

Written Public Comments

**IACC Full Committee
Meeting**

October 17, 2018

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Addressing the Panel on Employment for People on the Autism Spectrum: More persons with Autism are entering higher education (not speaking about the specialized supportive colleges - which can be great for some students). The whole area that was not addressed are the challenges, barriers, and civil rights discrimination at the schools of higher education (public and private) technical and university settings - from the application process, admissions, attendance, dorm room living, financial aid/loans, taking a less credit load, student life, classroom teams/bullying, academic/instructor bullying, unfilled accommodation requests, what are adequate disability support services, graduation rate, sexual assault/assault rate on campus of those with Autism, graduation, internships, into the workforce, and holding down a job at what level after graduation. How can a person with Autism be successful in the higher education setting (when many of these schools have not had to address serving such students - within the accreditation or auditing/reporting functions required - as their policies have not kept up with the needs of these students).

Christie Riehl

October 17, 2018

The IACC has presented research and recognized ABA as an evidence-based approach to understanding autism; developing successful approaches to severe problem behaviors; high level functional analysis as well as communication and learning strategies.

Of course the self-advocacy community should be heard as part of the work of the IACC. John and Sam are powerful self-advocates who have made great efforts to advocate on behalf of ASAN members as well as the autistic community.

John and Sam have also been clear in public discussions on other forums (Twitter, blogs, etc.) that they are unaware of any autistic adult who received ABA-based therapy as a child and would recommend it. Further they have stated that autistic adults often consider that they have lasting "psychic harm" related to ABA-based modalities.

Questions:

John and Sam: Do you feel that you have been able to make these concerns clear to the IACC?

John and Sam: As designated self-advocates on the committee, what would you like to see in regards to the scientific community's recognition/understanding of ABA as an evidence-based approach?

IACC: How can you effectively address self-advocates' concerns and questions about the accepted evidence-based status of ABA given the IACC charter?

Thank you for your time,

Christie Riehl
[PII redacted]

(Adapted from <https://corticalchauvinism.com/2018/06/11/yuval-levental-vitamin-d-and-autism/>)

What is the current status of awareness, research, and funding for genetic Vitamin D deficiency as a potential cause of autism? There is already some research on the matter (<https://www.ncbi.nlm.nih.gov/pubmed/28217829>), but I was not even aware of it until a few weeks ago. Recently, I have tried prescription-only 50,000 IU/week Vitamin D supplements to boost my productivity and overall energy, and the results are astounding.

My Vitamin D level is 12.9 ng/mL, about a third of the minimum level, and about a fifth of the recommended level. Before I was tested for it, I was eating right, getting enough exercise, and was even already taking over-the-counter Vitamin D supplements. According to the Harvard Medical School health blog, only 6% of Americans have vitamin D levels less than 12.5 ng/mL (<https://www.health.harvard.edu/blog/vitamin-d-whats-right-level-2016121910893>), so it is likely genetic.

Many autistic individuals may want to seek a treatment/cure because of difficulties with life skills, unemployment, and relationships (<https://www.npr.org/sections/health-shots/2015/04/21/401243060/young-adults-with-autism-more-likely-to-be-unemployed-isolated>). The difficulties are significant enough to the point where accommodations most likely will only work for a minority of autistics. Even though I did well on tests at school, I could only memorize but not synthesize bits of information, and had significant difficulty focusing at work.

Looking up information on Vitamin D, I learned that Vitamin D provides energy to a person's mitochondria, which are the batteries of the body's cells (<https://www.ncl.ac.uk/press/articles/archive/2013/04/vitamindproventoboostenergyfromwithinthecells.html>). Therefore, it is likely that for some autistic individuals, low Vitamin D can explain potential difficulties with employment. Awareness could involve knowing that treatment for this issue is lifelong but simple.

Robin Bresette

October 17, 2018

Support Title X funding.

Carin Burns

October 17, 2018

Please support Title X. This funding is crucial for the health and safety of all citizens.

Kara Churo

October 17, 2018

Support funding for Title X!!!

Ryan Carboni

October 17, 2018

There is no accurate test for autism. I have been a victim of false accusations of malingering which are extraordinarily difficult to disprove. While nothing could be done for my specific situation, the issue is something I wouldn't want others to face and is something that anyone should see as disturbing.

The most obvious method as far as I can tell is an EEG scam of a person completing various tasks and estimating latency. Otherwise diagnosis is equivalent to medieval guesswork.

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

Oren Evans

October 17, 2018

I have a hypothesis that explains the cause of autism, the male to female ratio, the seasonal variation, the unusual prevalence in the Pacific NW, in day cares, in preemies and the Amish community. It identifies the hereditary trait as well as the environmental trigger. It's too long to retype so I'm sending it as an attachment.

Please don't let my lack of medical background sway you, that is not what is needed at this point in the process. I have always had above average observational and problem solving skills. My job was to gather all the pieces of the puzzle developed by qualified medical researches and put them together in order to solve the problem..

Regards,

Oren Evans

AUTISM CAUSE a NEW DIRECTION

The Occam's Razor Version

By Oren Evans Private Researcher

What causes autism?

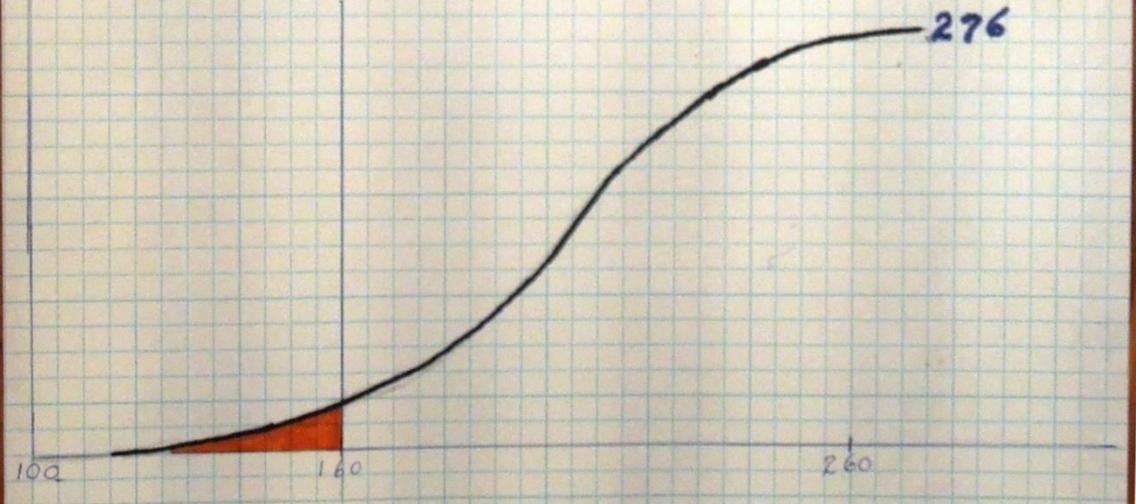
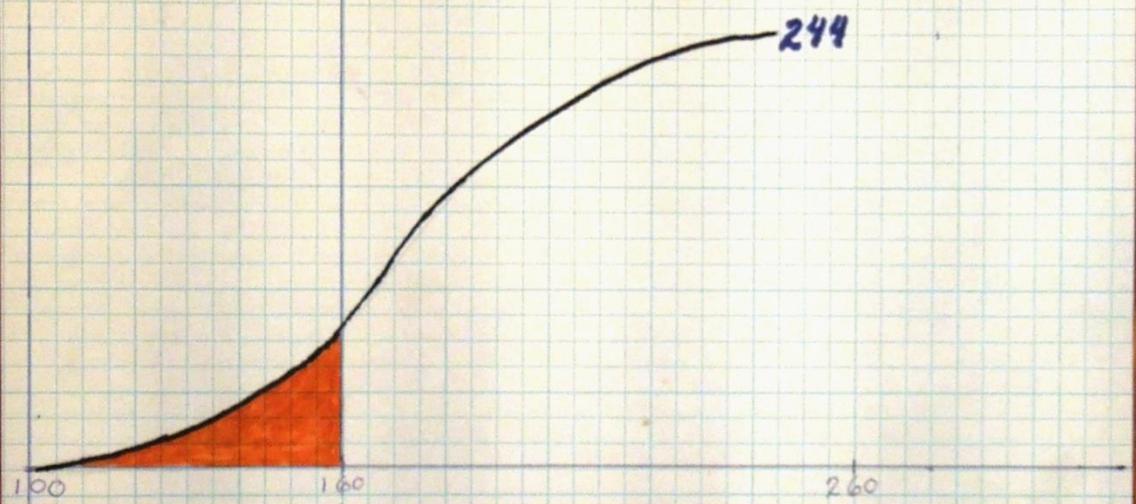
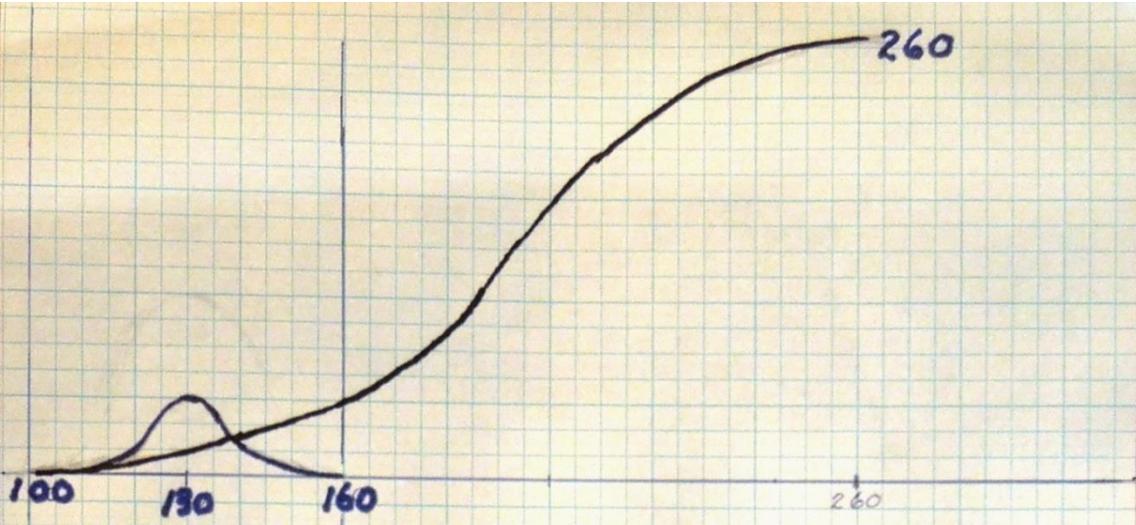
Autism researchers have developed many clues but haven't been able to find the answer. They all agree on one thing: autism has both a hereditary component and an environmental component. I would add one more thing to that, a very new fragile still developing brain.

Research at the University of Rochester found that autistic people detect motion twice as fast as the general population. [2] What they and others fail to recognize is that this group of people would have the same results even if they weren't autistic. I will show that this is the hereditary trait and prerequisite needed to become autistic. I will do this using autism research as well as research and data from other areas. By using this research and data all of the pieces of the autism puzzle fit together. The environmental trigger is determined; the male to female ratio is answered as well as the seasonal variation and the increased prevalence in the Pacific NW, in day care, in preemies, in the more affluent families and the low or no autism in the Amish community.

The left half of the bell curve for the general population and the bell curve for the autism group are shown at the top of the chart below. I didn't bother showing the right (slow) half of the curves. Notice that the curves do not go below 100 milliseconds because of the time it takes to click a mouse, tap a screen or push a button. The general population curves peaks at 260 ms so the autism group curve would peak at 130 ms and a uniform curve would go from 160 ms to 100 ms. While not a precise line you can see that children with a response time less than 160 ms are at a high risk of becoming autistic, of course only those in that group who are exposed to the environmental trigger may become autistic.

Males have a 13% faster visual response time than females.[1] This translates to about 32 ms so taking the general population bell curve and separating the male from the female requires moving the male curve 16 ms to the left with the peak at 244 ms and moving the female curve 16 ms to the right with the peak at 276 ms. If you then find the standard deviation and the Z values at 160 ms and plug them into a Z to percentile calculator about 6% (5.82%) of males will fall into the at risk group while only 1.5% of females are at risk. This explains the 4:1 male to female ratio that is seen in the autistic population and is an indication that we are on the right track. Of those at risk (about 7.5%) not all will become autistic; it will depend on the amount of exposure to the environmental trigger as well as the individual's visual response time. These two conditions produce the wide spectrum we see in autism.

It is interesting to note that calculations for the US male:female ratio and the at risk group indicate 3.98:1 and 7.5% respectively while in countries using 50 cycle electricity the calculations indicate a ratio of 3.50:1 and a 10% at risk group. Adding to the case for the combination of a fast visual response time and fluorescent light is the fact that when Somalis immigrate to developed countries their communities have a high prevalence of autism, but almost no autism in the home country.[15] The rate is so high that it appears that they may have more individuals with a fast visual response time than other ethnic groups.



If a fast VRT is the hereditary component, then the environmental component has to be a visual input. Now we need to look at the difference between people with a VRT below 160 ms and the rest of the population. There are pulsating light frequencies that those with a fast VRT can see and be affected by while those with a normal VRT only see a steady light and are not affected. This is known as the flicker fusion frequency and varies widely from individual to individual based on their VRT.

So the environmental component is quite likely a pulsating or flickering light. The main source of this light is fluorescent but LED, sodium vapor and mercury vapor all produce a flicker based on the electrical supply. Research using EEG brain wave monitoring proves that fluorescent light alters brain waves [3]. Brain waves of individuals with the fastest VRT are affected the most. Even if you are not conscious of the flicker your visual system and brain are still affected, this is known as subliminal flicker. Fluorescent lights, mercury-vapor and sodium-vapor lights are actually strobe lights, i.e., turning on and off based on the electrical frequency. This produces an unnatural visual environment to which humans had never been exposed. It's well known that strobe light can cause migraines, disorientation, and seizures. Much has been written about the detrimental effects of fluorescent light. Brain waves represent the brain's electrical activity. The five senses are the keyboard to the brain. The electrical input from these senses determine how our brains develop, who we are, and who we will become, what vocal tones and facial expressions mean and how we interact with the world. If one of the main inputs—in this case the visual sense—is producing corrupted brain waves, it is understandable that infants with a fast VRT and exposed to fluorescent light fail to develop a normal social skills foundation, resulting in autism. Some in the medical profession consider that all humans are born prematurely, before the head becomes too large to pass through the birth canal. The still developing brain is very fragile until the child is two or three years old. Without language and lots of memories to slow the brain down the infant brain may have a faster VRT than they will when older. Try to read this or try to interpret some one's facial expression while blinking as fast as you can and you will understand the problem.

Listed below are other cases of abnormal prevalence that can be explained using fluorescent light or the lack of as the cause.

- In the Pacific Northwest, more rain equals more autism [4]. The inordinate number of rainy and overcast days requires additional hours of artificial lighting including fluorescent light, resulting in additional cases of autism.
- There is a higher incidence among children conceived December to March [5]. They are born just prior to the shortest, darkest days of the year, again requiring additional hours of artificial light during infancy.
- The incidence of autism is relatively high among children born prematurely [6]. One in four infants weighing between 1 and 3.3 pounds show signs of autism as toddlers, 18-24 months. These children spend extended time in neonatal care, continually exposed to fluorescent light. The lower the birth weight the longer the time in neonatal care and the greater the risk. The male-female ratio for premature children developing autism was 6:1,

again indicating the fast VRT component. At the 6:1 ratio that's 43% of the boys and 7% of the girls.

- Children using daycare have a high incidence of autism [7]. Research using Google Earth's street-level function found that more than 90% of daycares are in strip malls or stand-alone commercial buildings, certainly all with fluorescent lighting.
- In New Jersey the prevalence of autism in households making over \$90,000 per year is 17.2/1000 while for households making less than \$30,000 per year it's 7.1/1000.[8] The lower income families have to use friends and family for child care while the more affluent can afford professional preschool and day care services. This trend holds true on a national basis, I graphed the lower 48 states based on median income, Maryland at the top and Mississippi at the bottom. The autism prevalence rate for each state followed the same trend, the lower the income the lower the autism rate.
- The four countries with the highest rates, and 7 of the top 10, use 50-cycle electricity [9]. Lowering the frequency from 60 cycles per second to 50 means a slower flicker rate, so those with a somewhat slower VRT can be affected.
- Researchers have identified 10 clusters in southern California with high rates of autism. These clusters are neighborhoods with expensive, upscale housing where both parents are highly educated [10]. Due to their education level, each may want their own career or both may have to work to support their lifestyle, resulting in preschool or daycare for the child and exposure to fluorescent lighting.
- The dramatic increase in the incidence of autism over the past three to four decades is likely due in part to the advent of the compact fluorescent light. From 2000 to 2007 CFL sales went from 21 million to 397 million, an annual increase of 52% [9]. By 2009 70% of homes in the United States had CFLs and averaged 4.4 CFLs each [9]. Japan, the country with the highest incidence of autism, had CFLs in 80% of homes as early as 1996 [11].
- Other factors contributing to the relatively recent increase in the incidence of autism are the increase in single-parent homes and the declining economy forcing both parents to work, both leading to an increase in the use of daycare and adding asbergers to the spectrum.

The Amish have little or no autism. The 350 thousand Amish use no electricity in their homes, so no fluorescent lights. Dr. Frank Noonan, practicing for 30 years and treating thousands of Amish children in Ohio, has seen no autism [12], and Dr. Kevin Strauss practicing in the Pennsylvania Amish area has seen no idiopathic, or classic, autism [13]. Researchers using 1,899 young Amish indicated a prevalence of 1:271. Of the 7 children found to be autistic only 3 of them (1:633) were found to be autistic on both of the tests that were used so all of them may be just able to make the aspersers spectrum. All researchers are biased including me, so I tend to believe the doctors who have no ax to grind. Autism is found all over the world, in all races and all cultures, so unless you believe that the Amish are from somewhere else in the galaxy their lack of autism should provide a strong case for fluorescent light being the environmental component of autism.

The wide range of ASD is due to the variation in exposure time as well as the variation in VRT for each individual.

During the many years that I have been researching autism what I have not found is almost as important as what I have found. I have never found a situation when a greater exposure to fluorescent light that resulted in a lower prevalence of autism or a lack of fluorescent light that resulted in an increase in autism. The amount of fluorescent light has always correlated with the amount of autism.

Evidence strongly points to the strobe effect of fluorescent lighting as the cause autism in the subset of children with very fast VRTs. Fluorescent light became commercially available in 1938; autism was first diagnosed by Dr. Kanner in 1943. An analysis of 11 children was used to make that diagnosis [14]. Dr. Kanner said that this was a new never before seen condition but many researchers believe it has been around for hundreds if not thousands of years. If Dr. Kanner and I are right autism couldn't have existed until pulsating light was invented.

Mercury-vapor and sodium-vapor lights were developed prior to 1910 and have the same strobe effect as fluorescent light. These were mainly used in warehouses and for outdoor lighting until the size was reduced for residential use. In fact, fluorescent lights are simply mercury-vapor lights with a fluorescent coating on the inside of the tube to improve the colors emitted.

I am still trying to gather data to confirm other predictions that I have made. UC Davis did a study linking autism to the proximity to the interstate highway system in certain locations where the dwellings were very close to the highway, measured in yards. Repeated requests for the exact location of the dwellings have gone unanswered. I predict that sodium vapor or mercury vapor street lights will be found that shine on the back of those dwellings. The main island of Japan is divided almost exactly in half, one half on 50 cycle and the other on 60 cycle electricity. I predict the 50 cycle half will have the highest prevalence of autism. There are remote villages in India that are not on the grid so I predict that, like the Amish they will have little or no autism. If proven true they will bolster the case for a rapid VRT and fluorescent light as the cause of autism.

This hypothesis has merit. I am open to suggestions on how I, a retired Plant Manager at a pulp and paper mill, can spread my hypothesis further. I feel I lack the expertise needed to write an article suitable for publication in a medical journal, but I am willing to discuss all of my research—much of which is not included in this general paper—as well as ideas for further research projects.

Respectfully,

Oren Evans

[PII redacted]

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

John Best

October 17, 2018

[profanity redacted] you, you lying bunch of [profanity redacted]. Autism is caused by mercury and cured with chelation using Alpha Lipoic Acid. Tell the public the truth. Again, [profanity redacted] you.

John Best

Londonderry, NH

Dear [profanity redacted],

The best outcome you can hope for with autism is gained by using Andy Cutler chelation to remove mercury from the brain. You [profanity redacted] liars refuse to tell anyone the truth about this and, for that, you should all be [offensive language redacted].

[profanity redacted],

John Best

Londonderry, NH

You lying [profanity redacted] know that autistic people need to chelate the mercury out of their brains to ameliorate their conditions. You have refused to tell anyone this as long as you have existed because you're all a bunch of [offensive language redacted] [profanity redacted]. Why don't you stop asking for comments and just tell the truth? Are all of you bribed to lie about autism? Are you employed by the criminals who poisoned our babies? You're all [offensive language redacted].

[profanity redacted] you,

John Best

Londonderry, NH

Resa Warner

October 17, 2018

Why isn't there more research being done on metal exposures? (this question two decades old) Why are anti-psychotic medications considered "treatment" for autism? Why is autoimmunity not a research priority since inflammatory cytokines are involved according to UC Davis research?

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

Linda (Angelique) Papadimitriou-Varsou, Ph.D., M.P.H., D.A.B.C.C.

October 17, 2018

WRITTEN COMMENTS FOR THE IACC FULL COMMITTEE MEETING OF OCTOBER 26, 2016

LETTER OF DESPAIR: WHERE THE IACC AND AUTISM RESEARCH ARE GOING?

October 18, 2016

10 Facts: **1)** Autism prevalence dramatic increase. **2)** Children with autism become adults with autism while remaining children. **3)** Suicides or suicide attempts are on the increase among adult children. **4)** Scarce services able to help autistic adults. **5)** The Health System, Hospitals, Emergency Rooms, etc. fail or refuse to treat autistic adults. **6)** The Judiciary System ignores the insights and special needs of autism with devastating and dramatic consequences. **7)** In 50% of families having children with autism, at least one parent (usually the father) remains in chronic denial with an attitude of *"flight instead of fight"*, which has detrimental effects on the child. **8)** The exponential increase of autism publications and research, besides the enrichment of researcher's CV, doesn't show any positive impact in autism. **9)** Autism societies and organizations have become more bureaucratic and money collectors than to offer advice or services to persons with autism without discrimination. **10)** Poverty afflicted families having a child with autism is the worst mirror image of any civilized society.

I am the mother and guardian of a 31-year-old brilliant and genius autistic son with the maturity of a 12-year-old, a scientist in academia for 40 years, associate professor in medicine, hygienist, immunologist, clinical biochemist with 2 PhDs, etc., an advocate for the rights and strengths of people with autism in Europe and US as well, promoting the true concept that ***"An Autism Friendly Society which will benefit us all"***. Despite all my endless efforts to fulfil the needs, wants and wishes of my son and not only, I have experienced firsthand all the above 10 facts with no help from anywhere.

I have followed the IACC's efforts since day one, with at least 7 presentations and many comments online up to now. Despite all the federal money and time invested to these absolutely necessary and important IACC's goals, when I see my son in his eyes, I can't tell him: *"My dear son, you are better off today due to the IACC efforts and strategic plans"*, because he is the victim of the judiciary and health system, of a millionaire father in total and chronic denial, in poverty and food stamps, an honor student who dropped off from college just before his graduation with a degree, and in a totally dramatic condition, in and out from the emergency rooms. He told me yesterday: *"Mom, I am not coming with you at the NIH next week because I don't expect anything from them; I rather prefer to stay home and watch my DVDs"*.

Is there any hope for the IACC and autism research? Yes and absolutely, but only if we start thinking and acting "out of the box"; if we leave bureaucracy and implement new rules, legislation and directives everywhere. Here are only a few examples addressing the 10 facts here above:

- 1) Address the environmental pollution and epigenetic factors which will benefit us all and not only autism.
- 2) Acknowledge that an adult with autism still remains a child although he can play a productive role in society and joint the workforce with special protection and services.
- 3) A suicide being the tip of the iceberg, mental health services and not poisonous drugs could reverse the situation.

- 4) Any service with human approach, understanding and compassion can be beneficial to autism, regardless the titles and certifications related to different autism educational programs. Autism needs first of all sensitive humans.
- 5) Instead of forcing hospitals or emergency rooms to put a label “We don’t accept patients with autism”, IACC could implement detailed directions on how to treat a patient with autism and enforce every hospital, ER or health facility to strictly follow them, if not some legal actions and sanctions must be taken against them.
- 6) As for the judiciary system, some Autism Law Centers must be implemented in every State where attorneys and judges must follow an educational program about autism, take an exam and only then continue their practice. The other alternative would be to separate them in two categories: autism educated and not. Also, autism organizations must have a list with attorneys knowledgeable about autism, pro bono and in contingency basis as well.
- 7) Regarding the dramatic issue of parental chronic denial, please read my detailed written comments of 1/12/2016.
- 8) The voluminous amount of publications and research articles fails to give solid results as many confounding factors have been omitted leading to fast, conflicting, misleading and non-reproducible results. The IACC could implement strict regulations and rules for the IRB committees, when an autism study is to start and be funded.
- 9) Autism societies must become less bureaucratic, more human and in contact with the families and people voting for their board. If not, they lose their role and existence.
- 10) Poverty has a negative effect to everyone, but in case of autism it becomes devastating. In a period of economic crisis, I am not asking for more federal money (SSI, Food stamps, etc.), but rather to implement measures to avoid poverty.

Note: For all the above mentioned facts and solutions, I have a huge amount of documents, photos, witnesses, websites and experts and I am willing to present them to any forum or federal NIH committee.

From Dr. Linda (Angelique) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Hygienist, Clinical Biochemist, Associate Professor in Medicine. *Mother and legal guardian of a 31-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. 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 where I studied neurosciences and initiated the “fever study in autism”. Current position: Associate Professor at the University of Athens School of Medicine in Greece, responsible for teaching 3rd year Medical students and graduate students in three MSc Programs at the Departments of Biology, Chemistry and Clinical Pharmacy -a position which allows me to spend more than half of the year in the US with my son, while continuing my teaching online.*

[PII redacted]

Patricia Duncan

October 17, 2018

Autistic Adults and other Stakeholders Engage Together (AASET) is making progress to identify goals and priorities of autistic adults nationwide.

We are inviting our collaborators and colleagues who are interested in implementing research that addresses what is important to autistic adults to attend a 1-day meeting. Attendees will learn about the priorities, and will plan to incorporate these into their research.

Join us on Saturday November 10, 2018 at the Renaissance Hotel in Washington, D.C.!

Register now, limited space: www.tinyurl.com/autisticmeeting

www.facebook.com/autistichealth

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

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

October 17, 2018

Comments for the IACC Meeting on October 17, 2018

Eileen Nicole Simon, PhD, RN
Conrad Simon Memorial Research Initiative
[PII redacted]

1. Inferior Colliculus

I want members of the IACC to discuss the importance of the inferior colliculus. I will continue to submit this comment until it is discussed by members of the committee, not just mentioned in summaries of stakeholder comments.

The whole world should know the importance of the inferior colliculus (plural colliculi) for comprehension of spoken language. I first proposed this 10 years ago at the IACC meeting held on November 21, 2008. My presentation remains online at https://iacc.hhs.gov/meetings/iacc-meetings/2008/full-committee-meeting/november21/slides_eileen_simon_112108.pdf. I do appreciate that the IACC has faithfully maintained this with all submissions to the Public Record.

The inferior colliculi are a pair of signal processing centers in the roof of the midbrain (the tectum). Blood flow to the inferior colliculi is higher than to any other structure within the brain. This seminal discovery was made by Seymour S. Kety and his research team at NIMH using a radioactive tracer. Kety's paper was published in 1962. It is free online, and includes an autoradiographic picture that shows the greater uptake of the tracer in structures of the brainstem auditory pathway. This picture is presented on slide 4 of the presentation I made in 2008.

2. Wernicke's Encephalopathy

I want members of the IACC to discuss Wernicke's encephalopathy, as the brain injury that may cause autism.

The inferior colliculi are easily damaged by alcohol, drugs, and environmental toxins in the blood stream. Symmetric bilateral hemorrhages in the brainstem were described by Wernicke 137 years ago in 1881. This should be common knowledge by now. If it were, we might not have so many people dying from drug addictions.

The inferior colliculi were the most severely damaged structure in the brains of monkeys subjected to asphyxia at birth. This damage was described by William F. Windle in the October 1969 issue of the Scientific American. I included pictures of the damage in the IACC presentation I made in 2008. Windle recognized the damage caused by asphyxia as similar to Wernicke's encephalopathy, but found no hemorrhages. The damage is, however, an ischemic form of Wernicke's encephalopathy.

3. Bilirubin Injury

I want members of the IACC to discuss brain damage caused by bilirubin. Jaundice and high bilirubin levels have been reported in some newborn infants who were later diagnosed with autism.

Brainstem structures stained by bilirubin are shown in slide 7 of the presentation I made in 2008. This was published in an article by JF Lucey, WF Windle and co-workers published in 1964 as part of an ongoing investigation of asphyxia at birth. In this research very high levels of bilirubin caused no damage to the brain. However, bilirubin staining in the brain was prominent in monkeys who were subjected to asphyxia at birth before given injections of bilirubin.

The inferior colliculi were most prominently stained by bilirubin, as can be seen in the picture on slide 7 of my presentation in 2008.

4. Umbilical Cord Clamping

Use of a clamp on the umbilical cord was first described by E. Magennis in *The Lancet*, May 20, 1899. Instructions for use followed the traditional textbook teaching to wait for pulsations of the umbilical cord to cease before applying the clamp. In other words, postnatal placental blood flow must not be cut off. Placental blood flow will stop once the newborn's lungs take over the function of respiration.

Blood transfusion became possible in the 1930s, and umbilical cord blood became valued as a source of blood for transfusions. This period coincides with the birth years of the patients described by Kanner. It may be too late to find out if their parents were among the first to give permission for umbilical cord blood collection at Johns Hopkins in Baltimore.

In the 1950s episiotomy became mandatory in some teaching hospitals. Clamping the cord was therefore recommended to remove the newborn from the "sterile field" before proceeding with the surgery.

In the mid-1980s, clamping the cord became mandatory to obtain a section of umbilical cord to test for oxygen levels. This should not be overlooked as a possible reason for the increase of autism that began in the 1990s.

Kristin Sullivan

October 17, 2018

At this point you can't hide the truth any longer - vaccines can and do cause autism! There's an army of us highly educated parents who know the truth. But even more than that, so does the CDC, Julie Gerberding, The Vaccine Court, top US scientists. It's time to get on the right side of history and stop protecting the vaccine program. Read JB Handley's book - How to End the Autism Epidemic.

[https://www.facebook.com/EndAutismNow/videos/1901171999965167/?_xts__\[0\]=68.ARCj84KR3q3wIDDN1wbHGIEEoXMkQ_e6_yv1BCipkrhqzcsezzwuLJEGK11H4Vp5LC3o4WjHibf5SJouN-GLxpHaD7utDknbMUjl371QJ5bOzSSfC0r1_SOCnlMa-XLaxbUaJL_9GzzlM7cQ37TBZlmbWLQ86VMDLDY4iDQith3rdx_RKIVi2CjmUGuQY3cQz_Ol_QA_26qJd9CkpkQ4pnvjDfUetONuXalSqzID&_tn_ =H-R](https://www.facebook.com/EndAutismNow/videos/1901171999965167/?_xts__[0]=68.ARCj84KR3q3wIDDN1wbHGIEEoXMkQ_e6_yv1BCipkrhqzcsezzwuLJEGK11H4Vp5LC3o4WjHibf5SJouN-GLxpHaD7utDknbMUjl371QJ5bOzSSfC0r1_SOCnlMa-XLaxbUaJL_9GzzlM7cQ37TBZlmbWLQ86VMDLDY4iDQith3rdx_RKIVi2CjmUGuQY3cQz_Ol_QA_26qJd9CkpkQ4pnvjDfUetONuXalSqzID&_tn_ =H-R)

International scientists have linked the aluminum adjuvant in vaccines to autism. Three of them wrote letters imploring the CDC to look into it last year, but nothing was done. Here are the letters:

<https://jbhandleyblog.com/home/2018/4/1/international2018>

Two additional prominent autism researchers - Dr. Richard Kelley, Professor of Pediatrics, Johns Hopkins University (Kennedy Krieger Institute) and Dr. Andrew Zimmerman - have also testified under oath that vaccines can cause autism in some children.

Please read How to End the Autism Epidemic by JB Handley where the science and testimonies are laid out for you.

Please do the right thing and have moral courage to look at vaccines. The army of highly educated parents, scientists, doctors and more will not be silenced. The truth is out and you best get on the right side of history.

<http://www.greenmedinfo.com/blog/clear-legal-basis-vaccines-cause-autism>

[https://www.facebook.com/EndAutismNow/videos/1901171999965167/?_xts__\[0\]=68.ARCj84KR3q3wIDDN1wbHGiEEoXMkQ_e6_yv1BCipkrhqzcszwwuLJEGK11H4Vp5LC3o4WjHibf5SJouN-GLxpHaD7utDknbMUjl371QJ5bOzSSfC0r1_SOCnlMa-XLaxbUaJL_9GzzlM7cQ37TBZlmBWLQ86VMDLDY4iDQith3rdx_RKIVi2CjmUGuQY3cQz_OI_QA_26qJd9CkpkQ4pvnjDfUetONuXalSqzID&_tn_=H-R](https://www.facebook.com/EndAutismNow/videos/1901171999965167/?_xts__[0]=68.ARCj84KR3q3wIDDN1wbHGiEEoXMkQ_e6_yv1BCipkrhqzcszwwuLJEGK11H4Vp5LC3o4WjHibf5SJouN-GLxpHaD7utDknbMUjl371QJ5bOzSSfC0r1_SOCnlMa-XLaxbUaJL_9GzzlM7cQ37TBZlmBWLQ86VMDLDY4iDQith3rdx_RKIVi2CjmUGuQY3cQz_OI_QA_26qJd9CkpkQ4pvnjDfUetONuXalSqzID&_tn_=H-R)

Maureen Block

October 17, 2018

Please open an investigation to look at all the science presented in JB Handley's book and force a change to our childhood vaccine schedule and re-examine the CDC's role in both promoting vaccines and doing studies supposedly to show the safety of vaccines. Please make each member of your committee actually read the book. This book has real footnotes, unlike Dr. Paul Offit's book, many of whose footnotes don't support the sentence or paragraph they relate to.

Tammy Kraft

October 17, 2018

Everyone at the IACC needs to read J.B Handkeys best selling book "How to End the Autism Epidemic" it is your job to know about autism...I have lived it for 18 years with my son. Our story fits right along with J.B.'s story with his son and so many others. It is time to get serious about ending this damage to our children! The science is all there in his book. I urge you to read it!

Tim Kasemodel

October 17, 2018

Why have you just dismissed those that have autism because of vaccine injury?

My son's first diagnosis is autism, but he also has a mitochondrial dysfunction, that led to reactions from his vaccines, including encephalopathy and seizure disorder at age 14! His immune system was so shot after the vaccines he spent his first 2 years chronically ill. He developed bowel disease. This autism is not genetic - over 400 in our family since his great grandparents - he is the only one with autism. Please read *How to End the Autism Epidemic* - if safeguards are in place - like testing prior to vaccination, not allowing the vaccinations when children are sick or on antibiotics, you will end the deep suffering of these children like my son. Vaccination has been made a sacred cow, and you will be just as guilty as those at the CDC if you do not look at this and make recommendations. If my son just had autism, we would be just fine - it is these severe and debilitating / life altering additional medical complications [his latest has been vomiting for over 2 years and they have not been able to find out why - the 1st 4 doctors did absolutely nothing except say that is "just autism"; at least we finally found one that did not tell us to check into a hospital and sign a DNR after he lost 70 pounds]

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

Emily Iland, M.A.

October 17, 2018

[PII redacted]

Last name is pronounced "Island"

Affiliation: I'm a parent, author, educator, curriculum developer and autism training specialist. In the past 20 years I've trained thousands of officers about autism and developed Experience Autism[®], the only independently-validated evidence-based police training in the country. I've expanded this work to include the BE SAFE program, training individuals on the spectrum to interact safely with the police. My son Tom, who is on the autism spectrum, is my co-trainer.

Comments: My thanks to you, the members of the IACC, for your work on behalf of people with autism of all ages and abilities. I would like to offer the following comments as you consider the important issue of training the police about autism. I've learned a lot about this subject over the past two decades as an active trainer and program developer, and would like to share the following considerations and key components.

Community-Based Approach: First, police training is not one-size-fits-all. The reason we don't have a single national police department is that local agencies feel they can best determine how to serve their own community. Therefore, rather than mandating or categorically imposing a single national autism training for police and other first responders I recommend that the IACC take steps to provide support and funding that will help communities implement autism training solutions that are responsive to local needs, including cultural competence and other factors.

Consistent with the values of community policing and procedural justice, I also recommend a community-based, personalized approach to training. I'd like to highlight the Experience Autism[®] program, the only independently-validated evidence-based police training in the country.

Experience Autism[®] uses simulation activities to help officers develop empathy. Officers discover for themselves how to accommodate individuals on the spectrum. In this inclusive training, local officers, community organizations and individuals on the spectrum are prepared to co-facilitate the training with us; we adapt as needed for the community. This program element creates local connections and continued dialogue around this subject that can last long after the training ends.

Comprehensive: There are two sides to the safety equation. While it is essential, it is *not* enough to just train the police about autism. We must also train individuals across the spectrum to interact safely with the police. These two parts are essential to help everyone develop the skills needed to understand one another and interact safely together.

I'd like to highlight the BE SAFE program, a pioneering program that is considered the "gold standard" for teaching youth and adults of diverse abilities to interact safely with the police. BE SAFE is currently being studied for effectiveness in two different research studies, one of which is federally-funded.

BE SAFE The Movie uses video modeling to show viewers what to do and say in police encounters. The video models reframes problematic behaviors (such as fight or flight) into positive behaviors including "stay where you are when you meet the police, and "Do exactly what the police tell you to do."

BE SAFE is a low-cost, accessible training solution for individuals with autism (or any kind of disability or condition). It is available to the public for purchase, and can also be streamed into any classroom in ABA format, via subscription with TeachTown. The Movie has English captions and Spanish subtitles. A 300-page differentiated companion curriculum in English and Spanish) provides teachers with evidence-based materials to reach learners with diverse needs.

A BE SAFE Certificate Course, another of our training options, further builds capacity for teachers, service providers and parents to use the BE SAFE materials with individuals or groups, in schools and the community, for years to come.

Relationship-based: After the death of her son Ethan Saylor at the hands of off-duty police officers, Patti Saylor, a leader in the Down Syndrome community, testified to Congress: “It doesn’t take an act of Congress, federal or state mandate, or even money to make you realize that relationships are everything.” Consistent with this essential tenant, we emphasize the need to bring police together with members of the disability community, to help officers recognize and respond effectively to the very people they serve.

I’d like to highlight a unique public safety event called a BE SAFE Interactive Movie Screening. This event brings officers together with community members with autism and related disabilities. They get to know one another, develop mutual understanding and begin personal relationships.

The Interactive Screening event is carefully structured for maximum effectiveness. First, the audience watches scenes from BE SAFE The Movie. Then, building on the video model, the officers and individuals with exceptional needs practice safety activities together, including asking for help and following instructions. Participants with disabilities and their families at the events we have facilitated report a tremendously positive response to the experience, including reducing anxiety and promoting positive relationships. Officers have called this impactful experience “a game-changer.”

Bridging the GAP: Our new training model is catching on in states such as California, Maryland, Nebraska and Arizona, and gaining national attention. First we train the police with Experience Autism®, next we train teachers and parents to use BE SAFE, and finally we bring trained police together with individuals with exceptional needs for a BE SAFE Interactive Movie Screening. We call this model “Bridging the Gap.” It illustrates the power of addressing the safety needs of everyone involved in a police encounter, and the importance of coordinating training that builds capacity and can have positive effects in the community for years to come.

Lessons Learned from Experience: While developing video training modules for officers can be helpful, using videos alone can have limitations for real-life application, which is why I recommend personalized approaches. If any consistent written materials or content are developed, departments still need leeway to use such materials in a way that is responsive to their needs and community. Rather than creating a separate training mandate (an additional requirement), consider the option of allowing departments to integrate the mandate and any materials into existing training, such as Crisis Intervention Training (CIT), police academy training, or other department programs. Many departments are using this model and are embracing the opportunity to include autism training in this way.

Conclusion: I hope that the IACC recommendations will support and enable local communities to look for solutions that address the need to train everyone involved in a police encounter. Options include

helping communities learn about and contract with experienced trainers who deliver evidence-based methods and best practices, and/or experts who can help communities design new training presentations that work for them. I believe that our unique training models can be a very valuable part of the solution.

Thank you for your consideration of these ideas.

For more information visit:

www.ExperienceAutism.com www.BeSafeTheMovie.com www.EmilyILAND.COM
www.ThomasILAND.com

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

Kerry Scott Lane, M.D.

October 17, 2018

IACC, October 2, 2018

Please submit the entire contents of these attachments as evidence the Etiology of Autism is via Metal intoxication and Oxidative stress from metal containing vaccines and Tylenol, aka Acetaminophen. This synergism depletes glutathione, needed to detoxify metals in these same vaccines.

Please be advised the whole world is watching....

Best,

Kerry Scott Lane MD

Palm Beach Autism Institute

A not for profit Florida Corporation

PROFESSIONAL ACCOMPLISHMENTS

-Board 184BRERZMKW0TW in Anesthesiology, April 2000, MOCA Recertification 2010.

-Published first peer reviewed Internet publication on Medscape.com, September 1999 "Aflatoxins-Tobacco and the p53 Tumor Suppressor Gene: Cancer's Missing Link?"

-Granted three United States and International Patents," Method and System for Assay and Removal of Harmful Toxins during Processing of Tobacco Products" May 2000-US 6,058,940, October 2003-US 6,637,438, September 2004-US 6,786,221.

-I was the Initial Movant in 1998 in the USDOJ vs. Philip Morris et. al. Trial, relative to the suppressed industry knowledge of aflatoxin contamination of tobacco. This resulted in the largest Civil Action in US history exceeding \$300 Million in costs to the USDOJ. This was formulated in conjunction with President Clinton, Attorney General Janet Reno and the author of the RICO Statute, Law Professor Blakely of Notre Dame.

-Submitted *Amicus Curiae* Brief in the First Circuit Court of Appeals in USDOJ vs. Philip Morris et.al. This resulted in the upholding of the 152 RICO counts against the Tobacco Industry in 2008. This brief showed the continuation of Obstruction of Justice and ongoing RICO in the aforementioned trial. Academic aflatoxin experts were tobacco employees, consultants, and witnesses in the trial, but denied any knowledge of aflatoxin induced tobacco toxicology under cross examination, committing perjury.

- Advisor to various Legislative and NGOs including Senator Kennedy's Office and the Senate HELP Committee in promoting FDA regulation of tobacco products from 1998 to 2009, resulting in the FDA Legislation being passed by President Obama in June 2009.

-Advocate for FDA applying foodstuff regulations for aflatoxin on tobacco, 2009-2011. I testified and submitted documents before FDA/CTP/TPSAC on the need for inclusion of aflatoxin action levels for tobacco. In August 2011 I testified at the FDA/CTP/MRTP Conference on the advisability of implementing aflatoxin action levels for tobacco products to create "Modified Risk Tobacco Products-MRTPs". My testimony is available from this hearing upon request as are documents and PowerPoint Presentations.

-Preeminent expert on tobacco and fungal-toxicology, especially Aflatoxin and Gliotoxin, with respect to Autism, Eclampsia, Pre-eclampsia, PIH, Gestational diabetes, cancer, vasculopathy, immunosuppression, oxidative stress, COPD, hypertension, diabetes, et.al.

-Testified before FDA in 2009 and Interagency Autism Coordinating Committee-IACC- 2010. See my PowerPoint presentation with 69 references at Google by entering "Autism Gliotoxin", entitled "Glutathione Depletion by Gliotoxin, then Acetaminophen, Results in Oxidative Stress, Metal Intoxication and Regressive Autism".

Kerry Scott Lane M.D. C.V.

-My Autism Lecture from the American Academy of Anti-Aging Medicine in April of 2014 in Orlando, FL can be seen on You Tube by entering "Autism Acetaminophen".

-Granted US Patent 9,442,092 in September 2016 entitled "Methods for Treatment of Autism" which describes novel testing and treatments for Autism and Alzheimer's disease. This is the first of its kind and should impact many lives.

-I was the movant and defendant in the DEA Forfeiture action resulting from the seizure of my restored historic sailboat- "Flash II"- which was once owned by President John F. Kennedy-as a teenager. The DEA seized my boat on the illegal theory that drug proceeds were co-mingled with my funds in the restoration of "Flash II". The case was heard in the Second Circuit Court of Appeals in Boston where it was found the DEA and USDOJ acting wrongly and Lane was compensated for his losses. This case set a historic legal precedent in drug and Civil forfeiture cases.

-**Established Palm Beach Autism Institute**, a Not for Profit in 2015 to encourage Multiple Academic and other Collaborations in an effort to expedite prevention, treatment and cures for Autism. I am applying for IRB approval to begin an Autism Clinic and Research Center to effect predictive tests for Autism susceptibility and prospective treatments in a Pediatric Settings.

-**Seeking Collaborations** to elucidate and confirm the role of fungal toxins in Pre-eclampsia/Eclampsia and Gestational Diabetes This knowledge, I believe, will lead to publishing of peer-reviewed papers, grant funding, tests, prevention, treatments and decreased morbidity and mortality in the Maternal-Fetal Setting.

-Former member National Ski Patrol and Great Gorge Ski Patrol, 1970-72.

References: John Sitarik M.D., Anesthesiology, [PII redacted]
Robert Gordon, D.O., Obstetrics and Gynecology, [PII redacted]
Richard Heathwood, NY State Police, Retired, [PII redacted]
Paul Roy Esq., Legal Counsel Time Warner, [PII redacted]

Kerry Scott Lane M.D.

February 27, 2018

Mounting data pointing at the potential for acetaminophen exposure during early childhood to induce autism in children. A review from scientists and clinicians at Duke and Harvard.

A summary of the evidence presented in the review

(<http://journals.sagepub.com/doi/pdf/10.1177/0300060517693423>) is as follows:

1. Eight peer-reviewed studies* now demonstrate that acetaminophen exposure is neurotoxic to the developing brain of humans. Seven of these studies evaluated the effect on children following exposure in utero. Effects of exposure evaluated by various groups included lowered IQ, autism, and behavioral problems. The only study to evaluate the effect of exposure after birth found more than a 60-fold greater risk (literally) of developing autism following exposure after birth than studies looking at the risk of exposure before birth.
2. A very wide range of factors, all of which are associated with inflammation and oxidative stress, are in turn associated with an increased risk of autism. Thus, it appears that whatever is inducing the epidemic of autism probably acts in concert with inflammation and oxidative stress. This conclusion is consistent with the hypothesis that acetaminophen exposure to infants and children after birth is a leading cause of autism.
3. Laboratory animals develop permanent brain damage characterized by problems with social function when they are exposed to acetaminophen during an early period of brain development that corresponds to human infancy.
4. Margaret McCarthy, chair of Pharmacology at the University of Maryland, has elucidated the mechanism by which acetaminophen damages the developing brain, and has explained why acetaminophen is more dangerous to males than to females. This potentially accounts for the increased propensity for males to acquire autism compared to females.
5. Acetaminophen substantially alters brain chemistry, and temporarily impairs awareness of social issues in adult humans. Although the drug could naively be considered to be anti-inflammatory, exposure to the drug actually causes inflammation, even in healthy adults, and depletes metabolic components needed to deal with inflammation. Further, the drug is immunosuppressive, blocking an important immune function (the febrile response).
6. No study has ever shown acetaminophen to be safe for the developing brain of a human or a laboratory animal. A major manufacturer of acetaminophen in the US acknowledges that the drug was never proven safe for brain development when used during pregnancy or in childhood. All safety tests that have been conducted were performed with the assumption that any side effects would be acute in nature (e.g., bleeding or organ damage soon after administration of the drug).
7. A very wide range of circumstantial evidence** points toward the potential for acetaminophen to be at the root of many if not most cases of autism:
 - (a) The epidemiology of autism matches the historic use of acetaminophen, with both rising sharply in the early 1980s following the identification of Reye Syndrome as a possible side effect of aspirin use in children.
 - (b) The qualitative nature of autism apparently shifted from infantile to regressive at the same time that acetaminophen use in infants and children became more popular, in the early to mid-1980s.

- (c) A wide range of inflammatory conditions that affect the potential to tolerate oxidative stress are associated with autism. It is expected that these conditions will adversely affect metabolism of acetaminophen. A notable exception is cystic fibrosis, a condition of oxidative stress not known to be associated with autism. Cystic fibrosis is also unusual as a condition of oxidative stress that actually enhances rather than impairs metabolism of acetaminophen.
- (d) The number of possible environmental suspects for the induction of autism at a level that would account for the epidemic is dwindling, leaving acetaminophen use in infants and small children as one of the few remaining suspects. A good suspect is one which is newly (since 1980) and widely introduced into the population, and which should be associated with a profoundly large (10-fold or greater) increase in risk of autism. Most suspects tested to date have shown moderate and sometimes variable (dependent on the population studied) associations with autism.
- (e) Genetic variants associated with autism, many associated with oxidative stress, likely influence the metabolism of acetaminophen.
- (f) Circumcision has been identified as a significant risk factor for autism, and the only reasonable explanation put forth for this observation is that acetaminophen use during the procedure is probably inducing autism.
- (g) History demonstrates to us that it is a mistake to ignore the observations of parents when it pertains to autism. Many parents who have historically blamed vaccines for their child's autism may have actually observed the effects of acetaminophen. In the 1990s, vaccination was advertised as the number one indication for use of acetaminophen.
- (h) The idea that acetaminophen use, particularly in infants and small children, is responsible for many if not most cases of autism is an attractive hypothesis, as it satisfies Occam's Razor in being a simple explanation that explains a wide range of observations.

Conclusions of the review:

1. There are several unknowns: We have almost no idea just how much benefit that acetaminophen actually provides. (That was never tested.) Perhaps it can be easily replaced by non-pharmaceutical means of reducing fevers, and perhaps not. Second, we don't know exactly how much neurological damage acetaminophen causes when administered to infants and children.
2. Despite unknowns, given the preponderance of evidence described above, we conclude that parents and doctors should know all available facts so that they can make informed decisions about use of acetaminophen.
3. An incisive study needs to be done as quickly as possible, with all available resources at its disposal. Despite the fact that acetaminophen is the most popular drug used in infants, children, and pregnant women, neither the benefits nor the risks of using the drug in those populations have been thoroughly evaluated.
4. The cost of an incisive study would cost less than the cost of raising and caring for three individuals with autism. Just three.

William Parker, PhD
Department of Surgery
Duke University Medical Center
Durham, NC 27710

* Our review cites 8 papers, but there are others, and more on the way.

- Skovlund and colleagues found that acetaminophen use but not opioid use during pregnancy is associated with a reduction in communication skills.
(<https://www.ncbi.nlm.nih.gov/pubmed/28168770>)
- A study by Liew et al (Epidemiology 2016; 27: 912–918) showing lower IQ associated with acetaminophen use during pregnancy is cited in our review but not counted as one of the 8 studies listed as showing neurotoxic effects of acetaminophen during development.
- Vlenterie and colleagues found communication problems and delayed motor milestone attainment associated with acetaminophen use during pregnancy.
(<https://www.ncbi.nlm.nih.gov/pubmed/27585674>)

** Additional circumstantial evidence exists, but was not cited in our review. For example, the unexplained and unusually high prevalence of autism in South Korea (<https://www.ncbi.nlm.nih.gov/pubmed/21558103>) just happens to occur in a country where children's acetaminophen capsules were inadvertently overloaded with active ingredient (http://www.saul.com/sites/default/files/3591_WCW062513tcgmp.pdf).

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Josefine Krapp

October 17, 2018

For the IACC Full Committee Meeting, October 17, 2018
Public Comment Submission October 7, 2018
To Dr. Joshua Gordon IACC Chair and Committee Members

Dear IACC,

first, my thanks to you for your work and your efforts to make the meetings accessible for the public.

Yesterday the New York Post wrote about the case of Darius McCollum, a non-violent criminal with diagnosed Asperger's Syndrome. The judge "designated McCollum a "track one" offender — the most dangerous assignment available — which will land him in a secure psychiatric institution indefinitely". His defense attorney Sally Butler said that he "won't get adequate treatment in whatever facility he ends up, because psychiatric hospitals are meant to deal with people who suffer from schizophrenia or bipolar disorders, and not those with Asperger's".

I believe this must change. Attorney Sally Butler described the kind of institution where McCollum will be sent as "a dangerous place for him, both from the staff, and from the inmates". And the judge, Ruth Shillingford read from her 70-Page decision "As such, this Court calls upon the legislature to consider looking at the overall track designations to address the issue raised by someone with Autism or Autism Spectrum Disorder as they interface with the criminal justice system." Attorney Sally Butler said: "The law is not set up to deal with people like him, but the sad fact is the law's not gonna change. (...) [Shillingford] says 'oh, the legislature,' but the legislature's not going to do anything here."¹

Now, there seem to be three possible outcomes of this. Either he stays in the psychiatric facility which Butler considers to be "a dangerous place for him", eventually for the rest of his life. Or the appeal is successful, which seems unlikely. Or, which is also unlikely, he leaves the facility after an evaluation, in that case a successful integration in society seems extremely unlikely if he stayed there for a longer time without adequate treatment.

Therefore, I want to ask you to advocate both changes which shall:

- ensure that psychiatric hospitals provide adequate treatment for people with Asperger's Syndrome and if necessary other disorders for which they do not provide adequate treatment yet and
- changes of the laws to prevent the classification of Asperger's Syndrome as a "dangerous mental disorder" and the classification of non-violent criminals as "track one offenders"

Thank you for reading my comment.

Sincerely,

Josefine Krapp

University student in psychology

¹ Source: <https://nypost.com/2018/10/05/transit-bandit-ordered-locked-up-at-secure-psychiatric-facility/>, last opened 2018/10/07



**Written Comment to the Interagency Autism Coordinating Committee
Provided by SafeMinds Executive Director Lisa Wiederlight
October 17, 2018**

SafeMinds is pleased to provide this written testimony to the Interagency Autism Coordinating Committee for its October 2018 meeting. We remain concerned about the Federal government's lack of urgency related to autism disability. Urgency and a commitment to rapidly improving outcomes are desperately needed due to the increased prevalence of autism over the past 18 years, from 1 in 150 in 2000, to 1 in 59 children today, and due to the significant mortality, morbidity, and lower quality of life associated with autism.

As these and other metrics worsen for our community, the Federal response seems to remain the same. There is little to no environmental causation research supported by the Committee, and little to no inquiry into effective treatments for people with autism today. Addressing autism requires research-based policies and programs to improve the safety, health, and independence of people with autism and their caregivers.

SafeMinds is also dismayed that the Federal response lacks full inclusion of all segments of the autism community and spectrum, and has little to no accountability to the American taxpayers who fund millions in research and services each year. This summer, SafeMinds, with The Thinking Mom's Revolution and Talk About Curing Autism (TACA) designed and implemented a 15 question "IACC 2018 Stakeholder Satisfaction Survey" to identify autism community stakeholders' views on the efficacy, responsiveness, and accountability of the Committee.

During the two-week survey period, we received 1,405 unique responses. The autism community stakeholders we surveyed included people with autism, caregivers of people with autism, autism service providers, physicians, and others. The survey results were striking. Almost half of the respondents had not even heard of the IACC before they completed the survey. Of those who had heard of the IACC, 46 percent stated that the work of the IACC had affected their lives either negatively or "not at all." Less than five percent of respondents answered that the work of the IACC had a positive impact on their lives.

Respondents reported similar negative impressions when asked whether the IACC represented their interests when it came to addressing autism in the United States. Over half of the respondents (59.6 percent) said that the IACC did not represent their interests. An additional 33 percent said they "did not

know” whether the IACC represented their interests. SafeMinds urges the Federal government to engage a more diverse group of stakeholders to find out why the IACC is not meeting community needs.

The survey results show that many autism community stakeholders feel disenfranchised by the IACC. Almost 94 percent of respondents said they had not provided comments at an IACC meeting. Of the respondents who did provide public comment, over 95 percent thought that the IACC had not appropriately addressed their concerns or issues. These respondents further stated that they were not given an opportunity to discuss their concerns with the committee, and were not provided enough time to properly explain the context and relevance of their issues.

Those who did not provide public comment cited two primary reasons. About 64 percent reported that they were unable to travel to the meetings in Washington DC, while nearly 33 percent of stakeholders said that they could not get childcare so they could attend the meeting. SafeMinds urges the IACC to hold meetings throughout the country, and to consider the use of technology that facilitates stakeholder-Committee interactions during the meeting regardless of the stakeholders’ locations.

These are only a few of the concerns which surfaced from the survey. A full report will be issued later this year. We would welcome the opportunity to discuss the survey with the Committee. The Federal response to autism must be improved, and robust engagement with diverse stakeholders is a necessary activity for improvement,

Respectfully submitted,

Lisa Wiederlight
Executive Director

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October 17, 2018

Dear IACC Members:

Please let autism parents and the public speak as many times as they can or possible and do not limit them to once per year. As autism parents, we have to repeat our messages for others to hear us, it is the least we can do. Please do not silence us. Autism has already silenced so many of our children and I don't think IACC should silence or limit any parent's ability to speak for their child.

Thanks much in advance and I hope you reconsider this horrible decision.

Idil