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THE COMMUNICATOR

A Publication of the Autism National Committee

The Combating Autism Act of 2006

On December 19, 2006, President Bush signed the Combating Autism Act of 2006. This act will funnel nearly 1 billion dollars in federal money over five years to enhance research, surveillance and education regarding autism spectrum disorder. The bill was authored by Senators Rick Santorum and Christopher Dodd and first approved by the Senate on August 3rd, 2006. Congress voted passage of the bill on December 7, 2006. The Senate, acting the day after the House passage, approved the legislation with a voice vote.

The goal of this bill is to improve the quality of life for children with autism and their families. It is supported by a number of parent-led organizations throughout the U.S. including The Autism Society of America, Cure Autism Now and Autism Speaks. A focus on combating autism is not found only in the United States. The Canadian Parliament passed a similar motion on December 5, 2006, allowing the government to develop a National Autism Strategy. This "strategy" will also focus on research, surveillance, funding, diagnosis and treatment.

Although neither of these pieces of legislation actually use the word "cure," it is a word that comes up in conjunction with this bill. For example, President Bush mentioned cure when he submitted this statement after he had signed the bill:

"For the millions of Americans whose lives are affected by autism, today is a day of hope. The Combating Autism Act of 2006 will increase public awareness about this disorder and provide enhanced federal support for autism research and treatment. By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and interventions, which is critical for children with autism. I am proud to sign this bill into law and confident that it will serve as an important foundation for our Nations' efforts to find a cure for autism."*

President Bush and Mrs. Bush at bill signing

A focus of discussion about this legislation has been whether or not a cure for autism is possible and, even more importantly, desirable. The Autism National Committee decided to take a closer look at what the concept of "cure" means to our members and

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requested articles on the question of cure for this issue of the newsletter. Note: The ideas presented in these articles are those of the individual authors and do not necessarily represent the views of the Autism National Committee. We would like to continue this discussion and take action that fits within the scope of the legislation and provides the most positive outcomes for those on the spectrum.

(*Source: The White House Press Release from the Office of the Press Secretary, December 19, 2006, and a Press Release from Andy Scott, Member of Parliament for Canada from Fredericton, NB).

President's Message

WHAT IF I HAD BEEN CURED??

Anne Carpenter

On this very first day of 2007, as I spent a lazy morning in bed, I imagined a scenario in which I was completely cured of all traces of autism. The treatment was proposed to me by a psychiatrist who had just arrived at a university in a neighboring state and was doing an experimental protocol that was purported to cure autism. I would be compensated with a large sum of money to be a subject in the treatment trial. At first, Mother and I were very reluctant to have me go through this, but at the time, my social skills were not quite as well developed, I still had a great deal of anxiety, and I didn't know how to solve problems in a flexible, creative manner, so I thought that it would be worth a try. I hadn't done as well in the previous year as I and others had wished—I had regressed quite a bit and hadn't handled all of the difficulties I experienced as well as everyone had hoped. I signed a consent form, acknowledging possible side effects from the large dosages of medications that would be involved and that the treatment might not be as successful as they hoped. It had been tried on a few other individuals with mixed but mostly positive results.

After extensive testing, including IQ testing (my IQ score was 110, though the doctor thought it was much higher but that the score had been dragged down by slower response times on the Performance part of the test), personality testing, neurological testing, including an MRI, fMRI, CAT scan and PET scan, I was assigned a date to start the protocol. On the treatment start date, Mother and I took the long trip to the clinic to get the medications and the materials I needed to read. When I got home, I read the manual carefully and felt a great surge of reluctance to take this risk, but because I had signed the forms and committed myself, I believed that I needed to go through with it. So that evening before bed, I took my first megadose of a new vitamin formula, two brand-new antidepressant medications that had just been FDA approved, and two shiny, black capsules that contained microscopic nanotubules designed to align the neurons in my cerebellum's Purkinje cells, amygdala, and hippocampus into their correct positions, thought to be necessary for "normal" brain function. After a relatively good night's sleep with only one nighttime bathroom break, I got up the next day and took another ten pills that I needed, which I had to do twice daily. I went to work at Autism Society of Michigan, went home, ate dinner and watched the Jim Lehrer Newshour, and took the night dosage of ten pills.


Autcom President: Anne Carpenter (with Larry Bissonette)

After a few days, I noticed a difference. I was able to keep from saying inappropriate and embarrassing things to people, but I felt slowed down somehow. Everything seemed duller, just the effect I had experienced after taking the old meds such as Stelazine and Dilantin, when I was a teenager. Gone were the "a-ha" insights that I had had. Gone were the neat, creative solutions to problems that I had come up with in the past. I was no longer anxious, but I wasn't excited about life, either, and my enjoyment of sparkly, light-up and glow-in-the-dark gewgaws was gone. In addition, I needed help to find solutions to problems because I couldn't think of new ways to solve them creatively. Because I lacked flexibility in thought and judgment due to the mechanistic nature of the "cure," I was no longer discerning about my choice of men, so I dated a man I had met at my place of worship that past Sunday who offered me money if I helped him to clean his house. I helped him clean his basement, but he never gave me anything. I trusted him, so I continued to date him for two weeks until my mother warned me about him. With chagrin, I told him I had to stop seeing him, and after an angry tirade, the whole thing ended. To add insult to injury, I was not permitted to drink coffee, tea or any other caffeinated beverage or to eat chocolate, because the doctors in the study feared possible negative interactions with the newer drugs and the nanotechnology involved.

I woke up each day rested, but flat. I did my work but needed my list of duties even more, because I couldn't think of other new things to do and couldn't come up with new ideas for moving the organization forward. The Director and her assistant were concerned about me, but I couldn't tell them about the treatment because it was experimental and secret, and if I told anyone, that would be a violation of the contract I had signed. After six months on the protocol, I was evaluated by the head psychiatrist in the study, with more IQ tests and another MRI, fMRI, PET scan and CAT scan. My brain cells were aligned perfectly, and I was declared to be fully CURED of autism! The story made headlines in major newspapers all over the country, and I was interviewed on National Public Radio and went on PBS for a Nova special. This was world news! The whole world was overjoyed, except me. What I had gained in being calm, composed and polite, I had lost in joy and excitement about life, creativity, and original thinking. I could no longer think of new ideas or solutions, and I went through life, taking 20 pills a day and existing in a robotic, mechanical way. Then the head psychiatrist declared me "cured" enough to stop the experimental treatment!

Overjoyed once again, I discontinued the daily regimen of pills and was tested once again. I hoped that I would go back to being my old, happy self, with my keen awareness of what was going on and my sheer fascination with life because of my heightened awareness as a result of being affected by autism. But what was done was done. I continued to see the world as just an ordinary place, and I couldn't see the beautiful nuances of color and light that I had seen before I was "cured." While I enjoyed the company of other people, the sharp intuition that I had had about how people felt and my ability to pick up on one's positive or negative mental energy was blunted, and I really missed having that ability. Also gone was the ZING of excitement I felt about life after having my three cups of coffee in the morning, even though I was once again allowed to drink coffee and tea in moderation. I felt less anxious, but I also didn't feel joy or excitement as keenly. I was not happy with my "new" self and I really longed for the "old" self that I was, before the treatment. I was a completely different person than I was before, and I really missed what I had been before. There was no turning back, so I needed to adjust to my new, cured self. I went to work at the Autism Society, wondering if I should continue that job now that I was no longer thought to be on the Autism Spectrum. I sent out resumes and finally got a job as reference librarian at the Ypsilanti District Library, which I enjoyed and found very interesting, but I still missed my old self. I was no longer creative and I no longer had the startling insights about life that I had had before. I very much regretted having gone through the treatment. My feelings about that didn't change, even as I was on every TV talk show, from Oprah to David Letterman and even as I went to conferences and spoke about the remarkable thing that had happened to me, which was thought to have been a miracle of modern medicine, but to me, felt like a terrible alteration to my life.

DISCLAIMER

The treatment scenario I was imagining and the long-term effects that I was imagining were inspired by Elizabeth Moon's frightening but realistic novel, *The Speed of Dark,* originally published in 2003 by Ballantine Books, about a man in his 30s who consents to undergo a treatment that would completely reverse his autism. He did this at the behest of his new boss who wanted to save money by eliminating the supports that were in place for the employees with autism at his company. The protagonist had learned to adapt to having autism, so the "cure" had unintended consequences.

Responding to the "Cure"
Questioning "Autism Speaks"

By Dave Spicer

In looking at the Autism Speaks web site, I am told that my way of experiencing life is seen as a "cruel embrace" that needs to be conquered and cured, and that achieving this goal would change my future.

It certainly would: the person that I am would cease to exist. The life I live a day at a time, with its rich mixture of challenge and accomplishment, its moments of startling clarity and insight and its times of frustration and exhaustion, its joyous celebration of the simplest things so many others ignore or take for granted—this life would vanish. In its place would be... what? "Fitting in," conformity, following the masses, keeping up with the latest styles and entertainment and distractions, joining in the social games of status and "who's in and who's out" and whose clique is the most popular, and just possibly wondering in the midst of having so much and doing so much why there's a nagging feeling of something being missing and thinking, "Is this all there is?"

I don't mean to indict all of conventional society; it's just that it looks so easy and tempting to go on autopilot and become so wrapped up in what "everybody does" that the deeper issues of meaning and purpose could be indefinitely set aside. If things come too easily, how much are they valued? In contrast to this, I find myself appreciating so many of the "little things in life"—a successful and cordial interaction with a store clerk, a shared smile with a passing toddler, the sensory delight of a spring day—that my ongoing struggles to communicate and understand and learn are richly rewarded. My son's eleven-year experience in therapeutic foster care is leading him in the directions of service, living in community, and valuing others' natures, however different they might be from one's own.

In what I speak and write, I try to emphasize the shared responsibility of people, both those on and those off the autism spectrum, to work toward improving our quality-of-life. The way things have been, and often still are, leaves much to be desired. During the years before my own autistic son started receiving the support and services he needs, we were desperately unhappy and fearful of the future, so I'm not suggesting that everything is fine as it is. My son's path has led through uncontrolled aggression and self-injurious behavior and mine through many years of active alcoholism until I started getting help (eleven years before I was finally diagnosed with autism). Suffering for suffering's sake does not appeal to me, and life with an autistic person (or as an autistic person) can be very hard indeed. Frustrations may abound. But it still doesn't follow, for me, that the best way to deal with autism is to eradicate it.


Dave Spicer

Autism is not something that conceals my "true nature" behind some impenetrable barrier. Rather, it *informs* my nature and is an inseparable part of who I am. I welcome support and understanding and resources in trying to be the best "me" I can. It is my responsibility, and opportunity, to learn to navigate in non-autistic society as best I can and to genuinely try to meet others partway. There is much work to be done, and I feel we all need to pitch in as best we can. This road is far more difficult than the one involving a hypothetical cure, but it can bring people together for support and understanding and shared courage in ways that might not otherwise happen, and lives are enriched because of it.

To me it is a sad irony that the organization is named "Autism Speaks," when the voices of autistic people are nowhere to be found on its website. Rather, others undertake, in all sincerity and with the best of intentions, to speak for what they believe are our best interests. But as long as autism and quality-of-life are seen as mutually exclusive, where one or the other can be present but never both, then it becomes impossible to value the contributions that autistic people can make or to accept that autistic people might prefer to live difficult-but-satisfying lives which express their natures. Evidently I should hang on as best I can until I am cured and get my life back. But I love the challenging, productive work-in-progress life that I already have. It takes everything I've got. I think that is how life is intended to be.

Just What is Autism, Anyway?

Gail Gillingham Wylie

The pamphlets arrive in my mail on a regular basis. Heartbreaking photos of children in distress, combined with extreme rhetoric describing autism as a devastating disorder that destroys families, of children who are "lost" in a world of their own, and of parents robbed of everything that is important to them. And then comes the pitch: for dollars desperately needed for research or for programs so necessary in the battle against the scourge of autism. I guess I get so many because I am known to be interested in autism, but they all go into the trash. The autism I know is so very different from the autism that they are trying to portray. I have no intention of curing or changing or eliminating autism. I'm having far too much fun getting to know people on the spectrum.

The headlines about combating autism have me deeply worried, however. They put autism on the same level as a war zone such as combating terrorism and protecting the public from harm. I know, without a doubt, that this type of attitude will harm not only the people I love but all of our society as we lose the gifts that I see expressed around me on a daily basis. My heart aches for all the parents and professionals who do not have access to these gifts because they are so focused on fixing those on the autism spectrum.

My access comes directly through an attitude of respect and unconditional acceptance, something not possible in the midst of a "cure" mentality, no matter how much one loves their child. If the person I am with is able to be a different person because of my attitude, how much of the "cure" being sought comes through understanding autism instead of trying to fix it? Is it not time to finally focus on a clear understanding of what autism is?

Gail Gillingham Wylie

In the past autism was thought to be a psychological condition created by cold parenting. We've discarded that definition and replaced it with another, now claiming that autism is a neurological disorder in the brain. This, in spite of the fact that we have spent millions of dollars and countless person–hours on research trying to pinpoint the specific disorder without success. Perhaps that's

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the problem. We're not looking in the right place, or shall I say places.

Whenever I am with people on the autism spectrum, I am struck more by how they are different from one another than how much they are alike. The one common feature that I have found within the spectrum is a heightened response to sensory input. This response appears to be more extreme in those who have the most extreme symptoms. Everything else seems to be based on an individual level, whether it is motor planning issues, executive function difficulties, mathematical or musical abilities, gastro–intestinal concerns, heavy metal toxicity, and so on and so on and so on. If we look at this variety with objective eyes, may we not determine that there is far more going on? Perhaps autism is basket in which we have thrown many different problems. Are we at all interested in sorting that out?

Perhaps the first step in "combating autism" should be to clearly determine exactly what autism is. Let's start by listening to those who are on the spectrum. There are many who want to share their wisdom with us. Only when we truly understand what autism is should we move on to finding solutions, that is, if any solutions are needed. Who knows—perhaps a clear understanding will be enough. But until we know what we are dealing with, we cannot move on or stop the horror of possible future decisions such as the following invented scenarios:

Researchers at the University College Hospital of London have applied for permission to begin using pre-implantation diagnosis (PGD) to screen IVF embryos for possible autism, even though there is no reliable test for the condition. Opting for what one commentator called a "close enough solution," the reasoning goes that since 90% of autism sufferers are males, the answer is to allow only embryonic girls to be implanted in families with a medical history of autism. This, they say, will allow families with autistic children "to have a daughter free from the condition."

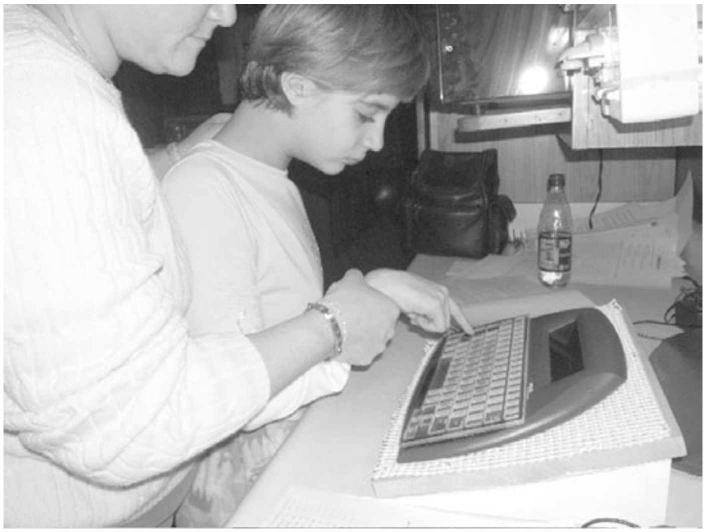
More disturbingly, the London hospital applied to use IVF sex selection techniques to help couples with a family history of autism by destroying all their male embryos. There is no reliable genetic test for autism, but boys are more likely than girls to have the condition. Implanting only females would dramatically reduce the risk but mean many perfectly healthy male embryos would be discarded.

My Life With Autism

My name is Maleia, and I am eleven years old. I feel like other kids my age, but my world is very different. I'm forced to live in the world of autism. To me there is a gospel different from yours. Autism affects me both academically and personally.

Autism affects me academically in many ways. First, I reason differently than you. Personally, I can't understand why people get so involved in good work when I'm just trying to get some feeling in my wooden body. You see lights, I hear lights. You see fun classroom, I see torture chamber. This makes it very hard for me to sit and do good work. I work best in quiet space, with dreamy lights and few people. Secondly, I'm affected academically by the foolish way my brain gets stuck. Words, thoughts, hoards of emotions spin a riot in my head. How can I speak or know drops of thoughts when there's an ocean in my head? Lastly, gears in my head don't work together. Rooms are empty in feelings, gears can't connect. How can I fit into a world forcing feelings I don't have? This makes understanding the classwork impossible.

Autism also affects me personally. I'm always trying to understand so many activities that are easy for other kids. You see fun game with lots of friends, but I see stupid game with too many people. Autism also affects me personally when people love me but don't feel that I love them. Too many people don't understand that I'm feeling love but don't have the words or the right look on my face. This is the hardest thing about autism. Tales of having map of


Maleia Darling

emotions I hear but don't see. Another way autism affects me personally is by racing through my body when I'm around other kids my own age. Truly I want to go places and be with other kids, but autism grows hungry with so many bodies and I'm lost because the map is gone, spares not around.

This is how autism affects my life both academically and personally. My gospel is different than yours and maps are different than yours. People who want to help me need to understand that they can't understand what my world is like and to hope for better days when I'm in control, not the autism.

Roy Bedward

Are We Using the Right Words?

By ROY BEDWARD

I'VE THOUGHT ABOUT IT, AND I BELIEVE CURE IS THE WRONG WORD TO BE USING. CURE IMPLIES ILLNESS, AND I THINK AUTISM IS MORE OF JUST A DIFFERENT PERSPECTIVE ON THE MATERIAL WORLD. YOU UNDERSTAND THAT, WHEN I SAY MATERIAL WORLD, I MEAN PRETTY MUCH YOUR WHOLE WORLD BECAUSE YOU NORMAL FOLKS HARDLY KNOW ANYTHING EXISTS BEYOND THE MATERIAL SPHERE THAT WE INHABIT. HOWEVER, ANY ONE WITH AUTISM WILL TELL YOU THAT THIS IS JUST ONE TINY SLICE OF THE PIE.

I WANT TO ADD THAT I HOPE READERS WILL UNDERSTAND I DON'T MEAN TO SOUND CONDESCENDING OR ARROGANT, BUT IT REALLY IS SUCH A SMALL PIECE OF THE BIG PICTURE. LET ME EXPLAIN THIS MORE FULLY. I HAVE VISION THAT SEES BEYOND THE IMMEDIATE CONTEXT AND HEARING THAT HEARS MORE THAN JUST SOUNDS. IT IS DIFFICULT TO DESCRIBE, BUT I CAN TELL YOU THAT THERE IS SO MUCH MORE TO THE UNIVERSE THAN YOU WILL EVER KNOW BY JUST USING NARROW VISION AND LIMITED HEARING. WHEN YOU OPEN YOUR SENSES TO ALL THAT EXISTS, MORE COMES TO YOU THAN YOU CAN EVER IMAGINE.

Want the Focus of Research to Change?

A petition directed to the NIH is available on the internet. It states in part:

"The past decade has witnessed an accelerated tempo of NIH research into the causes and character of autism. However, without exception, NIH funded research has approached autism from a perspective of pathology: Autism is envisioned as a disease to be cured and autistic citizens are characterized solely by their deficits and impairments."

We believe that the scientific study of autism needs to be radically reoriented. . . Rather than continuing to conceptualize autism as a disease, we believe that NIH must begin to conceptualize autism in the same human rights perspective as it conceptualizes sexual orientation. . . Rather than continuing to support studies aimed only at investigating autistic deficits, we believe that NIH must begin to support research that investigates autistics' unique strengths. And rather than pathologizing the biological and behavioral differences between autistic and non-autistic citizens. . . we believe that NIH must begin to embrace the diversity that autistic citizens embody.

For more go to:
http://www.autism-hub.co.uk/nih-response/

How Can We Respond?

Phil Schwarz

Parents and family new to a diagnosis are inundated with messages from the PR campaigns of the most powerful and well-heeled autism organizations about how autism is a terrible tragedy. They hear from zealots for one or another intervention approach about how they must scramble to pursue cures or recovery against a ticking clock – or else face a dire future of likely institutionalization for their autistic loved one.

And often the local autism organizations to which they turn for face-to-face support echo the same messages. In fact, the most radical cure-oriented organizations do this 1:1. Generation Rescue, the organization that claims that autism is really mercury poisoning, has a network of volunteers it calls "Rescue Angels." "Rescue Angels" are parents of children on the autism spectrum who are "willing to help other parents in treating their children, sharing expertise, local knowledge, and experience"… but it is the unsubstantiated pseudoscience and invasive quackery of the autism-is-mercury-poisoning movement that they share.

There is no comparable voice for our point of view out there. We don't have the media clout of Autism Speaks or the Autism Society of America. And we don't have presence in local autism support groups and in 1:1 contact with families new to a diagnosis.

But we can do something about that. We don't have vast financial resources. But the stock-in-trade we do have is potent at the 1:1 level: personal experience in navigating the circus bazaar of autism interventions, and personal expertise in tackling the day-to-day problems of living with autism and finding real-world solutions that really work.

There are two specific grassroots things I think we can do with that stock-in-trade.

The first of these is to create our own network of families willing to provide mentoring and moral support on a 1:1 basis to families new to a diagnosis. Our network would put families new to a diagnosis in contact with people who have been through the cure-and-negativity gauntlet and are living a better alternative. Our network's participants would be the real "rescue angels," rescuing families from the misguided approaches and quackeries out there waiting to take advantage of them, and teaching them how to problem-solve in ways that work with their family member's autism instead of against it.


Phil Schwarz

We are a small organization, so we don't have presence in every corner of North America, but we can start where we do have presence. And there is a significant new Internet resource we can all tap into, to provide families balanced reading material and additional people to correspond with. It's the Autism Hub – http://www.autism-hub.co.uk – a consortium of English-language blogs and bloggers from across North America and the British Commonwealth, some of them on the spectrum, some of them parents, who by and large share AutCom's approach and perspectives. Some of our board members already work with the consortium and its manager, Kevin Leitch, a British father of a classically autistic preschool-age girl.

I would like to see AutCom take steps in the next year to form the beginnings of such a 1:1 new-family outreach network.

The second way we can change the way people approach autism at the grass-roots level is by getting involved with the local autism support groups in our own cities, counties, and states. There is no conflict of interest in being both an AutCom member and an active participant – even part of the leadership – of your local autism support group or ASA chapter. The more we get out there and speak up at meetings – and get onto boards of directors – the more visible and effective AutCom's approach and messages will be.

It may be a swim-upstream-against-the-current to get out there into some of the more pity-and-cure-oriented local autism support groups. That is where the network of mentors and moral supporters I suggested earlier can serve a second purpose by helping our own, as well as new, families – with encouragement, listening, strategizing, and problem-solving to help our members venturing forth into "curebie territory" to succeed in winning hearts and minds. The written material and e-mail support of the bloggers at the Autism Hub will definitely help in that regard, too.

To further expand the reach of both initiatives beyond our small size and sparse coverage, I would like to see AutCom strike up working alliances with other progressive autism organizations. We've been incorrectly written off as "only relevant to severely handicapped autistic people and their families" and "only focused on FC" for too long. We need to become more connected with like-minded organizations. Some of them focus on less severely handicapping varieties of autism; AutCom's historical base complements theirs and extends our combined reach to cover the entire spectrum. People from these organizations can add to the 1:1 support network, and to the influx of progressive voices into the membership and governance of local autism support groups as well. And by pooling resources, we can together even have significant media impact.

A final thought: The debate over "cure" seems to have always revolved around a false dichotomy – the notion that the only two options that exist are to eliminate autism or to do nothing about it. This false dichotomy needs to be defused in order for our point of view to be heard and understood. I think the way we can do that is by steering towards the real solid middle ground in the "cure" debate. That middle ground is the realization – despite the strawmen to the contrary repeatedly constructed by those who seek to silence us – that both sides of the "cure" debate are in fact in agreement about mitigating the disabling factors secondary to autism, whether they be sensory, executive-function, motor planning, affective, communicatory, or whatever. I tried to identify that middle ground and call for consensus around it in an essay I wrote 11 years ago, but which I think is still relevant today: http://www.autistics.org/library/pschwarz.html

By defusing the false dichotomy and getting others to focus on mitigating handicaps secondary to autism, we can also get them to focus on also mitigating the obstacles in the surrounding society that make those handicaps as disabling as they are. And that, at the core of it, is what I think AutCom is really all about.

Ask Rob

Q:How do you feel when people talk about the "cure" for autism?

I FEEL WE SHOULD SPEND OUR MONEY ON GETTING THE SERVICES WE NEED.
I FEEL THERE IS NO CURE, JUST BETTER UNDERSTANDING OF US.
WE JUST WANT TO HAVE THE OPPORTUNITY TO ENJOY LIFE.
WE ARE HUMANS.
WE ARE NOT A DISEASE.
I AM ALL DONE. YES

Rob Cutler

Save the Date!

The next Annual Conference of the Autism National Committee (AutCom) will be held October 12 and 13, 2007, in Edmonton, Alberta, Canada. It is longer than past conferences for those who have so far to travel. Watch for more details in the next newsletter.

Do you have a passport? You will need one to get back into the United States!

INTERESTED IN CURRENT RESEARCH?

The National Institutes of Health (NIH) has announced the opening of the Autism Research Network (ARN) website: www.autismresearchnetwork.org .

NIH supports two research networks dedicated to understanding and treating autism: **The Collaborative Programs of Excellence in Autism (CPEA)** Network and the **Studies to Advance Autism Research and Treatment (STAART)** Network. This website provides a single source of information about these networks and the research they conduct.

Sharisa Joy

Congratulations to Sharisa Joy Kochmeister, AutCom Board member, for her recent appointment to the Colorado Developmental Disabilities Council. Way to go, Girl!

Here are a few words from the young woman herself:

Hi, Everyone out there in AutCom-land! My name is Sharisa Joy Kochmeister, and I'm a professional author of poetry and essays; a performed composer and lyricist; a graduate of The University of Denver with a 3.6 GPA and a dual degree in Psychology and Sociology; a professional speaker, consultant, trainer and advocate in the areas of disability rights, inclusion, and alternative methods of communication; a board member of AutCom and of the Colorado Developmental Disabilities Council; a member of WOW Colorado; and a future social psychologist and/or educator studying autism and other disabilities and continuing to advocate for children's rights as well as the rights of all people with and without so-called disabilities. Oh, and by the way, I have multiple disabilities, including cerebral palsy, autism, and epilepsy and being non-verbal and requiring a keyboard to communicate and a trusted assistant such as my Dad to ease my way. I have been to the White House and met President Clinton; have received awards for advocacy and community service; have written a fairy tale about autism to help people understand better; and am writing my autobiography, "My Life As a Zero and My Life As a Hero." I have been a high school and college literary magazine writer and editor and have a list of accomplishments too long to mention that I would be glad to share with anyone interested who e-mails me at either: sharisajoy@comcast.net or sharisajoy@aol.com.

Sharisa Joy

It's That Time Again!

January, 2007, has already passed. With each new year comes membership renewal time here at AutCom. Please fill out the membership form on page 11 of the newsletter and mail it to Wade with your check as soon as possible.

Remember: We do have a lifetime membership offer of $500.00 which allows you to make one payment if these years go whipping by far too fast for you to keep up.

Your membership and support keep AutCom alive and active.

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.

The Autism National Committee
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Time to Renew or Join Today!

Annual membership begins in January
(Membership form on page 11)

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

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