

Written Public Comments

**IACC Full Committee
Meeting**

January 16, 2019

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Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Whitney Ellenby

January 16, 2019

Hey friends! Please check out my op-ed published today in ***The Washington Post***, comments rising. Always interesting to see how offended people are about opportunities which in no way eclipse their own rights but expand for others who don't have them.

https://www.washingtonpost.com/opinions/my-son-has-autism-he-deserves-separate-sensory-friendly-opportunities/2018/11/27/b1268848-a0a4-11e8-8e87-c869fe70a721_story.html?utm_term=.6eba8e601eed

Warmly,

Whitney Ellenby

Author, ***Autism Uncensored: Pulling Back the Curtain (2018)***

[PII redacted]

James Kilpatrick

January 16, 2019

<http://www.educationviews.org/correcting-federal-neglect-of-the-autism-epidemic/>

Robert Johnson

January 16, 2019

Hey,

I'm Robert Johnson, a founder of a blog dedicated to woodworking and everything about it, called Sawinery.net.

We have explored different aspects of woodworking, and recently, we got interested in getting to know extraordinary woodworkers. Some of them include those suffering from PTSD who use woodworking as a form of therapy to overcome the symptoms of their condition.

Another great angle we've discovered is that woodworking can be done by people with autism, too. Our interest in exploring further about Autism and woodworking actually brought us to your website.

An amazing story we found was that of Gregory Chabolla. He was diagnosed with PDD-NOS back when he was a toddler. His mother was even told that he might never speak, write, learn, and even feed himself because of his condition.

However, Gregory fought against the odds of his autism and now, he even has his very own woodworking business.

We knew we had to publish Gregory's wonderful story, so we interviewed him and his mom and came up with an article:

<https://www.sawinery.net/blog/gregory-chabolla-story-from-spectrum-to-woodworking-business/>

Knowing more about Gregory's life story gave us an insight of the power of woodworking, as well as the ability of people to move past their autism diagnosis.

We're interested to know your thoughts about it, too. Waiting to hear from you.

Thanks, Robert

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Eileen Nicole Simon, Ph.D., R.N.

January 16, 2019

[PII redacted]

1. Research Plan

Dr. Gordon, thank you for suggesting my requests to discuss auditory system impairment should be submitted as a grant application! I am in the process of looking for a sponsor at UMass Boston, where I am currently enrolled in the Addictions Counselor Education Program (ACEP).

In brief, I want to: (1) look at postmortem sections from the inferior colliculi in brains of autistic people. Abnormalities in the superior olivary complex have already been reported by Lukose et al. [1]. Also (2) look for abnormalities using fMRI. High blood flow in the inferior colliculi is clearly visible in fMRI scans [2].

In the 1950s Seymour Kety used autoradiography to measure cerebral blood flow. He found the highest blood flow in the brain is to the inferior colliculi [3]. Audiologist Ladislav Fisch pointed out that this might have been expected, because the auditory system is constantly active, even during sleep [4].

Wernicke's encephalopathy (WE) was described in 1881 in two men who died from chronic alcohol use, and in a woman who attempted suicide by drinking sulphuric acid [5]. Damage of the inferior colliculi in WE was reported in many papers written in German. Neuburger brought attention to WE brain injury caused by circulatory arrest [6]. In monkeys subjected to asphyxia at birth, the most prominent damage was found in the inferior colliculi [7].

Inferior colliculus damage is also prominent in cases of vitamin B1 (thiamine) deficiency [8]. Vitamin B1 is an essential co-enzyme for aerobic metabolism, and was discovered during investigation of the disease beriberi [9]. Beriberi was an affliction of people who had switched from use of brown rice to refined white rice as the staple of their diet.

References:

[1] Lukose R et al. Malformation of the superior olivary complex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.

[2] Budd TW, et al.. Binaural specialisation in human auditory cortex: an fMRI investigation of interaural correlation sensitivity. Neuroimage. 2003 Nov;20(3):1783-94.

[3] Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed>

[4] Fisch L. The selective and differential vulnerability of the auditory system. In GEW Wolstenholm GEW, Knight J, eds. Sensorineural Hearing Loss: A Ciba Foundation Symposium. London: Churchill, 1970, pp110-116.

[5] Thomson AD, et al. Wernicke's encephalopathy revisited. Translation of the case history section of the original manuscript by Carl Wernicke 'Lehrbuch der Gehirnkrankheiten für Aerzte und Studierende' (1881) with a commentary. Alcohol Alcohol. 2008 Mar-Apr;43(2):174-9.

[6] Neubuerger KT. Lesions of the human brain following circulatory arrest. J Neuropathol Exp Neurol. 1954 Jan;13(1):144-60.

[7] Windle WF. [Brain damage by asphyxia at birth](#). Sci Am. 1969 Oct;221(4):76-84.

[8] Vortmeyer AO, et al. Haemorrhagic thiamine deficient encephalopathy following prolonged parenteral nutrition. J Neurol Neurosurg Psychiatry. 1992 Sep;55(9):826-9.

[9] Peters RA. The biochemical lesion in vitamin B1 deficiency. Lancet 1936 May 23; 227(5882):1161-5.

2. Early Intervention

The IACC should make language development the highest priority for proposed research and discussion. Speech therapy should be the focus of early intervention.

Delay in learning to speak is the most serious disability of children diagnosed with autism. That the language disorder is the result of a "social disorder" or lack of "shared attention" were ideas adopted in the 1980s, possibly to avoid consideration of brain damage or intellectual disability.

Aphasia is the most serious neurological affliction caused by stroke in adulthood. Language is much more than a means of communication. Language is the defining feature of the human species. We use language to formulate abstract ideas, and for imparting knowledge from one generation to the next.

Autistic children with language problems that persist into adulthood cannot be compared to those who receive an autism diagnosis later.

Please look at the book written by cochlear-implant surgeon Dana Suskind, *Thirty Million Words; Building a Child's Brain*. New York: Dutton, 2015.

3. Genetic Research

Language is unique to the human species. Norman Geschwind described connections within the human cortex that likely make language possible [1, 2]. These connections extend the signal processing capabilities of lower species.

What human genes make language possible? What stages of gene to connections within the human cortex take place? What are the steps of gene to peptide transcription, protein and enzyme assembly, and to formation of neurons? What guides growth of connections within the cerebral cortex that are only found in humans?

Loss of language, aphasia, is the most serious of all neurological disorders. Might it be possible to re-initiate development of brain structures and connections to re-establish language?

What brain structures or circuits are missing or damaged in children who fail to develop full language capacity? I suggested long ago that echolalic speech might reflect failure to detect stressed syllables [3].

My ideas were based on research by Roger Brown and Ursula Bellugi [4, 5]. Roger Brown later worked with my son Conrad, and provided even greater insight on echolalic speech [6].

Hearing syllable and word boundaries is an essential function of auditory signal processing. What about the child who never utters an intelligible word? Has Broca's speech area failed to develop during growth of the frontal lobes? What differences can be found in development of left and right sides of the human brain?

The autism triad (disorders of language, movement, and awareness) are neurologic problems. All are caused by injury during perinatal development. Genetic researchers should work toward understanding the stages of brain development. And also, why does repair not take place following injury of central nervous system components?

References:

- [1] Geschwind N. Disconnexion syndromes in animals and man. I. Brain. 1965 Jun;88(2):237-94.
- [2] Geschwind N. Disconnexion syndromes in animals and man. II. Brain. 1965 Sep;88(3):585-644.
- [3] Simon N. Echolalic speech in childhood autism. Consideration of possible underlying loci of brain damage. *Arch Gen Psychiatry*. 1975 Nov;32(11):1439-46.
- [4] Brown R, Bellugi U. Three processes in the child's acquisition of syntax. *Harvard Educational Review*. 1964; 34:133-151.
- [5] Brown R. *A First Language: The Early Stages*. Cambridge, MA: Harvard University Press, 1973.
- [6] Brown R. A collection of words and sentences, an autistic child. In R Brown RJ Herrnstein, *Psychology* (pp. 444-449). Boston: Little, Brown and Company, 1995.

In Massachusetts group-home staff are trained in "trauma-informed care," which is one more failing of the misguided community mental health system here. Following is something I wrote for a memoir writing group I attend. More about my son's death is recorded in the website I setup in his memory, conradsimon.org.

The IACC meeting on January 16 will also be the anniversary of the death of my son Conrad. Please understand that I will be at this meeting with a heavy heart

Season of Sorrow

I was banned from Conrad's group home in 1994. I was told staff had learned from a "facilitated communicator" all about the sexual and physical abuse I had inflicted on my son. A young staff woman at Conrad's house informed me this was likely the cause of his autism. Wrong! What an outrage, and how hurtful to be accused of such crimes!

Conrad would be 31 years old in December. He was tall and strong. The staff were all several years younger. To them he was often very scary.

The last time I saw Conrad was Halloween afternoon. This was his favorite holiday. I brought him a bag of candy. Suddenly a staff person started shouting at me.

"Out! Get away from this house! You were told you are not allowed here!"

Conrad was standing on the porch. He was wearing the purple ghost costume he had made himself.

"I love you Mom," he called out to me.

Those were the last words he said to me.

I called the house early in December.

"Can I come over to bring gifts for Conrad's birthday and Christmas?" I asked.

"You cannot come while Conrad is here," I was sternly told.

I was told not to come after three o'clock. That would be when Conrad returned from his day program.

I brought the gifts during my lunch hour from Meditech, about 25 miles away. I handed them to a scowling staff woman, then left immediately to get back to my desk by one o'clock.

On January 17 I had just arrived at work when my phone rang.

"Conrad is dead," my husband told me.

Conrad's brother Matthew had received the call from the medical examiner.

The shock of this memory hits me every Halloween.

My mother died unexpectedly on Christmas day in 1994. Conrad's death was three weeks and a day later. It was barely a week after my return from Denver, to help clean out my mother's apartment.

The group-home staff arrived grieving, and all dressed up, at the memorial service for Conrad. Near the end of the service a young woman stood up.

"Our Father, who art in heaven," she called out.

She and Conrad attended the same day-program for many years. I still hear her sweet voice whenever this prayer is said.

"Your mother took him," some of her friends told me; and I cling to this hope.

But November, December, and January remain my season of sorrow.

My statement and public request of the IACC board is once again, being repeated to address my previous letters from the last ~~FOUR FIVE~~ SIX meetings (that have STILL gone unaddressed).

I have a ~~6-½~~ 7-½ year old moderate / severe ASD son with tics and PANs who has a heavy metal toxic burden (Aluminum).

1.) IACC should speak with / survey parents more and focus research on their feedback. There is truth in the herd.

I request that the IACC facilitates a survey the parents of ASD children in the United States. I request that this survey is over 50 but under 100 questions pertaining an ASD child and overseen and co-managed by a third party foundation, or organization for Autism that is recommended and voted on by the public. I request that the IACC proposes and allocates funding for this study in the fiscal year of 2016-2018 to be published no later than the ~~spring of 2017~~ winter of 2018-2019.

Over the past ~~28 40~~ 60 months since my son's official diagnosis we have invested all our free time, over \$230,000 out of pocket on ABA, OT, Speech, accessories, learning aids, medical tests and vitamins. In addition to 28-32 hours a week of ABA in-home he is also attending a special education class 5 days a week, 4 hours a day. We've done the EEG's, 4 rounds now of different gene testing as well and completed a MicroArray in May of 2017.

23 months ago we finally gave in and had allergies, hair, stool and urine tested? My son is allergic to many items. He's off the charts in aluminum, copper, lithium, rubidium and cesium. Then he was diagnosed with PANs and had a scare of Lyme as well.

We immediately started natural chelation with nutrients. We went GF/CF/SF and eliminated all sugars. We went 100% organic and juice every day. All chicken is free-range, antibiotic free and expensive. All beef is grass fed, non-GMO. Every bit of food that enters his body is known to the source and purity, at the best of our ability.

Results::

- any gluten, any sugar causes extreme aggression and yeast flare
- any "normal" produce produces foul stool, changes behavior and increases stims

Also learned:

Our road has many miles to travel, but I've covered more ground with natural healing than I did with any Dr's 7 minute consultation or prescription recommendation (what ~~the hell~~ is Marinol anyways and why would my child be prescribed this and not natural cannabis oil?) I'm not the only one. My path was paved by many, walked by thousands and is continuously modified with new tests, strategies and nutrients.

Parents live autism. They see changes that are microscopic. They notice what causes changes. They talk to one-another and compare notes. Compare Dr's. Compare protocols. Compare results.

2.) Glyphosate. What are the affects on the human brain and gut microbiome? What are the affects on the human ASD brain and gut microbiome? Are there correlations, that have been studied between Glyphosate exposure and Autism Spectrum Disorders?

Why would a ~~5-½-6-½~~ 7-½ year old child on the spectrum who was breast fed for two years and ate a natural, healthy diet have over 3x the normal levels of Glyphosate in his blood? We do not live near a farm, he does not work in produce, nor any processing plant.

Can the IACC to investigate how Glyphosate is affecting children with ASD vs. Non-ASD in the fiscal year of ~~2016~~, now ~~2017-2018-2019~~?

3.) The IACC makes a formal request to Congress to subpoena Dr. William Thompson at the CDC.

Since his admission of falsifying tests, at the request of his superiors on how children receiving the MMR vaccine before 36 months were 340% more likely to receive an autism diagnosis or develop tics. Dr. Thompson made admissions to Biochemical Engineer Brian Hooker in a series of phone calls and not only gave specifics on how to obtain the correct data but also expressed remorse in his cover-up.

I ask: why hasn't the IACC been concerned with this information? Why hasn't the IACC even asked for clarification from the CDC and response been made public?

I request that the IACC makes a public, formal request to Congress to subpoena Dr. William Thompson of the CDC.

I request that the IACC makes a public, formal request to Nancy Messonnier, MD at the CDC for a full debriefing of the study to be included in the next IACC Summary of Advances in Autism Spectrum Disorder Research: Calendar Year ~~2016-2017~~-2018 that Dr. Thompson authored and the allegations of the link between autism and the MMR.

I request that the IACC demand retraction of published study (PubMed 2004 Feb;113(2):259-66.) at the AAP of the MMR/Autism paper co-authored by Dr. DeStefano and Dr. Thompson.

When will any of my requests be addressed or answered after six separate requests? Why are these logical, repetitive requests ignored?

Note: Profanity and derogatory language have been redacted in this document

John Best

January 16, 2019

Dear [derogatory language redacted], You [profanity redacted] have been lying about autism ever since this dishonest committee was formed. We know that mercury is the cause but you [derogatory language redacted] have always refused to acknowledge that fact. So, as always, I comment to let you know that you should [profanity redacted].

Note: Profanity and derogatory language have been redacted in this document

Benedetta Stilwell

January 16, 2019

Hi;

I have watched this panel of experts for years.

I see that they have no intention of stopping the rising numbers of other children joining the ranks of my family with brain injuries. Yes, I am talking vaccines. Ok, so they don't care about stopping it. I get it.

I doubt if the panel of experts really are aware of just who they are discussing? I thought I would at least write about how it is going here.

My son is now 32.

My son has mild autism. We have spent a lot of money on his continual education. Not just language and social skills, but for training to make him an attractive employee. He has a degree from Somerset Community college in electronics, electrical construction, even a few law enforcement classes (we thought security guard positions at local hospital might be an option), computer science for a semester (did not do well), now my husband has gone with my son, and they are both working on a degree for heating and air.

Communication will always be a problem for my son. Always. That quiet type turned out to be a problem in modern day society.

My son's first job that he landed for a month was with Pittsburg Glass Company; they make windshields for automobiles. My son was exceedingly happy to work for them. The main problem was his feet. He has flat feet and standing on concrete in steel toed shoes became almost impossibly painful. We used expensive inserts to keep him going, and soaked his feet every evening. These types of brain injuries begin with toe walking as babies and then the hypo muscle thing; low muscle tone sets in, and they get flat feet. Very painful for factory work. Might want to address that in your upcoming meeting.

The Pittsburg Glass Company had received a large order and they needed people to help them fill this order quick. They had no intention of keeping these workers. They were rather rude about letting my son go at the end. He, and the rest that were temps swept up on their last day, and were called on the phone the next day to not just say that we no longer needed him, but to criticize him like he was not good enough. My son was able to do this job and was willing and able. They needed him again before the year was out, and I told him to never mind. There will come a day perhaps when labor is accommodated? I hope so. IACC might need to do some GOD work and work with human resources about being human. Is that possible?

My son's next job was with Quality Assurance. They were a great company to work for. Decent to him and he got along well. He did various steps toward taking veterans' medical records, and turning them into digital computer records. He worked three years with them. Quality Assurance lost their contract with the veterans, and left. My son was laid off. 14 dollars an hour job. He purchased his own health insurance. [Profanity redacted] stuff.

My son worked for a month after that with the Rural Transport System in our town. He was hired as a dispatcher. HE had to learn to do every one's job. Three weeks in, all was going pretty good, until he went

in for his physical. Apparently he had to have a CDL. Which he maybe able to have? He has not had a seizure in over 12 years. However; once upon a time he had some seizures, and he is still on seizure medicines. People all think you can never have a CDL if you have ever had a seizure, or epilepsy. According to the information I got from our state; my son could hold a CDL. We will never know though cause, well everyone thinks they know the rules, and there is no discussion on the matter.

My son next worked for Source Hov. They did the same thing as Quality Assurance, turning veterans medical records on paper into digital. My son was very well aware of this company since Source Hov, and Quality Assurance did share the same building. He was not pleased to be working for them since they had the reputation of being very abusive to their workers. Yeah, locally we all know it is a sweat shop, and not like Quality Assurance that had a heart. My son worked over time: long hours, and every weekend that first year, as Source Hov tried to catch upon this very large contract. At the end of the year, we decided that instead of taking out individual health insurance, that he would take the company's instead. We found that it would cost the same, but they might cover "something" every once in a while which private health insurance does not, did not and never will. Our son came home all upset when we did, telling us that every one working at Source Hov told him that the company's health insurance was too high. That was another communication problem it turns out. Cause what they meant is that Source Hov terminated the employees that took the company's insurance. The end of January; the first month he had the health insurance, they called him in, and said he was not keeping up with his quota. Really, for a year of over time? Something that cannot be proven one way, or the other; except their word. 14 dollar an hour job all gone. Not hardly a job that he could have made a living on. Not that he will ever have a family to support. Good job in reducing the population, keep discussing useless bunch of [profanity redacted].

My son next worked for Southern States loading animal feed, fencing, caring for spring chickens, and helping customers. He liked that job, and they really liked him. But it was seasonal work.

So, back at school for heating and air, along with my husband too. My retired husband that majored in chemistry years ago, had a career in polymer chemistry, senior researcher for Dow Chemical. My husband that has an acquired mitochondrial problem from a DPT vaccine that he received at work, that they said was just a tetanus vaccine. My husband that went all the way down to Emory Clinic for a muscle biopsy after developing problems from that simple tetanus shot many years ago.

Anyway; wish us luck that Heating and Air will get my son ahead, because this is the route we are taking cause our autism is mild.

You got any other suggestions?

Hi anonymous representative of the IACC,

My son developed normally for the first two years of his life. Then he lost language, his ability to play and facial expressiveness. What you call ASD looks a-hellava lot like brain damage to observers of my son. The age of ASD diagnosis has not decreased in the last two decades. **When will the IACC publish a panel of biomarkers that discriminate newborns at risk for ASD?**

Has the IACC called upon DOJ and HHS to investigate alleged fraud and obstruction of justice by DOJ lawyers in the Omnibus Autism Proceeding? In 2008 Department of Justice attorneys Vincent Matanoski and Lynn Ricciardella used expert witness testimony from Dr. Zimmerman of the Kennedy Krieger Institute to award \$20 million to his friend and colleague Dr. Polling (for daughter Hannah's vaccine induced autism). The body chemistry of autistic children throughout this country are not different from Dr. Polling's daughter. Dr. Zimmerman's conflicting/outdated testimony was used in subsequent cases and at the Supreme Court - *Bruesewitz v Wyeth LLC*. Since that ruling, children diagnosed with autism have been denied a trial by jury, which is a constitutional right for everyone else in this country.

ASIA – or Autoimmune/inflammatory Syndrome Induced by Adjuvants (also known as Shoenfeld's syndrome) -- first appeared in the **Journal of Autoimmunology** four years ago. It is a collection of symptoms that result after exposure to “adjuvants” (metals) designed to stimulate the immune system. For over four decades research has shown environmental toxins, particularly the metals used in vaccines, can trigger an immune system chain reaction in susceptible individuals and lead to autoimmune disease. (for example my son has antibodies to dopamine receptors).

Please, **INSTITUTE POLICIES AND RESEARCH AGENDAS THROUGHOUT HHS BASED ON THE FOLLOWING CONCLUSIONS**

Associations of prenatal and early childhood mercury exposure with autistic behaviors at 5 years of age: The Mothers and Children's Environmental Health (MOCEH) study *Science of The Total Environment* Volumes 605–606, 15 December 2017, Pages 251-257 Conclusion: We found that blood mercury levels at late pregnancy and early childhood were associated with more autistic behaviors in children at 5 years of age. Further study on the long-term effects of mercury exposure is recommended.

The association between mercury levels and autism spectrum disorders: A systematic review and meta-analysis *Journal of Trace Elements in Medicine and Biology* Volume 44, December 2017, Pages 289-297 Conclusion: Results of the current meta-analysis revealed that mercury is an important causal factor in the etiology of ASD. It seems that the detoxification and excretory mechanisms are impaired in ASD patients which lead to accumulation of mercury in the body. Future additional studies on mercury levels in different tissues of ASD patients should be undertaken.

The Putative Role of Environmental Mercury in the Pathogenesis and Pathophysiology of Autism Spectrum Disorders and Subtypes *Molecular Neurobiology*, First Online: 22 July 2017 G. Conclusion: On the basis of these results, we would argue that more clinically relevant research is required to examine whether environmental mercury is associated with ASD or subtypes.

Blood Mercury, Arsenic, Cadmium, and Lead in Children with Autism Spectrum Disorder. *Biol Trace Elem Res.* 2017 May 8. doi: 10.1007/s12011-017-1002-6. Conclusion: The results of this study are consistent with numerous previous studies, supporting an important role for heavy metal exposure, particularly

mercury, in the etiology of ASD. It is desirable to continue future research into the relationship between ASD and heavy metal exposure.

Protective role of alpha-lipoic acid in impairments of social and stereotyped behaviors induced by early postnatal administration of thimerosal in male rat. *Neurotoxicol Teratol.* 2018 Feb 23. pii: S0892-0362(17)30086-7. doi: 10.1016/j.ntt.2018.02.002. Conclusion: the results of this preclinical study, consistent with previous studies on mice and rats, reveals that neonatal dose-dependent exposure to Thimerosal mimicking the childhood vaccine schedule can induce abnormal social interactions and stereotyped behaviors similar to those observed in neurodevelopmental disorders such as autism, and, for the first time, revealed that these abnormalities may be ameliorated by ALA. This indicates that ALA may protect against mercurial-induced abnormal behaviors.

The putative role of environmental aluminium in the development of chronic neuropathology in adults and children. How strong is the evidence and what could be the mechanisms involved? *Metabolic Brain Disease*, October 2017, Volume 32, Issue 5, pp 1335–1355 Conclusion: There are several mechanisms whereby significant quantities of aluminium introduced via immunisation could produce chronic neuropathology in genetically susceptible children. Accordingly, it is recommended that the use of aluminium salts in immunisations should be discontinued and that adults should take steps to minimise their exposure to environmental aluminium.

Clinical clues for autoimmunity and neuroinflammation in patients with autistic regression. *Dev Med Child Neurol.* 2017 Apr 6. doi: 10.1111/dmcn.13432. Conclusion: Our findings suggest that predisposition to autoimmunity, and immune/inflammatory activation, may be associated with autistic regression.

Alkyl Mercury-Induced Toxicity: Multiple Mechanisms of Action. *Rev Environ Contam Toxicol.* 2017;240:105-149. Conclusion: There are many commonalities/similarities in the mechanisms of toxic action of methylmercury and ethylmercury (from thimerosal)... Evidence for the similarity of the various mechanisms of toxicity include the following: • Both MeHg and EtHg bind to the amino acid cysteine (Clarkson 1995; Wu et al. 2008)... • Both decrease glutathione activity, thus providing less protection from the oxidative stress caused by MeHg and EtHg (Carocci et al. 2014; Ndountse and Chan (2008); Choi et al. 1996; Franco et al. 2006; Mori et al. 2007; Muller et al. 2001; Ndountse and Chan 2008; Wu et al. 2008)... • Both disrupt glutamate homeostasis (Farina et al. 2003a, b; Manfroi et al. 2004; Mutkus et al. 2005; Yin et al. 2007). • Both cause oxidative stress/creation of ROS (Dreiem and Seegal 2007; Garg and Chang 2006; Myhre et al. 2003; Sharpe et al. 2012; Yin et al. 2007). • Both cause effects on receptor binding/neurotransmitter release involving one or more transmitters (Basu et al. 2008; Coccini et al. 2000; Cooper et al. 2003; Fonfria et al. 2001; Ida-Eto et al. 2011; Ndountse and Chan 2008; Yuan and Atchison 2003). • Both cause DNA damage or impair DNA synthesis (Burke et al. 2006; Sharpe et al. 2012; Wu et al. 2008).

Aluminium in brain tissue in autism *Journal of Trace Elements in Medicine and Biology* 26 November 2017 Conclusion: While aluminium was imaged associated with neurones it appeared to be present intracellularly in microglia-like cells and other inflammatory non-neuronal cells in the meninges, vasculature, grey and white matter. The pre-eminence of intracellular aluminium associated with non-neuronal cells was a standout observation in autism brain tissue and may offer clues as to both the origin of the brain aluminium as well as a putative role in autism spectrum disorder.

Slow CCL2-dependent translocation of biopersistent particles from muscle to brain *BMC Medicine* 2013, 11:99 doi:10.1186/1741-7015-11-99, 4 April 2013 Conclusion: Nanomaterials can be transported by monocyte-lineage cells to DLNs, blood and spleen, and, similarly to HIV, may use CCL2-dependent

mechanisms to penetrate the brain. This occurs at a very low rate in normal conditions explaining good overall tolerance of alum despite its strong neurotoxic potential. However, continuously escalating doses of this poorly biodegradable adjuvant in the population may become insidiously unsafe, especially in the case of overimmunization or immature/altered blood brain barrier or high constitutive CCL-2 production. (my son got an extra vaccine that his twin did not)

Thank you,

Resa Warner

I am inspired by Big Pharma shill and vaccine inventor Dr. Paul Offit. In a 2002 interview, he even went so far as to declare that an infant's immune system is capable of responding to 10,000 vaccines at once. Now, recently uncovered video footage shows Dr. Offit admitting on tape that vaccination is a 'violent act.' In the interview, Dr. Offit states,

'Vaccinations aren't easy. This isn't an easy thing to do. We ask a lot of our citizens. To get as many as 26 inoculations in the first few years of life, and five shots at one time. It's hard to do that, especially given that vaccination is a violent act, you pin the child down, you give them this biological agent against their will. The biological agent generally isn't understood well by the parent, and to some extent not understood all that well by the physician.' [emphasis added] Interview from March 2011, the Mütter Museum of the College of Physicians of Philadelphia: <https://www.youtube.com/watch?v=MgxtTOxnFZg>

I propose that all members of the IACC receive the same treatment as our babies.

At the recommendation of vaccine expert Paul Offit, each member will receive 10,000 vaccines at once (even if against their will) while being documented by C-Span. They will be tracked for 15 days to see if they have any reactions listed on the "Table." This is the only way I would consider vaccines to be "safe and effective." If each member is not willing to do this, then I consider vaccines to be nothing more than a delivery system for biological war against our most vulnerable citizens.

REPEAL THE NATIONAL CHILDHOOD VACCINE INJURY ACT OF 1986 and the autism epidemic will disappear.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Caryn Harb

January 16, 2019

My name is Caryn Harb. My email is [PII redacted] and I can be reached at [PII redacted]. Feel free to call me because I would be happy to expound.

I am reaching out to you as the grandmother of a 15 year old boy who was diagnosed with autism before he was 2. I can only judge from the lack of action of this committee that no one is very concerned or personally impacted by autism. Ok, I get it. There are a lot of forces at work to politicize autism and the causes of the explosion in numbers. But the truth is that there has been an explosion of numbers of children diagnosed on the autism spectrum. Even though that is played down in the media, it is still a hard fact and should be a screaming headline. I am 75 and attended public schools in Miami Beach, Florida, New York City and three different schools in Beverly Hills, California. Geographically diverse, right? There were no special needs classrooms. There were no autistic kids mainstreamed in schools then because the numbers were 1 in 10,000. You can stall and you can hide, but eventually the truth will be known and you will be faulted for lack of action. The future is bleak for the victims of an **epidemic** that will shatter families, collapse social programs and lead to the death of our loved one at the hands of subpar caregivers, by wandering, drowning and crime against them because of their gentle, naive, autistic, trusting ways. Our public schools budgets are already struggling to meet the needs of special needs students. We need guarantees that Supplemental Social Security and SSDI will be there for this growing population. We need a return to group housing of multiple residents with proper safety and care and training of all staff - like Memory Care housing. A good portion of our more affected children will never be able to live in community housing or a group home because of their behaviors.

They are at RISK of assault by poorly paid caregivers. They are virtually guaranteed expulsion due to behaviors. They face restraint, seclusion, violence and rape. IACC has failed at every step of the way. **You** have failed every step of the way. If you feel angry reading a slightly hostile letter, try to imagine how our entire family feels about your lack of positive action. To be clear, family members are very angry. We are all very angry that nothing changes, nothing improves and the future is so bleak for our loved ones.

According to the NCHS in 2014, the rate was 2.24 percent for American children. The 2.24 percent number placed the autism rate at about 1-in-45 children; the 2016 figure represents an autism rate of 1-in-36 children. The prevalence rate for 2015 was 2.41 percent, or 1-in-41.5 children.

National Center for Health Statistics (NCHS) puts the rate for autism spectrum disorders (ASDs) in American children at 2.76 percent, or 1 in 36.

What are the numbers for 2017? 2018?

Consider doing the right thing.

Sincerely,
Caryn Harb

Michelle McCormick

January 16, 2019

To whom it may concern, we are desperately seeking on answers on the causes of this epidemic. We have a nephew with autism and need your support and help to find answers on causes and treatments.

Underwhelmed so far on the results and the engagement level of the committee. Let 2019 be the year you provide us with some answers!

Best,

Michelle McCormick

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Dan Fergo

January 16, 2019

Hello,

I am the father of a child on the autistic spectrum. He regressed to an Autism Spectrum Disorder (ASD) after receiving his MMR II vaccine at 15.5 months of age. We have clinical proof of a known injury due to the MMR II of pancreatitis, but did not get this until he was almost 5 years of age and outside of the National Vaccine Injury Compensation program (VICP) statute of limitations of 3 years from the administration of the vaccine. Our son lost his 7th Amendment Right to a civil trial because of the VICP and this 3 year statute of limitation.

Aside from that legal aspect of a liability-free vaccine, there is this question I have for this committee. My question is, when will there be a clinical study of this population that have been reported as regressing into an ASD versus their neuro-typical counterparts for biomarkers?

Sincerely,
Dan Fergo

[PII redacted]

Josefine Krapp

January 16, 2019

For the IACC Full Committee Meeting, Wednesday January 16, 2019

Public Comment Submission January 7, 2019

To Dr. Joshua Gordon IACC Chair and Committee Members

Comment on the usage of painful electric shocks as therapy

Dear IACC,

First, my thanks to you for your work and your efforts to make the meetings accessible for the public. Last July, the Judge Rothenberg Center received an allowance to continue the usage of painful electric shocks as therapy. The Guardian wrote about that: "But Judge Katherine Fields of the Bristol county probate and family court ruled that the state had failed to demonstrate that the procedure "does not conform to the accepted standard of care for treating individuals with intellectual and developmental disabilities"."

If this is the point, I would like to ask you to help demonstrating this. If this is not possible I would like to ask you to advocate a change of the mentioned "standard of care for treating individuals with intellectual and developmental disabilities."

Thank you for reading my comment.

Sincerely,

Josefine Krapp

University student in psychology

Dear IACC,

As I have forgotten the source for my last public comment, I wanted to mention that it is <https://abcnews.go.com/beta-story-container/Health/electric-shock-therapy-special-students-treatment-torment/story?id=56238582>, last opened at January 7, in case somebody wants to check it.

Yours Sincerely,

Josefine Krapp

To: Interagency Autism Coordinating Committee
 From: Caroline Rodgers
 Re: Urgent need to reexamine prenatal ultrasound possible autism risk factor
 Date: 1-16-2019

It is important to remember that **the autism “boom” is only 30 years old**, starting with children born in 1988-89, as determined by the National Health and Environmental Effects Research Laboratory, U.S. Environmental Protection Agency (EPA)¹. This single fact should be front and center when searching for the cause of autism. It suggests that autism is preventable and that the key risk factor is one that has been introduced within little more than one generation.

It is also important to remember that **inherited genetic changes affecting a population happen very slowly** and cannot begin to explain a neurodevelopmental disorder that has increased from 1 in 150 children born in 1992 to 1 in 59 children born in 2006.² Two papers published last month based on more recent research solidly place the prevalence rate even higher, at 1 in 40 children affected by autism^{3 4}. There is an important difference between inherited genes associated with autism and non-inherited genetic variations, such as the genetic variations that are implicated in children diagnosed on the spectrum. The question should not be just identifying which and how many such genetic variations exist but **what, in the course of pregnancy, could possibly cause the non-inherited genetic variations implicated in autism?**

For those believing that autism is the result of a complex interaction between genes and environment, let's pause to consider that the more factors involved in producing a result, the more opportunities there are for one or more factors to be absent at any one time, such that the result would not occur. **If autism were the result of a complex interaction of factors, the prevalence trajectory would look more like a volatile month in the stock market than the steady climb up a mountain it is today.**⁵

The only change in prenatal factors that has steadily increased across all industrialized nations is the expansion of ultrasound applications and scans per pregnancy. Women allow their embryos and fetuses to be scanned within weeks of conception, throughout all three trimesters, right up to the critical hours before birth, when they are continuously monitored by ultrasound fetal heart monitors. They do so because their obstetricians order it -- for myriad reasons that can be argued do not improve perinatal

¹ McDonald ME, Paul JF. Timing of Increased Autistic Disorder Cumulative Incidence. *Environ Sci Technol*. 2010 Mar 15;44(6):2112-8.

² <https://www.cdc.gov/ncbddd/autism/data.html>. Accessed 1-7-2019.

³ Xu G, Strathearn L, Liu B, O'Brien M, Kopelman TG, Zhu J, Snetelaar LG, Bao W. Prevalence and Treatment Patterns of Autism Spectrum Disorder in the United States, 2016. *JAMA Pediatr*. 2018 Dec 3. doi: 10.1001/jamapediatrics.2018.4208. [Epub ahead of print]

⁴ Kogan MD, Vladutiu CJ, Schieve LA, Ghandour RM, Blumberg SJ, Zablotsky B, Perrin JM, Shattuck P, Kuhlthau KA, Harwood RL, Lu MC. [The Prevalence of Parent-Reported Autism Spectrum Disorder Among US Children](#). *Pediatrics*. 2018 Dec;142(6). pii: e20174161. doi: 10.1542/peds.2017-4161.

⁵ For a good look at that mountain, check out the graph created by Autism Speaks from data provided by the Centers for Disease Control and Prevention (CDC): <https://www.autismspeaks.org/science-news/cdc-increases-estimate-autisms-prevalence-15-percent-1-59-children>. Accessed 1-7-2019

outcomes⁶. Some mothers even buy non-medically indicated “keepsake” ultrasound images because they believe them to be safe. What if this assumption is wrong?

One of the confounding facts to emerge from the Autism and Developmental Disabilities Monitoring (ADDM) Network, which started tracking autism in multiple communities throughout the United States in 2000, is the wide differences in geographic, racial, ethnic and socioeconomic autism prevalence. The latest ADDM figures, published last year, show that in Arkansas the autism prevalence is 1 in 77, while New Jersey’s rate is more than double that at 1 in 34⁷. **The answer may be as simple as the geographical, racial, ethnic and socioeconomic differences that determine which mothers receive early prenatal care that includes ultrasound scans.** Or it could be determined by which hospitals in the ADDM network provide continuous Doppler ultrasound fetal heart monitoring from late-stage labor to delivery, which has become increasingly routine to reduce staffing needs, among other reasons. We can’t find the answers if we aren’t asking the right questions.

Often, prenatal ultrasound does appear to be perfectly safe. Many babies who underwent one or more scans during gestation are born free of autism or other neurodevelopmental disorders that are on the rise, such as attention deficit hyperactivity disorder (ADHD), but clearly they are shrinking in number. A handful of safety studies did not find a significant correlation between prenatal ultrasound and autism, yet many well-designed studies -- including a multi-center prospective study proposed by highly respected researchers and a study that would have produced answers much more quickly by examining and comparing brain tissue of rodents exposed to prenatal ultrasound versus brain tissue that had not -- have been denied funding. Most if not all researchers in the ultrasound safety field have stopped applying for grants they know will not be funded, leaving a critical vacuum in knowledge that could have a profound impact on public health.

If prenatal ultrasound is causing neurodevelopmental disorders in an increasingly large percentage of babies, the good news is that it is preventable. What is needed is an immediate, exhaustive review of the known facts about the bio-effects of prenatal ultrasound (which are more extensive than its thermal effects). We also need to review what we have learned from mouse and non-human primate studies (especially a long-term publically-funded study conducted by eminent Yale neuroscientist Pasko Rakic that remains unpublished, years after its due date). **If prenatal ultrasound emerges as a possible risk factor, responsible medical associations and government agencies should strongly advise against its use in uncomplicated pregnancies and consider the extent to which “high risk” pregnancies – such as multiple gestations and older mothers – may actually increase the risk of bearing a child with autism due to the additional scans routinely ordered to monitor their progress.**

If we are serious about stopping the autism epidemic, due diligence requires that a task force be funded and formed to carefully reexamine the possibility that prenatal ultrasound may be a significant autism risk factor.

⁶ Cohain JS. Prenatal ultrasound does not improve perinatal outcomes. *Midwifery Today Int Midwife*. 2012 Summer;(102):46-7, 68-9.

⁷ Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018, 67 (No. SS-6): 1-23.

To: Interagency Autism Coordinating Committee
From: Caroline Rodgers
Re: My personal experience with prenatal ultrasound – and what I’ve learned since
Date: 1-16-2019

As an older mother of two children who were in gestation 26 and 23 years ago, I underwent several ultrasound scans. At the time, I assumed sonography was as harmless as photography. I did not know that the soundwaves, which were inaudible to me (although not to the fetus!), were transformed into heat when they were absorbed by tissue. If anything, the only sensation I felt was that of the cool gel that was applied to my abdomen to help the transducer glide easily. I did not imagine that the intrusion of ultrasound-related heat could tamper with the rapid development of my babies.

Since then, I have read studies regarding how critical fetal temperature regulation is to proper neurological development (1, 2). Different causes of increased maternal temperature have been associated with autism, such as:

- Fevers (1, 3)
- Infections (4)
- Fever-producing viruses (5)
- Drugs that disrupt the thermoregulatory system (6,7)

Scientists have long known that elevations in maternal temperature can have serious fetal consequences. Heat is a known teratogen – that is, it is known to cause birth defects. But a birth defect must, by definition, be visible at birth. Outcomes such as autism only become apparent over time. For this reason, fetal ultrasound safety experts consider neurodevelopmental disorders possible “subtle effects” of elevated temperatures and have long advised against the non-medically indicated use of ultrasound – recommendations that would seem to have been largely ignored.

For those who say that ultrasound has been in common use for 30 years, as if this were proof of its safety, I would remind them that 30 years ago is exactly when the autism increase began (8).

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- 7) Croen LA, Grether JK, Yoshida CK, Odouli R, Hendrick V. Antidepressant use during pregnancy and childhood autism spectrum disorders. *Arch Gen Psychiatry*. 2011;68(11):1104-12.
- 8) McDonald ME, Paul JF. Timing of Increased Autistic Disorder Cumulative Incidence. *Environ Sci Technol*. 2010 Mar 15;44(6):2112-8.

To: Interagency Autism Coordinating Committee
From: Caroline Rodgers
Re: Fetal x-rays vs. ultrasound – a warning from the past*
Date: 1-16-2019

Autism is thought to be caused by a complex interaction of genetics and environmental factors.¹ This makes intuitive sense to us because we perceive ourselves as victims of exposure to an increasingly large number of toxins. Yet the solution to an emerging public health problem can be simple.

For example, in 1951 British epidemiologist Alice Stewart set out to discover why there was an increase in leukemia among children between the ages of 2 and 4. She designed an extensive survey of possible prenatal factors and discovered, to her surprise, that just a single low-dose fetal x-ray doubled a child's chance of pediatric cancer.²

Is autism any different?

Today, mothers who do not get first trimester prenatal care are less likely to have children diagnosed with autism than mothers who do.³ This does not make sense, according to our understanding of the benefits of prenatal care.

The link between low-dose fetal x-rays and pediatric cancer is a reminder that diagnostic imaging, albeit bloodless and painless, can be a biological intrusion with consequences. In a world governed by cause and effect, why would anyone think that prenatal ultrasound, which has several bioeffects, would not sometimes alter fetal development? Perhaps autism is caused by a “perfect storm” scenario that depends upon the combination of gestational timing, amount of heat generated by the sound waves and genetic predisposition. If this were the case, it would be fair to say that at least some genetic predispositions would be inconsequential if the fetus were not exposed to ultrasound.

Experiments don't always turn out the way scientists expect. Some results seem counterintuitive, yet make sense when more information becomes available. When Dr. Stewart discovered that low-dose fetal x-rays increased pediatric cancer risk, radiation specialists believed only higher doses of x-rays were harmful. Dr. Stewart suggested that low-dose x-rays were more likely to cause mutations, but the scientific community at large did not buy it – or it would not have taken nearly 30 years for the major medical associations to recommend against routine fetal x-rays in 1980.

Facts that don't seem to make sense could actually be the best clues we have; as inconvenient as they may be, upsetting our preconceived ideas, they deserve further investigation. They may even lead to a simple explanation.

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² Gayle Greene, The Woman Who Knew Too Much: Alice Stewart and the secrets of radiation. University of Michigan Press, 1999. 78-92.

³ This reference relies on integrating information found in the following sources:

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- ***This is a condensed version of an IACC presentation made by Caroline Rodgers on 1-18-2011***

Linda (Angelique) Papadimitriou-Varsou, Ph.D., M.P.H., DABCC

January 16, 2019

"Issues related to ASD research and services activities"

January 8, 2019

The motto "*Time is Money*", in the ASD case becomes: "*Time is pressing*" due to its alarming increased prevalence rate, and "*Money is limited*" due to the economic crisis and the lack of collaboration, sharing data and expertise among different research groups.

Searching for unbiased, comprehensive, trustworthy, including all different confounding factors (i.e. genetics, preconception, prenatal, epigenetics, environmental, nurturing, training, etc.), ASD publications still remain a problem, as illustrated by the recent Cochrane Collaboration crisis.

Because "*Correlation doesn't always mean Causation*", we need to take into account all different environmental and epigenetic factors with possible contribution to the increase of ASD prevalence and severity. For example, the correlation factor of $R = 0.9972$ between the prevalence of Autism and the use of Glyphosate (*Roundup*), could explain some issues related to Autism, without taking into account the alarming increase of the Electromagnetic Frequencies or Radiations (EMF or EMR).

We humans are "electrical beings", receiving EMF energy from nature and producing in our body electricity from every single activity, which could become "toxic" without proper natural "grounding". Compared to the natural EMF radiation for instance back in the 1920's, today we are exposed to one quintillion times higher EMF radiation, i.e. 1×10^{18} times more EMR. Furthermore, this environmental "*electrosmog*", has dramatically increased in the last 2 decades (*the same as glyphosate exposure and the prevalence of Autism!*). Recent studies have shown that the womb has also the potential to "concentrate" the EMF radiation from the environment, and not only from the pregnant mother's cell phone!

Living today in an "ocean" of manmade electromagnetic radiations (cellphones, iPhones, microwaves, smart meters, AM, FM radio, TV, remote controls, wireless home telephones, Wi-Fi, cell towers, radars, etc.), every single brain is affected in some degree, definitely children more than adults, and probably the vulnerable people with ASD as well.

The "Facilitated Communication" by using computers is a very effective method for nonverbal people with Autism to learn and to communicate, if used appropriately (fiber optics, computer screen with wire grounded filter in a safe environment, etc.). If not, it could produce more harm than benefit.

As our society moves at high speed from the 1G, 2G, 3G, 4G, to the implementation now of the 5G (the 5th generation of cell antenna towers), the consequences of the last one will be detrimental to every human being's brain, much more to the brain of a person with ASD.

In conclusion: All the above are "common sense", worthy to be investigated and addressed for the health of people with ASD. But based on the concept that: "***An Autism Friendly Society will benefit us all***", if we reduce and control the EMF radiation and outlaw the implementation of the 5G, this "autism friendly" health approach, will benefit everyone.

Note: See also my WRITTEN COMMENTS FOR THE IACC WORKSHOP OF SEPTEMBER 27, 2018, "*Addressing the Health Needs of People on the Autism Spectrum*"

From Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Hygienist, Clinical Biochemist, Associate Professor in Medicine. Mother and legal guardian of a 33-year-old college student with autism; advocate for the Rights and Strengths of People with Autism, a fervent supporter of the concept: "*An Autism Friendly Society will benefit us all***".** SHORT BIO: Long-standing member of different autism related organizations and scientific societies in the US. Founding and board member of the Greek Society for the Protection of Autistic People and founding member of the Greek Scientific Autism Network. Long-standing member of "Autism-Europe", and elected member to its Council of Administration, resigned in May 2018. MSc in Biochemistry and postgraduate studies, Paris University; Specialization in

*Immunology, Paris Institute Pasteur, France; MSc in Public Health with honours; Diplomate of the American Board of Clinical Chemistry; Two PhDs in Diagnostic Laboratory Medicine; Research Associate at the University of Maryland School of Medicine, Faculty member at Johns Hopkins University School of Medicine, Department of Neurology, where I studied neurosciences and initiated the “**fever study in autism**”. Current position: retired Associate Professor from the University of Athens School of Medicine in Greece, where I am still teaching a graduate course in Clinical Pharmacology, a position which allows me to spend more than 9 months per year in the US with my son, while continuing my teaching online.*

[PII redacted]

Marc Spilo

January 16, 2019

To whom it may concern,

As the uncle of an autistic 15 year old boy, I have seen the devastating effects this ailment can have not only on the autistic person but also on all family members who are close to, and interact with this loved one.

It is past time for you to step up and recognize that we have a situation that is now of epidemic proportions in our country. This needs far more of your urgent focused attention to push forward with more research to understand and begin to stem this growing tide.

Respectfully,

Marc Spilo



New Advocacy Group Seeks Realistic Solutions for Severely Disabled Autistics

FOR IMMEDIATE RELEASE

SAN JOSE, California, January 10, 2019—Against a backdrop of increasing challenges for individuals with autism and their families nationwide, leading advocates have announced the formation of the National Council on Severe Autism (NCSA). The new organization is created to address pragmatically the many serious challenges in services, housing, and policy facing families, caregivers and individuals affected by severe forms of autism and related disorders.

"Autism is often romanticized and sugar-coated in media and social media," said Jill Escher, NCSA President. "In contrast, our efforts will be guided by pragmatic realities. For countless families devoted to the well being of their disabled loved ones, the daily challenges can be overwhelming, and the prospects for the future extremely bleak. We will work to increase capacity and a range of new options for this population."

The NCSA addresses forms of autism that, by virtue of any combination of cognitive and functional impairments, necessitate continuous or near-continuous supervision, services and supports over the lifespan. Individuals in this category are often nonverbal or have limited use of language, are intellectually disabled, and, in a subset, exhibit challenging behaviors that interfere with safety and well-being. Data from the U.S. Centers for Disease Control, along with other population studies, suggest that nearly 1% percent of children and adolescents in the United States likely have a form of autism meeting these criteria.

"The growth of the severely disabled autistic population—nearly 1% of all children in the U.S., together with a burgeoning population of young adults—requires clear-headed, matter-of-fact policy solutions that deliver results," said Amy Lutz, NCSA Secretary. "We look to work cooperatively with federal and state agencies to create cost-effective ways of finding quality places to live and well trained and dedicated people to help care for disabled relatives and neighbors. They deserve it, and wishful thinking about autism won't solve the problem."

"The establishment of the NCSA will be in invaluable contribution to the autism community, both in the U.S. and beyond," said Lee Wachtel, MD, Medical Director, Neurobehavioral Unit, of the Kennedy Krieger Institute in Baltimore, and who is not associated with the new organization. "It will provide a sensible and long-awaited voice for those living with highly challenging conditions with overwhelming impact upon individuals, carers, and the larger community."

Prominent practitioners, professionals, and policy experts noted for successful real-world autism advocacy comprise the initial board of the NCSA. The group includes President Jill Escher, President of Autism Society San Francisco Bay Area and founder of Escher Fund for Autism (California), Vice President Feda Almaliti, who helped spearhead insurance reform in her state (California), Secretary Amy Lutz, founder of the EASI Foundation (Pennsylvania), Treasurer Alison Singer, founder and Executive Director of the Autism Science Foundation (New York), and board members Frank Campagna, a television producer and popular blogger (New York),

Lisa McCauley Parles, Esq., a partner in Parles Rekem, LLP a law firm representing individuals with disabilities and their families (New Jersey), Dr. Gloria Satriale, executive director of Preparing Adolescents and Adults for Life (Pennsylvania), Dr. Matthew Siegel, Associate Professor of Psychiatry and Pediatrics of Tufts University School of Medicine, Vice President of Medical Affairs, Developmental Service, of Maine Behavioral Healthcare, and Faculty Scientist II at Maine Medical Center Research Institute (Maine), and Judith Ursitti, Director of State Government Affairs for Autism Speaks (Massachusetts).

The NCSA has published an initial set of Position Statements on important topics facing the autism community. These include: Guardianship, Vocational Options, Personal Safety and Abuse Prevention, Access to Appropriate Health Care and Crisis Care, Medicaid HCBS Residential Policies, Educational Placements, Need for Innovative Research.

The NCSA homepage features a sign-up block for its newsletters and updates, and invites input from members of the autism community. NCSA will also host accounts on social media, starting with Facebook and Twitter. The organization is planning to host a think tank on national adult autism policy as one of its initial efforts. "We have no intention to duplicate the vitally important work of other autism advocacy organizations," added Escher. "We aim only to add a strong voice for those who cannot speak for themselves."

NCSA has filed for Internal Revenue Code 501(c)(3) nonprofit status and will announce on its website if and when approval is received.

For more information:

Website: ncsautism.org

Email: info@ncsautism.org

Facebook: <https://www.facebook.com/ncsautism/>

Twitter: [@ncsautismorg](https://twitter.com/ncsautismorg)

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