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

THE E-NEWS

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THE CURE CONTROVERSY

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Hi everyone!

A topic that arises from time to time on message boards, chat rooms and now the E-News is the thread we like to call "The Cure Controversy". It is not our intention for this issue of the E-News to be controversial, but often this subject seems to touch a nerve. We are offering this theme today, not to cause trouble, but to help look at autism/PDD in a different way.

The question is put like this:

> "If you were offered a cure for your child's autism/PDD and any co-existing disorders, would you administer it? Our 'cure' has been proven to be totally safe with no side effects. Please tell us your feelings on this."

You might think everyone would jump at the chance, after all, look at the hoopla over secretin a few years back. Black marketers were offering it to anxious parents at $1,000 a pop! For our question, surprisingly enough, not everyone answered yes (although there were a few conditional yeses). Parents have a variety of responses and the reasoning in each of them is valid and sincere.

There are no right or wrong answers to this question. Your response may even be different on Monday than it was on Friday. One thing shines throughout all of the feedback – our love for our children!

There is no disrespect meant to those on the spectrum reading this issue. The interesting thing about this question is that it leads us to think of autism in a way we may not have previously. We are hoping to create a movement in the mind and spirit towards peace and acceptance. It is our hope to help ease pain and forge a path towards a positive future easing the frustration along the way.

This issue has been entirely written by parents of children with autism/PDD. Their feelings are sincere, and some of them are raw. Please keep in mind they are speaking for themselves only and no one is trying to push their views on anyone else. ☺ My deepest thanks go out to these awesome parents who opened their souls for us to have a peek! Special thanks to Becca who helped me shape this offering by lending me her words.

Bee Cool,
Liz

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TO START US OFF…*CONTRIBUTED BY "Becca"*

Seemed an appropriate time to post Jim Sinclair's piece **"Don't Mourn for Us"** in conjunction with the "cure/don't cure posts." Keep in mind that Jim is a high functioning Autistic and as such sees the world through this perspective.

As such he can also have difficulties understanding that the world might be different for a low functioning individual or a parent of a child in who suffers. His words however are eloquent and his insight amazing and his voice carries a wisdom with it that cries to be heard.

Anyone one with pieces representing an opposite perspective I encourage you to post these also. We need to see the world through as many perspectives as possible to be the best that we can be...

Don't Mourn For Us

By Jim Sinclair

[This article was published in the "Our Voice," the newsletter of Autism Network International (http://ani.autistics.org/), Volume 1, Number 3, 1993. It is an outline of the presentation I gave at the 1993 International Conference on Autism in Toronto, and is addressed primarily to parents.] J.S.

Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle.

But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have. Parents' attitudes and expectations, and the discrepancies between what parents expect of children at a particular age and their own child's actual development, cause more stress and anguish than the practical complexities of life with an autistic person.

Some amount of grief is natural as parents adjust to the fact that an event and a relationship they've been looking forward to isn't going to materialize. But this grief over a fantasized normal child needs to be separated from the parents' perceptions of the child they *do* have: the autistic child who needs the support of adult caretakers and who *can* form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child's autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them. For their own sake and for the sake of their children, I urge parents to make radical changes in their perceptions of what autism means.

I invite you to look at our autism, and look at your grief, from our perspective:
http://www.autistics.org/library/dontmourn.html

THE QUESTION: "If you were offered a cure for your child's autism/PDD and any co-existing disorders, would you administer it? Our 'cure' has been proven to be totally safe with no side effects. Please tell us your feelings on this."

THE RESPONSES:

"B" dad to "K" aged 7

If K would wake up in the morning leading a "normal" life, talking to me, saying his name and behaving like other 7 year olds i would do it in an instant.

I would continue to help children with special needs any and every step of the way, K's condition has opened my eyes to the problems and concerns other children have.

It may sound selfish but that's what i would do. I have people on the Internet that I consider very dear friends and they are High Functioning and leading happy and productive lives and I am not taking anything at all away from the brilliant spirit each and every one of you radiates.

As for The Mourn post,

Again my friends on the Spectrum do not think for an instant that I would change one iota of your lives even if I had the power, each and every one of you have accomplished many brilliant things in your life and I am very proud of you. But K’s situation is a little bit different from those with high-functioning autism. He cannot function without additional assistance and I also look at his brother, C would will one day have to become his brother’s keeper if K does not become able to take care of himself.

I admit I do not know how much the autism is a part of the K I love so much but to help him and his family lead a happier life I would want him to be able to talk and take care of himself.

“T” mom to “R” age 9

I like some of R’s quirks. Only thing I would like to have improved is his flapping and his understanding and communication...other than that his busy brain can stay. I’d miss his quirky imagination way too much.

It’s really a hard question to answer. If you could guarantee his personality and silly quirks would stay then sure a cure would be great...personally I'm use to the autistic stuff and don't really care either way if he's cured. I’d probably wait till he could decide and follow his lead.

Hard question!

“J” mom to “B” age 8

I'd have to think about it cause I love B just the way he is and I’d be afraid of him being a totally different person...would I know this person??? Would he still be the (usually) same sweet kid with the million-dollar smile????
I'd love to gradually get rid of his autism...so we both could adjust to the change...but a sudden overnight completely different kid.....I don't know...

“M” mom to “B”

I would wish B had more self-confidence and no issues that make him hurt (such as his sensitivities to touch and smell and taste).

I love his brain -- the way he thinks and the way he comes up with the ideas he does. For example -- he told his father that he wanted 6 dice so he could make up different combinations. Guess who bought B the dice? He has a really neat way of thinking.

If you had asked me this when he was 3 -- I would have said GIVE ME A CURE NOW but now he has come so far -- I am very pleased with the way he is. And I look forward to seeing him move up to the next step every day.

He has changed me so much -- I am such a different, better and stronger person because of B. One day I hope he knows how much better he has made me as a person.

And even if all of the traits disappeared tomorrow -- I would still spend my days with the friends who have helped me, made me laugh when I wanted to cry and visit every person I could on this board.

“L” mom to “J” age 6 ½

I love my son so much. He is so cool and so interesting. He is also sweet and even though he has difficult behaviors (like right now), I feel very lucky to be his mom.

If he were to wake up tomorrow without the autism, developmental delays, seizure disorders and anything else not yet detected, how would I feel? Definitely, let's get rid of the seizures...they frighten me! But would *he* be different? Would he lose the very J-ness that makes him J? Gosh, this is something I've thought about and it really gives me pause.

I have to sort out also whether it threatens my role. Boy, how honest is *that*? If J was 'cured' tomorrow, would I be shunned from this wonderful community and how would I feel about that? Does J's autism define *me* as a human being?

Okay, I think I have the answers. I'd like something that 'cured' modules of my son's challenges.

For tomorrow, I'd like the following 'cures':
1. Seizures
2. Incontinence
3. Fecal Smearing (ugh)
4. Uncontrollable (and indefinable) outbursts of tantrums
5. Anything that may be causing him misery or pain

I would like to gradually continue to work on the other stuff: social, expressive/receptive language etc. A sudden 'cure' might be a huge shock to the system. If we can get rid of some of the big stuff, the gradual acquisition of the skills that will help him lead an easier life might be gentler on J *and* myself!

* * *

"C" mom to "T" age 6

Everyone here has pretty much captured the thoughts and sentiments of both my husband and myself. When this diagnosis was made a few weeks ago, the doctor said "Now, there really is no cure for this...." Once we were home, we realized that we didn't really want a cure. Treatment, yes. Therapy to learn how to handle and deal with everything, yes. But get rid of it? Toughie, but like others have already stated, that would mean getting rid of a part of HIM - a part of his soul and absolute way of being. And I totally agree with the question raised of "What would that do to MY role"....as parents, we realize very early on that WE are a big part of their life force, and when something becomes altered, it alters EVERYTHING - not just with that person, but with the entire family structure.

Seeing as how everyone that has answered so far has pretty much said that they would not take an overnight "cure", I am curious to hear the other end of the discussion and see what makes up a yes answer! =)

* * *

"K" mom to "J" age 9

I would definitely love to wake up and my son be cured. In my situation Autism is such a painful thing. Every child is different, but my child is gonna be 9 and things are just not getting any better in a way. He is very hyper. Still puts himself in dangerous situations. He has to be held by his Mommy or Daddy's hand constantly.

Everyone has their own burdens to carry, my is too heavy. I would definitely want him cured. Not only for myself but for his only brother, who puts up with alot from him.

My life is constant worry. Never ever goes away. Sure, my son is the funniest kid you would ever want to meet. But it was real funny when he was younger, but now that he is getting older its not so funny anymore.

Don't get me wrong; I love my son with all my heart. But I am also his mother, to protect him from harm, all decisions come from me.

Don't mean to sound so bitter, but this is how I feel. I guess you asked the question at a wrong time in my life. LOL. We have tried at least 10 different meds, nothing seems to help.

My son can read and write, add and subtract. But......the fear of him running somewhere where he doesn’t belong really scares me to death. One of these days he is gonna seriously get hurt. Maybe he will pick up a poisonous spider or open a door with something very dangerous on the other side. His curiosity really scares me. Never mind the fact that he will be hitting puberty in a couple of years. Oh geeze, I could go on and on...LOL

If I were to answer this question a couple of years ago, it might be different, but reality has set in and this "autism" is really not going anywhere.

Hopefully I didn’t offend anyone or make them depressed, but this is my opinion, also my reality having a autistic child.

“J” mom to “N” age 5

I think he would only be better - and quieter! - if "cured". What makes N ***”N”*** would still be there and the best part is more people would see it.

“L”

If it were totally safe, with no side effects or long-term effects I'd take it and I'm not ashamed to say so. If my child had cancer and there were a cure I would take it. If my child had food intolerances and there was a cure (not just things to make it less worse) I would take it. If my child were a quadriplegic and there was a cure I'd take it.

I don't think my son would be any less special without his autistic features. It's not a matter of me wanting to have a "perfect" child or me thinking he is a burden or not good enough as he is (because he IS) but me wanting to give my son all the opportunities in life I possibly can. Being NT (neuro-typical or typically developing) will give him more opportunities in all areas - social, emotional, work, school, etc.

“B” mom to “A”

You're right this is a tough question. I often ask myself would I be the same person today if A didn't have autism? Would I be as compassionate, courageous enough, or have had the experiences that I've had such as meeting all the wonderful people that have touched our lives, such as A's speech therapist, ABA therapist, OT therapist, you guys, all the friends I've made in numerous boards, would I have a website that touches so many people, maybe not. It's a tough price to pay, in a perfect world we would be able to choose what we want and what we don't want for our child but unfortunately life doesn't work out that way. Maybe A would be the same child and would be able to look me in the eye and tell me how his school day went or point and tell me "look at the beautiful butterfly." Who knows? But if I had to make a choice right now I think it would be yes, a cure.

My biggest fear is his future and like K said, every decision that regards him me and my husband have to make. We can't leave him unattended at all and what's his future going to be like? Will his brother care for him or will we have to place him in a residential facility when he gets older? Although life brings many uncertainties, I’d choose a cure.

“K” mom to “B” age 2 ½

I would take that instant cure. Keep in mind that B is not yet even 3 years old. I don't feel yet that autism is a part of who he is - I still feel that it is something he is trapped behind. I absolutely hate what we are going through. In fact, if I were offered a different disability (paralysis, blindness, etc) I would even take that over autism. I think anything would be easier to deal with than this!

I realize that these feelings are coloured by the fact that B is so young, and the diagnosis only 7 months old. But these are definitely my feelings. Only less than a week ago, I dreamed B had a brain tumor. He went through a terrible operation, then woke up after surgery completely non-autistic. Goes to show you how I feel about it, doesn't it?

It has been really interesting to get to you know all of you in this way, thanks everyone for sharing.

“L” mom to “M” and “D”

Honestly, I never even thought of a cure and it's affects on my life. Each day when I wake up, I view raising my boys as a true "calling", even though it was not something I chose to do. Yes, I wanted children, and I wanted to be a mother. However, I didn't chose to be the Mom of 2 Autistic Boys. I kind of look at it this way: When your children are born you get to know them the first few months, and after awhile you bond and they become a very BIG part of your life. You notice all their little traits, and nuances. You see them for who they are, not what you expected them to be before they were born. I see both of my children for who and what they are, and I wouldn't have it any other way. Is there a cure for the joy we feel when our children accomplish little feats?? Is there a cure for when our child breaks through their little world and gives us a smile or a hug???? I guess what I'm trying to say is why would you want or need a cure for something that is intrinsically the unique essence of a person??? I for one wouldn't want to erase or take away any of that even if I could right now. I would however like to see my children grow and blossom ,be physically healthy, become independent, and know how to love just like any other person does in the world, with or without disabilities.

My children have opened my heart and caused it to grow to a size I could never have imagined possible. If a child, or any person could have such an affect on anyone I'd say they are a benefit to society, instead of someone that we'd want to change. So, no, I wouldn't want a cure, but I would want the world to open their arms and accept my boys just as they are. That would make me much more happy!!

“G” Mom to 6 kids

Our family deals with so many hereditary medical issues, and none of them have an "instant cure." I have a hard time imagining a cure for anything, really. I have just gotten used to the fact that life is a ride, and we may as well enjoy the good stuff that comes along, no matter what the hard stuff is.

My daughter's surgery Friday is supposed to be a "cure" for GERD/reflux. I am still struggling to imagine what she could be like without the chronic symptoms she has had all her life. I know I will cry with joy if the cure really works, and sigh and say, "oh well" if it doesn't.

A cure for autism? I would love a cure for social delays, for stimming, for aggression and regression, and one for the ignorance that other people show towards children with disabilities.

I would NOT, however, want a cure for my sons' gentle personalities, their unique perspective on the world, or their ingenious ways of learning to deal with things they cannot comprehend. They are sweet, intelligent, interesting people, and that would be a shame to miss out on.

G, who is: pessimistic about a "cure," but optimistic about the future for my sons

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“L. A.” mom to “C” aged 3.9

I’ve given a lot of thought to this question as I read all the previous messages in this thread.

I am very lucky in the fact that C, who will be 4 in October, has high functioning ASD. He said "mommy "and "daddy" for the first time back in February. They were the sweetest words I had ever heard. He has been progressing in leaps and bounds since then.

In regards to whether I'd cure him, I don't think so. Maybe I'm being selfish in a way but C makes everything seem wonderful and brand new. Every step he takes is exciting and it reminds me to be thankful for the small miracles that happen every day. C and his autism forces our family to slow down and appreciate the wonder that he sees in his world. It's also a good reminder to my 2 older sons to be tolerant and they are fiercely protective of him.

I'll keep my ray of sunshine just as he is.

A MOTHER'S THOUGHTS ON THE RELATIONSHIP BETWEEN AUTISM AND HER DAUGHTER'S CORE PERSONALITY

Contributed by Becca

I watched a documentary featuring Hannah, a young Autistic child involved in a program of ABA therapy. I found myself mesmerized, drawn in not so much by the therapy or family issues but by the moments frozen in time of Hannah happy within her Autistic world. Triggered in me were memories of not so long ago.

Something about Hannah… so precious and sweet reminded me of my youngest daughter at an earlier age. Her eyes, her mannerisms, and the expression of her Autistic self stirred within me thoughts of a time I had taken for granted… that slipped away. In my heart and soul I missed my sweet daughter that was. Tears came for this is a secret I rarely tell lest I offend someone in its telling. And I wonder did I ever really tell anyone how hard it was to watch her change… so unique, so precious, and so special in her Autistic world as she was.

At first I was hesitant about sharing this story but so often it has pressed upon my mind, perhaps if I try hard enough I can find the right words to do my daughter's story justice. Fair warning though mourning the loss of my daughter's Autism may not be what you expected.

You see once upon a time my little one was far more Autistic then she is now. It was as if she lived within a bubble world. Here she was safe, with her own self-made rules, laws and reasons for the world being as it is. In her bubble she knew naught of the pain and sorrow or evil ways of the world… nor that the world beyond could ever bring her harm. The gift of her lack of understanding and comprehension made this so.

At home I knew exactly what she wanted. What made her happy and what she expected to do when and where and how. I would put on the same video that she had memorized before... say Winnie the Pooh... she would watch it gladly and then act it out word for word. We became part of the movie as she came chattering at our knees and ending by calling us say Rabbit, or Tigger or Pooh. She would talk to the parking lot at the grocery story about it too. This was her world… repetitive, predictable, and ordered. And in this she too helped me to appreciate this calm. Removed from the world of chaos we both were.

I'd take her for walks. Fearlessly she would poke her fingers into dog's eyes. That beautiful precious lack of fear... that terrifying lack of fear that made us fight, both of us in tears all the way home from kindergarten every day. For unable to comprehend the meaning of being run over, being squashed or dead she had no fear of cars. The only thing that saved us was a fixation with white men and orange hands on the pedestrian lights.

The meaning of what they wanted became fixed in my daughter's mind. Something the school crossing patrol could not accomplish. So we went 20 minutes out of our way just to find a crossing light. Those walks were so precious. It was here I learned that she was stimulated to think and speak when walking. Wonderful observations she had and even the beginning of questions.

I cared not that the questions were always the same. I understood her need for security and encouraged the repetition in everything we did. I felt strongly that by meeting her in her world she could feel safe enough with the consistency that she could begin to move beyond. I saw in her a child content in the sameness of the rocks, the trees, the leaves, and a mother attempting to understand this need for sameness and learn her speech, her language and her Autistic ways. It was here I found her inner core of peace and a meeting of our hearts and minds.

These walks gifts born of her lack of fear, which was in itself a precious treasure of its own. I feel the memory of laughter bubble for this lack of fear she had brought to us many a joy. Still present as she began to emerge she said of her older sister's fear of thunder, "I will go outside and beat the thunder up." First signs of sisterly love… I saw the seeds of a miracle. But that lack of fear did dissipated and vanished along with so much more.

Now I remember her far younger. She could no longer walk with me, as she could not stand to hold my hand. I pulled her in a wagon where she sat looking at all the wonders of the world. Here she fell in love with flowers and rocks and pinecones, which I thought wasn't so bad till I was expected to pick them all up.

We lived in a gentle world. It was a world with no time or expectations. No demands that she develop any faster than she was... no expectations that she be anything other than who she was. Nor any fear we had that she just like myself would develop as nature intended. This was a happy world of perfect acceptance.

Not shattered yet by infringing schedules, doctor's dire predictions, teacher's pressures, timetables or fear of time pressing on with no progress. Our fairytale world filled with Dr. Seuss books neatly stacked, dozens of card decks, the same puzzles everyday, millions of Potato heads drawn in exactly the same and dozens of Lego pieces neatly lying in a row.

This was the world when filled with gratitude I was amazed not only at her neat and tidiness but at the fact that after four children this was the first who knew exactly where everything belonged. I was lucky and blessed to have such a child as she. And although she was late walking and talking so too had I been. One day the world would know as her father and I had always known… that this child with the big eyes searching eyes was the most intelligent of all our four children.

But one day as time went on her father and I felt inside that creeping fear. We knew she was developmentally delayed and I knew too well what her symptoms were a reflection of an Autistic disorder. So I designed an intensive program and worked with her all day and much of the evening. She began to emerge so innocent and lacking in comprehension. Her happiness abundant still except of course for the times that something went wrong. But when these times of intense negativity were ended she did not seem to remember they had ever been. Moment to moment she lived and even though her unhappiness with the inconsistency of the world came more often they still did not haunt her contaminating other moments of her life.

Yes she could be very grouchy, but she could make the whole family laugh… and think. She saw the world through different eyes. Her thoughts expressed through seeing differently could be insightful, helpful, or uplifting. For this is a gift given to those who see differently. The Neurologically atypical are needed so much for innovation and progress as typical minds are more likely to see what has worked but not necessarily what will. It still amazes me though how one of my daughter's comments can shed new light on a situation without her even intending on being helpful. It is simply because her brain can see what mine cannot. She is my daughter with the different eyes.

I remember how much she needed me, as if she and I were one myself vital appendage. At first she did not need me but gradually she decided that I was the authority on everything. With relatives in the middle of a sentence she would look over for the answer... exactly what pronoun is my Auntie anyways? For strangers she treated me as if I was an interpreter. What an ego rush with an Auditory Processing Disorder and Expressive Language Problems of my own. But heaven help me were I not available or contradicted some idea she still held firmly in her brain. My, did I get a lecture the day I told her that awful rule that the plural of goose is geese. She had wanted to show off her knowledge of added 's to words verbally. And I had to correct her. This correction was not gently taken as her entire world threatened collapse.

And then there were those moments when she asked so innocently, "Why is Grandpa's belly so big?" or she pointed at my breasts in front of relatives and said, "Can I touch your breasts?" At least she asked… lol. Then she finally got friendly with people and started hugging everyone. We just could not get her to stop. "That is what you do," she said, "when you meet people." And that was the end of the story for our little Autistic girl.

But slowly all that began to change as she emerged from her bubble. At first she was not able to process very much information in her brain but over time she developed more capacity to think and feel a range of emotions. First hint of this ability to understand other's emotions emerged when she spied a sad little girl. "Mommy," she said, "he is sad right?" The pronoun wasn't right but I was purely amazed.

Then she started copying her sister's play, social skills and emotional life. Her acting out of fear was dull, lifeless and without conviction for so long. Fear was game she learned to play with her brothers. All of them thought this game so much fun. But not so funny as when she decided to copy her sister's fear of bugs and strange toilet. All the moves she had but none of the soul of fear. Fascinated my other daughter watched. She thought her sister looked ridiculous and began that moment to give up a lot of her fear.

But one day our youngest daughter started to feel afraid and she actually began to worry. Her ability to see beyond the moment had begun. This now became a part of who she was. And sometimes she would worry obsessively... about being perfect and not getting anything wrong… about the future so far away. Once she came home from school and I asked, "why don't you speak at school?" and she told me she did not speak because she didn't talk good.... and a few days later we went to see her doctor and we talked about her problems with her in the same room... she came out and said " I am weird!"

It was then we fully realized that our daughter was now aware and capable of fear, sadness, apprehension and more. She could even evaluate herself and see herself from other's points of view and feel pain. Yes pain as she developed an obsession on the future loss of every single one of her loved ones. Having figured out death (my son's friend's father and cousin died in the space of a week) I told her that in most cases people are very old before they died. This was my mistake for being logical of mind she composed a mental list oldest to youngest and realized that she would be the last left of all her loved ones. This brought upon her great discomfort that has been hard to release her from.

For with the blessing of Awareness comes the price of pain. This was our daughter's price for being released from her bubble. Today she can at least partly register the unwarranted hostility of bullies although she does not yet completely comprehend their motives. It is Wrong because it is Wrong, she would say. And in tears she will cry I don't want to try because they will think I am stupid. She knows which areas the other kids do better in. She wants to be like them. This hurts her… this causes her pain. She has beaten the bubble but not the many disabilities she still carries with her.

We are born… we live… we are aware. The choice is not ours whether this awareness is ours or not yet with countless many it is those who are most aware who suffer the most pain. This is the sharp edge of an awareness that also bring to the world so much good. Nor do I find that those less aware have any less to give. It is truly amazing what a simple soul can bless others with without knowing much of what surrounds them. And oftentimes their happiness is such that my daughter had.

But she had no choice when I took this treasure from her thrusting her into a world of awareness she was ill prepared for. This I fought for as a gift of love but truly the driving passion came from a thirst inside my own soul. And in so doing her personality was altered. As she became less Autistic she became less of who she had been. This included elements of my daughter both wonderful and precious. Elements of my daughter born of an autistic mind. In this I lost a piece of my heart. I grieve for I have never felt completely comfortable for taking from my own daughter due to my own desires.

But right now she comes upon me throwing her arm full wide. Now she kisses me wet upon my cheek. Burrowing amongst the covers she finds daddy. To him too she gives a big smack. Hmmmm at least this precious little girl doesn't lick us anymore as she once learned from the cats. A few years back she had a moderate problem it seems with identifying which species she originated from. Don't know how she could have stood those cat hairs all over her tongue. But throwing a ball when she thought she was related to a dog was a bit more fun.

I think perhaps what was is precious, what exists now is different yet special as well, … and what lies in the future is undiscovered and mysterious in its hope.

And our daughter is our daughter... she is right the way she is....

IN CONCLUSION….

We ask that you take a look at "Living as an Autistic": http://www.geocities.com/growingjoel/whatisitlike.html where the author concludes with this passage:

"A Cure?

No way!

I am not sick, nor do I have a mental illness! Yes, I have many difficulties that I have to deal with, but I also experience incredible joy and success. I wouldn't be the same person if I was a neuro-typical, nor do I think that I necessarily want to be that person. I like who I am, although I do wish that society would allow people to be who they are, even if it is different than them. I believe that, in heaven, we will one day rejoice with many different brothers & sisters - even the ones that are different.

*I would prefer that people wouldn't pray for me to be "healed", either. When I hear this, I hear, "I will be praying that you will become a different person." I am a whole person. Autism is a key part of who I am. Asking me to want to give up that part would be like me asking you to give up a sense of humor! Without the autism, I would be **less** whole, not more whole."*

The rest of this website can be found here: http://www.geocities.com/growingjoel/

POTENTIAL TOPIC FOR AN UPCOMING E-NEWS

Please share with us how your child with ASD/PDD has changed your life.

What is different?

What would you change if you could?

What unexpected rewards have you reaped?

We are looking for 'warts and all' submissions.

Please email your answers to liz@deaknet.com for possible inclusion in an upcoming issue. Deadline is August 25, 2002

KEEP SWIMMING

Author Unknown

Two frogs fell into a deep cream bowl.
One was an optimistic soul.
But the other took the gloomy view.
"We'll drown," he lamented without much ado,
and with a last despairing cry,
he flung up his legs and said "Goodbye."

Quote the other frog with a steadfast grin,
"I can't get out but I won't give in,
I'll just swim around till my strength is spent,
then I'll die the more content."
Bravely he swam to work his scheme,
and his struggles began to churn the cream.

The more he swam, his legs a flutter,
the more the cream turned into butter.
On top of the butter at last he stopped,
and out of the bowl he gaily hopped.

What is the moral? It's easily found...
If you can't hop out, keep swimming around!

With thanks to Becca

ENEWS BITES:

1. **"AUTISM FRIENDS:** (www.autismfriends.com) Come check out our 800+ links, Shopping section fundraisers for parent run sites coming soon!) Family pages and our Community section for chats 5 days a week!

   Coming soon to Autism Friends! Parent tips, ponderings and wisdom!

   Autism Friends is a Member supported website run by a parent. We are always looking for parent contributions! Book recommendations, photos, best links, personal stories, poems & artwork by our creative geniuses. Contact Tina at: founder@autismfriends.com. Tina"

2.THE GENEVA CENTRE announces: a) **Summer Training Institute** is scheduled for August 19-23, 2002 in Toronto and August 19-20, 2002 in Halifax. Brochure may be viewed in PDF format at http://www.autism.net **b) Geneva Centre International Symposium** is scheduled for October 23, 24, 25, 2002 at the Metro Toronto Convention Centre. The Symposium 2002 brochure has been mailed out and is available at http://www.autism.net. This year you have the option to register on-line; major discounts for early bird registrations. Also, for the first time, delegates from around the world can access 8 presentations of the International Symposium 2002 live through the Internet. Some presentations have special interest for adults on the autism spectrum.

3.Autism Children's Intervention Services Inc. (http://www.aciscanada.com/) Grace Damouni, Director/Founder - 8171 Yonge Street, Suite 226, Thornhill ON, L3T 2C6, Tel 416. 219 2316, Fax 905. 832 3139 E-Mail: Grace@aciscanada.com

"Certified in PECS, Sensory Integration (went to Florida and took the course/lab with Pat Wilbarger), Greenspan's Early Infancy and Childhood course (Floortime/DIR), training in Lovaas, workshop in Handwriting Without Tears, degree in psychology and most importantly, many, (9) years of clinical work with children with PDD/Autism.

I work very closely with Dr. James Bebko of York University and Dr. Carolyn Lennox who are the consulting psychologists to ACIS.

I am proud to say our IBI program is very comprehensive as it includes collaboration with SLPs and OTs as well as the educational team. We help develop IEPs and provide trained shadows for classroom integration.

We do travel outside of the immediate catchments region (once every month or two depending on the time of year) to administer staff training, consultations, assessments and program development. We will travel to Guelph, Hamilton, Cambridge (for example) but only during certain times of the year. However, we do not provide ITs (mediators) to service this region although we can train staff that the family has already recruited. For parents who are not interested in hiring a "team" we can set up the programs/binder.

We do however, provide "teams" and oversee the program for our catchment region, which is Markham, Pickering, Aurora, Richmond Hill, Thornhill, North York, Maple, Woodbridge. If families live within this region we can offer a "team" with full services (assessments, programs, supervision etc) and this ranges in price from $20,000 and up depending on the treatment plan the family has in mind (we offer different plans). In this regard we are very flexible which I believe makes us unique-we customize plans so that we are able to take into consideration the families needs/expectations. *Grace Damouni, Director/Founder*"

4.Workshop Emphasizes Teaching Verbal Communication Skills to Children with Autism and Other Developmental Disabilities - Dr. Vince Carbone is a Board-certified Behaviour Analyst with over 25 years of experience designing learning environments for people with autism and developmental disabilities. He provides preparatory training and clinical consultation to certified behaviour analysts, teaches university courses, and consults with schools, agencies, and families. He is the developer and presenter of a series of workshops on teaching verbal behaviour (verbal communication skills) to children with autism.

Dr. Carbone will be conducting a 3 day intensive workshop "Teaching Communication Skills to Children with Autism and other Developmental Disabilities: Introduction to Verbal Behaviour" on October 28, 29 & 30, 2002 in Oakville, Ontario. The cost of the workshop is $400.00 per person if registered prior to August 15, 2002 and $425.00 per person after August 15, 2002. The workshop is sponsored by Express Yourself Speech, Language and Communication Services. For more information please call 905-333-9730.

Participants in Dr. Carbone's workshop will learn (1) to conduct a Behavioural Language Assessment, (2) to select the most appropriate form of communication for a child, and (3) to identify the communication responses and supporting skills that should be taught first. He shares a special emphasis on teaching verbal behaviour to the most difficult to instruct learners.

Through methods of errorless teaching, specific quick-transfer procedures, and the use of discrete trial training Dr. Carbone has helped many children improve their communication skills. The natural environment and intensive teaching sessions are both employed during program implementation. Dr. Carbone's introductory workshop will provide parents, teachers, therapists, psychologists, and speech-language pathologists with practical information
for program planning and implementation.

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5. “Last weekend, all the York Region Newspapers carried a family's personal story on their front pages entitled: ***Extend autism funding, parents urge***!!!!!!! You can currently view this article at:

http://yorkregion.com/yr/newscentre/vaughan/story/507395p-629397c.html

Last week also saw an amazing article in the Oakville today entitled: ***Families fight to get autistic children the therapy they need.*** This article can be found at:

http://www.visualodyssey.com/style1/news_detail.asp?EditorialID=588&Title=Community

May I suggest that we all send in Letters to the Editors of the papers that ran stories this past weekend; to the Oakville Today Newspaper and to the group of York Region papers commenting on the stories that have appeared, keeping the publicity rolling....

Remember to mention the site for the form letters for members of the public to send in their comments directly to our target ministers. Due to technical difficulties, the site has been moved, anyone using the old site address will be directed to this new site:

The new link is http://www.ontariondp.on.ca/issues/autism/index.html

Thanks to everyone for keeping the issues front and centre in our papers all summer long.... I trust that our MPPs are getting our messages.... MORRISONPN@aol.com”

Nancy Morrison

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6.ABA/IBI Training “The Next Steps” Presented by Autism Society Ontario Halton Chapter on August 16 & 17, 2002. For details, copy and paste this URL into your browser: http://www.bbbautism.com/aba_halton_wkshp.htm

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Do you have an event, announcement, information or a request? Email us at liz@deaknet.com and we'll put it in an upcoming E-News issue. Email early to avoid disappointment! BBB Autism is not responsible for misrepresentations of persons or agencies utilizing this service. **Due to the positive response we've had from this feature, we regret we are going to have to start limiting entries to no more than 50 words, plus one email address for each submission. This will be in effect next issue. Thanks for your cooperation! ☺**

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BBB PARENT GUIDES

CONTAIN PRACTICAL INFORMATION BY PARENTS FOR PARENTS Available on request, e-mail liz@deaknet.com **and ask for: (also available in PDF format)**

1. Halloween
2. Epsom Salts (Calcium too) – expanded version
3. Epsom Salts – condensed version
4. Pros and Cons of telling your ASD child his/her diagnosis
5. How we advocate for our children
6. Guide to holidays and large family gatherings

NOW AVAILABLE ONLINE: OUR BBB GUIDES IN A PLAIN TEXT FORMAT SUITABLE FOR PRINTING. FIND THEM HERE: http://www.bbbautism.com/bbb_guides_contents.htm

A notice to our readers...

The editor of this newsletter and founder of the BBB Autism support club is not a physician.

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