

# **Written Public Comments**

**IACC Full Committee  
Meeting**

**April 17, 2019**

## List of Written Public Comments

Stephanie Dorr .....	3
James Strack.....	17
Whitney Ellenby .....	18
Sally Pacholok .....	19
Elissa Leonard .....	20
PrabhakarGupta Garla .....	22
Suresh Kalkunte .....	23
Pamela Vandegrift.....	24
Sandra McClennen, Ph.D. ....	25
Clarissa Kripke, M.D. ....	26
Darlene Hanson, M.A. ....	27
Chantal Sicile-Kira .....	28
Jennifer Binder-Le Pape .....	30
Autistic Self Advocacy Network .....	31
Eileen Nicole Simon, Ph.D., R.N. ....	35
Hari Srinivasan .....	45
C. J. Shiloh, MT-BC.....	47
Allison Thurman .....	48
Cami Berkau .....	49
Jeanine Davis.....	51
Rita Rubin .....	52
Tracy Lattanzi .....	53
Elizabeth Vosseller, M.A. ....	54
Christine McKee .....	55
Mary Ellen Wells .....	57
Matt Hayes.....	58
Casey Woodfield, Ph.D.....	59
Kerry Lane M.D. ....	60

**Stephanie Dorr**

**April 17, 2019**

I was unaware that this committee even existed until yesterday. I have a son with Autism and recent information has come to my attention. I believe this committee was designed with the purpose to discuss issues related to Autism Spectrum disorder. I don't believe this committee can do that without a vital pieces of information to the disorder.

Please take the time to watch this youtube video.

<https://www.youtube.com/watch?v=NACBHtFMIIA&t=53s>

Respectfully yours,

--

Stephanie Dorr

Would you please share this sworn affidavit with the committee?

[https://namelyliberty.com/dr-andrew-zimmermans-full-affidavit-on-alleged-link-between-vaccines-and-autism-that-u-s-govt-covered-up/?fbclid=IwAR3hJWoJVifWmxm\\_eTF\\_aBIDlzhkpSigIBxXcw5gofvN8GAH-15wRgsSc8](https://namelyliberty.com/dr-andrew-zimmermans-full-affidavit-on-alleged-link-between-vaccines-and-autism-that-u-s-govt-covered-up/?fbclid=IwAR3hJWoJVifWmxm_eTF_aBIDlzhkpSigIBxXcw5gofvN8GAH-15wRgsSc8)

Thank you,

Stephanie Dorr

Dear Committee Members,

I would like to provide information/evidence regarding measles and vaccinations. The media is using propaganda to ensure an uptake in the vaccine program. I want to make sure you are all aware of the science instead.

Please review the information I am providing.

BMJ

VAERS

Newest Research regarding how aluminum travels through the body via vaccination.

Informed representatives of the people make better representatives for the people.

Thank you for your time.

Sincerely,

--

Stephanie Dorr

## MILD AILMENT

Dr. JOHN FRY (Beckenham, Kent) writes: The expected biennial epidemic of measles appeared in this region in early December, 1958, just in time to put many youngsters to bed over Christmas. To date there have been close on 150 cases in the practice, and the numbers are now steadily decreasing. Like previous epidemics, the primary cases have been chiefly in the 5- and 6-year-olds, with secondary cases in their younger siblings. No special features have been noted in this relatively mild epidemic. It has been mild because complications have occurred in only four children. One little girl aged 2 suffered from a lobular pneumonia, and three others developed acute otitis media following their measles. In the majority of children the whole episode has been well and truly over in a week, from the prodromal phase to the disappearance of the rash, and many mothers have remarked "how much good the attack has done their children," as they seem so much better after the measles.

A family doctor's approach to the management of measles is essentially a personal and individual matter, based on the personal experiences of the doctor and the individual character and background of the child and the family. In this practice measles is considered as a relatively mild and inevitable childhood ailment that is best encountered any time from 3 to 7 years of age. Over the past 10 years there have been few serious complications at any age, and all children have made complete recoveries. As a result of this reasoning no special attempts have been made at prevention even in young infants in whom the disease has not been found to be especially serious.



- polyneuritis (inflammation of several nerves simultaneously).

As of March 31, 2018, there have been more than 89,355 reports of measles vaccine reactions, hospitalizations, injuries and deaths following measles vaccinations made to the federal Vaccine Adverse Events Reporting System (VAERS), including 445 related deaths, 6,196 hospitalizations, and 1,657 related disabilities. Over 60% of those adverse events occurred in children three years old and under. Adverse events following MMR vaccination reported to VAERS include:

- lupus (autoimmune connective tissue disorder);
- Guillain-Barre syndrome (inflammation of the nerves);
- Encephalitis;
- aseptic meningitis (inflammation of the lining of the brain);
- deafness;
- cardiomyopathy (weakening of the heart muscle);
- hypotonic-hyporesponsive episodes (collapse/shock);
- convulsions;
- subacute sclerosing panencephalitis (SSPE);
- ataxia (loss of ability to coordinate muscle movements);
- parathesia (numbness, burning, prickling, itching,





## Researchers show where the aluminum travels to in the body and stays after vaccination

When it comes to the most widely used adjuvant ingredient found within vaccines, aluminum, many questions have yet to be answered, particularly when it comes to where the aluminum goes after injection, an issue known as biopersistence.

One reason this question arises is because a causative role has been established in what's known as macrophagic myofasciitis (MMF) lesion in patients who have myalgic encephalomyelitis, or brain inflammation. Myalgia, arthralgia, chronic fatigue, cognitive dysfunction, dysautonomia, and autoimmunity have been temporally linked to aluminium adjuvant-containing vaccine administration (Gherardi and Authier, 2003; Authier et al., 2003; Exley et al., 2009; Rosenblum et al., 2011; Santiago et al., 2014; Brinth et al., 2015; Palmieri et al., 2016 (<http://www.sciencedirect.com/science/article/pii/S0300483X16303043#bib0125>)).

**“Evidence that aluminum-coated particles phagocytosed in the injected muscle and its draining lymph nodes can disseminate within phagocytes throughout the body and slowly accumulate in the brain further suggested that alum safety should be evaluated in the long term.”** (source (<https://www.ncbi.nlm.nih.gov/pubmed/26082187>))

This study has prompted further research evaluating the potential hazards of injected aluminum, which begs the question, why hasn't proper evidence and evaluation been published showing that it's safe to inject aluminum into babies via several vaccines in a short period of time? Aluminum adjuvants may be effective for stimulating an immune response, but to simply presume there are no consequences for doing this, or to not emphasize or even state the adverse effects that have been discovered, is, I would argue, criminally negligent.

Such negligence is not uncommon when dealing with pharmaceutical companies, however. For example, a study published in the British Medical Journal (<http://www.bmj.com/content/352/bmj.i65>) and conducted by researchers at the Nordic Cochrane Center in Copenhagen showed that pharmaceutical companies were not disclosing all information regarding the results of their drug trials.



Even the FDA has been caught manipulating media and science press. (<http://www.collective-evolution.com/2016/10/21/new-foia-investigation-reveals-disturbing-manipulation-media-science-press/>)

Examples of such fraud and corruption are endless, and the result of what many have dubbed the “corporatization” of science. Many from within the field have published a lot of work with the intention of creating more awareness about this grim reality.

Dr. Marcia Angell, a physician and longtime Editor-in-Chief of the New England Medical Journal (NEMJ), one of the most prestigious peer-reviewed medical journals in the world, has said that **“it is simply no longer possible to believe much of the clinical research that is published, or to rely on the judgment of trusted physicians or authoritative medical guidelines. I take no pleasure in this conclusion, which I reached slowly and reluctantly over my two decades as an editor of The New England Journal of Medicine.”** (source (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2964337/>))

It’s good to see that we are entering a time when these vaccine ingredients aren’t just assumed to be safe, especially aluminum, which had no place on planet Earth until humans made it, and it definitely has no place in the human body. Because vaccines have, historically, been viewed as non-toxic substances, the FDA and vaccine manufactures simply didn’t conduct appropriate toxicity studies to prove the safety of vaccine ingredients, like aluminum. (source (<http://lup.sagepub.com/content/21/2/223.short>))

A study published in (<https://bmcmmedicine.biomedcentral.com/articles/10.1186/1741-7015-11-99>) BMC Medicine showed that alum-containing vaccines were associated with the appearance of aluminum deposits in distant organs, such as the spleen and brain, and were **still detectable one year after injection**. The same group from France published another study two years later (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4318414/>), emphasizing that there are **“several gaps in the knowledge on alum particles, including their exact mechanisms of action, their fate after injection, their systemic dissemination, and their safety on the long-term. Efforts have been done in the last years to develop novel adjuvants, but attempts to seriously examine safety concerns raised by the bio-persistent character and brain accumulation of alum particles have not been made.”**

Fast forward to this year, and multiple in vivo studies have been published showing that injected aluminum, and aluminum used as an adjuvant within vaccines, does not come into the same method of excretion as aluminum that accumulates in our body from our food, for example. Our bodies do a good job at eliminating this type of aluminum, but the same cannot be said of injected aluminum. This is why multiple studies are implicating injected aluminum with multiple neurodegenerative disorders, like autism in the short term, or Alzheimer’s in the long term, because aluminum could be going to the brain and staying there for life.

Apart from observed behavioural abnormalities, the 2017 study showed that the **“measurement of cerebral Al (aluminum) revealed a significantly higher Al level in brains from animals injected . . . than in brains from control group.”** (source (<http://www.sciencedirect.com/science/article/pii/S0300483X16303043#bib0135>))

What's also interesting is that there was "no significant increase" detected in the animals that were injected with a higher dose.

It's concerning, especially because we already know that environmental aluminium has long been suspected to act as a co-factor in several chronic neurological diseases (Van Rensburg et al., 2001; De Sole et al., 2013; Exley 2013, 2014

(<http://www.sciencedirect.com/science/article/pii/S0300483X16303043#bib0355>)). Please refer to these studies to see the mechanism by which these authors are suggesting aluminum is transported to the brain.

**“Experimental research . . . clearly shows that aluminum adjuvants have a potential to induce serious immunological disorders in humans.”**

– Dr. Lucija Tomljenovic (source

([http://www.meerwetenoverfreek.nl/images/stories/Tomljenovic\\_Shaw-CMC-published.pdf](http://www.meerwetenoverfreek.nl/images/stories/Tomljenovic_Shaw-CMC-published.pdf)))

Here is a great quote from Dr. Jose G. Dores, a professor at the University of Brasilia's Department of Nutritional Sciences who recently published a study in the International Journal of Environmental Research and Public Health. In the study, he offers the following observation: **“Despite their long use as active agents of medicines and fungicides, the safety levels of these substances have never been determined, either for animals or for adult humans—much less for fetuses, newborns, infants, and children.”** (source

(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4344667/>))

Below is a video with Dr. Christopher Shaw, a professor from UBC, explaining why injected aluminum is a concern. We also recently conducted an interview with him, and will be releasing some of that out to you soon.

The Effect of Aluminum in Vaccines on Humans



Here (<https://www.keele.ac.uk/aluminium/groupmembers/chrisexley/>) is a great video by Dr. Christopher Exley (<https://www.keele.ac.uk/aluminium/groupmembers/chrisexley/>), a Professor in Bioinorganic Chemistry at Keele University and Honorary Professor at UHI Millennium Institute. He is known as one of the world's leading experts on aluminum toxicity.

With So Many Studies Raising Concerns, Why Do So Few People Know About This?

The same thing has happened with mercury. Not long ago, Robert F. Kennedy Jr., Chairman of the World Mercury Project (WMP) (<https://worldmercuryproject.org/>), announced a \$100,000 challenge and initiative aimed at putting an end to the inclusion of mercury, a neurotoxin 100 times more poisonous than lead, in vaccines administered in the U.S and globally. He held a press conference presenting a number of scientific publications raising several concerns with regards to injecting mercury into children. As with aluminum, there are no studies proving it's actually safe to do this.

And a fairly recent Meta-Analysis published in the journal Bio Med Research International found:

The studies upon which the CDC relies and over which it exerted some level of control report that there is no increased risk of autism from exposure to organic Hg in vaccines, and some of these studies even reported that exposure to Thimerosal appeared to decrease the risk of autism. These six studies are in sharp contrast to research conducted by independent researchers over the past 75+ years that have consistently found Thimerosal to be harmful. As mentioned in the Introduction section, many studies conducted by independent investigators have found Thimerosal to be associated with neurodevelopmental disorders. Considering that there are many studies conducted by independent researchers which show a relationship between Thimerosal and neurodevelopmental disorders, the results of the six studies examined in this review, particularly those showing the protective effects of Thimerosal, should bring into question the validity of the methodology used in the studies. (source (<https://www.hindawi.com/journals/bmri/2014/247218/>))

You can read more about that here (<http://www.collective-evolution.com/2017/02/15/a-100000-message-from-robert-f-kennedy-jr-robert-de-niro-to-american-journalists-scientists/>).

So why does nobody know about this? Political insider Robert F. Kennedy Jr. explains:

Vaccines are big business. Pharma is a trillion-dollar industry with vaccines accounting for \$25 billion in annual sales. CDC's decision to add a vaccine to the schedule can guarantee its manufacturer millions of customers and billions in revenue with minimal advertising or marketing costs and complete immunity from lawsuits. High stakes and the seamless marriage between Big Pharma and government agencies have spawned an opaque and crooked regulatory system. . . .

Public health may not be the sole driver of CDC decisions to mandate new vaccines. Four scathing federal studies, including two by Congress, one by the US Senate, and one by the HHS Inspector General, paint CDC as a cesspool of corruption, mismanagement, and dysfunction with alarming conflicts of interest suborning its research, regulatory, and policymaking functions. (World Mercury Project (<https://worldmercuryproject.org/government/cdc-corruption/cdc-off-center/>))

There are real life examples of this too, like, William Thompson, a longtime senior CDC scientist who published some of the most commonly cited pro-vaccine studies, which showed that there was absolutely no link between the MMR vaccine and autism (Thompson,

(<http://www.nejm.org/doi/full/10.1056/nejmoa071434#t=article>) et al. 2007,  
(<http://www.nejm.org/doi/full/10.1056/nejmoa071434#t=article>) Price, et al. 2010  
(<http://pediatrics.aappublications.org/content/126/4/656>), Destefano, et al. 2004  
(<https://www.ncbi.nlm.nih.gov/pubmed/14754936>)). Dr. Thompson recently admitted that it was “**the lowest point**” in his career when he “**went along with that paper.**” He went on to say that he and the other authors “**didn’t report significant findings**” and that he is “**completely ashamed**” of what he did. He was “**complicit and went along with this,**” and regrets that he has “**been a part of the problem.**” (source (<https://www.youtube.com/watch?v=LhpckzxVEoc#t=381>))(source (<http://www.cnn.com/2014/08/27/health/irpt-cdc-autism-vaccine-study/>))(source (<http://morganverkamp.com/statement-of-william-w-thompson-ph-d-regarding-the-2004-article-examining-the-possibility-of-a-relationship-between-mmr-vaccine-and-autism/>))

I could go on, but I’ll conclude by saying that we must continue to raise our voices and demand transparency. We must not let the corporate world continue to wreak havoc and sacrifice our health for their greed.

### Sacrificing Animals For Science

Collective Evolution is a platform of animal activists, and it does conflict me to constantly look at studies where animals are bred and grown for such a sacrifice. That being said, perhaps for now, in some cases it can be looked upon the way the indigenous looked upon the animals they used to sustain themselves. You can read more about that here (<http://www.collective-evolution.com/2017/05/30/what-would-native-american-wisdom-say-about-going-vegan-or-vegetarian-would-it-agree-or-disagree/>), in an article discussing what Native North American elders might say about a vegan diet and the modern day meat industry. Some of the things animals are subjected to in the name of “science” are actually horrible. The cosmetics industry, to name one, is a heart-breaking example. Why are animals considered lesser beings? If these products are for us, they should be tested on humans. Perhaps one day we will be able to grow human bodies, devoid of any consciousness, to advance science, but then a number of other questions come into play.

As far as vaccines go, injecting aluminum into an animal is almost unnecessary at this point in my opinion, because as far as I’m concerned, we already know the result is not going to be good, so what’s the point of continuing to do so? Unfortunately, the language of science is far different, and perhaps these animals, on some deeper level, played that role so we can open our eyes and see the bigger picture. This type of perspective is discussed in the article linked in the previous paragraph, stories of Native North Americans and their relationship with animals might help with this perspective.

Not in all cases, but in many cases, alternatives to animal testing are sometimes more effective, quicker and cheaper. But this may not be true for all cases.

*For the rest of this article please go to source link below.*

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**By Arjun Walia / Collective Evolution Reporter**

I joined the CE team in 2010 shortly after finishing university and have been grateful for the fact that I have been able to do this ever since :) There are many things happening on the planet that don't resonate with me, and I wanted to do what I could to play a role in creating change. It's been great making changes in my own life and creating awareness and I look forward to more projects that move beyond awareness and into action and implementation.

Email (<http://arjun@collective-evolution.com>)

(Source: [collective-evoluton.com](http://collective-evoluton.com); November 21, 2017;  
<http://tinyurl.com/ycex8zf4> (<http://tinyurl.com/ycex8zf4>))



37.4K



70



502

Please watch <https://www.youtube.com/watch?v=vAQG51R45D0>

Thank you,

Stephanie Dorr

Dear Board of Directors,

Please read the attached document.

Thank you,

Stephanie Dorr

**Additional materials can be found at:** <https://icandecide.org/wp-content/uploads/whitepapers/ICAN%20Reply%20-%20December%2031%2C%202018.pdf>



Dear NIMH IACC members,

Attached you will find the HRSA data and Statistics for the National Vaccine Injury Compensation Program.

"Approximately 70 percent of all compensation awarded by the VICP comes as result of a negotiated settlement between the parties in which HHS has not concluded, based upon review of the evidence, that the alleged vaccine(s) caused the alleged injury."

I would like to point out that the above quote is negotiated settlements so that it protects the program not the individual. Even with the above claim there are still 30 percent of the cases compensation awarded because the vaccine did cause death, disability, and illnesses.

Considering 3/4 of the population nor the medical community was even aware of the 1986 National Vaccine Compensation Program that makes for a lot of not safe products. I bet if you surveyed most doctors and nurses prior to the last two years they wouldn't even know how to identify a vaccine injury.

This should bring outrage to our public officials and our community but the funny thing is all they here on the news is get your vaccines, they are safe and effective.

I don't know about you but numbers don't lie. We don't sacrifice people for a belief because that isn't science that is religion. I would like this information presented for public awareness please.

Thank you for your time.

Stephanie Dorr

**Additional materials can be found at:** <https://www.hrsa.gov/sites/default/files/hrsa/vaccine-compensation/data/monthly-stats-january-2019.pdf>

**James Strack**

**April 17, 2019**

Hello my name is James Strack and I would like to join the military and was denied because of my autism. I would like to change that law and I was hoping you would help.

**Whitney Ellenby**

**April 17, 2019**

Beloved Friends, from time to time I use unconventional methods to advocate for our children, and as I'm a big fan of disclosing Zack's Autism without shame, I decided to tell a salty tale. Please excuse the profanity but it was central to the story, and underscoring it is a serious & salient point about the lengths to which the public will go to help our beloved children if accurately informed. Please watch here, and feel free to share on social media:

[https://www.youtube.com/watch?v=AX2-m-7ZR3M&list=PLDGn\\_6N3BeYp0-8iK6Wmkmo-FZ8BgkZl&index=7&t=0s](https://www.youtube.com/watch?v=AX2-m-7ZR3M&list=PLDGn_6N3BeYp0-8iK6Wmkmo-FZ8BgkZl&index=7&t=0s)

Love,

Whitney

Autism Ambassadors

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

**Sally Pacholok**

**April 17, 2019**

1. How can we address autism if the medical and health care communities refuse to understand the fundamentals of pediatric B<sub>12</sub> deficiency?
2. Because it is well documented that vitamin B<sub>12</sub> deficiency in infants and young children causes developmental delay and regression, why aren't children suspected or diagnosed on the "autism spectrum," properly being screened for B<sub>12</sub> deficiency at the first opportunity (serum B<sub>12</sub>, methylmalonic acid, homocysteine)?
3. Are you aware that some children diagnosed on the autism spectrum are misdiagnosed and actually have a B<sub>12</sub> deficiency brain injury?
4. Why aren't women being screened for B<sub>12</sub> deficiency during their prenatal visits? Pregnant women and even those admitted to obstetrics units are not even screened for B<sub>12</sub> deficiency with a simple questionnaire, to obtain if they are vegan, vegetarian, autoimmune disorder, malabsorption syndrome, GI disease (celiac, Crohn's), GI surgery (gastric bypass), genetic mutations [MTHFR, MTRR, MTR), taking metformin or a proton-pump inhibitor—and then these same women who are at risk, are encouraged to breastfeed. Not only do we not test women, we do not screen with basic at-risk questionnaires. Women who are low or deficient in B<sub>12</sub> will have poor B<sub>12</sub> in their breast milk, which can permanently injure their child's growing brain for life.
5. For those clinicians who do test children for B<sub>12</sub> deficiency, what tests are they using and why aren't all clinicians testing and documenting the incidence?
6. Because of the knowledge deficit in the medical and health care community regarding B<sub>12</sub> deficiency, wouldn't it be prudent to start a B<sub>12</sub> Awareness campaign?
7. Who is responsible for this dangerous health care threat (B<sub>12</sub> deficiency) against women and children, and why is the U.S. government, medical community, and autism groups apathetic to the reality of this medical disorder?
8. Why aren't we screening infants at three or six months of age for low B<sub>12</sub> in their urine using the urinary methylmalonic acid test. Newborn screening will not detect a child who is borderline or low in B<sub>12</sub>, that then becomes deficient as the deficient mom continues to breast feed. This is how many children are silently being injured.
9. It is poor public health care to encourage women to breast feed if the clinician and health care institution fails to determine if that mother is low or deficient in vitamin B<sub>12</sub>.
10. Are health care professionals and institutions aware of what nitrous oxide does to B<sub>12</sub> in the body?
11. Should obstetricians be giving pregnant women hydroxocobalamin injections monthly at their prenatal visits to prevent low B<sub>12</sub> in children?
12. Should some funding be directed toward B<sub>12</sub> deficiency prevention, education, testing, and research?

Sally M. Pacholok, RN, BSN

[www.B12Awareness.org](http://www.B12Awareness.org)

[PII removed]

**Elissa Leonard**

**April 17, 2019**

Dear Interagency Committee on Autism,

Please retire your prior beliefs that B12 Deficiency is rare. It is time to test and treat this preventable condition that is devastating to all age groups.

Pediatric B12 Deficiency presents on a spectrum from mild to severe, just like everything you have been labeling "autism" (without properly screening) in era of high folic-acid-only supplementation. The symptoms are varied: failure to thrive, trouble feeding, developmental delay or regression, neuropathy, irritability, cognitive and behavioral problems, mental illness, seizures, severe neurological damage, cerebral atrophy. Left untreated the damage done quickly becomes permanent.

As you know, folate and B12 have an important shared metabolism and "folic acid only" interventions were forewarned to be harmful to people with low B12, including pregnant mothers and their offspring. Synthetic folate masks and exacerbates B12 Deficiency.

The combination of 1) poor dietary advice (to stop eating animal-sourced foods), 2) the unprecedented use of medications that block B12 absorption and/or render it useless in the body's processes, 3) high-dose folic acid that corrects the macrocytic anemia you may have been taught to look, 4) patient and physician ignorance, now means that B12 deficiency is common, and misdiagnosis has been rampant. Pediatric B12 Deficiency destroys lives and brains and families and wastes our healthcare dollars.

Tests are B12, Homocysteine, Methylmalonic Acid and an immediate trial of parenteral therapy for symptomatic patients. Do not assume oral B12 will cross the blood/brain barrier to address deficiency in the central nervous system. Shots, not pills, should be used to for treatment when patients have symptoms. Pills may be okay for prevention, but may be too little too late for a baby who acquired a brain injury in utero or during breast feeding. Remember a blood test does not tell you whether the brain has sufficient B12 for proper growth and development.

Sincerely,

Elissa Leonard

Diagnosing and Treating B12 Deficiency

<https://youtu.be/BvEizypoyO0>

**Additional materials available at:**

1. <https://www.ncbi.nlm.nih.gov/pubmed/23334842>
2. <https://www.ncbi.nlm.nih.gov/pubmed/29948967>
3. <https://www.maastrichtuniversity.nl/news/milk-and-cheese-are-limited-source-vitamin-b12>
4. <https://www.hsph.harvard.edu/news/hsph-in-the-news/vitamin-b12-benefits-pregnancy/>

Every day you fail to alert doctors and patients about pediatric B12 deficiency, which has the same symptoms as "autism", is a day more women and children and families are harmed and more healthcare dollars are wasted.

Pediatric B12 Deficiency presents on a spectrum from mild to severe. B12 deficiency is masked by high dose folic acid. Physician and patient ignorance is rampant. Damage done to growing brains is permanent. B12 awareness saves lives.

<https://www.cambridge.org/core/journals/british-journal-of-nutrition/article/maternal-plasma-vitamin-b12-concentrations-during-pregnancy-and-infant-cognitive-outcomes-at-2-years-of-age/BF000CA0351CAF7C9F00BAD3349C9B0E>

Maternal plasma vitamin B12 concentrations during pregnancy and infant cognitive outcomes at 2 years of age Jun S. Lai (a1), M. Na'im Mohamad Ayob (a1), Shirong Cai (a1) (a2), Phaik Ling Quah (a1) ... <https://doi.org/10.1017/S0007114519000746> Published online: 02 April 2019 Abstract Evidence on long term influences of maternal vitamin B12 deficiency or concentrations on infant cognition is limited. We examined associations between maternal plasma vitamin B12 and cognitive development in 24-months old infants. Maternal plasma vitamin B12 concentrations were measured at 26-28 weeks' gestation; infant cognitive development assessed with the Bayley Scales of Infant and Toddler Development-III at 24 months, for 443 mother-infant pairs from the Growing Up in Singapore Towards healthy Outcomes cohort. Linear regressions adjusted for key confounders examined associations of maternal vitamin B12 with cognitive, receptive and expressive language, fine and gross motor subscales. Co-occurrence of maternal vitamin B12 with folate or vitamin B6 insufficiencies on child's cognition was explored. Average maternal plasma vitamin B12 concentrations was  $220.5 \pm 80.5$  pmol/L; 15% and 41% of mothers were vitamin B12 deficient ( $<148$ pmol/L), and insufficient (148-220.9pmol/L) respectively. Infants of mothers with vitamin B12 deficiency had 0.42 SD (95% CI:  $-0.70$ ,  $0.14$  SD) lower cognitive scores, compared to infants of mothers with sufficient vitamin B12. Co-occurrence of maternal vitamins B12 and B6 insufficiencies was associated with 0.37 SD (95% CI:  $-0.69$ ,  $0.06$  SD) lower cognitive scores in infants compared to infants of mothers sufficient in both vitamins. No significant associations were observed with other subscales. Study findings suggest possible need to ensure adequate vitamin B12 during pregnancy. The impact of co-occurrence of maternal B-vitamins insufficiencies on early cognitive development warrants further investigation.

why intrathecal autologous adult stem cell therapy for autism is not discussed in this update. Duke study has published autologous cord blood stem cells to be beneficial in the treatment of Autism.



A possible cause of Autism:

From the book "Biological and Medical Aspects of Electromagnetic Fields"[1], I quote "In another experiment, Sprague-Dawley rats were exposed in utero to 2.45GHz Continuous Wave RF at SAR 2 W/kg for 21 h/d on GD 17 to 21. Power density measured was variable from 40 to 300 W/m<sup>2</sup> because of group exposure conditions"..."Thus, exposure to two frequencies of RF at similar SAR values (2.8 and 2 W/kg) yielded a reduction in the relative number of Purkinje cells for fetuses and newborn rats. Although the change appeared permanent for rats exposed in utero, it appeared to be reversible for those exposed postnatally".

Since Autism is characterized by reduction of Purkinje cells[2], confirming the findings in [1] will help shape a health policy by identifying boundary conditions in terms of exposure duration, intensity and type (frequency, SAR level, power density and related parameters) and publishing the same to make the public aware of exposure to radiofrequency energy as a risk factor in inducing Autism.

Thanks.

[1] "Biological and Medical Aspects of Electromagnetic Fields?", <https://www.crcpress.com/Biological-and-Medical-Aspects-of-Electromagnetic-Fields/Barnes-Greenebaum/p/book/9780849395383>.

[2] "Consensus Paper: Pathological Role of the Cerebellum in Autism", <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3677555/>.

**Pamela Vandegrift**

**April 17, 2019**

A Mother of a son who has fallen through or system. For 32 yrs. In 2015 it was brought to my attention. That my son is believed to have Autism. On hell of a journey through hell. Chemung County Mental Health facility, NY probation Department of Chemung County, County Court system, Attorney, Jail abuse, prison abuse once in 2016, and again in 2018, jail abuse once in 2016, and again March 2019. NY Parole, Federal Parole violation while on pretrial release. Stigma, discrimination, coercion, Abuse, mental physical, verbal abuse, when is the US going to step up! Fight for individuals with Autism, Add, developmental and neurological disorders. I'm outraged that our animals have more rights. Abusers get punished, fined, jailed. Our legal, mental health, is in repair.

**Sandra McClennen, Ph.D.**

**April 17, 2019**

To the Interagency Autism Coordinating Committee

As a psychologist who has worked for thirty years to provide both alternative communication and mental health access to people unable to speak due to disability, I am extremely pleased to see the United Nations using World Autism Awareness Day to highlight alternative methods of full expressive communication for those who are unable to use speech.

I request IACC to invite these speakers, or others who use alternative communication and others who provide the opportunity, instruction and support for alternative communication, to address IACC. Thank you.

Sincerely,

Sandra McClennen, Ph.D.  
Licensed Psychologist in Michigan and Ohio

The UN's World Autism Day program on Assistive Technology and Active Participation (<https://www.un.org/en/events/autismday/assets/pdf/2019%20WAAD%20Programme.pdf>; UNWebTV) highlighted the motor and sensory issues which underlie autism. These differences account for much autistic behavior. The program highlighted ways in which non-speaking people can learn to communicate their sophisticated thoughts. It also highlighted the work of people who are working effectively with sensory and motor differences to support communication and function. The program highlighted a number of potent autistic speakers who use low and higher tech to communicate, such as Ido Kedar, David Savarese, Tito Mukhopadhyay, and Chole Rothchild.

It is past time for IACC to talk about communication access and to invite non-speaking autistic people to present. Self-advocates have the most insight into the nature of their disabilities, and what approaches are helpful. They are also potent speakers on the issue of what isn't helpful. Autistic people are telling us that some standard therapies for autism have been either ineffective or even harmful to them. It is important to learn from non-speaking, autistic people themselves about this at IACC.

Clarissa Kripke, MD  
Clinical Professor  
Director of Developmental Primary Care  
University of California, San Francisco

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

**Darlene Hanson, M.A.**

**April 17, 2019**

I understand you are working with Congress to share the needs of the autism community in terms of funding, and I am sure other needs. I do hope that you are able to encourage and represent those individuals who are non speaking in your recommendations. Yesterday, April 2, 2019, the United Nations brought together professionals and communicators, as well as family members to share about the needs of those who do not use speech for communication and are dependent on augmentative communication as well as trained support persons. The individuals with autism who do not speak are dependent on technology, and dependent on professionals who understand how to train and support their communication differences. I encourage you to bring this populations needs to the attention of your group as well as Congress.

Thank you for your time,

Sincerely,

Darlene Hanson, MA,  
Speech and Language Pathologist  
Director of Communication Services  
[PII removed]



To Whom it May Concern,

My name is Chantal Sicile-Kira and I am an autism professional - author of 6 books on autism, international speaker - known for my practical advice for parents and educators. More importantly, I am also mother to Jeremy, 30 who is autistic, has synesthesia, and types to communicate.

First I would like to thank the agency for the work that the IACC does to help individuals with autism and their families.

Secondly, I would like to point out that it is crucial that the right to communicate and other concerns of non-speakers be considered when discussing autism.

You may be aware that recently on World Autism Day, the United Nations explored and supported communication access, choice, and rights for non-speakers, including communication as a human including a line-up of speakers who are non-speakers but type to communicate.

Having a form of communication is essential to taking part in the world and to be a successful, productive human being. Yet, this right to communicate is being ignored by many across the US. I'm going to share one example of how typing or pointing to letters on a letter-board can be life-altering :

My son Jeremy (now 30) graduated from high school with a full academic diploma and gave a [commencement speech](#) at his graduation in 2010. Advocacy for others like him who have no voice is an important part of Jeremy's life. After high school, Jeremy co-authored a book [A Full Life with Autism](#) (Macmillan 2012) and served as a Youth Representative to the United Nations for the Autism Research Institute (NGO); as a youth leader for the Autistic Global Initiative, and as a youth advisor to the California Employment Consortium for Youth (CECY). Jeremy is now a successful artist (see [Jeremysvision.com](#)), whose first curated [solo art show](#) was sold out and made national and local news.

Here in Jeremy's words:

"My name is Jeremy Sicile-Kira and I am an artist. About 6 years ago I began to communicate to my mom and support staff the dreams I was having every night: dreams that I was painting colorful abstract portraits of people I had met during the day. Then one night I dreamt I had a great art show of my paintings. Truly I was really excited and asked my mom how I could truly make my dream come true and have an art show. Mom frankly told me it could not very much happen unless I painted in real life. Truly I was surprised to see I could, by kindly trying hard, to learn to paint. My dream came true: In 2016, I had my first curated, solo art show in 2016. It was very successful.

**Communication has been my greatest challenge. Frankly if I had not learned how to point to letters on a letter-board or to type, no-one would have discovered this gift I have that makes people truly happy. Greatly the letter-board is my voice. Without a way to successfully communicate these gifts**

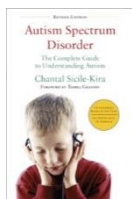
**may stay hidden forever. Kindly I hope my story inspires others. Frankly everyone should have a voice.**

Art has frankly given a meaning to my life. Dearly my gift of being able to paint people's colors is how I feel connected to other people, and how I can give back to the world. Frankly I believe that my ability is a gift from God. Truly I paint vibrant paintings of people's positive energies and emotions, because I believe that if I paint the best in people they will see how beautiful they are on the inside and greatly it will inspire them to act as nicely beautiful human beings. For the visitors to art shows or my website, I hope they feel the love I have, and respect I have, for each person or place I paint. I frankly hope my paintings inspire only the good in people, and I greatly hope that I make a difference in the world with my art.

Frankly I also provide "ability awareness" talks at schools in the San Diego area. First, I visit the school and I hear from or observe some teachers and students. Then I return two months later to give my talk, and presenting the school with a painting of their colors. Greatly the paintings and description are hung in the school lobby, a daily visual reminder to students and educators to "Believe in yourself," and to "Follow your dreams." Greatly I love inspiring the students and teachers."

Thank you again for all the IACC does.

Sincerely,  
Chantal Sicile-Kira  
Author | Speaker | Consultant  
Founder, [AutismCollege.com](http://AutismCollege.com)



Find out about all of Chantal's [books](#)  
Find out about Jeremy's [artwork and writings](#)



**Jennifer Binder-Le Pape**

**April 17, 2019**

Dear Members of the Interagency Autism Coordinating Committee -

I am the mother of an 18 year-old young man with autism. Due to significant motor challenges, speech has always been difficult for him. However, two years ago he learned to communicate through spelling out his thoughts one letter at a time. This has been life-changing for our whole family. How we wish we would have discovered this sooner!

We were thrilled to see the United Nations' program for World Autism Day devote significant time to "hearing" the voices of non-speakers with autism; such a tremendous step forward for our community. We would love to see more US effort around supporting communication choices and rights for non-speakers as well. Non-speakers have so much to share with us, but we need to help more of them access effective communication strategies.

Thank you for your consideration.

Sincerely,

Jennifer Binder-Le Pape



Nothing about us without us!

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network, in light of the recent 2019 reintroduction of the Autism CARES Act<sup>1</sup> and its annual commemoration of Autism Acceptance Month,<sup>2</sup> reiterates its commitment to autism research that enhances the self-determination of autistic people and our community integration. ASAN advocates for a vision of the world where not only is the broader community “aware” of the existence of autistic people, but where our value as human beings is celebrated and we have access to the resources and accommodations we need. Research *on* these resources and accommodations, however, remains woefully limited.

According to the 2016 IACC Portfolio Analysis Report, which contains the latest data available, only a meager 2 to 3% of all federal autism research funding in 2016 went to research on improving services and supports. Although the IACC reports 6% of total autism research funding went to services and supports (research which falls under the 2016-2017 Strategic Plan’s Question 5, “What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?”), *more than half of that funding* went toward the “practitioner training” subcategory. Funding for practitioner training, even if it is primarily focused on increasing the cultural competency of practitioners,<sup>3</sup> is not funding for research that enhances the quality and diversity of the services available to us. We call on the IACC to end the use of this “creative accounting”<sup>4</sup> and honestly report— and meet— the need for more research on services and supports.

Even though autism is a lifelong state of being, there is still far too little research funded that addresses how autistic people grow and develop across our lifespans. Only 2% of all autism research funding goes

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<sup>1</sup> Autism CARES Act of 2019, H.R. 1058, S. 427, 116th Cong. (2019).

<sup>2</sup> Autistic Self Advocacy Network, *Autism Acceptance Month: Acceptance is An Action*, <https://www.autismacceptancemonth.com/> (last visited April 5, 2019).

<sup>3</sup> The IACC notes that this is the primary focus of the practitioner training subcategory on pg. 52 of the 2016 Portfolio Analysis Report, stating that the supports and services subcategory includes “research to develop and evaluate the training of service providers who work with individuals with ASD, *particularly identifying culturally appropriate best practices*” (emphasis added).

<sup>4</sup> Autistic Self Advocacy Network, *ACTION ALERT: Tell HHS to Stop “Creative Accounting” with Autism Research*, July 10, 2012, <https://autisticadvocacy.org/2012/07/action-alert-tell-hhs-to-stop-creative-accounting-with-autism-research/>.

to lifespan-related issues, and 74% of this extremely limited funding goes specifically towards research on transition to adulthood. Only 6% of lifespan issue funding addresses research that would address our quality of life and ameliorate negative impacts of co-occurring conditions. While transition to adulthood is undoubtedly important, excessively focusing funding on only this phase of life means that other issues - such as aging in autistic people and the trajectory of autistic adulthood more generally - are left underfunded and under-researched.

The main focus of autism research funding unfortunately continues to be on the biology and causation of autism and on the elimination of autistic traits. In 2016, *more than \$127 million* — nearly a third of total funding — was spent solely on research on the biology of autism. \$86 million was spent on research on “risk factors” for autism and the “disabling aspects” of ASD. By contrast, total funding for research into lifespan issues in autism amounted to only slightly more than \$9 million. The continued disproportionate funding of research that does not serve the needs of the autistic community, and systematic underfunding of research central to our quality of life, is unacceptable.

ASAN strongly urges the IACC to advise the federal government - particularly the National Institutes of Health, which funds 64.3% of all autism research- to invest in research that supports and benefits autistic people ourselves rather than research that attempts to prevent our existence. It is far past time for the IACC, which has verbally expressed interest in supporting a better future for our community, to back up its statements with concrete, actionable steps to make that future a reality.

ASAN’s further comments on specific issues of interest are detailed below.

### **Gender and Sex Disparities in Autistic People**

ASAN appreciates the IACC’s strong interest in research on the needs of autistic women and girls, as expressed by its Cross-Cutting Objective in the 2016-2017 Strategic Plan and its support of research addressing that objective in the 2016 Portfolio Analysis. IACC’s 2017 Summary of Advances, for example, contains a research study which attempted to determine the ratio of autistic boys to girls and noted that “girls with ASD are more likely to be overlooked, misdiagnosed, or identified late.”<sup>5</sup> Prioritizing research into the services and supports that will help autistic girls and women thrive is critical.

However, in its 2016 Portfolio Analysis, the IACC’s Cross-Cutting Objective for Question 2, relating to the biology of autism, was “to understand the biological basis of sex differences in ASD, such as differences in brain structure and functioning among girls and boys.” This objective assumes that such differences exist and that they exist due to genetic or biological causes, rather than differences in how men and women are raised. Yet the evidence base for these assumptions is weak--and, by and large, there is not consensus that neurological sex differences in non-autistic people have genetic or biological causes. The

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<sup>5</sup> R. Loomes, L. Hull, W.P.L. Mandy, “What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis,” 56 *J. Am. Academy of Child & Adolescent Psychiatry* 466, 466-474 (June 2017).

IACC should expect the same level of basic rigor from research focusing on autistic people. We recommend that the IACC focus on research similar to that which was proposed (but notably not funded) in IACC Question 6, which would examine gender in autistic adults and how it impacts our health and our lives.

Furthermore, the IACC continues to omit any mention of the high number of gender nonconforming, gender non-binary, and trans autistic people in our community, nor does it describe the need for research which specifically addresses the needs of this population. The omission grows ever more troubling in light of the increasing number of research studies finding that autistic people are more likely to be LGBTQ<sup>6</sup> and struggle with finding support<sup>7</sup> for our sexual orientations and gender identities. We urge the IACC to better support and advocate for LGBTQ autistic people.

### **Racial and Socioeconomic Disparities in Autistic People**

Although we appreciate the addition of an article on racial and ethnic disparities in the 2017 Summary of Advances, more research must be done that addresses the underdiagnoses of autistic people of color, low-income autistic people, and autistic people who speak English as a second language. According to the Autism and Developmental Disabilities Monitoring Network's 2018 report, white children were 1.5 times more likely to be diagnosed with ASD than Black children, and 1.2 times more likely to be diagnosed with ASD than Hispanic children. Black children were 1.5 more likely to be diagnosed with ASD than Hispanic children.<sup>8</sup> While the report states that the disparities are smaller than they were in previous years, they nonetheless continue to exist. Ensuring that practitioner training is culturally competent is simply not enough to ensure that autistic people of color receive the support they need to thrive.

ASAN particularly encourages the IACC to advocate for research which examines differences in long-term outcomes (for example the percentage of people who successfully obtain competitive integrated employment) between white autistic people and autistic people of color. ASAN also advises the IACC to encourage investigation into systemic inequities which have a significant, known negative impact specifically on the health and well-being of autistic children of color, such as the disproportionate application of school discipline.

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<sup>6</sup> R. George and M.A. Stokes, "Sexual Orientation in Autism Spectrum Disorder," 11 *Autism Research* 133, 133-141 (2018).

<sup>7</sup> John Strang, "Why we need to respect sexual orientation, gender diversity in autism," *Spectrum News*, (November 27, 2018), <https://www.spectrumnews.org/opinion/viewpoint/need-respect-sexual-orientation-gender-diversity-autism/>; Evan Urquhart, "A Disproportionate Number of Autistic Youth Are Transgender. Why?" *Slate* (March 27, 2018, 1:33 PM), <https://slate.com/human-interest/2018/03/why-are-a-disproportionate-number-of-autistic-youth-transgender.html>.

<sup>8</sup> Autism and Developmental Disabilities Monitoring Network, *Community Report on Autism 2018: A Snapshot of Autism Spectrum Disorder among 8-year-old Children in Multiple Communities across the United States in 2014*. Washington, D.C.: Centers for Disease Control and Prevention, 13-14.

## Access to Communication

Access to communication is a vital human right. Autistic people may use a wide variety of possible forms of communication, including verbal communication, behavior as communication, and augmentative and assistive communication (AAC) devices. ASAN reviewed the Autism Research Database after it was updated with data from 2016 and found that research listed under Research Question 4, “Which Treatments and Interventions Will Help?” did contain important studies which examined the effectiveness of various forms of augmentative and alternative communication (AAC) for autistic people, mostly children. AAC-related studies were generally outnumbered by those which attempted to teach non-speaking autistic children how to speak or to improve the expressiveness of the speech of those with inconsistent speech. ASAN encourages the IACC to prioritize research into AAC and into the development of other forms of alternative communication in both children and adults.

ASAN, in partnership with a number of national disability rights organizations, cautions the IACC against claims that any particular form of communication is not “evidence-based,” such as those made by the American Speech and Hearing Association (ASHA) with respect to Rapid Prompting Method (RPM) and Facilitated Communication (FC).<sup>9</sup> The effectiveness of a communication support for a specific autistic person should be determined on an individualized basis. More research is needed to establish which methods work best for which autistic people, and how to best support every autistic person to access communication.

## Working with the Autistic Community

Meaningful advances in the scientific understanding of autism, in the knowledge of how autistic people grow and change across our lifespans, and on which services and supports best serve autistic adults, will not and cannot happen without the participation, input, and leadership of autistic people. ASAN continues to advocate for greater representation of autistic people on the IACC itself, including non-speaking autistic people and autistic people with a range of ethnicities, lived experiences, and support needs. ASAN supports robust partnerships between the research community and the autistic community, especially with respect to grant reviews, increasing the numbers of autistic researchers, and increasing the participation of autistic adults in research at all stages. ASAN urges the IACC to reach out to large federal funders of autism research (such as the National Institutes of Health) and request that they: (1) research autistic adults as well as children; (2) invite a diverse cohort of autistic adults to act as participants in autism research; and (3) consult with us specifically rather than only our parents or caregivers.

ASAN appreciates the opportunity to provide comments on the IACC’s priorities and the future of autism research. For more information on our comments, please contact Julia Bascom, Executive Director of ASAN, at [jbascom@autisticadvocacy.org](mailto:jbascom@autisticadvocacy.org).

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<sup>9</sup> Autistic Self Advocacy Network, *ASAN Response To ASHA Position Statements*, August 27, 2018, <https://autisticadvocacy.org/2018/08/asan-response-to-asha-position-statements/>.

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

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

April 17, 2019

### **Comments for the IACC meeting on April 17, 2019**

Eileen Nicole Simon, PhD, RN

[PII removed]

I planned to attend the April meeting of the IACC, but I am enrolled in a course at UMass Boston on how to prepare a research grant. The course meets Wednesday evenings for 7 weeks, and I don't want to miss the class on April 17.

At the October meeting Dr. Gordon said that discussion I requested of damage in the brainstem auditory pathway would require more knowledge from research, a million dollar research grant over a 5-year period!

The research I want to do is to look for damage in the inferior colliculi in the midbrain tectum (roof of the midbrain). Why? I believe these tiny pea-size auditory processing centers may in some way be essential for young children to hear syllable boundaries in the speech around them.

Roger Brown wrote *A First Language: The Early Stages* (Harvard Press, 1973); he determined that monosyllabic "baby talk" reflected a young child's ability to hear stressed syllables. Autistic children may not detect syllable boundaries, which could explain their use of phrase fragments (echolalic speech), which Kanner (1946) described as "metaphorical speech" (reprint in: *Am J Psychiatry*. 1994;151(6 Suppl):161).

I would like to look for damage in the inferior colliculi in brains from autistic people who had language difficulties in childhood.

Also, I would like to use fMRI. I was contacted many years ago by the lead author of a paper in which the inferior colliculi were prominently evident in fMRI scans: Budd TW et al. *Neuroimage*. 2003 Nov;20(3):1783-94.

Dr. Budd found my website online, [conradsimon.org](http://conradsimon.org). I put this website up in memory of my son 19 years ago (April 2000).

Following are components of a grant application I hope to make. Perhaps comments can be made on some of these ideas:

#### **1. A seminal paper**

Kety SS. [Regional neurochemistry and its application to brain function](#). Bull N Y Acad Med. 1962 Dec;38:799-812.

This paper is free online at [www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/).

Seymour Kety experimented with many methods to measure blood-flow in the brain. The technique of autoradiography was developed in the late 1940s. In the paper cited above, Kety published an autoradiogram picture showing distribution of a radioactive tracer 60 seconds after its injection into the bloodstream of a cat. High blood-flow to components of the brainstem auditory pathway is clearly evident in this picture.

## **2. Blood-flow in the brain**

Kety cited the paper where blood-flow values are listed in a table: Landau WM et al. The local circulation of the living brain; values in the unanesthetized and anesthetized cat. Trans Am Neurol Assoc. 1955-1956;(80th Meeting):125-9.

The paper by Landau et al. cannot be accessed online. I reproduced (with permission) the table with blood-flow rates on my website. The table can be viewed at [conradsimon.org/InferiorColliculus.html](http://conradsimon.org/InferiorColliculus.html).

The table lists blood flow in the inferior colliculus as 1.80 cc/gm/min. In descending order blood flow values are listed for other brain areas, including: sensory-motor cortex (1.38), auditory cortex (1.30), visual cortex (1.25), thalamus (1.03), association cortex (0.88), cerebellar nuclei (0.87), cerebral white matter (0.23), and spinal cord white matter (0.14).

## **3. Metabolism in the brain**

Sokoloff et al. (1977) used carbon-14 labeled deoxyglucose instead of the inert tracer used by Landau et al. (1955). Deoxyglucose is an analogue of glucose. Its uptake provides a measure of energy metabolism.

Sokoloff et al. measured brain uptake of deoxyglucose in monkeys and albino rats. In both species deoxyglucose uptake was markedly higher in the inferior colliculus than in any other area of the brain. The table from their article is also provided on [conradsimon.org/InferiorColliculus.html](http://conradsimon.org/InferiorColliculus.html).

On [conradsimon.org](http://conradsimon.org) I also discussed other measures of brain metabolism like blood capillary density, as well as known functions of the inferior colliculus.

## **4. Metabolism and function**

Processing of acoustic stimuli in the inferior colliculus plays a role in representation of space; this involves moment to moment damping of some signals to enhance focus on sounds of greater importance. Inhibitory as well as excitatory neurotransmitters work together in the inferior colliculi to provide detection of sound onset with a damping function to prevent persistent stimulation.

The hypersensitivity to sounds displayed by some autistic children may represent loss of inhibitory function. Inability to distinguish sound onset then relegate it to background awareness could also be part of the difficulty in recognizing boundaries between words and syllables in spoken language.

With advancing age decline of neurotransmitter function in the inferior colliculus may lead to loss of the capacity to detect and extract meaningful signals from background noise. This leads to difficulty

following a conversation in a noisy environment and may be the reason some elderly people withdraw from social interactions. Could the same or similar disability lead children with autism to avoid social contact?

## **5. Language Comprehension**

For the IACC meeting in November 2008 I made a presentation that remains the best summary of my viewpoint (<http://www.conradsimon.org/IACCfor21nov2008.pdf>).

Loss of the ability to comprehend spoken language has been described in at least 13 case reports following injury of the inferior colliculi. How much more serious this should be for an infant! Following is the list of case reports I provided:

- 1 - Howe JR, Miller CA. *Neurology*. 1975 Mar;25(3):286-9.
- 2 - Jani NN et al. *Neurosurgery*. 1991 Jul;29(1):106-8.
- 3 - Nagao M et al. *Neuroradiology*. 1992;34(4):347.
- 4 - Meyer B et al. *J Neurol Neurosurg Psychiatry*. 1996 Oct;61(4): 423-4.
- 5 - Hu CJ et al. *Neurology* 1997 May;48 (5):1448–1451.
- 6 - Johkura K et al. *J Neurol Sci*. 1998 Nov 26; 161(1):91-6.
- 7 - Masuda S et al. *Ann Otol Rhinol Laryngol*. 2000 Dec;109(12 Pt 1):1107-12.
- 8 - Vitte E et al. *Neurology* 2002 Mar 26;58(6):970–3. -- 2 cases
- 9 - Hoistad DL, Hain TC. *Audiol Neurootol* 2003 Mar-Apr; 8(2):111-223.
- 10 - Musiek FE et al. *J Am Acad Audiol* 2004 Feb; 15(2):133-151.
- 11 - Pan CL et al. *Neurology*. 2004 Dec 28;63(12):2387-9.
- 12 - Kimiskidis VK et al. *Otol Neurotol*. 2004 Mar;25(2):178-82.

## **6. Vulnerability to injury**

Wernicke's encephalopathy (WE) is a distinctive pattern of brainstem damage observed in cases of alcohol intoxication or exposure to poisonous substances such as lead, mercury, and toxic fumes. See citations below.

Vitamin B1 (thiamine) deficiency also causes WE. Vitamin B1 is an essential co-enzyme for aerobic enzymes. A disease known as beriberi became common in the early twentieth century in areas of the world such as Japan. This came about when refined white rice replaced brown rice as a dietary staple.

Cardiac arrest and asphyxia also lead to brainstem damage in a pattern similar to WE, as do some encephalitic infections.

## **7. Asphyxia at birth**

William Windle and co-workers undertook the study of asphyxia at birth as part of a research program aimed at finding ways to prevent cerebral palsy. They inflicted asphyxia on newborn monkeys first by pulling a surgical glove over the head at birth; in later experiments delivery was by cesarean section but the infant monkey left in the amniotic membranes for up to twenty minutes.

These procedures did not produce cerebral palsy and at first no brain damage could be found.



Seymour Kety suggested looking for damage by asphyxia in the inferior colliculi. He had recently found the highest blood-flow in the inferior colliculus using autoradiography. Windle looked again at the brains of monkeys subjected to asphyxia. Yes! Then he discovered the earlier overlooked damage in the inferior colliculi.

The inferior colliculi are tiny pea-sized structures in the roof (tectum) of the midbrain. They are posterior to the superior colliculi. The superior and inferior pair are also known as the corpora quadrigeminae. They are easily overlooked.

### **8. Hypoxia versus asphyxia**

Ronald Myers, a member of Windle's team, undertook a new series of experiments. He produced periods of partial oxygen insufficiency by clamping then unclamping the umbilical cord late in gestation. This procedure produced the expected damage within the cerebral cortex. The monkeys subjected to this kind of partial oxygen insufficiency did develop cerebral palsy.

### **9. Variability in sites of injury**

Variability in which of the brainstem nuclei of high metabolic rate are damaged is likely the result of a variety of protective biofeedback mechanisms. The inferior colliculus may have priority over areas with lesser metabolic demands.

The mammillary bodies are most prominently affected in Wernicke's encephalopathy, but in acute thiamine deficiency, or poisoning with chemicals like pyriethamine, the inferior colliculus is the most vulnerable.

### **10. Hemoglobin**

The initial experiments in which acute total asphyxia was inflicted produced a Wernicke encephalopathy like pattern of damage, and this was most severe in the inferior colliculus. This result can be compared with the finding of severe damage in the inferior colliculus in cases of extreme thiamine deficiency as reported by Vortmeyer et al. (1992), and damage of the inferior colliculus caused by administration of pyriethamine to laboratory rats (Chen et al. 1997). See citations below.

The inferior colliculus has the highest rate of aerobic activity in the brain. Why was this structure spared in the experiments of Myers? The explanation is that protective biofeedback mechanisms go into action when metabolic homeostasis is disturbed.

The way hemoglobin delivers oxygen to tissues provides an example.

### **11. Oxygen Delivery**

Hemoglobin releases oxygen in exchange for carbon dioxide. Body tissues with the highest metabolic rate produce the most carbon dioxide, and therefore make the greatest demand for delivery of oxygen. This is known as the "Bohr effect."

Carbon dioxide produced by the highly active brainstem sensory nuclei should force hemoglobin to give up what little oxygen is available when it is in short supply. The brainstem nuclei will then be spared, but leave nothing to be delivered to the metabolically less active motor centers of the cerebral cortex.

## **12. Oxygen Insufficiency**

Brief total asphyxia, as inflicted in Windle's experiments, is far less likely to occur with survival of the infant. But this might be one of the conditions that leads to the core syndrome of autism. Matsuishi et al. (J Autism Dev Disord. 1999 Apr;29:161-6) investigated outcome in survivors of a neonatal intensive care unit and diagnosed autistic disorder in 18 of 5,271 infants followed for five years; 57 developed cerebral palsy. Meconium-aspiration syndrome was reported as the most significant factor that distinguished children who developed autistic disorder from those who developed cerebral palsy or who developed normally. A brief period of total asphyxia can easily go unnoticed, but meconium aspiration is a sign that the infant was gasping for air.

## **13. Autism Spectrum**

A brief period of suffocation would seldom occur without being part of a more prolonged condition that interferes with aerobic metabolism. Could this be why the core syndrome of autism is so rarely seen? Most autistic children show some degree of mental retardation and signs of motor system impairment.

The work of Myers and Windle provides insight on how a spectrum of developmental disorders can occur ranging from motor disability at one end to sensory dysfunction at the other, and why most individual cases will include aspects of both. It seems likely that the Bohr effect is a factor whether the metabolic compromise is due to lack of oxygen, or caused by infection, prenatal exposure to alcohol, or by abnormal metabolites produced in genetic disorders such as phenylketonuria.

## **14. Citations on Vulnerability of the Inferior Colliculi**

Citations below are from [conradsimon.org/InferiorColliculus.html](http://conradsimon.org/InferiorColliculus.html), an essay posted online in April 2000. They represent hours spent looking things up in the library: (3 lists: Measures of Aerobic Activity - 12 citations, Functional Significance - 7 citations, Vulnerable Brain Sites - 60 citations)

### **Measures of Aerobic Activity**

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## **Additional Comment for the IACC meeting on April 17, 2019**

Eileen Nicole Simon, PhD, RN

[PII removed]

### **15. Reports of Auditory System Defects in Autism**

Comments 1-13 submitted above are from my website (posted in April 2000) and a presentation I made at the IACC meeting in November 2008.

In 2011 Kulesza and Lukose found abnormalities in the superior olivary complex in brains from 9 people who were autistic from childhood [1]. Malformation of the superior olives had been described in a paper by Rodier et al. [2].

Lukose et al. then exposed laboratory rats to valproic acid (Depakote) during gestation, and found similar derangement in the superior olives [3]. The superior olivary complex provides input to the inferior colliculi from lower brainstem auditory system centers.

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To the esteemed members of the IACC.

My name is Hari Srinivasan and I'm an undergraduate student studying Psychology and Disabilities Studies at the University of California, Berkeley.

I'm also a non-speaking autistic and type to communicate. In fact, I learned to type and thus communicate only at age 13. Till then my educators had decided that I was not capable of much and relegated me to severe special education classrooms which were no better than glorified babysitting. Ironically, my very learning to communicate came about due to a chance meeting between my parents and another autistic who typed to communicate. An alternative mode of communication is something that should have been tried by the formal educational system rather than based on a chance meeting. And even after I found a means to communicate and exhibit my intelligence, my school district still wanted to act as a gatekeeper and limit educational opportunities for me. They simply refused access to mainstream education due to preconceived notions built over the years about my intelligence. My family was forced to find ways to work outside of the traditional school district system and go through a charter school. It has been an arduous journey for me and my family without the support that the traditional educational system would have provided.

Today this same non-verbal individual (me) writes for The Daily Californian, newspaper for both UC Berkeley and the city of Berkeley. My newspaper column on autism was recently nominated as a finalist for a state journalism award. I also work at the (Prof) Hinshaw Lab as a research assistant. I continue to maintain my 4.0 GPA. And this semester, as a student instructor, I am teaching a 12-week, 1.5 hour class on autism to a group of 20 neurotypical students at UC Berkeley. Much like the butterfly effect, I believe that if I can change the mindset of even one individual student about autism here at Berkeley, it will have far-ranging effects down the line. My education and life long career will undoubtedly involve advocacy and involvement in public policy for disability and autism, especially non-speaking autism.

The fact of the matter is that opportunities are hard enough for autistics in general but the effect is unduly magnified when the autistic is nonspeaking. We are never given a chance at all to start with as we are assumed incompetent and unintelligent.

The focus should be on teaching alternative communication skills (whether it is via typing on a keyboard or letterboard) to the nonspeaking autistics early on so that we too may have the opportunity to live our potential. Communication is a fundamental human right. Cases like mine should be the norm, not the exception. While I have found the university environment to be very supportive it was the opposite during my elementary school years, which means the gates of opportunity are shut early on for many like me by the very system that is supposed to nurture and guide us.

In my Disabilities Studies class this semester I learned of the groundbreaking work done at the UNCRPD through my professor Dr. Victor Pineda who was a participant, and of the whole history of the disability rights movement which began at this very university leading upto the ADA and later IDEA. I now applaud and commend the United Nations for exploring and supporting communication access, choice, and



rights for nonspeaking autistics. Non-Speaking autistics like me have a lot to contribute to society. The world needs exposure to all range of the neuro diverse minds of autism. Only then will mindsets and perceptions change. The end goal for all us, speaking or nonspeaking, autistic or not, is to lead a meaningful and productive life.

We look forward to continued support from the IACC in helping the non-speaking autistic community gain access to communication, education, and inclusion in society. Both shifts in policy is needed to include communication access for this nonspeaking subpopulation of autism, as well as funding to back that policy.

Thank you  
Hari Srinivasan

**C. J. Shiloh, MT-BC**

**April 17, 2019**

I would like to applaud and commend the United Nations for their efforts on 04/02/19 in exploring and supporting communication access, choice, and rights of non-speaking autistic people. The IACC can and should follow this example, to pay more attention to alternative means to communication, which includes Rapid Prompting Method, Supported Typing, and other Augmentative and Alternative Communication devices.

**C. J. Shiloh, MT-BC**

*Neurologic Music Therapist*

**Owner, [Annapolis Music Therapy Services](#)**

[PII removed]

**Director, [The Musical Autist](#), 501c3 nonprofit**

[Read about our work in Huffington Post](#)

**Allison Thurman**

**April 17, 2019**

Dear Interagency Autism Coordinating Committee (IACC),

My son (13 years old) is a non-speaking autistic (his own definition of his disability) who uses a variety of multi-modal communication methods, including a Letterboard, an iPad application, and gestures.

We applaud and commend the United Nations for exploring and supporting communication access, choice, and rights for non-speakers. We highly suggest that IACC invite the same or similar speakers to deliver presentations at a future IACC meeting.

Sincerely,  
Allison

My name is Cami Berkau and I have a 22 year old son who is severely autistic and nonverbal. We were able to find, after years of research and looking for ways to help him communicate, a way using supported typing which has given us a huge insight into my son and he has even able to help now with medical decisions and daily needs and wants. We had to pull him from the local public school which decided against allowing him to communicate in this manner. We enrolled him in a private day school but it is very cost prohibitive and so many deserve access and the right to be heard. We were so pleased with the UN for allowing and looking in to to alter native communications for these non speaking individuals who have so much to say. My sons class watched the UN even t and these were his thoughts he expressed after watching.

From Josh Berkau:

"Hate is real but love gives way to hope! Listening to such a vast panel of presenters who truly understand what industry autism experts fail to consider, gives us(me and others with movement challenges ) hope! I need hope desperately . Friends help each other have. Hope! " 4/2/2019

Again this is from an individual who was considered mentally operating at a pre school level at 16 years old by the school system and all the experts. We had explored almost every avenue and this was what has allowed him to communicate with myself and his team. I am hoping in the future more presenters such as those who were there will be invited to give you their ideas and thoughts on how best to serve this large group of individuals who have for the most part been abandoned by the system and given up on and most efforts are spent trying to correct behaviors instead of looking at the massive movement dysregulation. Thank you again and again so excited to see a group such as yourselves willing to step outside the box!! God bless .

Cami Berkau. Mom to a future preacher !!!

**Damon Kirsebom**

**April 17, 2019**

Dear people of the Interagency Autism Coordinating Committee:

I would like to applaud the United Nations for highlighting that autistic people often require alternative modes of communication, and should have the right to do so in the way that is easiest for each individual.

I am non-speaking, and learned to type on an iPad or keyboard, however, there was push-back by some professionals while I was working towards independence.

The issue, I believe, is that these alternative ways in which some of us communicate is not "PECS," and requires a person who sits with us in order to help us regulate our anxiety and sensory challenges. My support person is crucial in my communication, as she helps me remain calm, and realizes when I am stuck, or off track.

I would like to add that I learned to communicate after 14 years of silence!!!

Finally, I am receiving an education, and will attend college in the near future. I would like to participate fully in my own life, and communication has enabled me to do so.

Further, I am a person who ALWAYS needs a support person--so having a person who sits with me while I type is not different to the times when I am not communicating. There are many misconceptions about using a letterboard, or typing. It is finally time for autistic voices to be the ones that are heard over the din that is autism service providers. We do know ourselves, and understand the types of support we need, or do not require.

Truly, I cheered when I watched the beautiful presentations by people such as Ido Kedar, and David Savarese! They speak the truth, and have shepherded so many non-speaking autistic people to real communication.

I thank you so much ,

Damon Kirsebom  
18-year-old autistic guy

**Jeanine Davis**

**April 17, 2019**

Abuse of Power by OC. Social Services have filed an OCR. complaint. Need Help being ignored!!!

I have a teen son with Autism Spectrum Disorder and ADHD. The OC Social Services agency has failed to recognize his lifelong documented disabilities and Abused their power by putting him into Foster Care 1 week prior to 18th birthday. Our family was already getting our own counseling services at time of removal. The agency failed to consider his low frustration tolerance, coping skills and aggression due to the nature of his disabilities. Numerous civil rights violations and apparently it is a systemic issue stealing disabled kids right before 18 for the \$\$ but yet agency is failing to provide these children's with the services they require, not letting them access their religious beliefs, and in my case have not let me see my son for 4.5 months. This is basically a kidnapping. We do not take children away from parents who raise their children up to 18 and then unlawfully put them into Foster Care. This is not what AB12 extended Foster Care is meant for.

Jeanine Davis

User Name: Jeanine

**Rita Rubin**

**April 17, 2019**

As the mother of a non-verbal adult daughter with autism, who has been active in the autism community for many years (thirty years on the Board of Directors of our local chapter of the Autism Society, fourteen as President) I would like to encourage the IACC to make communication a priority when looking at the needs of people with autism. My daughter was introduced to Facilitated Communication, a form of AAC, in 1991. After training for five years she was able to type to communicate without physical touch (which is part of the training). She was able to graduate from high school with honors, complete a Bachelor's Degree from Whittier College, and start her own business, "Sue Rubin Consulting". Without a method of communication this would not have been possible. Her experience, and that of many others, has led us and many researchers to the understanding that much of what appears to be an intellectual disability in non-verbal people with autism, is actually a movement disorder.

When something great happens to you or you did something great, isn't it better when you share what it was or what you did with someone else?

Think about something you just did that was really a great accomplishment for you. Did you tell someone or did someone else find out about it then you had a verbal conversation about it. Maybe people texted you, communicating to you how wonderful it was whatever you did. Maybe you posted it on social media to communicate it out to lots of friends and family really quickly, instantly.

What if you couldn't share it. What if no one knew. What if you did something great in your mind but no one knew about it. You couldn't tell someone because you couldn't communicate it. In fact then, no one would even think you did this great thing because they didn't know about it so why would they think you did anything. So maybe they would think you are not even capable of doing this great thing but you know you did it.

Communication through spelling or using an iPad or iPhone is communicating.

In fact remember you communicated that great thing you did earlier out to others using your iPhone or iPad and posted on social media or texted it, never saying a word but everyone that mattered to you knew and communicated the same way back with Likes and Loves and Wows and comments and emojis and punctuation. Man were you excited, 124 likes! A record for you. But you didn't verbally say anything and look at the pride, the gratification you got from that. How many times did you check FaceBook. How many times did you check your phone for text communication back from your friends and loved ones? Lots I bet because you loved the feedback. You loved the communication.

The United Nations put a line up of non-speaking people together who type and spell to communicate on April 2nd for Autism Awareness Day so the need for communication could be communicated to people who know how to communicate so that they could see how essential it is for people who cannot communicate to communicate.

My son Will did not communicate for the first sixteen years of his life therefore no one thought he could do much or learn or be educated including me his mother. At age sixteen we found spelling. Spelling. Yes a simple low tech thing that kids do in second grade when they take spelling tests. A simple concept has completely changed his life. He is in a neurotypical high school. He has goals of attending college and getting a productive technical job. He will need assistance to do these things but we know he is intelligent and can and will do so many things because he communicated it to us. He spelled it.

What is best way to spend money on people with autism? Teach them to communicate. They need it just like you do.

Tracy



**Elizabeth Vosseller, M.A.**

**April 17, 2019**

Members of IAACP,

I am writing to encourage you to follow the lead of the United Nations in their support of nonspeaking individuals who use alternative means to communicate, including methods that involve spelling or typing. Approximately one third of all autistic individuals are unable to use speech as their primary means of communication. It is also estimated that the incidence of apraxia as a comorbid condition with autism may be as high as 2/3. We need to recognize the need for innovative alternative communication for this population of autistics. Further, we need support for research to investigate how motor-sensory issues affect communication.

I would highly encourage you to invite nonspeaking autistics to meet with you to understand their communication needs, their successes and challenges as well as their concerns regarding access to communication.

Thank you for your consideration of this matter and your dedication to the needs of ALL autistic individuals.

Respectfully submitted,  
Elizabeth Vosseller

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

**Christine McKee**

**April 17, 2019**

My name is Christine McKee and I served as a public member of the IACC from 2007 to 2012 as a parent advocate. I served on the Services Subcommittee and was part of the impetus behind dedicating a portion of the IACC meeting in May 2009, to the issue of Augmentative and Alternative Communication. As many of you are aware, on April 2, 2019, as part of World Autism Awareness Day, the United Nations chose the theme of "Assistive Technologies; Active Participation." The UN program included presentations by several self-advocates, including those who type and utilize letterboards as part of their communication strategies. As highlighted in the UN program, communication is a basic human right and assistive technologies, like keyboards and letterboards, remove barriers allowing for equal participation and full inclusion.

A few years ago, my nonspeaking daughter, who expresses communicative intent in a variety of ways, started using a letterboard. One of the things she asked for was to be removed from special education classes and placed in high school grade level courses. She is currently in her third year of such placement and she has progressed from jobs within her school building, to jobs within the general community. The letterboard has changed her life as she can now openly communicate, direct her own future, and participate interactively with those around her.

Opponents of supported typing routinely assert letterboard usage is linked to false allegations of sexual abuse and therefore, letterboards are dangerous. My daughter's story turns that narrative around. What happens when an alleged sexual predator, caught on videotape, is your child's former school bus driver? My daughter, as a potential prior victim and/or witness to abuse, could proceed with an "approved" investigatory interview designed for "non-verbal" children, a format she has never been able to access. Or, she could use her letterboard to answer questions and risk opening the door to heightened scrutiny by letterboard opponents if she were to have pertinent information to the investigation. At stake right now, are the basic human rights of the nonspeaking autistic community. Statistics show that persons with intellectual and developmental disabilities are at an increased risk of abuse. The members of this community must be able to seek justice on terms equal to those of every other member of society. Individuals who type or use letterboards to communicate deserve to have their communication supported in their schools. And individuals who have yet to find a method of communication that works for them, deserve the opportunity to explore supported typing and letterboard use. My daughter's perspective on what is "dangerous" differs greatly from that which has been labeled as such.

There is a body of research which supports the validity of supported typing. It is summarized and available on several websites, including the United for Communication Choice website. I think it's important to call the IACC's attention to a Facilitated Communication program being implemented in one of the DC area's public school systems. It has been in effect for 6 years, since 2013. The children in the program are primarily nonspeaking or minimally speaking. They have moved from special education classrooms into the general education curriculum, they are progressing grade level by grade level, and are on track to receive high school diplomas. This is a school-based intervention, serving the

nonspeaking community; two factors that are highlighted as areas of priority in the current Strategic Plan. Review of this program's data, the student's IEPs, and the evaluations which take place under the state Autism Waiver program, etc., could be used as a starting point for inquiry into supported typing methodologies.

I encourage the IACC to follow the lead of the United Nations and to take action to further the interests of the estimated 5,000 children and adults in the United States who communicate, or are learning to communicate, via typing or through letterboards use.

Sincerely,

Christine McKee  
[PII removed]

**Mary Ellen Wells**

**April 17, 2019**

Hello,

I would like to applaud the United Nations for exploring and supporting communication access, choice, and rights for non- and minimally speaking autistic people. The lineup of speakers was just outstanding, many of whom I have heard about for years but never had the pleasure to see express themselves so eloquently.

Please invite these same speakers, David James Savarese, Soma Mukopadhyay, Tito Mukopadhyaya, Neal Katz, Ido Kedar, to name a few, to present at future IACC meetings. There is so much more to be said for access and inclusion.

I speak as the mother of an unreliably speaking autistic who gained access to his high school curriculum through the use of a letterboard and is now on track to graduate high school.

Thank you so much! What a riveting and inspiring event!

Mary Ellen Wells  
Windsor, California

**Matt Hayes**

**April 17, 2019**

I want to make my way forward as a person who is fully a part of society as a whole. This effort can only succeed if I have a viable way to communicate. My communication must be dictated by my needs, just as everyone else communicates based on their internal and external needs. I might write or sign or point to letters or use an iPad with an app like Word, but they are all viable and essential methods. If we do not support all methods of communication, we risk a crisis of unsustainable proportions because people without communication are cut off from society and forced into a dependent state that must be supported by taxpayer dollars.

Communication is a right, a necessity, and a financial imperative.

I am an autistic, minimally speaking person who has purpose and employment because of my communication.

Matt Hayes

Subject of Emmy winning PBS documentary My Voice: One Man's Journey to Overcome the Silence of Autism

**Casey Woodfield, Ph.D.**

**April 17, 2019**

Dear Interagency Autism Coordinating Committee,

Please accept this note as part of the public commentary for the upcoming IACC meeting. I am writing to commend the United Nations for centering and supporting communication access, choice, and the rights of nonspeaking and unreliably speaking people in the April 2, 2019 World Autism Day event. As a researcher, colleague, friend and ally living and working alongside the community of autistic individuals whose communication and inclusion is too often the most tenuous, it was encouraging and impactful to see the rights of nonspeaking people upheld by the UN last week. I want to highly encourage the IACC to invite those presenters, or reach out to the many other folks in the autistic community, to deliver presentations at further meetings.

Sincerely,

Casey Woodfield, Ph.D.

**Kerry Lane M.D.**

**April 17, 2019**

When will IACC address the eighteen peer reviewed articles that link Autism to Tylenol use in the peri-vaccination period. Tylenol depletes glutathione needed to detoxify metals in vaccines. Use of Tylenol began the Autism epidemic in the 1980s when aspirin use was stopped. Bringing this knowledge to the forefront will result in the rapid end to the Epidemic.