

BBB AUTISM SUPPORT NETWORK/ AUTISM SOCIETY ONTARIO (YORK REGION CHAPTER)

Autism Society

Ontario

PRESENT

THE E-NEWS

http://www.bbbautism.com/about_bbb.htm

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EVERY DAY HEROES!

he·ro (hîr **o**) *n. pl.* **he·roes**

- 1. In mythology and legend, a man, often of divine ancestry, who is endowed with great courage and strength, celebrated for his bold exploits, and favored by the gods.
- 2. A person noted for feats of courage or nobility of purpose, especially one who has risked or sacrificed his or her life: soldiers and nurses who were heroes in an unpopular war.
- 3. A person noted for special achievement in a particular field: *the heroes of medicine*. See Synonyms at <u>celebrity</u>.
- 4. The principal male character in a novel, poem, or dramatic presentation.
- 5. Chiefly New York City. See submarine. See Regional Note at submarine.

From dictionary.com http://www.dictionary.com/cgi-bin/dict.pl?term=hero

I am an extremely lucky woman!

Every day I get to meet with and talk to extraordinary heroes. Every time I fire up my computer, there are emails from amazing people, there are chats to attend and there are messages to be read on the BBB Autism message board. When I go to meetings and courses put on by the Autism Society of York Region, I meet many more. These truly are individuals who are noted for feats of courage or nobility of purpose. These are people who are parents of **children with an autism spectrum disorder.**

This issue obviously contains only a few of the absolutely wonderful people out there. There are thousands (millions?) more, but the idea of this issue is to celebrate we, the parents - and all our hard work. The people I contacted were all bewildered that they would be considered role models for the rest of us...well, I think that is part of what makes them heroes; they don't even realize how special they are!

This is not necessarily about the work these parents do, but the **way** they do it. They are positive and are inspiring in that way. Heroism is not **all** about advocacy, politics, running programs or following a diet (although that is certainly part of it). Although those are great and noble things, not all of us have the time, energy or funds to do those things. Sometimes heroism is just living day-to-day, taking time to smell the roses, enjoying our children and maintaining a sense of humour throughout it all! ①

Being an everyday hero is about being a parent and loving your child the best you can...doing what you can with what you have. We are not all rich; we don't all have Cadillac therapies happening for our kids. But we are making things work with a smile on our faces (most days, anyway).

Let's face it; every parent is a hero; whether his or her child has special needs or not. These parents represent a few of my personal heroes and I hope their stories will inspire, comfort and nurture you as well. Please join me in getting to know them!

Bee Cool,

Liz

http://www.bbbautism.com/about bbb.htm

Please note: Our children our precious to us. We always substitute their real names for an initial (unless otherwise requested). Additionally, we never include last names of contributors (or any personal information) without permission.

If you have any trouble opening graphics or have any other questions, please let me know by email: mailto:liz@deaknet.com



LAST CHANCE FOR POLL #1

We will be closing Poll #1 (concerning ADD, ADHD and ASD in families) February 14. Please take 10 seconds (that's all it takes) to follow the link below and vote.

Some of our upcoming polls will be just for fun. We will send results of the others (like the one below) to Dr. Jeanette Holden (e-mail, mailto:holdenj@post.queensu.ca who is doing this kind of research in the field.

Our first poll is concerning the incidence of ADHD and ADD in a family with an individual with autism spectrum disorder. Polls are voluntary and totally anonymous. Thanks in advance for your participation!

Please cut and paste this address into your browser or click on: http://www.bbbautism.com/poll 1.htm (choose Poll #1)



Quickie Poll

Is your child with ASD displaying particularly challenging behaviors lately (January and February)?

Please choose POLL #2 when you vote here: http://www.bbbautism.com/poll 1.htm

We've had more than a few posts on our message board lately with respect to increased challenging behaviors. Want to trouble shoot with us? Join our discussion here: http://www.network54.com/Forum/118931

Inspirational thought for the day: The Key to Inner Peace

I may have found inner peace. My therapist told me the way to achieve inner peace was to finish things I had started.

Today I finished 2 bags of potato chips, a lemon pie, a bottle of red wine and a large box of chocolate.

I feel better already.

...Found in my inbox (thanks, Di)

On Motherhood...

"If a woman has to choose between catching a fly ball and saving infant's life, she will choose to save the infant's life without even considering if there is a man on base." **Dave Barry**

DON'T FORGET TO BREATHE! By BBB Member Sue

My life is hardly heroic. I am, to put it bluntly, a survivor... and that does not mean the kind who goes to Pango Pango for a few weeks to eat rat meat, and who gets money as a reward. Actually, mine was a bit more complicated than that. Not any easier, really, either.

Well, to paraphrase one of my favorite comedians, "I started out as a child..."

After that, when I was 18, my mother and stepfather started what was then called a "Home Care Facility" out of Orient State Institution, caring for mentally retarded adults who were being moved out of the Institution, which was later closed and turned into a prison. We had between 7 and 12 patients there at any one time, all over age 21 and most over age 60. They were mostly profoundly retarded, although I think that this was not a particularly accurate diagnosis for them all, originally. The Institution used to take kids who were considered difficult or incorrigible. We had one blind woman who actually ended up not being all that mentally disabled, although she had a lot of problems from sitting for the past 60 years. I mostly ran it while my mother and stepfather worked elsewhere, far away, coming home for occasional weekends. This means cooking, cleaning, laundry, diapers, meds, charting, ordering supplies, everything. I got maybe one night off a month, if I was lucky. This lasted about three years. (No, I wasn't paid).

Although we had no Autistic individuals there, I did read voraciously, (still do), and ended up getting into reading about Autism and other disorders. I also had a brief course in what was then The Skinner Method or Behavioral Conditioning - now evolved into ABA. Not much, but a little of it. Mostly where they shove marshmallows into mouths for doing a tiny step of the desired behavior correctly. I did learn more about this later, and also got into the Sonrise method. Then I met friends who had CP and they had undergone "Patterning" at the "Institutes for Human Potential" in Philadelphia.

Later, after the home closed and my mother divorced, I left her and eventually went to nursing school in another part of the state.

I married after graduation, to an Iranian, (probably the only one in the States without a rug), who came here with a Fullbright scholarship to get his second MA, in linguistics this time. He had one in Education and taught English, of all things. He died after a decade of marriage, of Lymphoma. He did not teach while we were married, however. He did get certification but no one would hire him because of where he was from. He mostly ended up making salads in a restaurant. I ended up working a lot of overtime... often 72 hours a week. After he died I did try sitters. That was hell, literally. (they were) Stealing. Abusing the kids. Simply not showing up.... I gave up after a bit over a year and filed for ADC and SSI. This took an unbelievably long time to get - 8 months - and has a lot to do with the faith I have today. I mean we never missed one meal... just awesome how things went. Rough, though. Not at all easy. Ever...This is no free lunch, guys. They make you *pay*!

We had four children, two of whom are Autistic. I guess the diagnosis would be PDD-NOS, now. They do change things. "Behavioral Communication Disorder With Autistic-Like Tendencies" was the phrase before PDD. J, now 22 and recently using Facilitated Communication with some success is also severely ADHD and microcephalic due to hypoxia at birth. R, now 18, is Hyperlexic, and can read you the NY Times and not miss one word. He can even spell them all perfectly. What he can't do is understand most of them. Both of my sons are fairly low functioning. J is now in a group home about 80 miles away. I miss him and hate this, but keeping him at home is not a safe option for him as I am also now nearly deaf and have Menier's Syndrome, and he has an impulse control deficit and loves to run outside in the traffic.

I have two children who are also theoretically NT - although this is pretty iffy, if you ask me. JJ, who is 20, is mildly ADHD and a genius as well as a chronic underachiever who has been in Who's Who in High School twice and yet nearly flunked his senior year when he decided to learn guitar and be a (Punk) Rock Star. L, my 16-year-old only daughter, is also brilliant but has had CFS. She is a junior in high school and is presently being home schooled.

How to keep sane? Who said I was sane? Not meee! hehehe.... I still read voraciously, and as much escapist novel stuff as I can, like Sci-fi and Who Dun It's. I pray. I still meditate. I love music. I try to learn something new every day, (which is really not that hard, especially now that I am online). I stay curious... and that keeps me alive, I think. Counting my blessings reminds me that there is always someone who has less to work with than I do. It also reminds me that I also have the Big Man, Upstairs, to thank for an awful lot of things. Laughter, also, is a big factor in my survival. Without humor, I would not have made it.

Hopes? Dreams? Well, around the beginning of this year, my first love, (back from when I was ten and he was the 12 year old boy next door), found me online. We have been talking ever since. We plan for me to return to California this spring and see what we will see... umm? I guess I hope I will have a life after motherhood? Maybe.... Just imagine! I turned a half century old this year! And I am still as giggly as any teenager, which is silly, but oh I am having a ball!

Struggles? Mostly with the school systems through the years. I have lost more battles than I have won. Most of the ones that I won were lost, later, when they would make new laws the following year. Getting J into any school program at any time and keeping him there has been a life long struggle. He has been denied services off and on for his entire life.

Finances are a chronic struggle. My husband's death did not leave me much to cope with, monetarily. Being technically disabled, myself, with a hearing loss, does not help.

As my brother said once, "Life is not supposed to get that hard." So, maybe his isn't and he mostly has avoided mine. My family is not supportive at all. My mother has psychiatric problems. My sister, whom I was close to, died last year of cancer. No one catches me when I fall. It has been mostly going it alone... even when I was married, my husband was so deeply into denial about our sons' problems that he did not acknowledge that there was anything wrong with the oldest until not long before he died, and never did realize that anything was at all different about Raud, despite all my trying to get intervention. Mostly, it has just been fighting... and yeah I have a pretty bruised rear, sometimes. Still, nothing else to do but pick up and go on.

Rewards? Ummm.... I guess I am a lot stronger than I ever thought I would be, although I will tell you that I feel pretty broken down at times. Life goes on whether I am broken or functional, though it is smoother when I am able, and so I try to hang in there and keep my head as clear as possible. Not very easy at times, though. I have a different perspective from most of the people I know. Frankly, many people's problems seem so trivial. I mean, can you imagine getting upset over a ding in the fender? Not me... All seems so Sturm und Drang, dramatized; in comparison to the way things are in how I see life, anyway. I just cannot imagine why some people strain at gnats so much, and I am frankly turning into the *big* old lady who will get all crotchety and tell them whatever is on her mind. I want to knock them upside the head and tell them to count their blessings and shut up!

I guess that is my reward. I have four beautiful children whom I adore madly, even though the NT ones drive me bananas.... (you think that Autism is hard? Try an ADHD teenager)? My kids are terrific, just so sweet and special and I would not change one hair on their heads unless it would be to make them happier about things. I mean, talking would be nice, but it would not make me love them any more.

One thing I have tried to do, off and on, is to make sure that not quite so many moms go it alone, the way that I have had to. My path has been pretty solitary, and more difficult than it would have been if I had been able to have someone to turn to with some of my questions or concerns, or even just someone to listen. I have been online for a

bit over a year and it is like a whole new world, here, and boy! Do I relish the e-friends I have made! I am turning into a social butterfly, I guess.... and love every minute of it! Even though' my 16 year old daughter still insists that I am too old to need a social life online!!!!

Just take each day one at a time. If that is too much, make it one hour at a time, one minute at a time, and don't forget to breathe!

Love you! - Sue

Diana - BBB Autism Member

Liz seems to think that I am some sort of hero, but really I am just a mom! I have 3 children, 8, 6 and 4. The 6 yr old and the 4 yr. old are my boys and they both have autism. My daughter is 8 and the best big sister that you could imagine. I have a husband that works very hard to keep us in diapers and all the essentials of life...and he also makes enough so that I can stay at home and make sure that things run, "sort of" smoothly around here.

Balancing the needs of everyone in this house may seem like a daunting task, but it is something that we seem to have accomplished. The boys needs do tend to come first. They have IBI therapy, daycare and school, when they have free time, they hang out at home, and enjoy respite outings on occasion.

We try very hard to make sure that our daughter gets the attention that she needs. We use our respite hours very wisely. Some are for my husband and I to enjoy time out, and some is so that we can take our daughter out without her brothers. Family outings are not always successful, and she should not miss out on activities because of her brothers. On occasion, she gets out with our respite worker also, because she sees the fun that they provide for the boys and she wants to be included in that.

I always find time to get out by myself. Whether that is Girls' Night Out with some good friends, or just grocery shopping alone. These things are important. I play softball in the summer and for those few hours I leave the world of autism, and I get to be ME, not a mom of autistic children. My husband also gets time to himself. We all need space!

The thing that keeps me sane are my friends, and my outlook. I refuse to wallow in self-pitythat does not mean that I don't have bad days. because I do!!!, but I know that feeling negative and sorry for myself or my kids is counter productive. I am always reading and looking for information. I don't just jump into things lightly. I weigh it all out and I research. The computer has been the best thing that has happened to me. It provides me with information and information is power! The Internet has also opened up a whole new world of support for me. I have very good friends that know what I am going through, and understand. That is important and through opening up with them, I am learning about them but also myself and my children! Helping others is very important to me. I am kind of a 'behind the scenes' type of person. If I can help one parent at time, then I feel like I have done something worthwhile. The kind of help I give may be just a laugh to someone who has not laughed in a while or perhaps a shoulder and an ear. We all need people to lean on!

As I have come to accept my boys' autism, I have very slowly fallen into the world of autism awareness. I am not making a big splash, but I have made a few presentations to small groups of parents. I help with newsletters, and I volunteer on a couple of committees. It is important to give back. So many people have come into our lives, and have

worked with my children to make them the best little men that they can be. Autism really has made me look at the world in a whole new way. I have been so blessed in many ways.

Cindy Faria – President of Autism Society Ontario – Halton Chapter

'A' was diagnosed three days before his third birthday. The doctor told me to get him some speech therapy because statistics showed 50% of 'these children' never speak and he was nonverbal at this point. Her parting comment to me on that day was to "Be prepared to put him in a home when he reached 16 because he would be bigger than me then and chances are impossible to handle". We didn't have a computer then nor did I have a clue how to even turn one on and I knew I had to research for answers, because I wasn't willing to accept the doctors prognosis for my son's future. So I left my stores in the hands of a 17 year old to run them while I hit the libraries everyday. It took 3 months and a mountain of books until I found "Let Me Hear Your Voice". It was the first book that gave my son a chance at a future, I kept going until I found all the research journals that backed up ABA... and we've never looked back since. I hired Autism Partnership to head the program, at the time I choose them for one reason only... Ron Leaf and John McEachin, the directors, had been part of the original "Young Autism Project" at UCLA. They had been part of the team that had recovered children from Autism... so they new it was possible. No one locally would even consider such a possibility.

At the time a well-known local agency was just starting an ABA pilot project and had asked me to switch my son's program over to them. When I asked their representative how many children he had recovered from autism or if he even believed recovery was possible (to make a long story short) his answer was "No, children don't recover from Autism". I told him then that I could not put my son's future in his hands, if he didn't believe in it and shoot for it, then my son would never have the chance to meet it.

Now four and a half years later and still in a home program, I wouldn't consider him recovered... though I would venture to say he's sitting on the

edge of it. He has two best friends, he is near the top of his class academically bringing home all As and Bs, none of the kids in his class think that there is anything wrong with him... other than his jokes suck and he's gullible at times. He is in grade two with support for only one afternoon a week (an ABA trained volunteer). He has come a very long way...He loves the Pokemon, Digemon and the Power Rangers, he plays little league baseball and soccer (for me these accomplishments are a dream that I thought was lost for my child when we received his diagnosis). He's seven years old and he sticks up for his little sister at school as does she for him, she's six years old. She has an active play date for other children with autism in their home programs, actually she's like a walking miniature therapist, redirecting her play dates with comments like "No, you can do better try again" or "Do this", and best of all she has no idea that there is anything wrong with her brother, she has no memory of what he used to be like... she believes his therapists are teachers ... simply to help him learn. Yet at just six years of age she can pick out a child with autism easily saying "Mommy that little boy is like my friend George", but she never connects it to her brother.

Does she miss out on things, I'd be lying if I said no... there is less money to put her in all the programs she'd like to be in and if the time slot of a program conflicts with his therapy, then therapy wins out. She gets less one on one time than I wish... but her parents have much better parenting skills due to the ABA training they have received so she receives better quality time. Has she suffered... a little yes, overall no I don't think so... instead she has gained a brother who is now capable of sharing and participating in the experience of being a sibling. Not having that would have been a huge loss to her life and a burden to her as she grew up.

How I handled it in the past, is different than some... the same as others. When he had behaviours in public... I spoke up about the root of his behaviours to people who glared the icy judgmental stare we all come to know so well. Why? honestly because explaining it was easier sometimes for me to handle but I also looked at it in this light... if I let people know that he wasn't just a child that misbehaved but that it was autism... then maybe the next time they saw a child behaving like this that they wouldn't assume he was just being bad and give the parent un-needed grief... maybe they might help the parent instead of being so quick to judge them as having poor parenting skills. I've heard lots of parents say, "I owe no one an explanation and I don't tell people anything, it's their problem"... that's okay too... each of us has to handle it the way that works for us at the time.

Today life at our house is relatively normal, meaning that we can go anywhere and do anything as a family now, autism isn't a factor in what my son can accomplish. It still means we deal with issues because he has difficulties, but they can be handled by staying calm and talking through it, or worst case scenario we incorporate it in his program and he's gets it in no time.

To date my life still revolves around autism, because you still need to advocate and fight for what they continue to need to be successful, and because I volunteer in our local ASO chapter. It's been almost five years since he was diagnosed, though most of the time it feels like a lifetime ago, when really it's just yesterday in a lot of respects. It's still just under the surface, I remember all to easily how the bottom of my world fell out when I left that doctor's office, all my hopes and dreams for my son wiped out in a 20-minute appointment. At the time I would have killed to have a parent who had been there to walk me through it, tell me what to do and where to go... they were out there but we were isolated from each other... when I met my first parent we were at the same place so we

muddled through together. As time went on we met many more parents and we tried to help and learn from each other. Sometimes it was good sometimes not, we can't and won't always see eye to eye just because our children have the same diagnosis, but we can agree to try and educate each other and then hopefully not judge each other for the choices we make that are different.

Now I just try to help a new parent along so that they don't have to waste time searching for answers, but can get going with helping their child get what they need. I'm not an expert by any stretch of the imagination, I only know where I've been and I draw on that to help new parents, if they are interested in a treatment I'm not familiar with then I can help connect them to a parent who does that model. Really in the end it's not about us the parents it's about the kids and getting them what they need.

My hope is to help parents and lessen their confusion on how to help their child when their world is spinning out of control in the beginning.

My dream is for my son to be happy, confident and able to make his way in this world.

My goal, is to see that every child gets appropriate & quality treatment as soon as they are diagnosed... no waiting lists... no lack of funds. But this will only be realized when every single parent gets active and takes on the fight together... alone and in small groups we can be brushed aside...together there are so many of us they will have to listen and respond to save the children... ALL OF THEM! To me the saddest thing I encounter is the lack of available money deciding a child's future, no parent should ever have to shoulder the burden of knowing their was a treatment that could help their child but ... the provincial wait list was to long to access it...and they didn't have the resources to supply it themselves... that's cruel and inhuman for both the parents and the child.

BBB Member Becca Lynn "My Children, My Heroes"

Hi my name is Becca and I am Mom to four precious Angels. From youngest to oldest they are R (12), A (11) Gifted/Major Depressive Disorder, C (9) born with a minor DNA abnormalities, and M (7) and currently labeled PDD-NOS.

My children are my heroes each in their own special way. R is my hero because he does a wonderful job living with so many special needs siblings. He is generally kind, well balanced, tolerant and forgiving. It's a big weight life has put on his shoulders being the older brother to so many needy younger ones. A is my hero as he has managed to not only survive a major depression but to cope with many smaller ones as well. Major depressions are ghastly horrid things filled with tremendous pain and suffering. They are also extremely terrifying too. But our A has not only weathered the storm but is gradually learning to heal himself. I admire him for his determined inner strength. And his capacity to believe in a better tomorrow. Not an easy thing when you've met major depression face to face.

C is my little heroine because she has always struggled with phobias, fears and anxieties. Terrified out of her

mind the little mite would clamber up my body like a monkey right to the very top. Nor would she let go. She was afraid of so many things but she has been able to overcome all of her fears. Perseverance and patience, shaking and trembling, crying, wailing, fear. But slowly she learned to self-talk herself through each and every fear. C is my heroine because she can feel great fear and do the terrifying anyways.

M is a heroine in her own right. She is a heroine as her very existence and accomplishments inspire everyone who touches her life. Here is the child destined to stay a half-mute inside an Autistic bubble. This she did not in any way, shape or form. M is a heroine because her heart and soul are pure and as she interacts with the world she shows that purity that exists in the heart of every autistic child. And in her everyday actions she demonstrates how the world would be if they just laid down their hatred and unkindness. When she wraps her arms around her sister, or her teacher, or a friend and cries aloud to the world her inner love. That's why M is my hero. It's the purity of her love.

Rebecca Lynn (Bipolar II/ADD)

Brian - BBB Autism Member

Hi, my name is Brian and I have one child Kyle age 6 diagnosed with autism and also Chris Age 5 (neurotypical). Currently I share joint custody of my boys with my ex-wife. She has them on the nights that I work (Thursday through Sunday) and I have them through the week when I am off. I have gone back to college to get a degree in Network Administration and Support. So I don't miss any time with the boys I take classes during the time when they are in school and study after they are in bed or on the days that they are with their mother.

I spend time doing things that both boys like to do and try to take them out when I have them. I have an aide that comes and helps watch Kyle for 3.5 hours a day, which really helps with taking care of both boys' needs. I tell people at work and school about the situations that contributed to Kyle's situation and am finding out that a lot of people who have had to get their vaccinations redone for working at the hospitals have ADHD/ADD or Autistic kids.

I try to workout at the gym when not in school etc and that helps a lot to clear my mind (no comments from the peanut gallery please). Also I spend time looking at things on the Internet and scanning the news for information to help Kyle.

Blushing Brian

Gabrielle – BBB Autism Member

I am the mother of six children. Three have autism, one has ADD, another has speech delays and the last has multiple health difficulties. Balancing the needs of all my children and my husband come first in my list of priorities. They all have to know that I love them, and they have to have their physical needs met. Anything after that is extra...volunteering for Cub Scouts, working in a parent organization and going back to school have to take second place for me.

There are a few things I do for myself, to keep my sanity. I get up an hour earlier than everyone else, just to enjoy the quiet. Even if all I do is sit there and stare, wrapped up in a nice warm blanket, I feel it is still worth it. In the warmer months I work in my vegetable garden. Plants don't run out into the street, and you can see results from any small efforts you may put into them. My greatest luxury, though, has to be a long, hot shower. ©

I am a member of a small group of parents in our school district who are organizing a Special Education Parent Advisory Committee. It is hard work right now, gathering parents together to get it all started, but I am sure it will bring good results in the end. We hope to aid parents in their efforts to find good programs for their children.

I often find myself searching the Internet for answers to my questions about ASD. I am afraid I spend a little too much time doing it...there is so much to learn! I try to share that information with friends and family members when I can. I am in a local (internet) group of parents of children with ASD, and we share ideas when we can. I pass on so much information from this BBB Autism website...it is truly my favorite place to come for ideas!

A Day in the Life

- a humorous peek into the life of Becca, BBB Member

- 1. Mommy wakes up, stumbles out of bed and into the hallway. M meets Mommy in the hallway, yelling family fun night! Mommy finds a coffee and returns to bedroom. Husband spies her and says Coffee? Mommy goes looking for another coffee.
- 2. The dining room table is wobbly. Seems to be missing some screws. There is other furniture with screws missing. Mommy finds some screws lying around but can't locate the holes they belong in. *Makes mental note that someone has been messing with screws*. Goes and looks for screwdriver screwdriver is mysteriously missing. Hmmm!
- 3. Mommy finds M by the window with the screwdriver. She appears to be quite busy. "What are you doing?" Mommy asks. Apparently, M was fixing the window! Looks like M has been fixing a lot of things around here. *Mental note to unfix the fixed tomorrow and find new hiding place for screwdriver*.
- 4. Mommy is distracted when cooking. Accidentally puts seasoning in all hamburger patties after being distracted by screwdriver incident. Mommy forgets that seasoning in all the hamburgers is a problem.
- 5. Dinner is served. M loves hamburgers and lots of ketchup. She wants the bun separate. Mommy compiles. M commences eating. Suddenly there is a wail; "I don't like hamburger! This is not tasty, not like other hamburger!" Mommy apologizes and makes mental note to keep at least one hamburger unseasoned! Mommy disposes of hamburger in tummy receptacle. (Yum, very tasty!) M requests that her bun be washed. Mommy looks at bun. It appears to have been decorated with two hamburger eyes and one hamburger nose. Me claims the bun is unfit for consumption unless

cleansed. Mommy compiles. Mental note: Mommy has never washed a bun before.

- 6. Older brother, Reilly, Mommy's only completely normal child requests earplugs at the dinner table. *Mental note: Mommy will retest hypothesis that older brother is' normal'.*
- 7. Everyone is wearing earplugs at the table, except Mommy and A. Mommy talks to A. Ay says Huh! Mommy remembers on his IQ test his highest score was under an area called powers of non-distractibility. *Mental note: evaluate validity of what IQ tests evaluate*.
- 8. M says loudly, "Family Fun Night!" and goes upstairs. Mommy doesn't think about what M is doing upstairs. Daddy arrives home, gobbles dinner and talks excitedly about a new exciting fun game! Time to go to family fun night at the school! M is nowhere to be found. M is located, in Pajamas. "I thought it was night time," she said. Mommy had to agree it was nighttime! M got clothes on. Daddy and four children left the house with great fanfare (lots of noise)! C held M's hand (very touching). Mommy reminded older brothers to take care of their father in case he got lost or slipped and fell. Mommy closed door with Mommy on the inside!
- 9. Mommy had fun!

Books that Inspire! Readers' Favourites!

In a recent poll we conducted, parents were asked about the books they've found most helpful. Here is what they recommend:

- **❖ Let Me Hear Your Voice** by Catherine Maurice
- ❖ Building Bridges Through Sensory Integration by Ellen Yak, Shirley Sutton and Paula Aquilla
- **❖ A Parents' Guide to Autism** by Charles A. Hart
- **❖ One on One** by Marilyn Chassman
- **Asperger Syndrome** by Tony Attwood
- ❖ Right From the Start by Sandra L Harris PhD and Mary Jane Weiss PhD
- ❖ A Work in Progress by Ron Leaf and John McEachin
- The Child with Special Needs by Stanley Greenspan
- Unraveling the Mystery of Autism and PDD by Karyn Seroussi
- **❖ Keys to Parenting a Child with Autism** By Marlene Targ Brill
- **❖ An Anthropologist on Mars** by Oliver Sacks

- ❖ Aspergerger's, Huh? by Rosina G. Schnurr
- ❖ Behavioral Intervention for Young Children with Autism edited by Catherine Maurice.
- The World of the Autistic Child by Brynna Seigel
- **❖ Autism: Handle with Care** by Gail Gillingham
- Special Diets for Special Kids by Lisa Lewis
- Linda Hodgdon Books
- ❖ Books by Lorna Wing
- ❖ Simon Baron-Cohen,
- **❖** Temple Grandin (2)
- ❖ More than Words by Fern Sussman

...Looking for a good list of ASD reading that includes title, author and ISBN? Email me at mailto:liz@deaknet.com and ask for the BBB reading list!

WE ARE ALL HEROES...HERE ARE SOME HOMEPAGES and/or WEBSITES BY PARENTS

- Becca http://home.talkcity.com/HealingWay/santanawildfire/
- Deb http://members.tripod.com/the_delps/
- Dana's View from the Inside: http://autismchannel.net/dana/
- Bernie: <u>Ariel's Home Page</u>
- "Sully's Story" http://pages.sprint.ca/autismfriends/cjfam.html
- 'Autism Friends' designed, implemented and maintained by our very good friend, Tina: http://www.geocities.com/autismfriends/home.html

Note: To me, the Mothers From Hell epitomize the hero. They are battling for their kids with humour and grace. If you haven't paid them a visit before, please take the time to do so now!

http://www.mothersfromhell2.org/

Special Etiquette: What You Need to Know

By Jean Yates, reprinted (with permission) from the Mothers from Hell newsletter, Vol. 8 No. 1, Feb/Mar, 1999 Jean Yates lives in Pound Ridge, NY with her husband Jim and five sons, two of whom have autism.

Ever since the first (not the last either!) person came up to me and asked: "what is the MATTER with your kid?" and, when I replied, "He's autistic" said, with way too much gusto, "gosh!! that's HORRIBLE! I am SO SORRY for you!!" I have felt there should be a guide, an etiquette book of a sort for special Ed situations. As with "classic" etiquette, there is a crying need for people to get a handle on how to behave at certain times and in certain places. So I'm here to fix all of you and I'm gonna learn you a thing or two. Let's do it!

Attitude: (you KNOW what this is!) Your attitude is something you can control. You cannot control the attitude of others. Therefore, I suggest, that whenever a little something goes awry, possibly, for example, when your child removes all his clothes in the grocery store and you can't find half of them, you take a deep breath, tell yourself something affirmative - something that works for you personally (I usually say to myself, "I am a Supermodel on vacation in the Bahamas!") Then quietly rectify the situation as best you can. In a grocery store "incident" for example, you might pile cases of diet soda like a tower around your naked child until only his head can be seen. Then march serenely past the checkout counter and casually toss them a twenty. If anyone says anything, just say, loudly, but non belligerently, "WHAT?" A lady's attitude will take her far in Special Circumstances.

Fortitude: (That means strength) You must be stout hearted though not foolish when you entrust your child to the hands of his teachers. Of course, do your research and call as many people as it takes to find out if this is an appropriate school for your child. If the timing is right, I am sure you have already done this. Why am I sure? Because I have met countless parents of countless special ed children and I have never seen such a bunch of hard working, loving, devoted people than the members of this group. But, equally as important to your child's well being is your own. In order to stay strong, you're gonna have to SLEEP sometimes. That is Special Ediquette rule #2: If you don't snooze, you lose. And try to be strong about going to the movies sometimes. And if you do go to the movies, and you see a good one, would you mind writing me and telling me about it? Thanks.

The Dude: ("DUDE!") Nothing to say here. I finally say The Big Lebowski, that's all.

Pulchritude: (That mean beauty) "Everything is beautiful, in its own waaaaaay..." The song is a little corny and yet so true. I may be alone on this one, etiquette wise, but I believe that if you have a special needs child you should knock yourself out to keep your son or daughter as clean and well dressed as you possibly can. This acts as a defense against the odd person who might make negative judgments about your child. It also shows your child's teachers in an unspoken way how much you love and value your child. At this point, many people can see clearly enough to see the beauty of our children, both inside and out. But for those that can't, show them. And while you're at it, stop wearing your husband's t-shirts and boxer shorts around the house as a daily outfit. Oh wait. Maybe that's just me.

Beatitude: (That means blessedness) The final lesson for today (please be here next Tuesday for tea; watercress sandwiches and lemonade will be served.) This has to do with our "public relations problem" as parents of special needs children. Has anyone ever said this to you: "you're a Saint!" or how about this: "My, my, you certainly have a full plate!" How do you feel when someone says things like this to you? I feel A) Awkward because I am not a Saint... at least I wasn't the last time I looked, and B) angry because my differentness has been pointed out. In fact, I don't even HAVE any plates-- my wild man kid broke them all. Here's how I'd like to be seen: just struggling, the same way anyone does, trying to raise a family, trying to get some plastic plates that can go in the microwave.... oh I don't know -- just being me.

I have found the optimal response to the Saint and Plate (Pause and silently imagine you are a Supermodel on vacation in ... London, yeah, London) then smile serenely and say, "why yes, I AM a Saint and yes, my plate IS full. Would you like to BABYSIT?"

UPCOMING PARENT EMPOWERMENT WORKSHOPS

...Proudly Presented by Autism Society Ontario ~ York Region Chapter and BBB Autism Support Network

<u>Registration Required, Limited Enrolment. Email asoyork@axxent.ca Location: 11181 Yonge</u>

Street, Richmond Hill

...HOPE TO SEE YOU THERE

- Siblings of Children with Autism ~ Victor Predo, TRE-ADD TUESDAY, MARCH 26, 2002
- Autism & Sexuality ~ Deanna Pietramala, Leaps & Bounds TUESDAY, APRIL 9, 2002
- Social Skills ~ Deanna Pietramala, Leaps & Bounds TUESDAY APRIL 23, 2002
- School Discipline & The Exceptional Student ~ Lindsay Moir TUESDAY, MAY 7, 2002
- **Behavior Management** ~ Deanna Pietramala, Leaps & Bounds **TUESDAY**, **JUNE 4, 2002 ALSO:**

Finalizing details on:

- 8-week Behavior Management Courses
- Hanen's More than Words Course

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Past Issues

To request, email <u>liz@deaknet.com</u> and indicate which volume/issue(s) you prefer. You can order in HTML, MSWORD or PDF. Newsletter Archives are also available on our website at http://www.bbbautism.com/news_arch.htm.

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Volume 1; Issue 2 SUMMER CRISIS

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Volume 1; Issue 4 SENSORY INTEGRATION

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Volume 3; Issue 2 HOW TO ENJOY DISNEY WORLD

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BBB PARENT GUIDES

CONTAINS PRACTICAL INFORMATION BY PARENTS FOR PARENTS

Available on request, e-mail mailto:liz@deaknet.com and ask for:

- 1. Halloween
- 2. Epsom Salts
- Pros and Cons of telling your ASD child his/her diagnosis
 How we advocate for our children

AS ALWAYS. WE LOVE TO HEAR YOUR SUGGESTIONS AND INPUT!

A notice to our readers...

The founders of this newsletter and the BBB $\mbox{\it Autism}$ support club are not physicians.

This newsletter references books and other web sites that may be of interest to the reader. The founders make no presentation or warranty with respect to the accuracy or completeness of the information contained on any of these web sites or in the books, and specifically disclaim any liability for any information contained on, or omissions from, these books or web sites. Reference to these web sites or books herein shall not be construed to be an endorsement of these web sites or books or of the information contained thereon, by the founders.

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