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

SPOUSAL CONCERNS

VOLUME 1; ISSUE 3 Collaborators: <u>BBB Autism</u>, ASO York Region, ASO Halton July 26, 2001

What We Love About Our Spouses

With Contributions by <u>BBB Autism Network</u> Members: Lynn, Becca, Bernie, Liz, Gabrielle, Vicky, Bev, Michelle, Khris, Susan and Wendy

- * I LOVE that my husband loves my kids. (3)
- * I LOVE that he was doing Floortime with J. before I even knew it existed
- * I LOVE that he reads to our kids (2)
- \star I LOVE that he notices and supports all my efforts in autism education and awareness
- * I LOVE that he suggested I might want to go back to school to study this field (4)
- * I LOVE that he planned a romantic weekend/activity for our anniversary (3)
- * He likes to bake/cook/prepare frozen entrees (4)
- * He will do laundry! (2)
- * He will do dishes! (2)
- * He wants to do whatever will help A.!
- * He has a fantastic work ethic!
- * He is friendly and outgoing!
- * He is talented with all things mechanical! This is important for saving money on car repairs!
- * He's never let me down once when I needed him.
- * He waters my plants for me.
- * He participates in all the kids activities, plays, T Ball, soccer games.... etc.
- * He's very romantic...but I won't go there
- * He's my best friend and October 19th will be our 10th Anniversary!!
- * He's the one who deals with most of the teachers and school staff for all our special needs kidlets bringing with him my instructions and my notes.
- *I think it really helps that we understand (and respect) our individual coping styles.
- * ...Never learned to change a diaper until we had our first baby, but he became a pro at it anyway.
- * ... Always gives me a card on special days because flowers make me sneeze
- * ...Is very good at taking advice on child care issues, doesn't take it as an insult

- * ...Doesn't take it personally when I say "it comes from your family"
- * ...Lets me sleep when I just have to (2)
- * ...taught me how to drive and didn't flinch even once
- * ...Lets me stay home to care for the children, even when the money is tight
- * ...Loves my family as much as I do
- * ...likes to spend time with me, even if it is just cutting back the weeds in the back yard
- * ...let me learn to cut his hair
- * ...assumes that I didn't meant it the way it sounded
- * He is the knot that keeps my bungee-cord personality from flying out of control!
- * Our 15th anniversary is in September. We will celebrate our "family birthday" by taking the children out of school for the day and attending a popular county fair in our area. I also might get my wedding ring sized up so I can wear it!
- * He does bathrooms, showers and ovens.
- * He cleans up the kitchen even when I really make a big mess.
- * He takes care of the bills and picks up the mail.
- * He doesn't get mad (any more) when I start five things at once.
- * Has a strong sense of family.
- * We brainstorm ideas to deal with certain situations with Thomas.
- * He kisses, hugs and plays with our boys.
- * He works nights and watches the kids when I go to work part-time at 7:00 am.
- * He follows the way that I handle T. that is he learns from my actions.
- * His intelligence he learned all about computers and video editing all on his own.
- * He doesn't get mad when I want to go on <u>BBB Autism</u> and it's what time is it now- 12:35 am.
- * I love the fact that he loves wilderness and nature as much as I do.
- * I love the fact that he loves art.
- * He is my best critic and so supportive of my paintings.
- * And he is so proud of his children.
- * He loves me UNCONDITIONALLY
 - * We are best Friends
 - * He is an Excellent DAD
 - * He roots for me even when I can't root for myself.
 - * Has much more confidence in ME than I do
 - * Is always bragging about his children and his wife
 - * Lets me drone on and on when I am in "Autism Mode" lol
 - * Has mostly accepted that I am "ADD" and doesn't get on my case when I am scatter brained or disorganized (he has gotten used to this LOL)
 - * Since his hours are crazy at work he wants the aupair here to give me a break and insists that we have back up sitters so we can spend quality time together when ever possible.
 - * Usually goes off the diet we keep trying to stay on at the same time as me lol he is very understanding on the weight loss issue. (2)
- *I love the fact that he gave me the most beautiful child in the world.
 - * I love how much he loves our child

- * I love him for the way he picked up our lives (especially mine) and continued on when we received the heart-breaking news of a PDD diagnosis.
- * I love the way he struggled day after day for every benefit our child has right now when I was too shattered to even say the word/words, PDD/Autism.
- * I love the way he looks when he's asleep.
- I love how he makes me smile
 - * I love the way he lets my kids call him daddy (we are not marred yet)
 - * I love how he will let me lock myself in the bedroom on a bad day
 - * I love the way he let me get someone to help me with the house even thow we can't aford it
 - * I love the way I get to sleep in on sundays and wake up to breakfast
 - * I love the way he will come home and make dinner
 - * I love how hi keeps his job so he can be home by 3 instead of taking the higher paying one and being gone all the time

What Drives Us Nuts About Our Spouses

- * He gets to sleep late on the weekends, and I have to get up
- * He has a short fuse when it comes to A.
- * He thinks A. will "get better"
- * He has a hard time acknowledging he is wrong.
- * He won't learn things about how to help A... I will tell him things I have learned and he will say, "Well I will just do it my way as it works for me!" AARRGGHH!
- * I think he drives too fast but that's me. (3)
- * He really isn't an animal lover so he really doesn't care much for Winston (my cat). Although I have caught him on occasion petting him. Hee hee
- * He has a tendency to leave his towel after he's dried himself on the doorknobs, chairs, etc....everywhere except in the bathroom where it belongs.
- * He doesn't scrape the food off his plate.
- * He says there is only one thing that can upset him... me getting upset... LOL, so he wants me to stay happy and calm and well why don't you just put me in a jar and screw a lid on real tight!
- * Mutually incompatible reactions to stress.
- * Do dishes? Not my husband!
- * If I ever want to hide anything from him, I put it with the cleaning supplies!
- *...He has perfect teeth, even without flossing
- * Not dressing up for Xmas.
- * His work clothes especially this Rogers t-shirt when he has to do some jobs around the house.
- * Documentaries that he likes to watch on TV.
- * Meal decisions sometimes it's liking pulling teeth.
- * Expects me to learn to drive a standard (with him teaching me!)
- * Leaves all autism research & battles up to me (not that he's not interested, just

thinks I'm the one who should)

- * Has conveniently forgotten how to cook
- * Has also forgotten where the vacuum cleaner is.
- * After 11 years of marriage, I don't analyze too much anymore!!
- * HE is very organized -lol not a bad thing but it's hard for an ADDer.
- * He drives me crazy when he harps on all the things he thinks I can do (like finishing my degree) LOL -
- * He works too hard but he does it for us.
- * There aren't very many negatives about Rob.
- * I wish he still looked at me the way he used to before everything in our lives turned upside down.
 - * I wish he still said "I love you" before I said it first.
 - * I wish he would tell me what I could do to make him happy, whether it would hurt me or not.
- · He thinks I'm mad at him every time I try talking to him about us
 - * He don't get as into the boys and helping them as much I do
 - * He don't know where the break is on the car
 - * He took away the tools so I can't try to fix the cars wile he is al work
- * ...He makes gray hair look GORGEOUS!!! Okay, so I like that one...LOL
- *All in all The last 10 years together have made us closer. We appreciate each other and it's always us vs. the kids lol. And us vs. everyone else who can irritate us (like school system, etc. LOL

POST OF THE WEEK

Our Kids!

by BBB Autism Member Khris

- »I was just going back through some posts, and caught one from you to me that I never saw about J. You asked what I attributed his progress to (he was diagnosed PDD-NOS and with mild MR just after his 3rd birthday, probable Asperger's Syndrome with obsessive/compulsive tendencies at 4 1/2 and no "official" dx, but the pediatric neurologist that just saw him at 5 said he is AD/HD and nothing else) Anyway, he never was "severe" in any sense of the word- always somewhat social, starting talking at 11 months with no regression, had some imaginative play from early on, etc. But he also has come a long way. I think some things that really helped him were:
- 1) the pure luck that we discovered his sensitivity to dairy at an early age
- 2) having a parent who really understood what it felt like
- 3) never letting his Autism be a reason to exempt J. from regular life experiences (although we modify things to make it more pleasant for all involved- i.e. we may go to a party but only stay for an hour)
- 4) carrying over the interventions used in therapy to everyday life (which requires some reading and exploration on parents part)
- 5) we practice a somewhat predictable routine, but throw a wrench into things every so often, and are always aware of new obsessions forming and try to expand them before they become a rigid routine<<

Here are a few of my Happy Secrets....

by <u>BBB Member</u> Becca

- 1. Care about what he really wants in the depths of his heart. Try to help him accomplish his dreams.
- 2. Never tear him down when he is already down. Build him back up emotionally and confidence wise.
- 3. Bide my time when it comes to addressing important issues.... the right time and the right place are worth the wait....
- 4. He doesn't have to be perfect, although I might want him to be...
 I'm not so why should he be....
- 5. Forgiveness and Forgetting the most important secret of all.... included in this nonjudgmental attitude....
- 6. Last but not least build a friendship treat your husband as you would a precious treasured friend....

Becca Lynn:)

Marriage, patience, crisis and the power of time... by BBB Autism member Becca

Although marriage is entered in this society with a great deal of happiness and joyful anticipation before long this rosy glow wears off and various elements of the marriage need to be accepted and adjusted to.

This process is very like that of the grieving process, especially in some cases. For example you or your husband might need to grieve the loss of your former freedom and single life.

This is an inevitable development in the course of a marriage. First letting going of the past - past single life - another marriage or even a fixation on the family of origin. And then building a new shared life - full of shared values and shared experiences, which cement the husband wife unit together as one.

When Children are born (any children including healthy children) the process of grieving, letting go and accepting and building a new life,

which includes the child/children, has to begin anew. So one of these children suffer a handicapped this process has to begin yet again.

This takes time like any grieving process.... and although two years or so of grief sure feels long when you are in the midst of it, in reality it is a very short time to get caught and held in intense grief....

The unfortunate thing about grief is that individuals often become extremely introspect. This can lead the other partner to conclude that their spouse does not care for them or maybe even their child. What has happened is that grief and pain generally blind one's eyes to others needs. Naturally at this time one turns within and shuts everything else out.

A normal reaction under these circumstances is anger and irritation on the part of the partner shut out. After all his/her needs are far greater at the point of time - that is logical. Unfortunately the anger tends to push the two partners farther apart...

What they need is to recognize the grief. Women are generally able to verbalize more but just because her partner cannot speak feeling aloud doesn't mean that it doesn't help to let him know you understand what he is going through....

In my experience the majority of anger in relationships stem from one of more of those involved being in emotional pain... Anger - the emotion we use to protect ourselves when feeling threatened with pain...

Becca Lynn:)

FEATURED ARTICLE

Stresses on Families

The following excerpt is taken from Chapter 10 of Pervasive Developmental Disorders: Finding a Diagnosis and Getting Help by Mitzi Waltz, copyright 1999 by O'Reilly & Associates, Inc. For book orders/information, call (800) 998-9938. Permission is granted to print and distribute this excerpt for noncommercial use as long as the above source is included. The information in this article is meant to educate and should not be used as an alternative for professional medical care.

Withdrawal and Over involvement

A pattern often in seen in families with a disabled child is one parent who stays as remote from the situation as possible while another's involvement borders on obsession. The withdrawn parent may be just as concerned, but either doesn't have the coping skills or has delegated responsibility to the more-involved partner. Generally--but not always--fathers tend to withdraw, and mothers tend to jump in with both feet.

My relationship with my husband is changed due to his (and most males', I'm finding) lack of whatever it takes to deal with this disability.

--Holly, mother of three-year-old Max (diagnosed PDD-NOS and apraxia of speech)

This situation is not healthy for either parent, nor does it really benefit the child. Parents need to keep the lines of communication open, even when job responsibilities and schedule conflicts force one partner to be more directly involved in activities like in-home ABA training, attending school meetings, or talking with doctors.

Set up a time each week to talk about events and, perhaps more importantly, feelings and frustrations. Try to find ways to keep the parent who has a tendency to pull back actively involved. Perhaps that parent can take part in some rambunctious playtime while the other fixes dinner, or can take on a special weekend activity, such as Scouting, team sports, or a hobby. The trick is to actually schedule these activities and make sure that they happen. It's a rare pair of parents who are absolutely fifty-fifty in their involvement, but for the sake of their partnership, the most-

involved parent needs to know that there will be regularly scheduled break times ahead.

This article continues here.

...and because we all agree that humor helps so much....

A Prayer for the Stressed

and smack someone in the mouth.

Grant me the serenity to accept the things I cannot change, the courage to change the things I cannot accept, and the wisdom to hide the bodies of those I had to kill today because they got on my nerves And also help me to be careful of the toes I step on today as they may be connected to the feet I have to kiss tomorrow. Help me to give 100% at work... 12% on Monday 23% on Tuesday 40% on Wednesday 20% on Thursday and 5% on Friday and help me to remember.... When I am having a bad day and it seems that people are trying to wind me up, it takes 42 muscles to frown. 28 to smile and only four to extend my arm

HOW TO KEEP A HEALTHY LEVEL OF INSANITY

- 1) At lunch time, sit in your parked car and point a hair dryer at passing cars to see if they slow down.
- 2) Page yourself over the intercom. (Don't disguise your voice)
- 3) Insist that your e mail address is: Xena-goddess-of-fire@companyname.com
- 4) Every time someone asks you to do something, ask if they want fries with that.
- 5) Encourage your colleagues to join you in a little synchronized chair dancing.

- 6) Put your garbage can on your desk and label it "IN."
- 7) Develop an unnatural fear of staplers.
- 8) Put decaf in the coffee maker for 3 weeks. Once everyone has gotten over their caffeine addictions, switch to espresso.
- 9) In the memo field of all your checks, write 'for sexual favors.'
- 10) Reply to everything someone says with, "That's what you think."
- 11) Finish all your sentences with "In accordance with the prophecy."
- 12) Adjust the tint on your monitor so that the brightness level lights up the entire work area. Insist to others that you like it that way.
- 13) Don't use any punctuation
- 14) As often as possible, skip rather than walk.
- 15) Ask people what sex they are.
- 16) Specify that your drive-through order is "to go."
- 17) Sing Along at the opera.
- 18) Go to a poetry recital and ask why the poems don't rhyme.
- 19) Find out where your boss shops and buy exactly the same outfits. Wear them one day after your boss does. (This is especially effective if your boss is the opposite gender.)
- 20) Send e-mail to the rest of the company to tell them what you're doing. For example: If anyone needs me, I'll be in the bathroom.
- 21) Put mosquito netting around your cubicle.
- 22) Five days in advance, tell your friends you can't attend their party because you're not in the mood.
- 23) Call 911 and ask if 911 is for emergencies
- 24) Call the psychic hotline and just say, "Guess"
- 25) Have your coworkers address you by your wrestling name, Rock Hard.

- 26) When the money comes out of the ATM, scream "I Won!", "I Won!" "3rd time this week!!!"
- 27) When leaving the Zoo, start running towards the parking lot, yelling "Run for your lives, they're loose!"
- 28) Tell your boss, "It's not the voices in my head that bother me, its the voices in your head that do"
- 29) Tell your children over dinner. "Due to the economy, we are going to have to let one of you go"
- 30) Every time you see a broom yell, "Honey, your mother is here!"

AN IDEA TO INVOLVE THE SPOUSE WHO WITHDRAWS

During our spousal chats, we discussed how some of our husbands/wives have withdrawn since the diagnoses of our ASD kids. It is important to ask yourself why your spouse has withdrawn. One reason may be that s/he simply doesn't feel equipped to handle the enormity of it all. S/he may be leaving all the planning, researching and organizing to you due to feelings of inadequacy. After all, who better to do everything than you?

One way to involve your spouse is to educate them. This doesn't have to be done in lecture mode, a simple way of keeping them informed about your child's day to day life is an Emergency Binder.

The main reason for such a binder is, of course, in the event of an emergency. The withdrawn spouse might be feeling they would become completely lost in the event of illness or hospitalization, so they have to be armed with a tool to help.

The binder contains pertinent information about your child...assessments, physical issues and more, but also contains a list of names, addresses and phone numbers of every professional that sees him/her. There is a description of what each person does and how often s/he is seen. Bus information should be included. Name of drivers and arrival/departure times are essential.

You can also include an up-to-date calendar. Very important to add is a medication guide. Not only with meds, overseeing docs and their doses, but also warning signs to look out for in overdose and/or side effects. All allergies should be listed here as well.

Don't leave out school information. Your child's favorite subjects and teachers (also important for buying small gifts at end of year), a schedule indicating gym days and things your child likes to take for

lunch.

Tell your spouse you have put this together and let him/her know where the binder is. Ask for input. This will hopefully encourage your spouse to read and learn.

Please remember to have several copies of this binder; one to be kept outside the home (in a safe deposit box) and another at a family/friend's home.

Education is empowering, it just might help your spouse to feel comfortable in adding more to your child's life.

Good luck to us all!

Liz

Question of the Week: What are some of the things your spouse does with your ASD child?

Favorite Links

Parenting Children With Developmental Disabilities

<u>Support for families with Special Needs (Government of Canada)</u>

The Risk and Prevention of Maltreatment of Children with Disabilities

<u>Direct and Indirect Financial Support for Families</u> (covering USA, Canada, United Kingdom, Ireland, Australia and New Zealand)

<u>Anger Management</u>

The Divorce Support Page

Avoiding Divorce

Surviving Divorce

Self Assessment Tools for Stress

Parent and Family Issues: Stress and Knowledge

BBB Autism Support Network

STRESS MANAGEMENT

10 Quick Time Management Tips

Avoid these 10 Stress Pitfalls

<u>Psychology Self Help Resources on the Internet</u>

Anti-stress Kit

Stress Management Glossary

ARTICLES

<u>Is Divorce Written in our DNA?</u>

<u>Supporting and Empowering the Family</u>

Survival Guide for Marriage and Money

Arguing Isn't Always Bad

<u>How to Fight Fairly</u>

When to Tell Your Spouse: "We Have a Problem"

Be Free of Guilt and Resentment

<u>Forgiving</u>

The Unaffectionate Spouse

New Beginnings; What to Do, What to Do...

<u>Troubled Marriages: Where Can They Turn for Help?</u>

COMING SOON:

August's newsletter schedule is half done, and I am asking for your favorite links, plus stories and articles you have written yourself on the following topics:

- 1. Home programs: this includes anything you have on ABA/IBI, OT, SLP, Floortime, Miller method, Options, gfcf diet, sensory diet, swim therapy, music therapy and anything you can think of. Hints for hiring (and firing) employees...anything of that nature.
- 2. Difficult Behaviors: this includes violence, self-injurious behavior and also issues like stimming, echolalia, puberty, masturbation, inappropriate behavior of any kind. Stories of how you handle these behaviors in public would be precious to all our readers...

Thanks for all your support, Liz

UPCOMING THEMED CHATS:

Thursday, July 26 Sensory Integration hosted by Liz 1:00pm and 8:30pm EST..

Convert to your time zone here.

Regular chats take place Mon-Fri at 1pm and 8:30 pm daily. If no one is in the chat room when you get there...give it a chance. You never know who might drop in!

Enter chat room here.

Attention: Single Parents of ASD children:

An upcoming series of chats and Newsletter themes will be discussing this issue. We would greatly appreciate any input (i.e. links, articles, book reviews and/or personal stories you may have. Anonymity is assured! Please forward submissions to:

<u>elkowen@deaknet.com</u> or <u>statuesque_f@yahoo.com</u>

Your help is appreciated!

Autism Society Ontario – York Region Chapter

was thrilled to be presented with a cheque for

\$ 22,000.

as one of the two benefiting charities for the proceeds from the 8th Annual Town of Richmond Hill Mayor's Charity Golf Tournament.

Our sincere thanks to the following VOLUNTEERS who gave of their time and enthusiasm on June 18th at Richmond Hill Golf Club and Richmond Hill Country Club

Brian Beedham
Lynda Beedham
Scott Beedham
Cindi Buick
Adrienne Day
Gary Day
Charlie Grant
Gala Grant
Judy Hayami
Paul Kalmykow
Melissa Paczek
Aron Parks
Marilyn Parks
Carol Sweet
John Venditti

The success of this event was due to the ORGANIZING COMMITTEE:

TOWN OF RICHMOND HILL: Lynton Friedberg, Arnie Warner, Christine Morgan,

Marg Dunn, Bruce Gilmour, David Dexter.

ROYAL BANK FINANCIAL GROUP: Ross Pountney AUTISM SOCIETY ONTARIO: Lvnda Beedham

YELLOW BRICK HOUSE: Lisa Rae

RICHMOND HILL GOLF CLUB: Winston Jageshar & Bruce Pridham

Our sincere thanks to the many Sponsors and Contributors that have made this Tournament such a success!

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