cheryl.frampton@delautism.org

Vacation: Get There & Back and Live to Tell About It



Having made countless trips to the Jersey Shore and more than 14 trips to Disney World (6 of which were with my two autistic children), I thought I'd share some of the tips that I've picked up along the way for getting to your destination and back and living to tell about it.

First, you need to decide, should we go at all? That is a decision, unfortunately, I can't help you with. You are the one who knows your child best. You will know if he will be able to handle the change in environment, noise levels, heat, crowds, etc. I will say, however, that, in my opinion, we, as parents to these special kids, tend to be overprotective and don't always give them a chance to show what they're capable of. That said, it's really your call to say whether your child (and you) will be able to handle it.

So, you decide to go. Next decision...How to get there? If you're traveling by airplane, here are a few tips that have helped me through many flights:

- Book as early as possible. On most airlines, this will allow you to choose your seat assignments ahead of time which will be important as explained in point #2.
- 2. Try to get the bulkhead seat. This is the first row in coach. There's no one in front of you so if your child starts a kicking tantrum, they won't kick anyone else's seat. If you cannot book the bulkhead, arrange your seating so that one adult in your party sits in front of your autistic child. Then he's kicking the seat of someone you know which will avoid a possible nasty confrontation with another passenger.

By: Deanna Principe

- 3. About 24 hours before your flight, call the airline to confirm your reservations. Speak with an agent directly and make sure your seating assignment is in order. Then ask them to note on your reservation that you're traveling with an autistic child.
- 4. When you get to your gate and they begin boarding, they will call 1st class passengers first, then people with small children or those who need extra time boarding, then they start general boarding by row. Resist the urge to get your family on the plane! That's right, wait until the last person is boarding and get on the plane after them. The plane ride will be a few hours long. You don't want your child to have to sit in his seat one minute longer than necessary.
- 5. If your child uses a stroller, take your stroller to the airport. It will give you an extra pair of hands and you'll know where your child is at all times. Also, when you get to your destination airport, strolling is much easier than carrying. Especially if your child is having a tantrum or just doesn't want to walk.
- 6. When you arrive at the gate, ask the desk agent for a "gate check tag" for your stroller. Just before you board the plane, fold the stroller and hand it to the gate check agent. There are usually a few other strollers so you'll know where to leave it. If not, just ask.
- 7. When you board the plane, inform the flight crew that you are traveling with an autistic child. That way if he has a tantrum or screams or makes one of his famous noises, they can tell the other passengers





Please welcome the following new members to ASD...

Lisa Arnold
Rhonda Burton
Amy Murray
Michelle Imperiale
John and Marie Kelleher
Robin Carr
Zameta Washington
Diane Black
Stephen & MarRae Sipple

ASD Options Policy

All information provided or published by the Autism Society of Delaware (ASD) is for informational purposes only. Reference to any treatment or therapy option or to any program, service or treatment provider is not an endorsement by ASD.

You should investigate alternatives that may be more appropriate for a specific individual. ASD assumes no responsibility for the use made of any information published or provided by ASD.

LDAF Summer Programs



The following summer programs are being offered by the Lower Delaware Autism Foundation:

The **Summer Swim Program** supports the development of appropriate pool conduct, safety, physical fitness and peer interaction in a safe and supportive environment. It begins June 19th and you must pre-register.

The **Adaptive Bike Camp** runs from August 25 through August 29 at Mariner Middle School in Milton, DE. It is first open to children with autism in Sussex County. If spots are still available then it is open to children in Kent and New Castle Counties. If your child is a DAP student, ask your physical education teacher if he/she is a good candidate to attend the bike camp and if there are available spots.

For more information, visit www.ldaf.com and click on LDAF Programs and Services or call LDAF at 302-644-3410.

Check Out the ASD Summer Recreational Resource List

http://www.delautism.org/recreation_resources.htm

This list is provided as a service by the Autism Society of Delaware. The following camps and facilities are in no way associated with the Autism Society of Delaware and are being provided as information only.

The Autism Society of Delaware is in no way responsible for the programs, their content, structure or guidelines.

Coming soon to www.delautism.org

A list of autism family owned businesses, businesses owned by individuals with autism and employers of those with autism.

Check back at www.delautism.org later this summer!

Next Deadline for Submissions to The Sun: August 1, 2008 Share your family's story, tips or information with everyone! delautism@delautism.org. Or mail it to us (address on page 2).

Let Your Voice Be Heard!



what's going on if they ask. And remember that these flight attendants have usually seen and heard it all when it comes to kids, special needs or not.

8. If your child uses PECS or pictures as a means of communication, make a picture book with photos every food item and toy that you are packing so he can make choices. Not having to figure out what he wants will relieve some of his stress and yours. You can talk with your speech therapist about this as well.

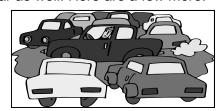
There are a few things you should definitely bring with you on the plane:

- ✓ <u>Have a full change of clothes</u>-(pants, shirt, and underwear or diaper). You never know when your child will spill something or become air sick.
- ✓ <u>Have enough food for several</u> hours-It's not unheard of to have to sit in the plane on the runway for a long period of time for whatever reason. Most airlines no longer serve food and if they do, they may not serve anything your child can or will eat.
- ✓ <u>Bring wet wipes</u>-There's bound to be a spill or accident at some point during your trip.
- ✓ <u>Bring Toys</u>-It's a good idea to bring a new fun toy that your child has never seen before to keep them occupied. A quick trip to the dollar store can accomplish this with minimal expense. However, it's important to bring a few of their favorites as well so they feel safe and more at home on the trip.
- ✓ Invest in a portable DVD player-If your child enjoys watching movies, it's a good idea to invest in a portable DVD player. They are everywhere now and can be purchased at many retailers for under \$100. Keep in mind, however that you will not be permitted to have it on during takeoff or landing and the battery typically will only last for 2 1/2 to 3 hours. Having a few favorite books with you will usually occupy a child until the captain gives the all clear for

electronic devices.

✓ <u>Use a backpack</u>-An average sized backpack will hold all your gear, keep your hands free when walking through the airport and will fit perfectly under the seat on the plane. Each adult should carry one, if possible. One can pack the food and the other can pack the entertainment. Typical kids who are able should carry all their own gear in the own backpack.

If you'll be traveling by vehicle you can use many of the airline tips in the car as well. Here are a few more:



- DO NOT ATTEMPT TO DRIVE STRAIGHT THROUGH! Unless you live less than 3 to 4 hours from your destination or your child is exceptional in the car, it's not a great idea to go straight through. Your child could become frustrated, bored and more likely to have behaviors.
- Map It Out Use an online mapping service like Mapquest or Yahoo Maps. Not only do they give you turn-by-turn directions to your destination, but also tell you how long each segment of the trip will be. This can save you and your driving partner a lot of time and aggravation.
- Book Hotels and Some Fun in Advance The above mapping services can also direct you to lodging and other services and tourist attractions along your route. The world's largest ball of string may be 2 short hours away!
- And Don't Forget to Have Fun!

Taking a little time to do some simple planning, making a few lists and a bit of thinking it through can make the difference between a great family vacation and a great family war story.

ASD Bowling Night



Looking for something to do on "hump" day? Well we have just the right thing to help you get over the mid week blahs. Mark and Cher Frampton took a spin off from the Special Olympics bowling and created the very autism friendly ASD Bowling Night. Bowling nights are held on ever Wednesday at the AMF Price Lanes at Prices Corner on Kirkwood Highway in Wilmington. This is the BEST part; there is only ONE rule....please email or call Mark or Cher the Monday be-fore bowling to RSVP. The size of the group keeps growing and we need to let the bowling alley know how many lanes to reserve. After that, NO rules!

Here is the break down on how it works:

-You call or email us by Monday night. markdelautism@yahoo.com or (302) 998-1466

-You arrive at the bowling alley between 5:30-6:30 p.m.

-Parents and siblings are welcome to bowl.

-There is no age limit.

- -You can come once a month or four times a month, no commitments!
- -You can bowl one game, half a game, 10 games. It is entirely up to you.
- -You pay for your games and shoe rentals.
- -The snack bar is open.
- -No keeping score!
- -Bumpers for whoever wants them.
- -No worries if the weather is too hot, cold or wet!
- -We are usually located on the far end in the 40's and 50's. So we have a side door exit and bathrooms right behind us.
- -There is also a game room for those who need to take a break or want something a little different to

So that's it! Just give us a call and come out to have some fun!





The Big Move!

It's official! After months of looking, we are happy to announce that we have found new office space at 930 Old Harmony Road, Newark. We will double our space, growing to 2500 sq ft, with enough room for POW&R and ASD staff to be able to have a private phone conversation, to accommodate vocational assessments, to hold meetings and trainings, and to even have some ability to grow. There are many good things about this space - it is close to our current office, close to Brennan School, close to I-95, offers good parking, great windows (that we do not currently have), and it's coming to us at a great price.



I would like to thank Steve Dobraniecki of Emory Hill Commercial Real Estate for helping us find this space. We liked other offices, only to have them disappear as soon as we decided we wanted them. Steve kept at it and found the ideal place for us. He has done a great job for us and we appreciate it.

The one sad thing about leaving our current home is that we will miss

The Parent Information Center. We have been sharing an office with the PIC over the past three years and we have become friends and shared advocacy efforts. The good news is that PIC is growing as well, so they will put their additional space to good use with their new staff. They don't need all this space, so they will be looking for a tenant to use some of the current ASD space. If you know of a one or two person business that needs space on Kirkwood Highway, please have them contact Marie-Anne Aghazadian at the PIC, telephone (302) 999-7394.

Social Skills Training

You've been reading about the "train the trainer" on teaching social skills with Dr. Jim Ball for more than a year now. The workshops are underway and we have been thrilled with the response. Our intent was to bring training to each county, but we held our breath to see if it would work. The good news - we sold out in New Castle and Kent, and we would have sold out in Sussex but we were able to find larger space. In total, our registration is at 148 statewide. This includes teachers and other school staff, psychologists, parents, autism consultants, behavior analysts, and many others. This is part of our effort to expand the capacity of parents and professionals in Delaware to teach critically needed social skills to people on the spectrum across all ages. And best yet – the reviews have been great! Thanks to Dr. Ball and Heidi Mizell for all their efforts in pulling this together.

ASD Committees

Lisa Albany, Artie Kempner, and Debbie Markwood are the ASD Board members who have been hard at work these past few months planning our three annual fundraisers—Walk the High Road for Autism, Drive for Autism (the golf event) and Autumn Auction-along with dedicated staff – Cheryl Frampton and Kim Siegel—and many, many committee members. The Auction Committee would like to welcome new members Jill Gordy and Anne Jackson to their committee this year. Jill will be heading a new effort to develop local corporate sponsorship. Greg Burch has joined the Walk committee.....

We also have to mention Judy Hedrick. Judy has really adopted ASD as her second home. She has taken on our role of Volunteer Coordinator, recruiting volunteers for work for our events and committees. You will understand what a big job this is when you realize she has 72 volunteer positions for the Walk alone. Welcome a call from Judy. She has a great job for you!

Sussex Chapter Meetings

ASD sponsored its first Sussex Chapter Meeting in March. Marie-Anne Aghazadian, a charter member of ASD, was the featured speaker. Marie-Anne spoke to 15 parents and educators about what it's like to have a child in adult services, what to expect, and what parents need to know. She spoke from the heart about her son, his job, his group home, and her ongoing role as an advocate. Sussex can look for us to come twice a year with a speaker. We will schedule meetings following a local PAC meeting.

We are also looking for members to help us create more social activities in Sussex. Susan Patel is putting together a dance that ASD will help to pay for, and Chie Kelly is setting up bowling similar to the

(Continued on page 7)

Inside the ASD

(Continued from page 6)

one in New Castle. There are many services that we can offer if we have local volunteers to lead the way. Please contact Theda Ellis at theda.ellis@delautism.org if there is an activity you would be willing to chair.

ASD and LDAF

Rob Gilsdorf and John Willey, the presidents of these two important autism organizations recently met over dinner. Over the past few years, ASD and the Lower Delaware Autism Foundation have started working more closely together. We combined forces to bring Jackie Marquette to Delaware in 2007, and we have been working closely to obtain funding for the Self Directed Support Waiver. With so many issues yet to address, we know that we'll all do better with a single voice and position, so you can look to see more collaborative advocacy efforts in the coming months and years. In the meantime, please meet with your legislators to support the Self Directed Support Waiver.

Parents Love Their Coffee Hour

ASD started a new tradition about three years ago, meeting for coffee once a month at convenient family restaurants in Newark and Wilmington. Each month we would have from three to eight parents. Along came Prince and Marsha Johnson three months ago with their beautiful restaurant, not to mention the juice, pastries, bagels and cream cheese they offer, and the parent coffee hour grew rapidly to 12 and was a record 20 people this month. It goes to show you that convenience is secondary to great coffee, great food, and really great company! Did we mention that Prince and Marsha are also parents of a child with autism too?

We would like to think Prince and Marsha for their warm hospitality at Prince on Delaware. One mom went so far as to say that she feels honored to be part of this community and this great group of parents who meet there. We all appreciate the hospitality.



Board Changes

ASD Board Member, Yolanda Flanigan has retired from the board in order to serve as county liaison. Yolanda is holding down the home front with son Jacob and daughter Isabella since her husband, Lester, was deployed to Iraq earlier this year. During her time on the board, Yolanda provided many invaluable services to ASD. She translated the brochure and new parent information packet into Spanish and serves as a parent mentor to those who call ASD seeing information in Kent County and to anyone who is Spanish speaking. Yolanda has testified for us, helped with holiday parties and chapter meetings and has been a strong support in Kent County for the past three years. We will miss her on the board but are glad she is taking on this new role.

Mark Rossi will complete Yolanda's term of office as the representative from Kent County. Mark is currently the Vice President of Sales and Marketing for Dover Motorsports, Inc., and is responsible for coordinating the sales and marketing initiatives for the entire Dover Motorsports portfolio of properties. Rossi is a graduate of the University of Rochester in 1987 with a B.A. in Economics and a Graduate School Certificate of Management Studies in Marketing. He has served on several boards including VASPA, and "Operation We Care," the Board of First State Strings.

With the new bylaws, the Board is opening some new positions as well. The first open position will be filled by Robert Dunlap. Rob expressed interest in serving on the board last year with these words. ...I wholeheartedly support the programs and goals of ASD. My personal experience is as the parent of an adult son with Asperger's Syndrome. My son suffered the many problems of Asperger's Syndrome at a time when neither his parents nor the medical/professional community had any knowledge of this disorder". Bob is a lifelong resident of Delaware, and a retired attorney familiar with Delaware law, policy, and government.

We welcome these two new members to the ASD Board of Directors.

Transition Planning

The transition planning process for students with autism is a proactive strategy that should be used to benefit students and staff. Although it may appear time consuming, this preparation will save parents and staff from time spent in reacting to negative behaviors that may occur when students do not understand or accept the change in school, teacher and routines.

Here are a few things to consider as your children make the big move from elementary to middle school or middle to high school:

- ✓ Start thinking about transitions toward the end of the school year by setting up a meeting with your IEP team to discuss placement and services your child will be receiving in his/her new school.
- ✓ Take a tour of your child's new school and request to meet with all possible teachers and therapists. Take your child on this tour so he/she is familiar with the layout of the school ahead of time.
- ✓ Set another meeting about 2 weeks into the start of the new school year. In this meeting you can assess the transition and determine if the student needs additional supports or services.
- Communicate daily with your child's teacher at least for the first few months so unwanted behaviors can be identified and addressed quickly.



Walk The High Road For Autism

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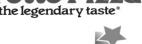






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child succeed that her other relationships were really suffering. There was the single mother afraid that nobody would date – let alone marry – her when she was lugging such heavy baggage.

The Review

By: Robin Ireland

Every time I see something in the newspaper and on TV about autism, I am thankful – no matter how small the gesture.

When Alec Baldwin wore an Autism Speaks pin at the Golden Globes a few years back, I literally joined the Alec Baldwin fan club and sent him a thank you email. I laughed through my tears during the "Night of Too Many Stars" benefit on Comedy Central. As a newspaper reporter, I know that consistent media coverage of our cause is a very, very good thing.

And so it was with great excitement and enthusiasm that I watched the recent HBO documentary, Autism: The Musical, despite its dreadful title. The program was everything I thought it would be – funny, touching, sad - a quick tour through the usual realm of emotions. Nothing new or illuminating but very nice.

Yet, days later, I couldn't stop thinking about that show. And not about the children with autism either. It was the parents that kept creeping into my brain. Normally, the focus is on the kids. In this case, producers told the story of whole families. And I began to recognize familiar adult faces from the autism community I know and inhabit.

There was the mother so deeply rooted in shock and denial that she simply could not appreciate her daughter's lovely singing voice and gentle nature. Another mom was working so hard to help her child

There was the worn out father who just let everyone else run the show – and another dad who clearly harbored major escape fantasies.

People were running out of patience, yelling at their child's teacher, being role models of grace and creativity, shining good cheer wherever they went. They were people reacting to exhausting, life-changing scenarios in a variety of ways. They were people on a spectrum. Just like their children.

In that way, the show was a fantastic exercise for developing sympathetic compassion. I've met many different personalities in the autism community. Queen of denial. Grand inquisitor. Disbeliever. Protector of hope. Frantic nut job. Those with lawyers on speed dial. Those too fragile to ask for anything. Those who pick up the newer, weaker members and carry their mantle.

Most parents with severely disabled children cling to some sort of emotional edge most of the time. And we need to open our eyes and try to be more understanding and tolerant of one another.

Still, seeing it in digital clarity in my living room was a bit shocking. I expected to see my son in that show. Watch it. You'll probably see a child who looks somewhat like the one you live with, too. But which one of those parents looked like me? Or did all of them?

ASD Sponsored Parent Training Review From Dover

Dear Dr. Pam, Mr. L, and Theda,

Dr. Battaglini was incredible! Thank you all so much for making this happen. In the past I have read about replacing the undesirable behaviors with desirable ones. but never had the "how to" mapped out for me. We are so excited to finally have the tools on replacement behaviors, that we immediately put one DR schedule in place for both boys, and we are working on another. Dr. Battaglini speaks the truth- this stuff works! To quote Miss Sophia (Oprah Winfrey) in "The Color Purple" movie: "Things are gonna change around here!"

I just feel sorry for all the people from Capital and Charlton who missed this wonderful learning opportunity. We feel like we now know some of the teachers' secrets, and the answer to "why does he only do that at home and not at school?"

And another bonus, Jack and Ben were forced to be together for two whole days without mommy or daddy (they had a BLAST at Charlton, and wanted to go back on Monday!). They played together, no sibling rivalry, no fighting, no yelling, and now seem to be closer to each other with this new bond. This is huge!

A special thanks to Ms. Bonnie, Ms. Irma, and Ms. Lourdes for taking such good care of our guys. I was able to focus 100% on the training by knowing they were in such capable hands.

Have a great day!

Kate Stomieroski Dover, Delaware



Parent 2 Parent

for parents by parents

Why I Need To Live To Be 100...

By: Barry Sipple

The thought of living to be 100 does not appeal to me. There is no escaping the fact that things don't seem to work as well as one gets older. Colonoscopies, prostate tests and cholesterol screenings... let's face it. Getting older is a wake up call.

I have been a father for 17 years and I have a child, Jacob, who has autism. Who is going to take care of Jacob when I'm gone? I'm not talking about the "bare bones" care of food, clothing and hygiene. I'm talking about the nurturing that is necessary to keep Jacob's life on track and give him the opportunities for as much "normalcy" in his life as possible. Now, with mortality staring me in my 50+ year old face, the stark truth hits me. There is no one else.

There are no adequate assisted living facilities available. Siblings grow up and start their own families. Neighbors grow old. So, it's just Mom and Dad.

I have a plan. I am going to live to be 100! I am going to resist fatty foods and late night snacks. I am going to exercise. Already, Friday night cocktails have turned into the occasional beer or glass of wine instead. Thank God I don't have to stop smoking – only because I never started. Skydiving, parasailing, bungee jumping, class IV kayaking, and tackle football are all in the past!

Yes, a better diet and a better lifestyle are my credo now. I have to be here as long as possible to take care of my son, Jacob. I need to live to be 100.

Come Out and Play

By: Jen Nardo

Having a child with autism brings many unique challenges when trying to find something for them to do. You know the difficult behaviors all too well; temper tantrums, squealing, flapping, running away, hitting.....too many to list. You also know the fear and frustration that goes into deciding what outings to try. Can I take all my children to the movies? We'd like to be around other families (especially other adults). How can I do that?

If you have ever attended a social event with ASD, you know a few things you can do already. The greatest feeling that I've experienced at an ASD event is relief. My son can be who he is, do what he needs to do, and make any noise he wants to make. All of this is done in the security of an accepting crowd. People who are going through the same fears and dealing with the same behaviors that would be annoying or incomprehensible in other circles. At ASD events, if someone is looking at you during a stressful episode, they just want to help. There is no judgment. There is no ostracism.

I am not sure of the first ASD event that Jake attended. Was it the Spring Egg Hunt or the Fall Festival? It doesn't matter because each outcome was the same. Jake had a great time. He participated in the activity, danced at some point, played and ate. Certainly, those activities mean a great party where Jake is concerned. I was able to relax a little. If Jake ran off, it was to the stage covered in straw or to the table filled with cookies for a snack. My instincts still told me to follow him, but the beauty of it was that I really didn't have to. He was fine. He was happy. He was relaxed, too. An ASD event is created with our kids in mind because parents of kids with autism came up with the idea.

If you go online to ASD's website, www.delautism.org, you will find lots of information for recreation. The calendar lists all of the social events like the upcoming ASD Night at the Blue Rocks. You can also find links to many activities and camps offered by other groups. There are the autism-only weeks at Easter Seals' Camp Fairlee Manor. There are therapeutic horseback riding facilities. There are Special Olympics, Challenger Little League and TOPS Soccer. Keep searching, talk to other families about their experiences and give it a try.

Summer Sib Workshop

By: Melanie Matusheski

These kids understand each other. That's what Laura Donnelly says of the siblings who attend the Summer Sibling Program at DAP. Every summer for the past several years, DAP school psychologist Laura Donnelly and behavior analyst Heather Calkins have offered a summer program of fun activities that let siblings of autistic children learn about themselves and about autism. It's an opportunity to share feelings, gather information, and make new friends. "We talk a lot about autism," says Laura, "but really it's about the differences among people. It's about the strengths and weaknesses of people."

Laura and Heather create a fun environment for the kids where they can learn but also develop friendships with one another. Often the kids exchange phone numbers and get together after the program is over. Through the activities the kids learn to handle difficult situations and talk about common experiences.

According to Laura, the kids have a lot in common, but there is also a lot of variety in how they relate to their sib-

(Continued on page 17)



Sibling 2 Sibling

Where Have All the Grown-Up Sibs Gone?

By: Sara Graham, age 25

My sibling experience is anything but typical. My only younger brother Nick has autism, so in that way we are anything but typical. That is obvious. What I mean is that when I was a child, Nick was such a part of my life that I rarely thought about the fact that my family was "not normal", even though all I ever heard from adults was concern for my well-being. I never even understood why I was going to youth sibling support groups to play games about our feelings. I had little interest in being on any team as a kid, much less one full of siblings, all of whom had different experiences and a different range of needs.

Experts say that sibs either act out or become over-achieving in the face of competing for their parents' attention and reconciling the huge amount of uncertainty that comes along with growing up with a sibling who has autism. I fell into the latter category and maintained an optimistic opinion of my brother's disability and how it affected me through my childhood. We had a swing, a trapeze and a plethora of bouncy balls in our basement (all suggestions of Nick's OT), and there were often treats in the house to reinforce Nick's PECS training. As a 10 year-old kid, everything seemed hunky dory! In fact, as a smart, weird child who preferred rock 'n roll to baby dolls, I often celebrated my brother's autism because it made my family unique.

This attitude was only propelled during my teen years when my family uprooted from Missouri to Delaware for Nick's education: in my brain, we were rebel pilgrims. Though I threw a tantrum or two about leaving a high school I loved (I was 15 at the time), I saw the whole transition as an opportunity

to reinvent myself (every teen's dream) and instead of blaming Nick for changing my life so drastically, I decided it merely made up the fabric of my interesting life. It didn't hurt that my parents gave me their old car (against their hard-working Midwestern sensibilities) and my years of being responsible and overachieving (which I do, in part, have Nick to thank for) were rewarded with an extremely independent high school life. I had a full social circle and even avoided the proverbial "embarrassed -to-bring-yourboyfriend-home -while-your-brother runs- around-naked" scenario- my boyfriend at the time loved Nick. I felt very, very normal as a teenaged sib, ironically enough.



Then adulthood came. Adulthood doesn't offer the resilience and acceptance that children and teens naturally have because they control so little of their lives. With adulthood came pensiveness, isolation from my family and my peers and the startling realization that Nick's life would continue to be challenging as I struggled to find my own way, apart from the family I was so entwined with as a sibling. I lost the primary way of relating to Nick when I went to college because I was no longer was his helper or protector. I felt estranged from my parents because I felt they had lied to me about the "independent, unburdened" life I was promised, a feeling they couldn't even understand because they didn't grow up with disabled siblings. I actually began to resent my parents' normal sibling upbringings, which was the first time I realized the difficulty of being Nick's sib that I had never acknowledged before.

The idea of the "independent, unburdened" life that every parent wants for their typical child is not a lie. It wasn't that I felt angry because it was not there waiting for me when I graduated from college and moved to New York to pursue a writing career. But every time I made a life choice, there was a nagging feeling that I couldn't put my finger on. Is it guilt? Is it not being worthy of creating my own, uncomplicated life? These are feelings that only siblings can understand. Unlike people who have typical siblings (our parents included), how do we move away from home and not worry about our siblings? As we make choices to live the lives we deserve—the "normal" lives everyone told us we'd have growing up—and seek the interactions we want with people who don't know our families, how does our history with autism inform our lives as adults? I've found that it informs my life in so many more ways than I ever imagined it would. Most of these ways are positive: Nick has made me the person I am, giving me a crash course in tolerance, patience and acceptance.

As my relationship with Nick continues to change, I find myself reflecting on the attitudes I had as a child, when my anxieties were kept at bay with rebellious optimism. I also look forward with hope. Nick and I make up the first generation of sibs in history who have grown up with proper early diagnoses, trial and error (hopefully for the better) in public education and the attitude that institutionalization is not an option. With the rising numbers of diagnoses. there is finally a dialogue about the uncertainty of the futures of millions of people like Nick everywhere. One thing I can be certain of is that the future will hold an ever-evolving relationship for Nick and I-transitions, lessons and all. After all, sibling relationships are the longest of any in life. I trust that Nick and I have all the time in the world to take on whatever comes our way.





Asperger's/HFA Teen Night Space is Limited!

Next Game night is Monday, May 16th
Interested parties should contact ASD's
Asperger's Resource Coordinator,
Heidi Mizell for additional
information and to make RSVP's.

Heidi.Mizell@delautism.org or (302) 472-2638, ext 205.

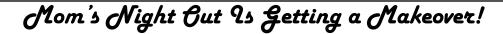
See ASD's calendar of events for dates, times and locations or visit www.delautism.org

Dad's Night Out

June 10, 2008
Time and Location TBA
(They always wait till the last minute to plan things!)
Who can go? Dads, Uncles,
Grandfathers or Friends of

those living with autism.
Interested? Of course you are!
Contact:

Mark Frampton markdelautism@yahoo.com (302) 998-1466



Donna O'Neill will be joining forces with Monica
McMahan to plan future Mom's Night events.
The pair are already gearing up for the next event.
Ready for a road trip? The next Mom's Night Out will be a trip to fun and exciting Delaware Ave. in Philadelphia! In order not to clash with the DAP Day of Fun or the ASD Night at the Blue Rocks, the date has been pushed back a bit to *Saturday*, *June 7th* and we'll leave around 5pm.

Please RSVP to Monica at 235-2101 or m.mcmahan28@comcast.net



PARENT'S COFFEE HOUR

The Second <u>Tuesday</u> of Every Month Join us at our elegant new location in Historic Old New Castle!

> Prince on Delaware 124 Delaware Street Historic New Castle



The response to our new location has been amazing. We have new parents coming out every month.

Please make plans to join us. Whether it's as a parent with lots of questions or someone who's been around and can offer special insight into new families struggles.

Parents, Grandparents or anyone with a connection to autism are welcome to attend.

Little ones not in school? No problem, bring them along, too. Coffee is on us!

A HUGE "Thanks" to Prince & Marsha Johnson for hosting the parent coffee hour.

Prince and Marsha are not only the owners of Prince on Delaware,
they are also the parents of a young son with autism.



Autism Society of Delaware

Page 13

Childcare is available at all regular ASD chapter meetings. Please contact the office at 302.472.2638 or delautism@delautism.org no less than 7 days in advance. Childcare registration is mandatory.

ASD Chapter Meetings

- ► May 7, 2008—Chapter Meeting, Diet/Nutrition
- ► September 19, 2008—Chapter Meeting & Annual Meeting

Social Events, Public Awareness & Fundraisers

- ► May 10, 2008—ASD Night at The Blue Rocks (see page 14 for details)
- ► May 12, 2008—ASD Board Meeting, 7pm, ASD Office
- ▶ May 13. 2008— Parent's Coffee Hour, 9am, Prince on Delaware in Old New Castle
- ► May 16, 2008—Teen Game Night, 6:15-8:15pm, Neurology Associates, Newark
- ► May 17, 2008—Mom's Night Out/Time & Location TBA
- ► May 26, 2008—ASD OFFICE CLOSED
- ► May 29, 2008—7th AnnualDrive for Autism Research
- ► May 30, 2008—ASD OFFICE CLOSED
- ▶June 9, 2008—ASD Board Meeting, 7pm, ASD Office
- ▶June 10, 2008—Parent's Coffee Hour, Prince on Delaware, Old New Castle
- ▶ June 10, 2008—Dad's Night Out/Time & Location TBA
- ▶July 8, 2008—Parent's Coffee Hour, 9am, Prince on Delaware in Old New Castle
- ▶ July 19, 2008—Mom's Night Out, Location TBA
- ► August 12, 2008—Dad's Night Out, Location TBA
- ► August 12, 2008—Parent's Coffee Hour, 9am, Prince on Delaware in Old New Castle
- ► August 17, 2008—ASD Beach Picnic, 10am-4pm, Cape Henlopen State Park
- ▶ September 9, 2008—Parent's Coffee Hour, 9am, Prince on Delaware
- ► September 20, 2008—Mom's Night Out, Location TBA
- ➤ October 12, 2008—NCC Fall Festival, 1-3pm Bellevue State Park

Support Groups

Parents/caregivers of an individual with an autism spectrum disorder are welcome. (Autism, Asperger's Syndrome, PDD-NOS). For more information on ASD's new support groups, visit us on-line: www.delautism.org or call us at (302) 472-2638.

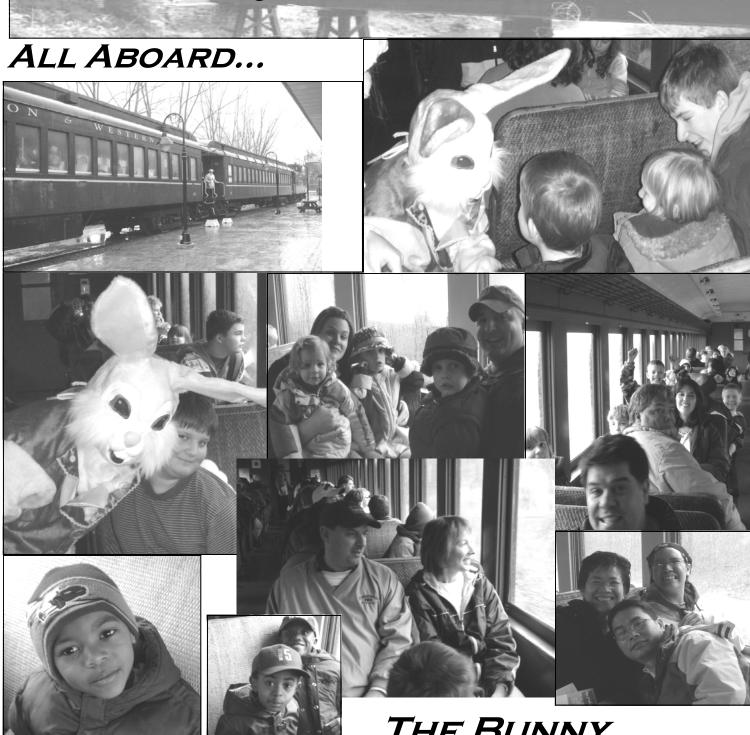
- ► May 20, 2008—Kent County Support Group; "Positive Outcomes Charter School", 193 South DuPont Highway, Camden (near B&B Music Store) 7pm
- ►June 17, 2008—N.C.C. Support Group, 7pm, Special Olympics Building, Newark
- ► August 19, 2008—N.C.C. Support Group, 7pm, Special Olympics Building, Newark
- ► September 21, 2008—N.C.C. Support Group, 7pm, Special Olympics Building, Newark

Other Events

- ▶ July 9-12—Autism Society of America Annual Conference, Gaylord Palms Hotel, Orlando, FL
- ▶ August , 2-8—Autism Family Cruise. Please visit www.ntheseas.com or contact Mike Sobbell at info@alumnicruises.com



ASD Spring Train Ride March 8, 2008 Wilmington Western Railroad



..THE BUNNY EXPRESS



The Autism Society of Delaware Celebrates 10 Years of Serving the Autism Community in Delaware

10th Annual Autumn Auction

The Hidden Treasures Of Autism

November 15, 2008 DuPont Country Club, Wilmington

Dinner, Dancing, Live and Silent Auction, a fun evening for a great cause!

More information on reservations coming in September.

Help make our 10th year the best ever!

Get involved with collecting auction items.

It's easy! Just contact ASD for an information packet with a guide on how to get items. Some of the categories of items we are looking for are: Wine, Jewelry, Artwork, Holiday Fun, In the Kitchen, Home Décor, plus the always popular Gift Certificates to Restaurants, Spas, Hotels, Shopping and other services. Also popular is Sports Memorabilia and Tickets to Events, and Children's Toys and Games. And don't forget those one of a kind items...they are always a hit!

Auction sponsorships opportunities are available.

Interested in sponsoring the auction? We have many levels of sponsorship available! Call ASD at (302) 472-2638 for sponsorship information. Invitations for seats and tables will be sent out in September.

Visit www.delautism.org for updated information.



RDI Comes To Delaware

By: Lisa Mulrooney, MS, OTR/L

What is Relationship Development Intervention or RDI? This is a question I hear often these days as I enter my second year of training to become a certified RDI consultant. RDI is a program for educating and coaching parents and teachers of children with Autism Spectrum Disorders, but to me it is much more than that. It is a different way of understanding and working with people who have autism. It changes one's perceptions of what is possible for a person with autism and offers invaluable insight in how to change one's own interaction style in order to make interaction more inviting and satisfying to a person with ASD. It is a way of helping people with ASD overcome the obstacles that prevent them from forming meaningful relationships with people. Our current definition of success (socialization/compliance, speech and academic progress) has no real connection to quality of life. Research on adult outcomes of people with ASD indicate that regardless of IQ, ability to perform academically and use verbal communication; as many as 90% remain unemployed, 95% report immediate family as their only significant social contacts with only 5% living independently. Difficulty forming and maintaining relationships and responding to problems in a dynamic flexible manner seem to be at the crux of this limited quality of life. These are the core deficits of autism that RDI addresses.

RDI is a way of empowering parents to help their own children, lessen their dependence on schools and therapies and give them a way to systematically address their child's obstacles. It restores the

parents' natural role as facilitators and guides of their child's mental development. RDI teaches parents and teachers how to create daily opportunities for the child to respond in more thoughtful, flexible ways to situations and problems that gradually increase in complexity as the child's abilities grow.

As an pediatric occupational therapist with a special interest in autism for the past 30 years, RDI is for me the" missing piece" in treating autism. As an OT working in the public schools I have seen and treated a great many children with autism over the years and have always been amazed at the progress that these children could make with Sensory Integration Therapy, a subspecialty of OT that focuses on addressing the sensory needs and the way that sensory information is processed, especially in the vestibular, tactile and propriocepive systems. In spite of great improvements in attention span, eye contact and communication I knew there had to be more that could be done.

When I first heard about RDI from a fellow OT and began to read about it, I knew that this was "it". Dr. Steven Gutstein, PhD, a clinical psychologist, and his wife, Rachelle Sheeley, have developed this method. They have taken the best of clinical practices with ASD and the best of developmental research and combined them. Preliminary research has shown that RDI is a powerful and effective means for increasing children's capacity and motivation for experience sharing as well as their flexibility and participation. Parents involved in RDI report not only improvements in their child

with ASD but in the quality of life for the whole family unit. Competence emerges from children acting as 'apprentices" alongside their more experienced 'guides". Parents are guided by certified consultants who provide assessment, education, modeling, and feedback as the child progresses through increasingly more complex challenges and discoveries.

The Connections Center, RDI headquarters, is located in Houston, Texas. They maintain an extensive website containing extensive information on all aspects of this exciting work.

(www.rdiconnect.com)

Currently, I am seeking a family to work with utilizing this unique and exciting approach. If you are interested in learning more; please e-mail me:

lisamulrooney52@yahoo.com.

ASD Options Policy

All information provided or published by the Autism Society of Delaware (ASD) is for informational purposes only. Reference to any treatment or therapy option or to any program, service or treatment provider is not an endorsement by ASD.

You should investigate alternatives that may be more appropriate for a specific individual. ASD assumes no responsibility for the use made of any information published or provided by ASD.

Summer Sib Workshop (continued from page 10)

Some are caretakers. Some are embarrassed by their sibling. Some ask if they can "catch" autism from their sibling. Laura and Heather put together playful activities to address all these issues.

The program was started a few years ago by Tammy Fillibin and is designed to meet the needs of 7 to 12 year olds. Typically there are six to eight siblings in the camp. Feedback from parents has been very positive. According to Laura, parents want the camp to be longer, more often, and to meet during the school year.

Cheryl Frampton says the program began a dialogue between her son Jarod and herself. Before he attended the Summer Sibling Program, Jarod, age 7 at the time, never asked questions about his big brother John and autism. "I didn't realize that Jarod didn't realize the severity of John's autism. Once he did, he started asking questions about what John could and couldn't do. Then he went through a grieving period because he became more aware of what his brother's life was like and what it meant to the family. He realized that John's autism wasn't going away."

After the grieving period, Jarod interacted with John the same as he always had, but he understood things better and felt comfortable asking questions. Jarod also had a lot of fun at the program. He looked forward to going, although he was a little disappointed that he was the only boy the year that he went.

Registration for this summer's session is already closed, but if you're interested in getting more information or signing up for next year, write a note in the home school book and the teacher can contact Laura or Heather. Also, you can contact Laura at DONNELYL@christina.k12.de.us.

EMERGENCY RESPONSE GUIDE FOR PERSONS WITH AUTISM



The start of summer is often the time for a break in a family's regular routine. The break in routine can cause an individual with autism to become easily confused and make it more likely for them to wander from their parents or caregivers.

If a loved one or someone you know has autism, it is important to receive a prompt and proper emergency response in the event of a wandering incident. All wandering incidents should be considered emergencies. The following procedures can help families or caretakers of those with ASD deliver the necessary information to 911 call centers and also provide the necessary information to responding law enforcement officers.

CALLING 911

In an emergency, it is important to remain calm when calling 911. If a wandering incident has occurred, it is your responsibility to contact 911 and inform them of the incident before you begin to search. Be prepared to provide the following information to the operator and or to responding units. This information should already be recorded and located near your telephone.

- 1. Name of the child or adult
- 2. Current photograph and physical description including gender, race, height, weight, eye and hair color, any scars or distinguishing marks
- 3. Names, home, cell and pager numbers, addresses of parents, other caregivers
- 4. Sensory, medical, or dietary issues & requirements if any
- 5. Inclinations for elopement and any atypical behaviors or characteristics that may attract attention
- 6. Favorite attractions & locations where the person may be found
- 7. Likes, dislikes, approach and de-escalation techniques
- 8. Communication methods, verbal/non-verbal, sign language, picture boards, written word

IDENTIFICATION OPTIONS

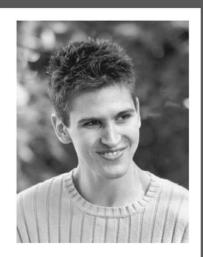
- 1. Medic alert style bracelet, anklet or necklace
- 2. Joggers shoe tags
- 3. Laminated information card hanging from belt loops, information sewn in to clothing
- 4. Silk screened information on underclothing
- 5. Non permanent tattoos for persons with sensory issues (www.tattooswithapurpose.com)

For additional information go to www.autismriskmanagement.com

POWIR

Productive Opportunities for Work & Recreation

A Community-Based Service of the Autism Society of Delaware for Adults with Autism Spectrum Disorders



We see the World in a Different Way...

We envision the world where all people with autism live fulfilling lives. To do this, POW&R works with adults and their families and friends to create individualized vocational and recreational supports in the community.

...It's About Life

POW&R/Autism Society of Delaware 5572 Kirkwood Highway ~ Wilmington, DE 19808 (302) 472-2638 www.delautism.org

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