

AUTISTICS ALOUD

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WILD ABOUT ARI

His interests include Doctor Who, Battlestar Galactica (the new series), and sushi, he has just completed his first year at the University of Maryland Baltimore County campus, taking a double major in Political Science and History, and he is someone that you should expect to read about often in future editions in this newsletter. Ari Ne’eman is heavily in demand and currently juggling several assignments at once; he has published papers written in favour of neurodiversity, and is president of the Autistic Self-Advocacy Network based in Washington, DC. ASAN has expanded into several other places in the United States so far, and we are currently in the process of starting up our own affiliation here in Halifax, Nova Scotia. (This writer is currently the acting president of the local chapter).

Mr. Ne’eman is originally from New Jersey, and early on he was known for “causing trouble”. When he was in high school he had to fight to get out of a segregated ‘Special Education’ school and into an honours program in regular high school where he could be considerably more academically challenged, with help and support from his parents. While still in

by Danny Melvin

high school, he was appointed by Governor Jon Corzine to the New Jersey Special Education Review Commission and later became chair for the Public Policy Committee for the New Jersey Coalition for Inclusive Education. He has also spoken in the state legislature and in the Interagency Autism Coordinating Committee (IACC). Governor Corzine also signed 7 bills relating to autism in September of last year and on April 2nd this year, the first World Autism Awareness Day, he appointed Mr. Ne’eman to one of five positions of a newly created New Jersey Adults with Autism Task Force.



Ari Ne’eman, Founding President of the Autistic Self-Advocacy Network

Recently, Mr. Ne’eman helped to raise awareness over the now-widely publicized case from Florida of a 5-year old autistic boy who was voted out of his class ‘Survivor’ style, and he was frequently quoted in the May 23rd edition of “New York” magazine (not to be confused with “the New Yorker” about the burgeoning autism rights movement (currently available online at <http://nymag.com/news/features/47225/>), and co-wrote an *amicus* with ASAN vice-president Scott Robertson to a San Diego court regarding the release of a 19-year-old

Recently, Mr. Ne’eman helped to raise awareness over the now-widely publicized case from Florida of a 5-year old autistic boy who was voted out of his class ‘Survivor’ style, and he was frequently quoted in the May 23rd edition of “New York” magazine (not to be confused with “the New Yorker” about the burgeoning autism rights movement (currently available online at <http://nymag.com/news/features/47225/>), and co-wrote an *amicus* with ASAN vice-president Scott Robertson to a San Diego court regarding the release of a 19-year-old

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FINDING OUR OWN ANSWERS

We welcome your opinion of this editorial. If you would like to comment on this, or on any content in Autistics Aloud, or on any autism topic in general, you can find the contact information on page 8.

It's April as I begin to write this, and I'm currently feeling miserable about the state of autistics in the world. Why do I feel this way? You might ask why SHOULD I feel this way? The United Nations has reserved a special day for us, although it could be easily said that it is 'a day late'. And we have suffered a huge setback in the United States, where a Federal Court submitted that vaccines may have caused a young girl's autism by something called a 'mitochondria' predisposition. This is something that I and likely 99.9% of people (perhaps most GPs) had never heard of before. Already 'curbie' groups are declaring a total victory, while it is (hopefully) premature, it speaks volumes of the power of popular legal muscle. I also cannot help but wonder if it is possible that some completely obscure genetic makeup may trigger autism, could a civil court still hold the pharmaceutical companies accountable, even if there were no clearly foreseeable consequences? In any event, it does not bode well for the current states of law or science.

Who is Jonathan Howard anyway? And why is he 'Running the Dream' anyway? (Link: www.runthedream.ca) Many of us are wondering why he picked this particular cause, because we just do not know. Then there's good ol' Jenny McCarthy going on the talk show circuit, making a return appearance on Larry King Live on International Autism Day and being allowed to swear on coast-to-coast television to doctors and scientists she was debating, she even went to 'The Hour' with George Stroumboulopoulos to de-

A LETTER TO THE EDITOR

Dear Danny,

I don't know if Autistics Aloud accepts input from tippies, but I would like to comment about Allistair Fraser's article on curing autism.

Autism can be a significant handicap, as much as

scribe how her son was 'cured' of autism and other fallacies that she believes in. Also, on Sunday April 13th, I was switching channels, and happened upon a 'Night of Too Many Stars' to benefit Autism Speaks which is being hosted by Jon Stewart (I will still watch 'The Daily Show', but he has lost me as a fan). While the show featured different acts, among others, Sarah Silverman, Gilbert Gottfried, Adam Sandler, Ben and Jerry Stiller (no, they do NOT make ice cream), Conan O'Brien, and the force behind it all, Robert Smigel (I bought a DVD of his often hilarious cartoon spoofs which are featured on Saturday Night Live) whose son is on the spectrum. While it appears to be a laudable goal to educate autistic children and teachers, their collective attitude leaves much to be desired, as has been talked about in previous editorials. The thing that most offended me about the entire spectacle was the phone number that they gave for donations, which was 1-877-WRIT-OFF. I do not think that I need to explain what the offense was. Even if their intentions were pure, you know what gets built with good intentions.

The main question that I have right now is in two parts. The media often speaks of an 'autism community', but does it really exist? And if so, where is it? Since autism by definition is something which makes people prefer to be alone, it is not easy for us to make friends, or to be friends, never mind getting a bunch of us in the same room. However, with the increased attention (to the point that many people are calling it an 'epidemic'); we are starting to have strength in numbers as adults. And speaking for myself, I

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we wish otherwise, and Corrine Graham's comments, in the same edition of your magazine, are one example of this. The sensory problems that often accompany autism are a challenge to the autistic as well as those around them, and a 'cure' for this aspect of autism would be useful. After

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TO HELP ASPY FOLK

In this world, it can be tough to tell who is on whose side, and who your friend is and who is an enemy. We aspy folk might indeed need a little help with a world we don't always grasp, but we have many gifts. We are certainly the secret race of silent intellect which can conjure up the idea, even if we don't always have a clue how to execute the plan. But the world really needs aspy folk if they are going to come up with any new thinking to escape the conformity which we all seem to take comfort in. To help us is not only to give us the tools to grasp the world better, but also to understand how our strengths and gifts can benefit mankind in general. That is often the forgotten part.

We may think that groups devoted to quick fixes are helping us, but whose interests do they really represent? Do they represent us aspy folk who want to fit in? Or do they represent the needs of a select few fundamentalist neurotypicals, uncomfortable with our tics and unusual behavior patterns, who try and make us believe we want to be cured? It comes with the latent prospect of joining the ranks of the overrated normalcy, but at the same time, may also destroy some more than latent advantages which could be a strong force for good if utilized wisely.

TO DISCLOSE, OR NOT TO DISCLOSE

by Corinne Graham

Throughout the abundant literature on Asperger's and employment runs a consistent thread, like an indelible truth: it's usually best for individuals with Asperger's to disclose- or have an advocate disclose- their disability. In her book *How To Find Work That Works for People with Asperger Syndrome*, author Gail Hawkins suggests that "By law, no one is obligated to disclose that they have a disability; however, it is a great advantage to do so" (p. 257). She adds that it's best to bring up the diagnosis during the actual job search process, as opposed to later on, once one is hired.

While it's tempting to yield to her logic that many employers are compassionate people or have pro-disability hiring protocols, this could merely be

by Allistair Fraser

A few months back, a little girl was born in Bangalore with several extra limbs. Doctors chose to cut off those limbs so that she wouldn't be perceived as a "freak". But was that really such a good idea? If those limbs proved to be more than vestigial (which they probably were), this girl would have some definite advantages. For all those times we wished we had an extra set of hands or legs, this girl had them – and this could certainly make short order of many tasks that require more than two hands. We aspy folk have something extra, too, in the form of brain cells, memory and thinking power. It doesn't make us an obvious freak, but I still think we'd be disadvantaged if a group such as Defeat Autism Now cuts it off. There has always been some autism in the great thinkers and minds of the past – maybe what these "cure" groups fail to realize is that they risk destroying the next generation of these great thinkers. Autism has a purpose – it is god's "special assignment" where we are capable of thinking of the idea and we are the backbone of all intellect, and all the great leaders may need somebody to solve their deeper problems and invent the devices to solve it. That's what autistics are good for! ■

utopian thinking on Hawkins' part. It's hard to find an Aspie who hasn't been taunted, rejected or otherwise singled out for their neurological differences. To presume that the folks who do hiring within competitive businesses are exempt from participation in this very prevalent behaviour is perhaps giving them too much credit, in advance of knowing where they truly stand on the subject of Asperger's. Perhaps the best place to find out their opinion on that topic isn't in the midst of one's job interview!

It would be a wonderful thing if all employers could consider every type of disability in the same accommodating light. But it's prudent to consider

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WILD ABOUT ARI

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autistic man, Nate Tseglin, back to his parents after having been taken from them by Child Protection Services, but he has been particularly busy in the last two weeks. He appeared June 11th on “Meet the Peetes” on the Oprah and Friends channel on XM Satellite Radio; was interviewed by National Public Radio (available online at <http://www.npr.org/templates/story/story.php?storyId=91054523>); and made a televised appearance on ABC’s “Good Morning America” to explain the concept of neurodiversity.

Mr. Ne’eman and ASAN entered national consciousness when New York University’s Child Study Centre put out advertisements in the form of ransom notes on December 5th last year, which said to the effect that “We have taken your children and robbed them of their social skills and condemned them to a life of isolation” and signed them “Autism” and “Asperger’s Syndrome” and they had a similar ransom note for children and youth with Attention Deficit Hyperactivity Disorder, depression, and bulimia. To Mr. Ne’eman, this illustrated some stigma building against people with mental disabilities, such as the belief that they are a detriment to themselves and everyone around them, that they would never be able to look after themselves and end up institutionalized, and would become self-fulfilling prophecies if they were left unopposed. Two days later, he decided to counter this by starting a petition and a

letter-writing campaign condemning the “Ransom Note” ads and enlisted the help of other disability rights groups.

Mr. Ne’eman’s initiative was a tremendous success, he had NYU Child Study Center withdraw the “Ransom Note” campaign two weeks later and made a name for himself in the realm of disability rights. He is either loved or hated, depending which side of the neurodiversity debate that you are on. Whether you are pro-cure or anti-cure, pro-mercury or anti-mercury, he and ASAN are becoming more widely known and he is helping people on the autism spectrum to speak for themselves in the face of people who would just have us shut up and be made “normal”. Lastly, he asks in his essay “Difference is Not a Disease” which was published in “The Jewish Week” in March of last year, he asks rhetorically if respecting the other is not part of American and Jewish traditions? I would like to think that most Canadians are not alien to that concept ourselves, but it is the sincere hope of people like Ari Ne’eman that we can at the very least be heard and included in decisions that affect the lives of people on the autism spectrum, and that we are not all summarily dismissed as irrelevant or deranged.

You could say that he has accomplished quite a bit despite being only twenty years, yet he is taking on more tasks and issues all the time. Stay tuned, there’s more to come.

OUR WORLD

by Allistair Fraser

It has been said that we aspy folk live in a fantasy world. Somehow, our special needs have left us with little grasp of how the real world functions, and I know that sometimes, intelligent as I may be, I do not understand the point of having such a negative view of reality, why we must assume the whole world is out to get us or wants to gain something personal by feigning old fashioned values like caring, trustworthiness or altruism. We learn that if it doesn’t gain anything for us, then it’s simply not worth doing it. But I find that we aspy folk

live in a world where we like to believe these values still exist and it is something about our world that we are more than happy to share with neurotypical society. This is one of the best things about our world, and I can only hope that by sharing an example of what people can be, people will also see the value of such random acts of kindness in which you hope to gain nothing other than feeling good for doing it. And that is a feeling which is often underrated for sure, but you do feel good af-

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TO DISCLOSE, OR NOT TO DISCLOSE

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these questions: is Asperger's the kind of condition likely to elicit a warm and fuzzy burst of compassion in a stranger? Or could it be that for many business owners, Asperger's will only be an ominous question mark, perhaps used to silently discriminate against the job candidate?

Asperger's syndrome sounds, to the uninitiated, like a mental illness. Mental illness still carries a heavy stigma in the workplace, unlike most forms of physical disability. It appears more likely the average work site can accommodate a wheelchair or seeing eye dog than some of the more difficult requests equated with mentally ill staff, such as tolerance for emotional outbursts, extended absences, extreme lethargy, etc. If one wishes to disclose Asperger's status to a person in charge of hiring, it seems wise to differentiate the syndrome from psychiatric illnesses, in order to avoid being "tarred with the same brush". Yet this also seems like a potentially dangerous route, as what was meant to be a job interview about one's skills and qualifications turns into an explication of Asperger's and/or a session on why an Aspie often is a diligent, committed and talented worker. The focus drifts from the applicant to the diagnosis, and there's no telling if or when it will return to the applicant. There are, no doubt, people in hiring positions within companies who can and will be won over by one's revelation of having Asperger's. Hawkins has made it her specialty to cultivate and locate such individuals, and arrange for them to meet with job applicants who have Asperger's.

FINDING OUR OWN ANSWERS

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have always longed to meet with people who seem to think, act, and feel the same or at least similarly as I do. It has always been my opinion that 'two autistic heads are better than one', and one thing that I keep reading about is how much technology, particularly computers and the Internet, are enabling people on the autism spectrum to express themselves and communicate with others like themselves. Of course you have local groups like those we host here at the Provincial Autism Cen-

Her book indicates she's been very successful at this. But it's striking that the majority of case study examples mentioned in *How to Find Work...* deal with low-wage, entry level jobs- which are already a veritable Asperger's employment ghetto! If one plans on competing for high-skill, well-paid positions, disclosing any area of vulnerability may not be advisable. Dr. Tony Attwood writes, in his essay "Diagnosis in Adults" (in the *Coming Out Asperger* compilation), "If there is considerable competition for a particular vacancy, then an applicant having a diagnosis that is unknown to the employer might lead to the application being rejected" (p. 51). He continues that it might be a good idea to provide a one-page description of Asperger's, but it's unclear whether he is suggesting that it be presented during the interview, in advance, or after being hired.

Hawkins' best argument for disclosure is that one's Asperger's characteristics will flare up soon enough once one is hired, so it's best to "out" oneself pre-emptively. A better practice might just involve keeping one's diagnosis—and all the baggage it can carry—to oneself, and sticking to jobs in areas where one's brilliance shines through. Hawkins makes a compelling case for bringing job coaches into the workplace to assist the Aspie, but perhaps that Aspie wouldn't need such an accommodation were s/he to be working in his or her area of skill, and not forced into those abundant customer service and menial labour positions for which many with the diagnosis are ill-suited in the first place. It's certainly something to think about.

tre, and national group meetings like Autreat.

On the more serious side, do you not feel insulted when you see autism and autistic people portrayed in the worst possible way, even by people who are 'well-meaning'? If so, then what can you do? How do you get your question or message out there? As I was just talking about, we can broadcast what we want to say on the Internet (and on a side note, Autism Online is finally getting under-

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FINDING OUR OWN ANSWERS

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way at the Autism Centre), but what do we do when the people who are supposed to be representing us are the ones bringing us down, and never letting us have a serious say in things? Here's the answer, we start our own advocacy group! There is an Autism Self-Advocacy Network in the United States that is starting to make a splash on legal and journalistic issues, and the good people here at the Autism Centre have already helped us to start up and host our own chapter. We are also in the process of becoming formally affiliating with them through the main ASAN website at www.autisticadvocacy.org.

This group is open to anyone who self identifies with Autism Spectrum Disorder (ASD) and the purpose of it is to provide a dissenting voice to the way that we are portrayed by many charities and organizations to mass media. Perhaps we have trouble viewing our individual selves, and that is symptomatic of autism, but as a community, we could change at least that aspect of ourselves. One of the reasons that people have friends is to provide a sort of mirror for themselves, so they can see themselves better the way other people see them and to provide differing perspectives. The point is not to stop being autistic, we would still be autistic, but it would make us more whole, individually and collectively. We could disagree and argue with each other, and learn to better accept other people's perspectives.

A LETTER TO THE EDITOR

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all, Matt Savage and his audiences enjoy the results of his auditory integration therapy.

Autism also gives the person a wonderfully, if somewhat quirky, different view of the world. I have long come to realize that my son's autism is as much a part of him as the other aspects of his personality, and comes with some challenges but

The main point here is that, as a community, we can forge our own identity, and not let others who do not really understand us to define us, because that just creates a largely inaccurate, dark, and scary picture. We should also be able to show the good side of ourselves, and refuse to allow others to portray us in blatantly offensive ways without having our own say. This is what communities do, we stick together. This is why people get together anyway, to challenge those who would do us harm and to support one another. Our new advocacy group will get involved in anything involving autistic people that we see as unjust, and may just help you one day if you have been treated unfairly.

In the course of a month since I started writing this piece, I have been 'up' and 'down'. Now I am full of hope. Autism self-advocacy groups are starting up in the United States, and right here in Halifax. We are in the public consciousness like never before, but that trend will not last. Our time is now, it will not happen unless you take the initiative, to find our own voice, to take charge of our lives, and to make people listen to us, even if they do not want to hear. We have plenty to talk about, and it is time to make our own impression in the world as an autistic community. For more information on how to join ASAN-NS please email me at dannymelvin@autismcentre.ns.ca.

many benefits. I remain convinced that autistic teenagers can be much more fun than tippie teens. A cure for autism? No way! I love my son just as he is, enjoy his world view and wouldn't change a bit of it. On the other hand the more typical teenage stuff - - - Thank you for another, thought provoking, edition of Autistics Aloud,

Pippa Moss

ALLI THE ASPY



SO I OFTEN PONDER "WELL, WHAT IS NORMAL?" AND WHAT'S SO SPECIAL ABOUT IT?

... AND I LOOK AROUND, BUT SOME THINGS JUST DON'T MAKE ANY SENSE



YUP, IT'S TRUE... NORMAL PEOPLE SCARE ME

SOMEHOW, I'D RATHER BE AN ASPY THAT PEOPLE DON'T KNOW, THAN BE KNOWN AS ANYTHING BAD

About this newsletter

Autistics Aloud is a forum for people on the autism spectrum to express their opinions and their talents. It will be published four times a year and any letters, submissions, or ideas should be addressed to:

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“Support Means Success”

**OUR WORLD**

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ter being good.

There will come a time in your life when you will need help. In your great hour of need, you expect people to help you, but if you have never cared about anybody, then why should they help you? People will remember your actions, good, bad or neutral, and these actions become part of your character. Sometimes, it's not apparent at first, but the way people remember your actions is of greater concern than any personal or material reward you may get from doing these things. I like to think that despite the façade sometimes, we aspy folk really do care, if only based on this concept that we would treat others in a way that, in our fantasy world, humans are supposed to act. We aspy folk might live in a fantasy world, but at the end of the day, is that really such a bad thing?

In high school, I recall sending my worst enemy a teddy bear. This was not a peace offering, nor was it me trying to buy a truce. It was me recognizing that there was no purpose, in my mind, to being an enemy and that I did not want to continue this needless dispute. There were bigger things to worry about, and that we are both human beings. She may have come from a foreign land, but we were still both human and had the very same needs and wants, and that perhaps something higher seems to think that there is no point in human beings in general fighting. As an aspy, I saw the end of the dispute occurring with somebody making a move towards peace; no authority figures could ever hope to settle it by choosing sides. I knew the first step was for one side, namely me, to stop retaliating and to not hold a grudge. If you are still out there, (you know who you are, ed.), here is a hug from me. ■

Upcoming Events/ Programs at the Provincial Autism Centre**Autistic Self-Advocacy Network—Nova Scotia**

Advocacy for people on the autism spectrum by people on the autism spectrum. Contact editor for information on how to join.

Social Groups

Adult and Teen Social Groups. Call PAC for more information.

Online Social Groups

Quicktopic.com boards for adults and teens. Autism Online should be up any day after numerous delays. Call or e-mail PAC for details

Library Services

A comprehensive collection of reading materials for loan.