



Volume 17, No. 3 - Fall 2008

# THE COMMUNICATOR

*A Publication of the Autism National Committee*



**Don't Miss It!**

## **AutCom Conference 2008**

**October 17th & 18th, in AnnArbor, Michigan**

**Registration Deadline, October 12th**

There are many good reasons to come to the Annual AutCom Conference. The picture on the right illustrates one of the best of them (see caption). This year's conference theme is **Embracing the Hope and Joy of Autism**.

Many people on the autism spectrum ask, "Why so often won't my body do what my brain wants or does what my brain doesn't want?"

Friday's full-day workshop responds to these two very important questions.....and more!

Friday evening, a performance will explore a relationship in which one person experiences autism and the other does not.

On Saturday, all but one of the presentations and panels have been developed by people on the spectrum. You will learn about autism and Asperger syndrome from people who "walk the walk."

Go to the AutCom website for more information ([www.autcom.org](http://www.autcom.org)).

We want this conference to be as comfortable as possible for people on the autism spectrum. All food events will include a gluten-



From the 2007 conference in Edmonton: Tyler Lazunuk is introduced to facilitated communication by Char Brandl as his parents look on.

free, casein-free option. There will be a quiet room with natural lighting, and all presentation spaces will have incandescent rather than fluorescent lighting.

CEUs are available for Michigan teachers and social workers.

*Sandra McClennen, Conference Chairperson*

Web Site: [www.autcom.org](http://www.autcom.org)

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## President's Letter

Sharisa Joy Kochmeister

It's time again to talk about AutCom, and all I can think about is the upcoming Annual Conference in Ann Arbor, Michigan, in October and all of the wonderful and accomplished presenters we have on the agenda and how exciting a time we will have learning and teaching one another all about autism and life and socialization and awareness and uniqueness. I think it's been a

good year for AutCom, and I look forward to an even better year ahead. I want to thank all of the Board members for your unique and unselfish sharing and contributions, and I want to thank in advance the new Board members we will welcome in October! So let's all get ready to party, teach, learn and share, and let's encourage others to do the same!

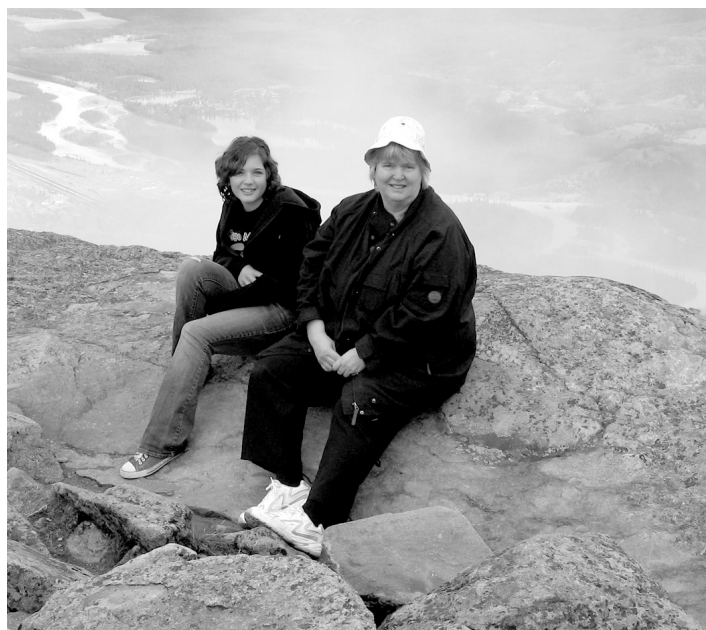
## A Fond Farewell

Gail Gillingham Wylie

I'm looking forward to the annual AutCom Conference in Ann Arbor with anticipation, as this is one of my favorite gatherings of each year. But I also feel a sense of sadness as I face the reality of the end of my second term on the Board, which I have held with pride these last 6 years, and as I bid farewell to my job as editor of *The Communicator*. Yes, I have been asked to stay on, but there is a major shift happening in my life at this time. This doesn't mean that I am finished with AutCom. I will continue as a member, come to the conferences and perhaps even write articles for *The Communicator*, but my focus on autism is taking me in new directions. I will not have the time or energy to fill the position of editor effectively, and so I give it up.

I attended my first AutCom Conference in Valley Forge, PA, in 1997. What a joy that was. As an author, I had been attending autism conferences all over the States, in Canada, and even overseas, and I had never seen anything like AutCom. Most conferences didn't have a single person on the autism spectrum present. Others had one "token" autistic speaker but few, if any, in the audience. And here I was in a world where there were as many people with autism as those of us without. I have been coming back ever since.

Last year we took AutCom to Canada, and my clients got to experience what I have been raving about all these years. One of these people was Tyler Lazaruk, who was introduced to facilitated communication at that conference and who typed



Gail and her granddaughter, Ebony

his first words in front of the CNN cameras. Tyler has come so far in his ability to share with us during the past year. He is currently writing an article for his local newspaper in which he types, "Autism is the worst affliction that you can imagine as it doesn't allow a person to form his own life as he'd like. It prevents one from developing one's potential and it imprisons one forever. Please understand that one could be the most intelligent person but one cannot apply one's talents because of the autism." A question was asked of him: Could you tell us about the body-mind disconnect? He wrote, "The body mind disconnect is a problem for autistic people. It is good to understand that good connections are missing from the frontal

lobes of our minds so we can't make our bodies listen to our brains. For most people, what they think of is what they do, but for us it doesn't happen every time."

This year we gather together in Ann Arbor and more people will have the opportunity to experience their first AutCom Conference. Who knows where that will take them? My

hope is that we as an organization continue to demonstrate an inclusive world for those with autism for many years to come so that in time everyone will have a chance to be a part of it. I hope my time as *The Communicator* editor has helped move this dream forward, and I wish my successor all the best as we continue to share AutCom's vision through the upcoming issues.

## True Inclusion

Gail Gillingham and Wally Wojtowicz, Jr.

I so often hear families making decisions to exclude people on the autism spectrum from family gatherings. They give a number of different reasons, explained very rationally, without any thought of how the exclusion affects their family member on the spectrum who, so often, has no way to express if he/she wants to be included and why. This is one of the reasons that facilitated communication can be so important in the lives of those who cannot speak with their voices.

Wally Wojtowicz, Jr. is a member of AutCom who uses facilitated communication. He has not been well in the past years, so his family wondered if he was strong enough to attend the baptism of his godson. However, instead of making the decision for him, his parents asked him what he wanted to do. We share Wally's reply and subsequent photo taken during the event. Please don't ever assume you are doing a person a favor by excluding them from anything.

"I WANT TO TELL YOU THAT I EAGERLY WANT TO GO TO CARSON'S BAPTISM. THEN I REALLY REALLY WANT TO GO TO THE RECEPTION AT THE STOCKADE RESTAURANT. YOUR NEPHEWS, PERHAPS, WILL CARRY ME UP THE STAIRS TO GET IN. THIS IS THE EASIEST WAY TO GET ME UP THE STAIRS. WHEN YOU ARE TALKING TO ERIN, PLEASE TELL HER THAT I AM TRULY HONORED TO BE THE GODFATHER FOR CARSON WALLACE MASSARONI.

I THINK THAT I REALLY REALLY WANT TO PARTICIPATE IN THE FESTIVITIES AS MUCH AS POSSIBLE. YOU AND MOM REALIZE I LOOK FORWARD TO THIS EVENT. PLEASE



L to R: Rosemary Centi, Godmother, Erin Massaroni, Carson Wallace Massaroni, Wally Wojtowicz Sr. and Wally Wojtowicz Jr., Godfather

WAKE ME UP IN THE MORNING SO THAT I CAN MAKE IT TO CHURCH. I DON'T WANT TO MISS THIS. TOO, I WANT TO MEET THE GODMOTHER. WE WANT TO GET THIS BOY GOOD RELIGIOUS BEGINNINGS. THE ONLY THING THEN IS TO LOOK, NOT TO OURSELVES TO TAKE HIS HAND TO LEAD HIM TO GOD, BUT TO BE THE EXAMPLES FOR HIM SO THAT HE WILL PUT HIS OWN HAND UP TO TOUCH THE HEAVENLY FATHER'S HAND. THIS I THINK WE CAN DO. THIS TOO WILL TEACH CARSON TO BE TRULY A LOVING PERSON. I AM LOOKING FORWARD TO HIS FIRST COMMUNION."



## About Being Seen as a Role Model What It Means to and for Me and Others

Sharisa Joy Kochmeister

For many years I have either been praised for or asked to be a role model and reminded how important I am, not only to others like myself but to all the world. About to turn 30, I often ask myself why I am a role model - now that I grudgingly accept that I am one - and my best answer to that is that it helps me help others, and helping others is my greatest pleasure in life. When I was first accepted for inclusion in school at age 15 (half a lifetime ago), people wondered if I was "truly ready" and questioned if it would help ME at all. My response to this was: "I will never be ready if I'm not ready now; and being excluded until now sure hasn't helped and doesn't help me in any way, so why would I choose THAT?! Also, I want to be challenged because you are boring me to tears in 'special school!'" As it turned out, inclusion DEFINITELY helped me - but much to everyone's surprise and wonder, I wasn't the only one helped by my inclusion! Suddenly, we were all confronted with the reverse and totally unexpected positive effects of my inclusion on all those rough, typical, and honors students, princesses and jocks! Good golly! That wasn't supposed to be the outcome! I was expected to fail! "Bless her heart" (they said and still do) - "that gal's too smart to be out in public!" Just imagine, a woman with brains, common sense and no verbal voice! Many men seem to think: "Ah! She's the perfect mate!" I think: "No way! They could never keep up with me!" That's why it's taken nearly 30 years to start dating... someone had to see me for who I truly am... not easy! And I'm still not sure dating works for me! I also wonder why I'm an editor, writer, Board member and president of the Autism National Committee, teacher, trainer, public speaker and (huge shudder) "role model." My best guess is that it's because I'm qualified to be all of these and more in a life filled with possibilities! Now it's my goal to bring a life filled with possibilities to as many other people as possible! This leads me to:

## Square Pegs Do Have a Place in a Round World!

Sharisa Joy 3/12/96

(Revised 8/13/08)

This world would be a boring place  
If we were all the same  
In looks and personality,  
Feelings, thought and name.

One language and religion,  
One job, one goal, one school;  
No way to be a genius  
And no way to be a fool!

One planet with no humor  
Except the kind that's bland;  
No protests and no fighting,  
Nobody with a stand

On anything important,  
Or different or unique...  
One thought and one opinion  
Would mean no one needs to speak.

No Einsteins and no Edisons,  
No DaVincis or Van Goghs  
No need for creativity,  
No Michelangelos.

No friend, no foe, no strangers;  
No plots, no schemes, no ploys,  
No angers and no dangers,  
No sorrows and no joys.

No need for heavy poetry  
In a world where all is light;  
No need for any wisdom  
Where we all have just one sight.

No lawyers and no judges  
When we never disagree.  
No "square pegs trying to fit in  
To round holes," such as me.

## Waking up Scared and Broken

Johnny Seitz

(written for the stroke patients he works with)

I KNOW WHAT IT MUST HAVE FELT LIKE WAKING UP ONE DAY TO REALIZE THAT THERE WAS SOMETHING VERY "WRONG" IN YOUR WORLD.

I KNOW WHAT IT IS LIKE TO DISCOVER THAT THERE IS SOMETHING REALLY WRONG AND THAT "WRONG" MUST BE SOMETHING "WRONG" WITH ME.

INSIDE YOU PROBABLY DIDN'T FEEL ANY DIFFERENT, BUT THE UNIVERSE HAD JUST BEEN SHIFTED 90 DEGREES AWAY FROM YOU.

THE PEOPLE YOU LOVE AND WHO LOVE YOU WERE SUDDENLY LOOKING AT YOU AS THOUGH YOU WERE A STRANGER.

SILENCE HAPPENED WHEN PEOPLE ENTER THE ROOM YOU ARE IN.

THOSE CLOSEST TO YOU SEEM TO STEP AWAY JUST A LITTLE WHEN THEY LOOK AT YOU.

EASY CONVERSATION WITH OLD FRIENDS DRIES UP SOON AFTER, "HELLO, HOW ARE YOU?"

OH, THEY TRY TO HIDE IT AS MUCH AS THEY CAN, BUT YOU CAN SEE IT, YOU CAN STILL FEEL IT.

YOU HEAR IT IN THEIR VOICES WHEN THEY TALK TO YOU.

YOUR TOUCH SEEMS TO REPULSE THEM A LITTLE, JUST A LITTLE.

AND NO MATTER HOW HARD YOU TRY, THEY JUST KEEP SLIPPING AWAY FROM YOU. YOUR WORLD IS NOT GONE, JUST GONE "WRONG".

YOU WORK HARDER THAN YOU'VE EVER WORKED BEFORE; INSTEAD OF PRAISE, THEY SAY, "IS THAT IT?"

NO MATTER WHAT YOU MASTER, THEY JUST KEEP WANTING MORE.

I KNOW A LITTLE OF WHAT THIS MUST FEEL LIKE BECAUSE ONE DAY I DISCOVERED THAT THERE WAS SOMETHING "WRONG" WITH ME.

MY LITTLE IDIOSYNCRASIES HAD A NAME AND IT WASN'T ME ANYMORE; IT WAS A DIAGNOSIS.

GIVING IT A NAME DIDN'T MAKE ME FEEL A PART OF SOME GROUP OF PEOPLE WHO ARE LIKE ME. IT JUST MADE WHAT WAS "WRONG" WITH ME SEEM EVEN BIGGER AND THERE WERE NOW MORE WAYS THAT IT MIGHT EXPRESS ITSELF IN ME.

LIKE YOU I CAN'T EASILY DO MANY OF THE THINGS THAT ARE EFFORTLESS FOR THE OTHERS.

THINGS THAT OTHERS NEVER EVEN HAVE TO THINK ABOUT, I HAVE FOUGHT TO ACHIEVE.

I'M NOT SAYING THAT THEY'RE WRONG TO WANT ME 'NORMAL.' I JUST FEEL THAT, IN THEIR EYES, I AM THE ONE THAT IS "WRONG" FOR SOMETHING THAT I COULDN'T HELP.

YOU MUST FEEL LIKE SCREAMING, "LOOK DEEPLY INTO MY EYES AND YOU WILL SEE THAT I AM STILL HERE AND MAYBE YOU'LL FIND YOUR OLD SELF IN THERE TOO."

THOSE WHO HAVE NEVER BEEN CHALLENGED LIKE THIS, IT SEEMS, WILL NEVER UNDERSTAND.

JUST BECAUSE IT'S EASY FOR OTHERS, YOUR CONQUERING YOUR STROKE CHALLENGES IS JUST LIKE MY APPEARING "NORMAL" TO "THEM."

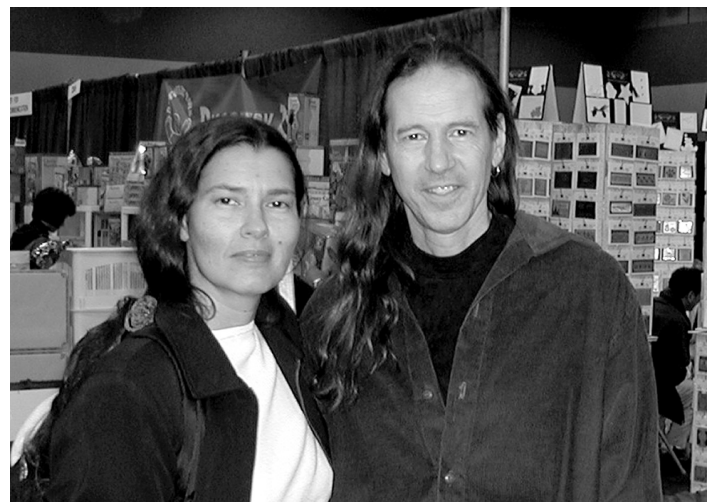
IF I FIGHT TO FIT IN, AND WHEN I DO, SO SEAMLESSLY, THEY GIVE ME NO CREDIT, THEY HOLD ME IN CONTEMPT FOR NOT DOING IT IN ALL THE YEARS I STRUGGLED. I AM SURE YOU KNOW WHAT I MEAN.

INSTEAD OF, "GOD, THAT WAS FINE!" YOU GET "WELL, IT'S ABOUT TIME!"

AND SOMETIMES OTHERS SEEM TO WANT TO BLAME THEIR LIVES GONE "WRONG" UPON YOU.

BUT NEVER FORGET THAT WE HAVE EACH FOUND WAYS TO BE OF VALUE IN OUR WORLDS. WE HAVE BOTH LEARNED SELF-RESPECT AND HAVE EARNED THE RESPECT OF OTHERS.

I AM PROUD IF I AM IN ANY WAY SIMILAR TO YOU.



Chris and Johnny Seitz who will perform "Does God Make Garbage?" at this year's AutCom Conference

## Making Airports Autism Proof

Jacob Pratt

Consultant/trainer, Autism Spectrum Differences  
Institute of New England

The first thing airports should do to be friendly to people with autism is provide quiet places for us to get away from the sensory overwhelming stuff. Of course, if they got rid of it, they wouldn't need quiet places. I refer to several things:

Why do they have beeping lights and sounds on the carts? It's not like there are a whole lot of blind people walking around unsupported. Maybe if they created a lane just for the carts, the people who are inattentive enough to walk in front of them would learn to stay out of the lanes after one or two were run over.

Why do they bother with loudspeakers? If I had a dime for every neurotypical person who said, "What did they just say?" I'd buy my own airport.

I wonder why they have TV on? No one listens or watches, but it adds to the confusion.

The next thing they should do to make airports friendly to people with autism is to make sure the flights are on time. If they can't be, there should be clear signs explaining why not, and passengers should be told when things change. We need visuals, some of us for simple daily stuff like making a sandwich or brushing our teeth. It is way too hard to function in an unfamiliar setting without a clue.

The third thing to make airports more friendly to people with autism is to let stranded passengers have someplace comfortable to lie down. I have used every bit of self-control I had presenting today, and I am in desperate need of sleep. How can I sleep on the bed of hard plastic that is not wide enough for me to sit on, never mind lie down.

I also think that airports should have clocks everywhere instead of on just the few walls near some of the waiting areas. It is hard enough to wait even if planes are on time, but to not know exactly how many more minutes or hours in the case of our last trip is agony. Schedules should

be posted at each gate to prevent anxiety.

I am torn between having to get on early or having to get on last. Optimally, I would get on first but have the opportunity to relax in first class with a drink of orange juice and a snack. Then I could watch other passengers get on so I know who is safe and who will be bugged by me. The only problem would be if I couldn't stay in first class. Maybe ticket agents should understand it is better for all of us if people like me got to stay in first class instead of allowing people without space issues to upgrade at the last minute. To me that would be a reasonable accommodation, as long as we didn't have to pay more for it.

The bathrooms—At some airports like Bradley they are already fine, but I wonder who thought everyone at O'Hare wanted to pee like cattle at the same time. If they can't make more single stalls in the places where there are none, they should at least install hug machines.

There are probably a whole lot of other things that would make airports more friendly to people with autism, but all of us are different. Maybe just some sensitivity to that fact alone would make travel less stressful than it already is regardless of the condition of your central nervous system.

## Trains And Taxis

Hope Black

### Trains

I love the train, but not the stations. They are difficult for people with disabilities. You need a Redcap to help and must avoid escalators when your mother is with you and isn't in good shape.

### Taxis in NYC

They are crazy drivers in New York and many don't speak good English, but they are necessary in the city. You need every address before you get in. Overlook their inability to take the best road each time.



# MEMBERSHIP FORM

Because I endorse the principles of the Autism National Committee, I would like to (circle one):

JOIN NOW

RENEW MY MEMBERSHIP

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY, STATE, ZIP \_\_\_\_\_

PHONE \_\_\_\_\_

E-MAIL \_\_\_\_\_

I AM A (circle): Family member Person with autism Friend Professional (field \_\_\_\_\_)

Annual membership: \$30.00. Persons with autism: \$10.00. Supporting membership: \$75.00

I am enclosing an extra \$\_\_\_\_\_ to speed up the good work.

Make checks payable to Autism National Committee and mail to:

**Autism National Committee**  
**Wade Hitzing, Treasurer**  
**1045 Wittman Drive**  
**Fort Myers, FL, 33919**

*The Autism National Committee is a 501 (c) (3) charitable organization. Your contributions are tax deductible and will be promptly acknowledged for your records*

## PRINCIPLES OF THE AUTISM NATIONAL COMMITTEE

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of appropriate community services, including education, residences, jobs/job training programs, and of individually appropriate and adequate support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their disabled family member in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individual's behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.

## Autism National Committee

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## *Time to Renew or Join Today!*

Annual membership begins in January  
(Membership form on page 7)



THE COMMUNICATOR is a publication of the Autism National Committee, Inc., a 501 (c)(3) charitable organization founded in 1990 to protect and advance the civil rights of people with Autism/Pervasive Developmental Disorder and related disorders of communication and behavior. Contributions of articles, information and letters are welcomed. The Communicator does not carry advertising or fund raising announcements, and we reserve the right to edit all submissions. Your comments are actively sought. Send them to Gail Gillingham at PO Box 11245, Main Post Office, Edmonton, Alberta, T5J 3K5, Canada, or e-mail her at: [exgr@telus.net](mailto:exgr@telus.net)

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