



THE COMMUNICATOR

A Publication of the Autism National Committee



Autcom Bookstore on the Move!

The AutCom Bookstore has officially moved from Wisconsin to New Hampshire. Thanks to the efforts of members of the AutCom Board, the Bookstore was featured at the TASH conference in November. Then the unsold books were packed and shipped to their new home, the Institute on Disability (IOD) at the University of New Hampshire. Board member Mary Schuh is now in charge of the bookstore with support from a Bookstore Committee. The bookstore is featured on our website: www.autcom.org as well as on the Institute's website: www.iod.unh.edu. Order books online or through the toll-free number: (800) 378-0386 (US only).

The AutCom bookstore came into existence in 1994 through the volunteer efforts of Anne Donnellan and her colleagues at the University of Wisconsin. Its focus has always been books and videos that are carefully selected to reflect the social justice and humanitarian values of the Autism National Committee and books that have been written by people who are part of the spectrum of autism.

Beginning in 1997, the bookstore was taken over by Sally Young, who was working on her graduate degree at the University of Wisconsin at the time. The books were moved from Anne Donnellan's basement to

Sally's garage. Although paid a minimal amount, Sally has put in more volunteer hours than anyone else for AutCom over the years as her perseverance and dedication have kept the bookstore open and active for the last nine years. Thanks, Sally. You have done an outstanding service for our organization! We hope that you enjoy the extra time and space that you now have.

Sally's love of books has allowed us to increase our titles from 20 when she began to almost 150 at present. Each book and video we sell has been reviewed by at least one member of the AutCom Board to ensure that they fit within our mandate. We hope this makes it easier for people who know little about autism. One can spend a lot of money on books that are not worth buying.

Published writing by people with autism was almost non-existent twenty years ago. During the past two decades, however, much has changed. We specialize in carrying books for which a person with autism is the primary author, and we have enjoyed watching this list grow over the years. Although we know that every person with autism is unique, reading these first-hand accounts is the best way to learn about the experience of autism. We look forward to adding more of these autographical books as they are written.

In This Issue:

- Page 2 - Words from the President
- Page 3 - Protect Our Voices
- Page 4 - Remembering Rita Gorham Treacy
- Page 5 - A Stranger Among Us
- Page 6 - Ask Rob; Conferences; Thumbs Up & Down
- Page 7 - Have You Forgotten?

Words from the President

By Anne Carpenter

Dr. Martha Herbert's Viewpoint On Autism: Some Considerations

In September, I attended the Autism National Committee's annual conference in Nashua, New Hampshire. The conference began with a presentation by Martha Herbert, M.D., a neurologist at Massachusetts General Hospital. I was so excited, because I had read a mind-blowing article by her, stating that we shouldn't mess with our natural processes; rather, we should tap into the innate potential that is already there. I was eagerly anticipating her keynote lecture at the AUTCOM conference, because I felt sure that she would touch upon that same theme.

That Saturday morning, she delivered the keynote address, but it wasn't quite what I was expecting. One of the first things that she mentioned was that the brain might be "downstream" and that the autism process may have actually originated in the child's entire system. That made sense to me, but I felt uneasy, nonetheless. Where else would this whole process originate, but in the brain, the seat of regulation itself?

What Dr. Herbert was saying appeared to reflect a newer view of Autism Spectrum Disorder—that of a person's whole body being poisoned by toxins, possibly through the use of thimerosal in vaccines, mercury from the environment, or stress experienced by the mother. To her credit, she stated that this was not completely proven but was a hypothesis and still very preliminary. Her view was that the child's body was affected, as evidenced by a greater likelihood of allergies, food sensitivities, and a compromised immune system. This seems to be true for many people with autism.

She also discussed some fascinating brain findings, including the recent discovery that people with autism seemed to have more white matter than gray matter when the brain was developing, and she discussed abnormalities



Autcom President: Anne Carpenter (with Larry Bissonette)

in myelinization relating to that. Dr. Herbert burst into tears when she talked about how the environment was being poisoned, and I was moved, too, but when she mentioned treatments, she mentioned the current standbys, including chelation therapy, which disturbed me deeply, in light of the recent death of a 5-year old boy in Pittsburgh who underwent intravenous chelation therapy.

As I listened to Dr. Herbert's lecture, I was fascinated but also concerned and somewhat underwhelmed. Much of what she said made sense, but I hated the idea of autism once again being thought of as a disease that needs to be cured. This could open the door to inappropriate and potentially harmful treatments, such as chelation therapy to treat heavy metal poisoning in children with autism, which has not yet been firmly established as a cause. This will also make people with autism feel badly about themselves. Believing that they are harboring an illness could lower their self-esteem and could also open the door to discrimination from employers, reluctant to pay high medical and insurance costs for treatment of people on the autism spectrum.

Rather than the brain being downstream, I'd like to suggest another strong possibility—that of the whole process starting in the brain, then cascading though the rest of

the person's bodily system, since the mind and body connection is so powerful. This would be in line with a newer theory of fibromyalgia, which states that the person's brain can't regulate his body's pain signals. If autism were indeed a movement/regulatory difference, then wouldn't it stand to reason that the person's brain has difficulty with the regulatory processes governing perception, behavior, communication, motor functions,

bowel and bladder functions, immunity to diseases, sensitivity to foods, and responses to toxins in the environment? This can be a very powerful theoretical foundation to build on and to help individuals on the spectrum use that most fascinating, wonderful, complex tool in the universe that has unlimited potential—their own three-pound mass of protoplasm known as the Brain.

Protect our Voices

by Sandra Radisch

An Important Lesson about Facilitated Communication

I have had an unusual and unfortunate experience with facilitated communication (FC). I was introduced to FC in the early 90s. It was both exciting and scary. Exciting because without FC I have no reliable means of communication. My apraxia rules out reliable gestures, sign language, picture exchange and the very complex motor coordination needed for speech. I spit out non-meaningful speech when I am stressed and am able to bite my wrist to get attention.

It was exciting to finally be able to express my needs, my thoughts, my questions and my desires. I dared to dream of a different life. I experienced freedom, made choices, made friends, went to classes, got respect, wrote part of my life story for my friend Sally Young's Ph.D. dissertation, traveled and spoke at conferences. I was considered to be the expert of my own life, once I wrestled control away from my well meaning Mom, which in itself felt scary. It was scary because I had to learn to negotiate, to argue, to assert myself, to entrust others with my innermost thoughts and feelings.

I live in a group home with five other women and four men. Each of us have diverse needs. I have lived in this house most of my adult life. Some of my housemates have moved out. Staff have come and gone. The only constant has been that those who speak get the most attention.

I have had the experience of having full access to communication, with all the staff being trained and willing to take the time. I have also experienced times when staff are trained but skeptical, uninterested or unwilling to take the

time. I have experienced times when no training was provided, so I was forced into silence again.

When a child, my parents were told that I was retarded. It was assumed that my habit of flushing things down the toilet was an autistic obsession, but it was not. I was truly trying to find out how the plumbing worked and I couldn't ask. Oh, the money and time I could have saved my parents if I only had a voice. Without a voice most people assume retardation. Others talk about you, for you and around you, but they rarely talk to you. Apparently my intelligence is in your mind, not my own.

Without a voice you become invisible. The group home staff once left me at a beach, not realizing I was missing until after they arrived home. That's pretty invisible. Now you see me, now you don't. It's quite a trick you can play on me.

My advice to those of you considering introducing FC is that you can never go back. You must be willing to continue to train and support communication partners for every FC user. It takes commitment and perseverance. You must never take away a voice once it is found.

New FC users, you must push yourselves relentlessly towards independent pointing on any level to protect your right to communicate. I plead for your chance to gain access, and I await your words.

In Memory of Rita Gorham Treacy

Christmas was a little sadder for some of us this year as we mourned the loss of a dear friend, Rita Treacy, of Highland Falls, New York. Rita was one of the parents who took it upon herself to learn FC and teach it to her son Dan back in the early 1990s. Dan is now 39 years old and has been using FC for about 14 years. Dan is one of the authors featured in SHARING OUR WISDOM. His work has also appeared in various newsletters and books. Rita was a staunch advocate for FC and for people with autism. She also worked with the medical community to try to understand and relieve the gastrointestinal difficulties that Dan experienced. If anyone is interested, memorial contributions may be made on Daniel's behalf to the Rita G. Treacy - Mary S. Burton Supplemental Needs Trust, P.O. Box 242 Bronx, NY 10464.

The death of a loved one reminds us of what is truly important in life. Thanks to the efforts of Rita and many others, voices that had been silenced for years were allowed to speak out through facilitated communication. The following tributes come from those on the autism spectrum who knew and loved her.

I would like to tell you what a fantastic woman my mom was. I would still be locked in the lonely world of autism if not for her tireless efforts to break through the walls that imprisoned me. She would put my needs first. No matter what she could do, it was never enough to satisfy her. I hope she is proud of the way things have turned out. I have her to thank for infinite numbers of things. My future is less fearful than just half a year ago. Mother was always encouraging me to be optimistic and hopeful. She never doubted my ability, not for one second. She always said that each day was a gift from God. Now she is in His tender arms. I miss you moth and I always will. Have fun in heaven, moth. I love you.

Dan Treacy



Dan and Rita Treacy

I AM SAD THAT OUR MOST BELOVED AND CHERISHED FRIEND RITA TREACY HAS PASSED ON. I FIND IN MY HEART THAT IT IS JUST AS SAD TO LOSE SOMEONE YOU TRULY LOVE WITH PASSION AND FEELING LIKE A FAMILY MEMBER AS IT IS TO LOSE YOUR FRIENDS WHO YOU TRUST, LOVE, AND ENJOY LIKE RITA. I'LL PRAY FOR RITA'S SOUL. I KNOW THAT SHE IS NOW LOOKING DOWN AT US FROM HEAVEN AND IS REALLY AT PEACE. LOVING A GOOD FRIEND LIKE RITA IS AS NATURAL AND EASY TO DO AS IS LOVING YOUR MOTHER. I THINK OF RITA WITH JOY IN MY HEART AND A SONG ON MY LIPS AS I REMEMBER HER IN LIFE. REMEMBERING HER PASSION ABOUT FC WILL ALWAYS BE ONE OF THE QUALITIES ABOUT RITA THAT WILL KEEP HER ALIVE IN MY MIND.

Wally Wojotowicz, Jr.

A Poem for Rita

By Michael O'Reilly

She is a tall
and gentle giant
of a woman,

her soul lifted higher,

never held down
by detours in the road.

She is Rita,
My friend...
Exploring autism

So as to understand
The world of my brain.

No stone unturned,
That's Rita!

She is forever
discovering
points of light,

anything
everything

that may heal
autism's sting.

If she could
Rita would single-handedly

Lead us out of the darkness
of this mystery disorder.

She says
There is an order to us,

And maybe it is the world
That does not fit!

Rita sees my beauty.
And I see hers.

Dedication: I dedicate this poem to Rita Treacy, who is the mother of my friend, Danny, who also deals with autism. Rita is a champion for autistic people. Thank-you, Rita, always.



A Stranger Among Us

Congratulations to Lisa Lieberman on the publication of her book, **A Stranger among Us: Hiring In-Home Support for Children with Autism Spectrum Disorders or Other Neurological Differences.**

The book is based on her personal experience - her husband of 26 years has multiple sclerosis and her 17-year old son has autism - so she has years of experience hiring caregivers for her family.

"Hiring in-home support is truly not work for the faint of heart. For those who choose to bring that stranger into your home or assist others in doing so, I hope it is clear how everyone wins: parents, children, spouse, providers and ultimately the community in which you live. My family has been truly enriched by the presence of wonderful 'strangers' who have entered the circle of our family."

"Mostly, it's good practices in educating unconventional people eccentric on the outside but normal on the inside that lops off weak branches of disability and promotes possibilities for new growth."

Larry Bissonnette, **My Classic Life As An Artist: A Portrait Of Larry Bissonnette** (2005)

Ask Rob

by Rob Cutler

Are there environmental factors or consideration to support you in dealing with your autism?

Weather and being comfortable are keys to my successes and failures too. I like the weighted collar. It puts pressure on my shoulder and is relaxing. Calming the body down with pressure helps, yes. You can get me away from people and noises. I could listen to ocean tape while people talk about things. Better background sound. Please talk to me when I am there. Ask me what I think. I am happy to be asked. But I need one voice at a time. I know fc is for me. We are human beings who want to be treated with respect.

Conferences

Identifying and Building Strengths and Nurturing Talents

11th Annual ASD Symposium, March 17 - 18, 2006, in Providence, RI. Hosted by Barry Prizant, Ph.D., and Barbara Domingue, M.Ed. Keynotes by Stephen Shore and Temple Grandin. Workshops on literacy, arts and identifying strengths and talents. For more information call 401-467-7008 or go to: <http://www.community-autism-resources.com>

A 2-day National Conference Honoring Diversity

April 21 - 22, 2006 Sheraton Syracuse University Hotel. Sponsors include Facilitated Communication Institute and Center on Disability Studies, Law and Human Policy. For more information go to: <http://soeweb.syr.edu/cego/conferences.htm>

Mark this Date!

September 8 and 9, 2006 for the next AutCom Conference in Nashua, New Hampshire Watch this newsletter for further details.

Thumbs Up & Down

by Gail Gillingham

Thumbs up to Wendy Partridge and the people in Illinois who have organized a workshop series on supporting communication which will take place between February 2 and 4, 2006 with skill building sessions to follow in May. We regret that the limited number of newsletters we produce did not allow us to advertise this in advance. The workshop will focus on providing the opportunity to learn the techniques of facilitated communication within the context of the principles common to all communication support approaches. It is a collaborative effort of the Illinois State Board of Education, Illinois Autism/PDD Training and Technical Assistance Project, Project CHOICES, Autism Society of Illinois, and York High School.

Thumbs down to the U.S. Supreme Court and the Bush administration. On November 14, 2005, the Supreme Court ruled that parents who disagree with a school system's special education plan for their child have the legal burden of proving that the plan will not provide the "appropriate" education which all children are entitled to. This decision is a great disappointment for parents and disability rights groups who argue that making the parents responsible to prove that special education programs are inadequate gives school districts little incentive to address any complaints. Until now both sides have often tried to mediate and work things out, but this decision tips disagreements in favor of schools, so they will be less motivated to do so. The Bush administration had originally entered the case on behalf of the parents, but when it reached the Supreme Court, the administration switched sides, arguing that the court should apply the "traditional" rule in civil cases such that the party initiating and seeking relief bears the burden of proof.

The problem with this whole procedure is that the current view of disability means that very low standards of education can be found acceptable by a school district which has low expectations for their special education students. One of the major lessons we have learned through facilitated communication is that a lack of verbal output does not equal a lack of intelligence. We must be diligent in the struggle to ensure that every child with autism receives the education to which he or she is entitled.

(From an article in the New York Times, Nov. 15, 2005)

Have You Forgotten?

January, 2006, has already passed. Have you sent your membership dues in yet? If not, mail them now using the form on the back page of this newsletter.

Remember also that we have a Lifetime Membership offer of \$500.00. This may be a good option if the years go whipping by far too fast for you to keep up.

Officers and Chairpersons

Anne Carpenter, M.S., *President*
 Margo Williams, *Vice-President*
 Anne Bakeman, *Secretary*
 Wade Hitzing, Ph.D. *Treasurer*
 Ralph Maurer, M.D., *Scientific Advisor*
 Anne Donnellan, Ph.D., *International Representative*
 Jeff Strully, Ph.D. *Past-President*
 Carolyn Nuyens, *Information and Referral*

The COMMUNICATOR Committee

Alan Kurtz, M.Ed.
 Barbara Cutler, Ph.D.
 Gail Gillingham, M.S.
 Rob Cutler

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.

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. THE COMMUNICATOR may be copied in its entirety or individual articles reprinted without permission except when otherwise noted. Please credit them to the Autism National Committee.

**The Autism National Committee
Information and Referral
Carolyn Nuyens
P.O. Box 429
Forest Knolls, CA, 94933**

www.autcom.org



Time to Renew or Join Today!
Annual membership begins in January.



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