

# **Written Public Comments**

**IACC Full Committee  
Meeting**

**April 8, 2014**

## List of Written Public Comments

Lorrieann Geyer .....	3
Eileen Simon.....	4
Victoria Beck .....	5
Allison Chapman .....	6
Maria Lujan Ferreira.....	7
Marian Dar .....	8
Maria Lujan Ferreira.....	9
Eileen Simon.....	10
Dr. Toril Jelter.....	13
Lea Googe .....	20
Kerry Scott Lane .....	22
Eileen Simon.....	24
Eileen Simon.....	25
Shannon Des Roches Rosa .....	26
Haven DeLay and Gerard Dziuba .....	27
Courtneay Reid.....	30
Nora Brock .....	31
Joseph M. Jason .....	32
Carol Fruscella.....	33
National Autism Association.....	34
Victoria Beck .....	36
Brian Kelmar.....	39
James Blanco.....	40
Laura Cellini.....	42

**Lorrieann Geyer**

January 12, 2014

To Whom It May Concern:

I am a mother of two sons diagnosed with ASD. They are both registered with the DDD (PerformCare). My eldest will be seventeen this month and his brother will be sixteen in April. The sixteen year old has a twin brother who also has a Specific Learning Disability. It has been a very long and emotional road for our family and it seems that we have "hit a wall". Our one son has become extremely aggressive and can be physically intimidating at times. We have reached out to every possible resource, but the only option was to admit him into a facility that has no experience with Autism and made up of a mixed population of young adults with addictions or suicidal. I am also a Special Education Teacher and work with emotionally disturbed teenagers. I am also pursuing my MA in SPED. There is absolutely no support in place for families like us who are facing issues such as property damage, self-injurious behaviors, maladaptive behaviors and overall aggression. These problems occur during puberty and families are not equipped to manage the behaviors while continuing with their other responsibilities. The government has to support families who are desperately trying to keep their children in their care. If families are unable to undertake the hardship of caring for these young adults, it will become the government's responsibility. Furthermore, many of these young adults have lived in a loving family environment and will be thrown into an institution like atmosphere with Thorazine is administered and the threat of physical and sexual abuse.

I know that I am not alone and the federal government must begin planning for residential housing strictly for autism and provide respite/retreats for these individuals before the age of 21. I hope this email was helpful to your panel. Please let me know if there is anything else I can do to assist you with this monumental task.

Mrs. Lorrieann Geyer

**Eileen Simon**

January 13, 2014

I have decided not to attend the IACC meeting tomorrow. I would like to see an addendum made to the Strategic Plan for making developmental language disorder a high priority for research, if even just one brief sentence.

Language development for parents is the most serious and pressing issue. Evidence is lying dormant in the medical literature on vulnerability of the auditory system to perinatal injury, and how the auditory system guides maturation of the language areas of the cerebral cortex. Since the Autism Summit in 2003 I have been trying to point this out, but members of the IACC have pointedly refused to consider anything that a parent like me might have to say.

Sincerely,  
Eileen Simon

--

Conrad Simon Memorial Research Initiative  
To seek understanding of brain system impairments in autism.  
<http://conradsimon.org/>

**Victoria Beck**

January 13, 2014

*Subject: My Open Letter to the Interagency Autism Coordinating Committee (IACC)  
Meeting of January 14<sup>th</sup>, 2014*

Please find, below, a link to my open letter to the committee members of the IACC, written in preparation for their meeting tomorrow, January 14, 2014.

<https://www.youtube.com/watch?v=h4FQJj8R8TY#t=13>

Thank you,

Victoria Beck

## **Allison Chapman**

January 14, 2014

Hello, I am watching the IACC meeting which I do often and I first would like to second Lynn Redwood's remarks, as I am a parent of a regressive child with autism and feel there is so much more that could be done! (Acetaminophen should be black labelled for around vaccination for instance) Now that I've said that I have a very doable educational suggestion that could really help, teachers teach, the children individually and the families. A public, national teacher sharing website. ABA for instance takes forever to break down everything that needs to be learned and once you have an affective lesson done for a child they learn it FAST and hasn't been time to develop the next lesson or stage. A sharing website for teachers could allow immediate access to many different ways if breaking down the same information and new lessons, rather than putting the child on maintenance only for too long. The children waste way too much time in maintenance. Much more could be learned which would ease all areas of the children's learning. The website should be free and teachers, students and parents could rate the methods that work best for them. Please feel free to contact me I would gladly elaborate but we need to do more implementation less talking and strategizing.

Thank you,

Allison Chapman Andover, MA

**Maria Lujan Ferreira**

January 15, 2014

Dear staff of NIMH,

With the last information about "IACC voted AGAINST including the words immunizations or vaccines in the strategic plan despite the link to immune response in ASD"

The IACC has failed many families and children around the globe on this topic in the worst way: abandonment.

Several years ago this group was a hope, now it is only the dogma talking in the context of obsolete models that, at least for my son and my family, failed in all possible ways.

M. L. Ferreira  
Argentina

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Marian Dar**

January 15, 2014

Dr Insel had asked me for remarks on yesterday's video. My intent was to share experiences that might be of interest and value to others, and also present some ideas and questions:

- GI/microbiome. If at least 25% of those with autism and a significant minority of the general population have GI issues -- should pregnant moms be on mild probiotics during pregnancy? (might also reduce colic)
- Psych + primary care. How can a Federal agency influence the AMA and other professional organizations to work together and defragment medical care in the community -- may be ok in large medical centers.
- Music. The therapeutic value is already widely recognized. One piece, learning new information with few repetitions (when sung vs spoken) has been observed. Why? Does music somehow, like a metronome, synchronize a confused cerebellum?
- Vitamin D. Final photo of [PII redacted] in video, age 2, is with his arm in cast. A small rollover in bed and... a hairline fracture! There is talk of studying teeth, what about bones; what about possible (subclinical) malnutrition?

Thank you,

Marian Dar



**Maria Lujan Ferreira**

January 26, 2014

Dear Staff of NIMH,

With these news from SAFEMINDS

<http://www.safeminds.org/blog/2014/01/23/new-disclosures-vaccine-safety-datalink-vsd/>

It is very much beyond my understanding the voting about excluding vaccines from the research agenda.

M. L. Ferreira

Argentina

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Eileen Simon**

January 31, 2014

Dear Dr. Koroshetz,

Autism is a severe neurological disorder. Language and choreo-athetoid movements are its primary disabilities. Language is unique to the human species, and its loss referred to as aphasia is recognized as the most serious of all neurological disorders.

Attached here is printed version of a Powerpoint presentation I hope to make at the IACC meeting on April 8. I have listed a few accompanying comments below.

I hope you can take a few minutes to peruse what I plan to present, and even perhaps provide feedback/ discussion ahead of time. Thank you.

Sincerely,

Eileen Nicole Simon, RN, PhD (Biochemistry)

[PII redacted]

cc: [IACCPublicInquiries@mail.nih.gov](mailto:IACCPublicInquiries@mail.nih.gov) (to include as written comments for IACC)

--

Following are comments on some of the Powerpoint slides I plan to present:

**Slide 3** - This is a diagram of the auditory pathway I made for my doctoral dissertation.

**Slide 4** - This issue of the Scientific American arrived in my mailbox shortly after I entered graduate school in the fall of 1969 at the Boston University School of Medicine.

Severe damage in the midbrain auditory pathway seemed to explain what might have happened to my son [PII redacted], who had to be resuscitated after birth.

**Slide 5** - Nuclei of the auditory pathway have higher blood flow than any other area of the brain, which explains why they are vulnerable to damage by asphyxia.

**Slide 6** - Functional MRI has revealed that the highest blood flow in the human brain is also in the inferior colliculus.

**Slide 7** - Loss of the ability to understand spoken language has been described in several case reports following injury of the inferior colliculi.

How much more serious this injury should be for an infant.

**Slide 8** - Isabelle Rapin in her 1997 review article commented that comprehension and speech are always deficient in young children with autism.

She described this as a compromised ability to decode the rapid acoustic stimuli that characterize speech.

She noted that this is referred to as “verbal auditory agnosia” or “word deafness,” and that children with verbal auditory agnosia understand little or no language. They fail to acquire speech and may remain nonverbal.

**Slide 9** - Asphyxia at birth damages the blood-brain barrier, and allows anything in the circulation to enter and cause further damage to brainstem nuclei.

**Slide 10** - Nuclei in the brainstem auditory pathway are fully myelinated before birth.

These nuclei produce trophic neurotransmitters that guide maturation of target areas in the cerebral cortex during infancy and early childhood.

**Slide 11** - In my doctoral research, laboratory rat pups subjected to asphyxia exhibited growth retardation. This was clear-cut and males were more severely affected than females.

This was a completely unexpected result.

**Slide 12** - Since the mid 1980s all infants are subjected to the likelihood of asphyxia at birth if they don't breathe before the umbilical cord is clamped.

There is no health benefit from clamping the cord at birth.

This is a medical error and should be stopped.

**Slide 13** - I have so much more to say. Understanding autism has been my life's work for the past 50 years. I would appreciate being allowed to discuss this further.

**Additional slides, 14-18:**

Evidence of auditory dysfunction in autism.

Damage of the inferior colliculi has been reported in human infants.

Language begins with children hearing and reciting stressed syllables. This ability is lost by adulthood, which is why learning a foreign language becomes difficult.

Language development depends upon integrity of the auditory system. The auditory system is vulnerable not only to asphyxia but also exposure to toxic substances.

**Additional slides, 19-24:**

Evidence of auditory system vulnerability has been available for more than 50 years, as has evidence of highest blood flow in the auditory system.

Highest blood flow in the human brain is now visible by functional MRI.

Early maturation of nuclei in the auditory pathway guides development of target areas in the cerebral cortex.

Slide 24 is a summary of what I have tried to get across here.

--

Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

Eileen Nicole Simon's attachment can be viewed here:

[Attachment](#) (PDF – 953 KB)

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Dr. Toril Jelter**

March 11, 2014

I have attached a summary that may be of interest at your upcoming meeting and a separate hand out regarding what to do about it. I have also sent a letter to the FCC with some case histories.

**ATTACHMENTS:**

**OVERLAP**

Toril H. Jelter MD FAAP  
MDI Wellness Center  
325 North Wiget Lane Suite 130  
Walnut Creek, CA. 94598

Office: (925) 935-5425  
Voicemail: (925) 788-8904  
drjelter@mdiwellnesscenter.com  
www.mdiwellnesscenter.com

The following physiologic dysfunctions have been found in some children with an autism spectrum disorder. The same dysfunctions can be exaggerated or caused by electromagnetic radiation that is currently considered to be "safe".

- ⑩ Genetic alterations and chromosomal changes
- ⑩ Cerebellum changes on MRI
- ⑩ Retina/ optic nerve damage/ visual problems
- ⑩ Increased inflammatory reactions
- ⑩ Increased hypersensitivity/ allergic reactions
- ⑩ Immune shift or dysfunction
- ⑩ Genotoxicity
- ⑩ Increased oxidative stress
- ⑩ Increased risk with older parents
- ⑩ Altered fetal development
- ⑩ Genetic dysfunctions
- ⑩ Mutations
- ⑩ Somatic alterations
- ⑩ Disturbance of orientation in space
- ⑩ Increased autoimmune risk
- ⑩ Cerebral cortex abnormalities
- ⑩ Altered molecular and cellular development
- ⑩ Latent effect
- ⑩ Brain and cerebellar nerve cell damage
- ⑩ Microdeletions on chromosomes
- ⑩ Protein expression abnormalities
- ⑩ Increased cellular stress response
- ⑩ Morphologic alterations of immune cells
- ⑩ Changed lymphocyte viability
- ⑩ Decrease of Natural Killer cells

- ⑩ Decrease of T-lymphocytes
- ⑩ Uteroplacental circulatory disturbance
- ⑩ Increased membrane permeability
- ⑩ Altered cytokine profile
- ⑩ Disturbance of gastrointestinal function, gastric 'juices', enzymes, motility, inflammation etc.
- ⑩ Serotonin dysfunctions
- ⑩ Decrease of melatonin and sleep difficulties
- ⑩ Dietary opioid peptide abnormalities
- ⑩ Behavioral dysfunction
- ⑩ Cognitive dysfunction
- ⑩ Hypo or hyperactivity
- ⑩ Memory problems
- ⑩ Deficits in understanding complex ideas
- ⑩ Increased seizure risk
- ⑩ Autonomic disturbance
- ⑩ Poor visual and perceptual motor skills and auditory memory
- ⑩ Headaches
- ⑩ Fatigue
- ⑩ Depression
- ⑩ Anxiety
- ⑩ Lack of concentration
- ⑩ Increased irritability
- ⑩ Decreased appetite
- ⑩ Aggression
- ⑩ Hormonal disturbance
- ⑩ Electromagnetic hypersensitivity (3.2% in California)-common reported signs and symptoms of the latter are: Headache, thought processing difficulties, memory impairment, heart palpitations, sleep disorder, general malaise, blurred vision, weakness, dizziness, chest discomfort, muscle pain, tinnitus, fatigue, nausea, night sweats, restless legs or paresthesias

When a researcher notices that environmental factor A can cause B and that entity B has been identified in children with autism the researcher will no doubt wonder if environmental factor A is somehow contributing to or causing dysfunction B in children with autism. What do YOU think a researcher thinks if electromagnetic radiation currently considered “safe” can cause or worsen over 50 of the pathological processes already identified in children with autism? There are many things we as a global community can do now if we wish to nurture the next generation of children. For example: Try a 2 week EMF remediation trial: See how your family feels: Turn off the wireless router for 12 hours at night and use an ethernet cable during the day, unplug all cordless phones use wired instead and turn off the electricity to the bedrooms at night IF you know how to do this safely. You may be surprised by what you discover!

For more information see the following websites:      Wired Child  
   EMF Safety network  
   Citizens for safe technology

Sources: The Bioinitiative Report by Dr. Carpenter and Cindy Sage 2007 and 2012  
 Autism edited by Andrew W. Zimmerman  
 Changing the Course of Autism by Dr. Bryan Jepson  
 Autism and its Medical Management by Michael G. Chez MD

Cross Currents by Dr. Robert O. Becker  
Naval Medical Research Institute (Bibliography of reported biological phenomena ('effects')  
and clinical manifestations attributed to microwave and radio-frequency radiation (10/4/71)  
Toril H. Jelter M.D. F.A.A.P.  
Office (925) 935-5425  
[PII redacted]

## ADVICE TO PARENTS OF CHILDREN WITH AUTISM (ASD) ADHD AND ADD

To the extent you can do this, eliminate all wireless exposures from your child's environment. This is home and school.

For improved sleep, less insomnia, better sleep architecture (better REM sleep) no light at night, no computer, laptop, cell phone or cordless phone exposures before bedtime. The body 'sees' EMF as light-at-night. This interferes with melatonin production and the sleep cycle. No tech gadgets and no charging electronic devices in a bedroom while you sleep.

Ask your immediate neighbors to turn off their wireless routers at night, and when not in use. The effective biologic range of a wireless router is about 300'. Where you have several wireless signals shown on your computer, each is an RF stressor on you, and can interfere with sleep, memory, concentration, and behavior.

DO NOT DO THIS	DO THIS INSTEAD
• No wireless routers	• Cable modem (wired)  • Be sure to get a non-wireless router as your firewall... most routers are default wireless, whether you USE it or not. And, you won't be able to tell if it is transmitting wirelessly.
• No wireless laptops	• Wired computers and laptops
• No cell phones, iPhones Blackberry type PDAs	• Corded landline phones
• No cordless phones	• Corded landline phones
• No baby monitors or wireless surveillance	• Your eyes and ears
• No compact fluorescent bulbs	• Use regular incandescent bulbs
	* Use Graham Stetzer filters to filter electricity below 25 GS units



## FCC LETTER

Toril H. Jelter, M.D. FAAP  
M.D. I. Wellness Center  
325 North Wiget Lane  
Walnut Creek, CA 94598

Sept. 2, 2013

Re: The reassessment of FCC radio frequency exposure limits and policies

Dear FCC:

I am writing to you today to request that you reevaluate current FCC safety standards for wireless technologies and “dirty” electricity. The reason I am requesting this is because current research and what I see in my clinical practice indicate a revision of current safety standards is long overdue. Children are suffering disability and disease in much higher numbers than 30 years ago. Their EMF exposure is clearly a significant contributing factor. The fastest, most reliable way of educating yourselves on this topic is to read and understand the Bioinitiative Reports of 2007 and the 2012 update. Table 1-1 “Summary for the public” would be a good starting point.

1. Children have a right to live and play and learn where their DNA will not be damaged by non-ionizing radiation. This is not the case today. See sections 5 and 6 of the 2012 Bioinitiative Report for evidence for effects on genes and protein expression and genotoxic effects – RFR and ELF DNA damage with current “safety standards.”
2. Children have a right to live and play and learn in locations where their immune systems are adequately protected from detrimental non-ionizing radiation. This is not the case today. See Section 8 of the 2012 Bioinitiative Report “Evidence for effects on immune function.” Children are developing allergies and cancer at much higher rates than before.
3. Children have a right to live and play and learn where non-ionizing radiation will not adversely affect their neurology or behavior. This is not the case today. See Section 9 of the 2012 Bioinitiative Report “Evidence for effects on neurology and behavior”

### CASE HISTORY

A four-year-old boy presents to my office with his parents. They request help for their son so he may be able to learn and behave better. He moves around my waiting room like a hurricane, turning over chairs, pulling at the blinds, damaging the blinds, and screaming. His parents look on with their shoulders drooping and their hands in their pockets. They love their son dearly but he is so out of control they have no clue where to begin. We agree on a two-week EMF remediation trial (no Wi-Fi for 12 hours at night, no cordless phones, and Stetzer filters to decrease detrimental EMF from house wiring). Within one week I received an email from his parents. “The EMF remediation trial is working. Our son is now able to have more back and forth conversation. We have better eye contact with him and he is even receptive to the idea of a star chart for good behavior. In addition his bowel movements are now normal.” At follow-up in my office, which now had RF filters throughout, this child was calm, poised, made good eye contact and could converse at age level. His “bad” behaviors were gone.

### CASE HISTORY

A five-year-old boy presents with parents who tell me their child has uncontrollable arm flapping daily and has been diagnosed with an Autism Spectrum Disorder. They disagree with the diagnosis because when he visits grandma in rural Tennessee for a month, the arm flapping stops completely! When they

return to the San Francisco Bay Area the arm flapping returns. The parents also mention that there is no cell-phone reception in grandma's area of Tennessee.

#### CASE HISTORY

A three-year-old child is being evaluated for speech delay and learning disability. He also has frequent high-pitched screaming and head-bangs and rocks a lot and has great sleep difficulties. But when he visits his aunt in rural Oregon (where there is no cell-phone reception) he sleeps for the first 24 hours and then wakes up like a "new child."

He no longer screams, he is calm, he plays normally, he can sleep at night and be awake during the day. When the family returns to their home in California, their son has high-pitched screaming again when they reach the Sacramento area, and his sleep difficulties and other problems return.

4. Children have a right to live, play and learn in locations that protect them from developing cancer at a young age. This is not the case today.

#### CASE HISTORY

A 12-year-old girl presents with her dad. She is diagnosed with liver cancer. Six months later, shortly after her 13<sup>th</sup> birthday, she succumbs.

#### CASE HISTORY

A five-year-old girl develops a severe headache. She takes the ice cream from the grocery cart and puts it against her head for relief. She has a brain tumor. She spends the next year in and out of the hospital. Finally, she has an uncontrollable seizure and dies.

#### CASE HISTORY

A two-week-old child is diagnosed with cancer. He spends the rest of his life in and out of the hospital. At age five he says to his mother "I can't do this anymore." That night, he breathes his last breath. See section 11 and 12 of the 2012 Bioinitiative Report for evidence of brain tumors and acoustic neuromas and childhood cancers (leukemia.)

5. Children have a right to a good night's sleep. See the Bioinitiative Report section 13. Evidence for effects of low-intensity electromagnetic radiation on melatonin (the sleep hormone.)

#### CASE HISTORY

A four-year-old boy presents with his parents with a complaint of sleep difficulties. He hasn't slept for two years and climbs in his parents' bed every night, so they also have had poor sleep for two years and are exhausted. The evening before they came to see me, they gave their son some melatonin and it seemed to help. Knowing that EMF can lower melatonin, I suggested a two-week EMF remediation trial. (No Wi-Fi 12 hours at night, no cordless phone, and Stetzer filters to lower extremely low frequency EMF.) They followed my EMF remediation instructions and stopped the melatonin supplement. Within a few days the son and the parents were sleeping fine without a melatonin supplement.

6. Children have a right to live, play and learn in locations that permit them to retain their fertility so that they may reproduce when they become adults. That is not the case today. Most schools have Wi-Fi and more. Young girls place laptops on their laps where non-ionizing radiation from the laptop can damage their future offspring as all their eggs are mere inches from the laptop. See section 18 of the 2012 Bioinitiative Report. Fertility and reproduction- effects of EMF.

7. Children have a right to live play and learn in locations that permit them to grow up and have the ability to reproduce and have healthy children.

#### CASE HISTORY

A young woman with excellent health and good pre-natal care gives birth to a boy with a heart defect. No previous relatives on either side had a heart defect. During her pregnancy, she lived in a building across the street from a power substation. The light bulbs burst frequently in her apartment and needed to be replaced often. This is a sign of too much dirty electricity in the home. Too much dirty electricity (ELF) contributes to birth defects. See section 19 of the 2012 Bioinitiative Report. Fetal and neonatal effects of EMF.

8. Children have a right to live, play and learn in a location that permits them the ability to speak.

#### CASE HISTORY

A 12-year-old boy comes to my office with his parents, who are asking for help with his aggressive behavior. He has also been diagnosed with autism and is unable to speak (non-verbal). They agree to a two-week EMF remediation trial. Within three days this young man said a complete sentence much to the disbelief of his mother and himself! His aggressive behaviors disappeared. See section 20 of the Bioinitiative Report. "Findings in autism consistent with EMF and RFR"

Over 1% of America's children now have autism. And the numbers continue to rise. In addition to the pain and suffering these children and families experience, this problem alone threatens to bankrupt whole school systems at a time when we can least afford it. When I as a physician need to perform a potentially dangerous procedure on a child, such as a spinal tap, I need to explain why it is necessary and what the risks are. Then I need to get written consent from the parents and the parents have the right to refuse. Currently, we are performing large-scale experiments on America's children without informing children or their parents of the risk. Children and their parents have not given their consent nor have they been given an option to opt out. See section 2, 3 and 4 of the 2012 Bioinitiative Report. "Statement of the problem, the existing public exposure standards and evidence for inadequacy of current standards." A nation that does not protect its children has no future. Please reevaluate the FCC Safety Guidelines for non-ionizing radiation. America's children have the right to sleep, speak, behave, learn and – as adults – to reproduce. Please don't take these from them. Please help America's children and America to have a future.

Thank you for your time.

Sincerely,

Toril H. Jelter M.D. FAAP

P.S. – All case histories are real patients, minor details have been omitted or changed to ensure privacy.

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Lea Googe**

March 13, 2014

*Subject: Autism Parent Testimony*

I am a mother of a 5 year old with severe Autism.

My child was vaccine injured. I want a fire wall between the CDC and the vaccine manufacturers. I want to see a large scale study done to show vaccines that are in the CDC schedule are safe, a blind study - one with each vaccine shown safe when combined with others. A study also needs to be done on infants who were vaccinated vs those who were not. No previous study has done this - some were done without one ingredient and this is not acceptable. If the vaccine inserts were presented to me with all the side effects clearly listed like those on a cigarette box my decision would have been different. Pediatricians cannot be paid by vaccine manufacturers this is a conflict of interest. Vaccines should not be administered by non - doctors. Mercury should not be given to pregnant women in a flu shot - when they are told to avoid mercury in fish!

Fluoride is not a safe chemical - it should not be in our water if we are told not to swallow it by children.

GMOs have been shown to cause "autistic" symptoms in animals so why are we forced to eat them without labels? Russia has banned our US GMO corn - why are we forced to eat it.

Autism is not a psychiatric condition and should not be under the psychiatric evaluation committee. It is a medical condition. Update your research on what medical conditions all autism children have in common - auto immune issues, mitochondrial dysfunction, mercury poisoning, toxic overload, methylation issues, GI problems, allergies, sleep disruption, significant developmental delays.

Why are we accepting this year's CDC count of autism that is counting people older than 12 years old - and not including anyone younger? (They counted 8 year olds in the year 2008 and older in the 1 in 88 count) If they can get an exact count of west Nile victims in a week - surely they can get a count of the current years autism community without excluding huge amounts of the population.

Please direct moneys away from redundant genetic studies, give money to families who have been paying 60k a year on services for their child. Start looking at prevention. Have a plan for when these children who are now becoming adults and they need services, housing, care and families need trained doctors. Not pediatricians who get 1 hour of autism training in medical school.

If you want to really see the number of families affected today go ask a school district who will tell you (some on their websites) how many children are receiving special education services. The number is close to 20%. Admit this is an epidemic.

This would be a start.

Kind Regards,  
Lea Googe  
mother to [PII redacted]  
[PII redacted]

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Kerry Scott Lane**

April 1, 2014

I have included numerous documents supporting my theory Autism is triggered by depletion of Glutathione by Acetaminophen, aka Tylenol. Please post these so your reviewers are able to read them. The Autism Epidemic began when Tylenol usage replaced aspirin in children, see the paper by Dr. Partin, whose lab I worked in during 1978...

[PII redacted]

[PII redacted]

[Autism Speaks Clinical Research on GI and Neurobehavioral Processes Request for Applications](#)

### Articles

Bender RP, Lindsey RH Jr, Burden DA, Osheroff N. N-acetyl-p-benzoquinone imine, the toxic metabolite of acetaminophen, is a topoisomerase II poison. *Biochemistry*. 2004 Mar 30;43(12):3731-9. [PMID: [15035644](#)]

Brandlistuen RE, Ystrom E, Nulman I, Koren G, Nordeng H. Prenatal paracetamol exposure and child neurodevelopment: a sibling-controlled cohort study. *Int J Epidemiol*. 2013 Dec;42(6):1702-13. [PMID: [24163279](#)]

Frye RE, Delatorre R, Taylor H, Slattery J, Melnyk S, Chowdhury N, James SJ. Redox metabolism abnormalities in autistic children associated with mitochondrial disease. *Transl Psychiatry*. 2013 Jun 18;3:e273. [PMID: [23778583](#)]

Ghanizadeh A, Akhondzadeh S, Hormozi M, Makarem A, Abotorabi-Zarchi M, Firoozabadi A. Glutathione-related factors and oxidative stress in autism, a review. *Curr Med Chem*. 2012;19(23):4000-5. [PMID: [22708999](#)]

Kern JK, Geier DA, Adams JB, Garver CR, Audhya T, Geier MR. A clinical trial of glutathione supplementation in autism spectrum disorders. *Med Sci Monit*. 2011 Dec;17(12):CR677-82. [PMID: [22129897](#)]

Lauterburg BH. Analgesics and glutathione. *Am J Ther*. 2002 May-Jun;9(3):225-33. [PMID: [11941382](#)]

McBean GJ. The transsulfuration pathway: a source of cysteine for glutathione in astrocytes. *Amino Acids*. 2012 Jan;42(1):199-205. [PMID: [21369939](#)]

Partin JS, Partin JC, Schubert WK, Hammond JG. Serum salicylate concentrations in Reye's disease. A study of 130 biopsy-proven cases. *Lancet*. 1982 Jan 23;1(8265):191-4. [PMID: [6119559](#)]

[Shaw, W. Evidence that increased acetaminophen use in genetically vulnerable children appears to be a major cause of the epidemics of autism, attention deficit with hyperactivity, and asthma. \*J Restor Med\*. 2013 Oct;2\(1\):14-29.](#)

Best regards,

Kerry Scott Lane MD

[www.PalmBeachAutismInstitute.org](http://www.PalmBeachAutismInstitute.org) [PII redacted]

Kerry Scott Lane's attachment can be viewed here:  
[Attachment](#) (PDF – 245 KB)

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Eileen Simon**

April 1, 2014

Attached is a 15-page pdf file with 13 brief comments for members of the IACC and the Public Record. Please let me know that you have received these. Thanks.

Sincerely,  
Eileen Nicole Simon  
[PII redacted]

--

Conrad Simon Memorial Research Initiative  
To seek understanding of brain system impairments in autism.  
<http://conradsimon.org/>

Eileen Nicole Simon's attachment can be viewed here:  
[Attachment](#) (PDF – 195 KB)



**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Eileen Simon**

April 1, 2014

Attached here is a pdf file of pictures from a Powerpoint (Apple/Keynote) presentation I had planned to present at the IACC meeting in January. I am submitting it as written comments for the meeting next week. If possible, I might like to display the first 3 pictures after I read my oral comments.

Sincerely,  
Eileen Nicole Simon  
[PII redacted]

--

Conrad Simon Memorial Research Initiative  
To seek understanding of brain system impairments in autism.  
<http://conradsimon.org/>

Eileen Nicole Simon's attachment can be viewed here:  
[Attachment](#) (PDF – 465 KB)

## Shannon Des Roches Rosa

April 2, 2014

Thank you for reading my comments today. My name is Shannon Rosa, and I am the parent of a thirteen-year-old, thoroughly wonderful, autistic young man who does best with 1:1 support. I believe it is the responsibility of all those involved in autism policy to work towards guaranteeing autistic people like my son the support they need to succeed in life, no matter their abilities.

For that reason, I would like to thank the IACC for the positive work it does in advising on autism policy. However, I'd like to speak out about what the IACC can do to help people like my son, and families like ours:

- 1) Focus on getting supports and resources to autistic people and their families. The CDC's new 1 in 68 numbers for autism prevalence are an excellent opportunity to reinforce the message that autistic people of all abilities have always been part of our society, and that we will all benefit if the proper autism resources are allotted -- whether for housing, employment, respite, education, health care, or therapies.
- 2) Focus on research that helps the autistic people who are already here. We need to know more about autism and sensory issues, autism and anxiety, autism and co-morbid medical issues, and so on. This should be a higher priority than research into causation.
- 3) Recognize the agency of autistic people, and include more of them on the IACC itself. I have spent many years working with and learning from autistic adults regarding what my son needs and how he experiences the world. While I support the involvement of parent advocates and autism professionals on the IACC, autistic people themselves should be the majority representation when it comes to advising about autism policy.
- 4) Finally, stop accommodating pseudoscience. I still keep seeing mentions of vaccine or mercury autism causation theory in the IACC proceedings. Such theories have been debunked repeatedly by legitimate research. Setting aside any time to discuss them is a waste of the IACC's resources, and does not help autistic people.

Thank you for your time,

Shannon Des Roches Rosa  
Senior Editor, Thinking Person's Guide to Autism

--

writer | editor | parent | geek

[www.Squidicious.com](http://www.Squidicious.com) | [ThinkingAutismGuide.com](http://ThinkingAutismGuide.com) | [BlogHer.com](http://BlogHer.com) Get the Thinking Person's Guide to Autism book: [is.gd/TPGAonAMAZON](https://is.gd/TPGAonAMAZON)

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Haven DeLay and Gerard Dziuba**

April 2, 2014

I request that this letter become a part of the public record and that a copy be given to each committee member. I regret that I cannot be there in person. It is difficult to travel with a child who has suffered vaccine damage.

As I watch the last committee meeting, I was outraged and appalled at some of the decisions proposed by the committee. The main one of course is the lack of support for independent research into the autism-vaccine connection, which in truth is far more than "autism." We know it to be "Post Vaccinal Toxic Encephalopathy." It carries with it not only behaviors but NUMEROUS and diverse medical comorbidities. We rarely use the word "autism."

As a parent who witnessed in horror the immediate change in my fifteen-month-old son following four vaccines (three of which contained the full complement of mercury), and having now over thirteen years into the study of this disorder, I believe my insight to be valuable.

[Medical record redacted]

First I do not just "think" vaccines triggered my son's disorder – I KNOW IT. I was an eye-witness to the immediate regression of my child. My child was subsequently diagnosed with "Heavy Metal Intoxication" by a prominent pediatric neurologist at a well-known children's hospital. He admitted that the mercury had to have come from the vaccines, though he could not publicly state it as he said, "That idea is just not well-accepted here." No wonder since this hospital AND medical school is largely supported by the vaccine and prescription drug industry. He apologized, after he examined my son and read my research (which he asked to copy). He said, "I am SO sorry. I thought they took that stuff out of vaccines." But you've just got to understand, by mass vaccinating, we are saving so many, but there are going to be "LOSSES." Your child is ONE of them, and you just need to go home and accept it." I ask the committee members if THEY could accept the knowledge that their child was sacrificed to a perceived "greater good" without them knowing or having a choice there would be a possible sacrifice. This was my ONLY child. He is the ONLY male child in the family that could have carried on the family name. He will most likely not have children of his own.

I am outraged that the consideration that toxic vaccines, for which there have been NO synergistic studies continues to be swept under the rug and no one dares to touch the issue because it is politically incorrect to do so.

If you do not address this form of research, and if the current vaccine program cannot stand up to scrutiny, then that is a huge red flag. If the vaccine program is afraid of it, that is even more of a red flag.

Even if you support various therapies but continue to add to the number of vaccines being given to infants and toddlers – and now PREGNANT WOMEN, the autism epidemic will continue to proliferate, and all your efforts are moot.

I strongly believe this disorder has been misnamed. Autism is only PART of this disorder and the medical co-morbidities are paramount in this disorder and yet this committee continues to bury its head in the sand.

I have lived with having to watch my son suffer with numerous medical co-morbidities which include metabolic, immune, neurological, psychological, dermatological, and digestive disruption.

It seems to me that this committee is a lot of talk and VERY LITTLE actual MEANINGFUL action. You will NEVER solve the issue of what triggers autism until you research the role of vaccines in this epidemic. I believe that it should begin by comparing the long-term health and well-being of vaccinated children to totally unvaccinated children.

The other issue is that since parents are denied the right to sue drug manufacturers in open courts with impartial juries, one of the most pressing issues these families have is that of financial devastation due to the cost of care for children with this disorder. Making insurance pay for this or that is still not enough. My son is now fourteen and his care to date has cost close to 1.5 million in lost wages and out of pocket expenses. Of course, I believe the solution is to allow parents to sue these companies in civil court and let each family's evidence speak for itself.

It almost seems as if you exist just to give platitudes to parents. You really don't have the money to do anything, and then when you do have some money, you appropriate it away from the true cause of this iatrogenic disorder.

I warn parents. I tell them the truth about how if their child is damaged they cannot sue and that the VICP is a JOKE. I make sure they know they will be on their own. It will cost their life savings- everything they have worked hard for and beyond, and their dreams can be shattered after ONE shot. That one shot can never be taken back once it is given. If only it could be.

It took but a few months to put 237.5 mcg of mercury into my son's body and brain. We are now in our thirteenth year of trying to get it safely OUT. As we have succeeded over the years, his so-called "autism" has improved. He has gone from moderate-severe/non-verbal to high functioning and very verbal. However, I believe the metabolic disorder NOS and the immune disorder NOS that vaccine damage caused will last a lifetime. In his fourteen short years of life, my son has suffered too many infections to count. Between March 7, 2001, and the end of 2010, my son suffered an infection with a fever roughly EVERY TWO WEEKS. Our lives revolved around sickness. My son has suffered pneumonia nine times, meningitis twice and too many numerous bouts of strep, staph, and cellulitis to count. He cannot even fight the bacteria that gets introduced from an insect bite. He will develop radiating staph form every bite site, which quickly turns into cellulitis, putting him at risk for MRSA, septicemia, and even death. Vaccines and blind trust did this to my child!

It is my sincere hope, that before any more children are lost, the IACC will own up to its mistakes, and create valid ways to help these children. Start by admitting we have vaccinated too young with too many shots without appropriate synergistic studies. Furthermore, I call for the IMMEDIATE ban on thimerosal in any way in the manufacturing of vaccines. Extraction after manufacturing is unacceptable. Likewise is the inclusion of aluminum and other toxic chemicals.

If the committee cannot take immediate and decisive action, then I call for new leadership and the inclusion of parents of vaccine-damaged children on the committee.

Sincerely,

Haven DeLay and Gerard Dziuba

**Courtney Reid**

April 2, 2014

I am commenting to raise concern and to address the GAO report and the 1.5 billion that has been spent on research with up to 84% of that being duplication while also not transferring to application. The IACC has not fulfilled their intent nor should they be funded further in a re-authorization of the CAA.

C. Reid

Texas

**Nora Brock**

April 2, 2014

Dr. Thomas Insel and Committee Members of the IACC,

I feel there is little that can be said to change the directory of this committee. Many concerned citizens since 2007 have spoken or sent their comments before me to no avail. I feel as if the fix is in and the causes of the autism epidemic are not going to be addressed.

I just want it to be known that my grandson is one of the disappeared. He regressed from a normal child from the physical injuries caused by the vaccines he received in his first year of life. I am very much aware of regressive autism and the government's efforts to control the dialogue regarding this subject.

So at this sad juncture, I am merely writing as a witness. I want future generations to understand what happened to this generation of children. I want to leave a written account so that in the future the archives will reveal that this de facto committee was for all intensive purposes a sham, a charade. This committee has worked to obfuscate the truth and muddy the waters. All in an effort to cover the tracks of a hideous government experiment inflicted on an unwitting public.

I imagine that when this committee was formed there might have been an honest effort to investigate the rise in autism. But when it became apparent to those studying the data that the scope of the injured children was so dramatic, I am sure that is when the mission changed to a cover-up effort.

So now, you are all here today to silence the truth. Let it be known that this will never happen. These children deserve to have their stories told and I will not rest until justice takes place for the vaccine injured children. I pray that the members on this committee working to defray the original purpose of this committee reflect on their actions and change their course.

There will be a time of reckoning for all of the false efforts involved with this committee. In past human experiments, where pain was inflicted on unknowing participants, those who participated and collaborated in said injustices faced harsh punishments. Do not feel that you are safe from scrutiny because of your government position. The government has no loyalty. When the tide turns and mark my word it is tuning faster than you can control, you will be left with the debacle. Your committee will be blamed and all of you will have to defend yourselves. You will have no careers and your lives will be left in the rubble. Justice will be served and I encourage you to join the justice train or forever be part of the bleak history of this absolute failure involving this vaccine experiment.

Sincerely,

Nora Brock

Grandmother to vaccine injured child.

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Joseph M. Jason**

April 2, 2014

My son has been undergoing cruel and unusual punishment within the criminal justice system since 2007 in Iowa. Due to his Asperger Syndrome, Iowa prosecutors have continued to incarcerate him for non-violent crimes. He is presently facing 55 years. I am always concerned for his safety in jail and prisons since he is prone to be bullied.

[The crucifixion of \[PII redacted\] in Iowa City, Iowa Posted on September 28, 2013 by josephmjason](#)

Joseph M. Jason, President NAMI BA

Board Member of Criminal Justice Advocacy for People with Mental Illness

Member/Director of CURE

[PII redacted]



## **Carol Fruscella**

April 2, 2014

To the members of the IACC panel

With the latest numbers just released from the CDC being 1 in 68, I kindly must ask... if your hearts are in this fight.

I wonder if at times if some of you attend, because you must attend.

14, years ago today, about 3800 of us (or more) meet in the Mall for the First National Rally for Autism Awareness. We were always 'informed' that we were 'over reacting'. We were told THEN, Autism had 'always' been around but was being better understood and DX. Yet, here we are... 14 FULL YEARS LATER. Being told the exact same thing. The numbers then... 1 in 500... The numbers today 1 in 68.

How about, I personally meet you 1/2 way. Maybe High Functioning Autism has been around for much longer than we all knew. Now, will you meet the group of deeply concerned parents 1/2 way, by finally admitting that the Lowest Functioning form of Autism has only happened in the last 70 years.

It does not take a Ph.D. to realize that 30 years ago Autism was not seen in the general population. One can hardly go anywhere now without seeing Forms of all Autism.

When my oldest son was first DX, he was the only person I knew with Autism. Now in a neighborhood, that I moved into 17 years ago, from a different state, I have an Autistic young adult directly across the street. I have a direct neighbor who has a son with ADHD and Asperger's. My most direct neighbor on my other side has a Grandson who is over the age of 3 that is 'nonverbal'. My neighbor behind me had one older son DX. I raised two children in my own home with Autism. You cannot blame the environment as we moved from 'all over' to here.

Every other trip I make to the grocery store I witness a 'melt down'. This is not bad parenting. This is not better DX. This is not better world acceptance that 'we' go out in public now. This is not a spoil child acting like a brat... This is Autism sensory overload!

I begged 14 years ago today, April 8, 2000, for answers. Today, I will no longer beg. I would like to know, what your PLAN is to take care of the 'least of these' with the Autism DX. The clock is ticking and the cases of the most impacted with this disorder keep increasing.

If your heart is not in this fight... Please resign, as we cannot wait any longer for real answers. A 30% increase in Autism in two years... When will this become an issue to maybe meet on monthly?

We have children and adults and their families waiting for answers. Not more excuses, Not better counting... Answers.

**Note: Personally Identifiable Information (PII) has been redacted in this document**

## **National Autism Association**

April 2, 2014

### **STATEMENT FROM THE NATIONAL AUTISM ASSOCIATION INTERAGENCY AUTISM COORDINATING COMMITTEE | 04.08.14**

At the National Autism Association, we represent individuals with Autism Spectrum Disorders (ASD) at highest risk of injury or death. This includes those with nonverbal autism, regressive autism, intellectual disabilities, aggressive and suicidal behaviors, and underlying medical conditions.

In addition to advocacy for medical treatment and environmental research, our key issues include autism safety, autism abuse, and crisis prevention.

The population we represent cannot be at your meeting today to advocate for themselves, nor can many of their parents or caregivers. They require around-the-clock care, assistance with basic daily living skills, supervision and protection. Some live in a constant mode of crisis and physical pain accompanied by irritability, aggression, sleep disorders and self-injurious behaviors. Many are unable to effectively communicate, putting them at staggering risk of becoming silent victims of maltreatment and brutal physical, mental and sexual abuse – without the ability to defend themselves. They often suffer from debilitating comorbid medical conditions that continue to go unacknowledged and untreated due to the blatant failure of our federal agencies to direct research funding toward effective treatment.

#### **RISING AUTISM RATES ARE A TRUE INCREASE**

As of 2014, an estimated one out of 68 individuals carries a diagnosis of autism, an increase of 30% from the 2012 data. These rough data are sure to be an under-ascertainment of children with an ASD since they are largely based on medical records. In 2006, after the Government Accountability Office investigated “Federal Autism Activities,” their findings showed that while autism research funding increased, surveillance challenges between agencies like Centers for Disease Control and Prevention (CDC) and Department of Education (DoE), needed to be resolved. It is 2014 and surveillance challenges remain unresolved. Further, the CDC reports that the prevalence of autism is much higher in sites that have access to education sources. With the lack of qualitative data, we also remain unclear on what percentage of our population will need ongoing care into their adult years and throughout their lives. Although other countries share similar prevalence numbers, the autism surge in the United States is still sugarcoated as an illusion of diagnostic criteria changes, along with better overall awareness and diagnosis. As a community focused on the more severe effects of autism, we know these explanations to be invalid. The majority of new autism cases are the result of a very real rise in autism. Resting on unproven explanations only stalls progress for our entire community.

#### **WHAT WE NEED**

Treatment, therapy, housing, adult services and supports, abuse prevention initiatives, training for schools, first responders and clinicians, family services, early screening, safety initiatives, meaningful research, and access to critical resources on all fronts are all needed right now.

We also need minority representation and resources. Currently this population is grossly underserved and under-represented in our community and on the IACC. Greater federal efforts need to be made to provide information, resources, services and earlier diagnosis to these families. The level of neglect is both sad and disturbing.

**OUR NATION IS UNPREPARED**

We are completely unprepared for what's ahead. Regardless of any DSM changes, criteria or definition changes, if the prevalence of ASD is a loose estimate, and we have no way of knowing the depth of cognitive deficits among our own population, then no doubt we are about play a game of pin the tail on the donkey with our community's basic needs at stake. We need immediate and long-term solutions in the form of a federal autism strategy or national plan. As federal members and community leaders, you are in a unique position to ensure these needs are met.

We leave you with the names of those who have died from wandering/bolting since last April's IACC:

- [PII redacted], age 14
- [PII redacted], age 4
- [PII redacted], age 29
- [PII redacted], age 3
- [PII redacted], age 9
- [PII redacted], age 7
- [PII redacted], age 2
- [PII redacted], age 13
- [PII redacted], age 5
- [PII redacted], age 16
- [PII redacted], age 15
- [PII redacted], age 7
- [PII redacted], age 6
- [PII redacted], age 7
- [PII redacted], age 12
- [PII redacted], age 9
- [PII redacted], age 11
- [PII redacted], age 8
- [PII redacted], age 5

## Victoria Beck

April 2, 2014

*Subject: My Open Letter to the Interagency Autism Coordinating Committee (IACC) Meeting of January 14<sup>th</sup>, 2014*

As a parent who has been on the front lines of autism over the past several decades, there is not much indifference – *from within the ranks of the political, medical or psychological communities* – that surprises me anymore. Millions of other parents, just like me, have sought reasonability and common decency from the majority in those ranks, for years, only to receive intolerance and indecent commonness in return. Frankly speaking, no particular educational degree and no special initials after one's name is an excuse for such treatment. Much to the dismay of those who have chosen to arrogantly dismiss our parental concerns for our own children and, much to the chagrin of those who would elect to view our advocacy for our children as inconvenient to accepted professional biases regarding autism, we in the parent community are *still* here, are *still* convicted and have no imposed "deadline" for giving up on our kids.

My own child was 4 years old when he was first in the news for his tremendous response to a serendipitous infusion with natural porcine secretin hormone. He will be 21 years old in two weeks; thank God I paid no attention to our detractors. Thank goodness we continued to seek medical help from compassionate and dedicated doctors who were capable of actually thinking out of their proverbial medical boxes. Today, he is almost indistinguishable from his typical peers (and actually much smarter than most of them). Back then, few doctors would listen to our hunches about biomedical connections to autism, and even fewer would heed our pleadings to treat intestinal involvement as part of the diagnosis. There were also some who actively sought to sabotage our efforts and desires to help our fellow parents who had children with similar issues. One such doctor in this last group actually sits on the IACC today. Personally, I now believe his interest in the ongoing welfare of our community of children to be counterfeit, at best. It makes a mockery of a process upon which so much rests, for so many well-deserving and dedicated families and their affected children.

One of the highlights of the November 2013 meeting was witnessing one of the female doctors proudly declaring, that when the IACC had convened in 2009, the committee had concluded that there might be some biomedical connections worth exploring. I watched this proclamation in abject amazement, stunned that so many at the IACC could have come to the party so late. It seemed incredulous that, if they *finally* had begun to believe what the parent community had been saying to them *for over a decade prior*, it was beyond disgraceful that research funding for such biomedical connections had not been adequately allocated or emphasized. Four years later, in November 2013, it was obvious to anyone watching the proceedings that this sort of lip service had likely impressed no one except, perhaps, those sitting around the big, important IACC table... which brings me, conveniently, to my next observation.

Aside from that which was discussed in the November 2013 meeting (or, not discussed, as the case seems to be), there was a very powerful visual about the meeting that serves as a sad metaphor for the state of relations between the IACC and the autism community, and which speaks volumes for precisely why real progress has been near non-existent for so very long. With the "important" people seated around the table (name placards and impressive credentials front and center), the few parent attendees sat, off to the corner of the room, waiting patiently for their five-minute turn to talk. Ladies and gentlemen of the IACC, is there any reason why the parents – who know the most about and who care

for our children – should not have a seat at the table **with** you? Is there a good reason their voices should not have a place in **every** facet of “your” discussions? Especially considering that your committee saw fit to acknowledge intestinal involvement **fully nine years after thousands of parents were castigated and ridiculed for suggesting the same**, do you not think it might be prudent to finally engage those people now? Granted, they might not have “M.D.” after their name but they are most certainly your intellectual equals.

Whether you are willing to believe it or not, every single person on your committee could learn a lot from our community, especially as regards our children with autism. To suggest otherwise or to continue to proceed in such a self-righteous and sanctimonious fashion is both futile and unproductive. The autism community is tired of this kind of window dressing. We also seek funding that benefits our children directly, not that which merely props up academicians. The parent community rejects forums wherein objectives are discussed but where accountability and follow-through are largely non-existent. Most of you, would be hard-pressed to look at the members of the parent community in the eye – figuratively or literally – if you had to account for the **billion-dollar tab** that has already been spent. You would be embarrassed if you had to explain, definitively, exactly what has been accomplished, discovered, or directly helped our children with autism, with those funds. Perhaps that’s why keeping our parent voices in the back corner of the room is such an effective strategy for you to employ.

I will offer an analogy, as I close with some words from the movie *Gangs of New York*. Those who have seen the film know that it creatively illustrates the dynamics of a sort of personal civil war. The corruption of the New York establishment comes face-to-face with the growing population of Irish immigrants reaching the shores of that city. Leonardo DiCaprio’s character represents the latter group and, toward the end of the movie, he observes,

***“The earth turns, but we don’t feel it move. Then, one night, you look up and the sky’s on fire.”***

I submit, to the members of the IACC, that there has been a civil war that has affected the autism community for decades. There are establishment doctors, psychologists and other professionals who defend their positions and their turf – in spite of the facts, in spite of parental outcries, and in the absence of factual information or proven research that favors their faulty assertions. A few from within these groups have crossed the equivalent of the “thin blue line” with their colleagues to ally and partner with parents like me. ***They are the ones who know that the earth has, indeed, been turning.*** Parents of children with autism feel it move, every single day. In fact, for many among us, it has been a veritable earthquake of mental, emotional, social, spiritual and financial movement. Unfortunately, the inaction and the wrongful actions of the IACC seem to indicate that it doesn’t really feel it move, yet.

I would, however, caution each IACC committee member to look up and see that the sky is already on fire. The sky is on fire with an epidemic of new children being diagnosed each and every day. The sky is on fire with children who have grown up in the past two decades, with no group homes or adequate help today, as they enter adulthood. The sky is on fire with parents whose lives have been shredded because little to no help has been there for them and their children. Most importantly, the sky is on fire because this community has some of the most passionate and dedicated warrior moms and warrior dads who are not going to be relegated to the back corner of the room, by you, your actions or your inactions. To do such, to try and dismiss us, our perspectives or our knowledge of our own children, is just another reminder of our families’ suffering.

From our great (and growing) numbers comes great strength.  
***We are still gathered... and our drums are still beating.***

Tonight, I urge my fellow parents to keep their lighted candles in their windows, so friends and allies will know how to help them in the dark. Keep them burning so those who are in the position to help – such as those on the IACC – know that you and your children with autism will *never* be placated by lip service. Keep them burning to signal that you and your convictions will not go away, until the day when our 1 in 88, personally, can have an equal place, and voice, at the table with members of the IACC and those in professions that they represent. I urge you to never become complacent in your advocacy. The only thing that isn't moving fast enough in the world of autism is ***progress***.

Sincerely,

Victoria A. Beck

The narrated letter follows, here, in a public YouTube video:

<http://www.youtube.com/watch?v=h4FQJj8R8TY>

## Brian Kelmar

April 2, 2014

Please reinstate the Safety Committee that was considering not only safety issues, but civil rights issues for those with autism.

My son has been through a nightmare with the Judicial system. He is autistic and got charged with a serious felony, when he was the victim. His civil rights were taken advantage of.

Here is a quick background:

- Never had any friends, so when this girl started texting my son after a while, he was not sure what to do.
- Her Texting turned in to very explicit sexting, which my son had no clue what she was talking about. As noted by the sexual psychologist : He clearly did not understand the sexting and she was clearly the sexual aggressor
- The girl pushes and pushes to meet and gets very sexually aggressive, although no sexual act was completed.
- Police arrived at 4 in the morning and questioned him alone. As a pleaser and thinking she was in trouble because she sexually attacked him, he told the police what happened. Never reading his Miranda rights before they started, even though clearly they intend was to come and arrest him as the only suspect
- Her father was a former prosecutor, so he knew all things to tell the police
- Our attorney had no experience with Autism nor did the prosecutor or the judge.
- We were forced to plea bargain at the advice of our attorney, not realizing he would be penalized for life as a violent sexual predator for something he did not have a clue what was going on. Besides all of this, we later found out our attorney was suffering from Mental illness at the time of my son's defense,
- There was no one to turn to. We never experienced anything like this so we did not know. There should be some early intervention especially when overzealous prosecutors ignore the facts or the situation and just looking for a win. Now besides his struggles with autism, he will have little hope of any kind of career or life. Having a label as a violent sexual predator for life for a one time incident that he was the victim could have been mitigated with the right Autism support and mitigation.

There needs to be a safety committee to look in to similar situations. Our children with Autism are easy prey for people to take advantage of and the justice system is one that very easily sweeps autism people into a process that turns in to a snowball effect when they should have be properly mitigated and received support at the very beginning.

Brian Kelmar

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**James Blanco**

April 2, 2014

Dear IACC committee

My comment for public comment mirrors most of the mothers who have written today. I am not pleased at the course this panel has taken:

These are the reasons why

1. No acknowledgement of the role of multiple vaccines and the bio-accumulative effect of heavy metals and viruses in those vaccines. The science is incontrovertible since CDC on package inserts alone say autism is a side effect after a dTAP vaccine. The FDA has a comprehensive and thorough ingredient list, with the full package insert. Unlike the CDC which gives you a vague summary-- which includes "reactions are extremely rare" the FDA includes reactions that have been reported in VAERS. Autism is listed as reaction for some of the vaccines, so is encephalitis-- which is the precursor to most autism cases. CHANGE THE LAW...that ALL physicians must read aloud this package insert to all recipients....This is TRUE INFORMED CONSENT. You state that vaccines are safe and effective but as a member of the scientific and healthcare community I'm not sure how you came to that conclusion. You see, vaccines are not researched effective because they are not subjected to double-blind placebo controlled studies using a saline solution that is the standard for evidence-based medicine. Vaccinations are tested against other vaccinations, adjuvants, and complex vaccinations – this not only yields inaccurate results but altered and inaccurate safety data. How can you know if something is truly safe if it is not tested against a placebo?

2. Mainstream Media claim the anti-vaccine (pro-holistic health) movement is unscientific. They have vastly under-estimated the intelligence & inherent wisdom of this fast-growing community. Not only that, it is the least funded of all research. Fund research on the environmental causes of autism, including multiple vaccines and vulnerability markers such as neuroimmune/metabolic problems INSTEAD OF GENETIC GO NO"WHERE on purpose studies. Fund independent research now~! For instance...The Physician's Desk Reference from 2001 has implicated the MMR Vaccine in 'Severe Afflictions affecting nearly every body system -- including blood, lymphatic, digestive, cardiovascular, immune, nervous, respiratory, and sensory disorders.', based on multiple studies.

3. We have no freedom of speech in media anymore. What is espoused as scientific is tobacco science, and non-touch child draw blood studies, which would confer actual truth to the links between vaccines and autism, or pesticides and autism, etc. We need the FCC to give equal footing to parents, independent research studies of these links, instead of silence, maleficence, and blocking the public from knowing what most autism parents know. Every eight years, news local stations must pass a test that they are looking out for the public interests...now it's a rubber stamp no problem if you speak of lies in this regard. FCC should be sued for not letting the public say what is happening to our children. We should seek truth, instead of [PII redacted] powerholdings on no talk of unsafety of vaccines and other damagers. According to [PII redacted], [PII redacted] we should have: 'Journalism Jail' For Faulty Medical Reporting. By now, all the news outlets should have a life sentences! "But because the CDC has done such a good job of convincing the media that a vaccine-autism link has been



discredited, most journalists don't realize the conflict staring them in the face. They don't understand that the CDC cannot be trusted with anything bearing on the cause or frequency of autism, that it can't be treated as a credible and disinterested source. It's amazing really: the folks that caused this train wreck by falling asleep at the switch are investigating the cause and counting the casualties, and the media treats it as gospel."

4. 27-40% of us have the CBS gene that allows toxins direct access to the liver where they throw off the P-450 enzyme and glutathione that helps us detox! How many kids are we going to throw under this CBS gene bus vaccinating them willy nilly without concern of this connection, or others like Mitochondrial Dysfunction, Severe Oxidative Stress, Activated cytokine panels, Hyper IgE, Mastocytosis, Autoimmune Family histories, MTHFR dysfunction, LOW VIT B12/Glutathione?

5. We have drug companies buying off every kind of official to sell their witches brews, from the Supreme Court to Federal Agencies such as EPA, FDA, Health Department, NIH and even Agriculture. Corporate interests are willing to murder to sell fraudulent health care and that includes vaccines. YOU CANNOT make the poisons they put into the vaccines SAFE. YOU CANNOT make mercury safe, aluminum safe and a hundred other chemicals being added to vaccines which include things that read like a witches brew. We need to know the combined effect of having babies swiftly vaccinated, if not their pregnant mothers, combined with agricultural foods and their toxins what that does to monkeys, rats, who cares...some study of the gravity of all these exposures in children....show me the study~!

6. I think the biggest problem we are seeing is the increasing infiltration of our State Congresses with pro-vaccine/pro-pharma representatives, whether it be lobbyists or the legislators themselves. That and the new imperative to vote in lock-step with the Party lines. That it (vaccination, but also allopathic medicine in general) is an enormous racket and total scam is overlooked by many people, who still entrust their health to "authorities" versus using common sense. There is a naiveté among the general populace that somehow medical officials are "above" jeopardizing peoples' health in order to make a profit. While that should be the case, it quite obviously is not, and unfortunately, much of our economy is invested in people being sick, versus having optimal health.

7. And last, I cannot say this enough, fire all of you...you have not done your job and held the public interest at heart. Why haven't we asked for a federal audit of their inside memos, papers, financial disclosures and ties to vaccination companies ie conflicts of interests? Is it that hard for congress to ask for them, especially when they are funded by them? And, why hasn't anyone asked WHY we fund such agencies when they clearly a), haven't cured or alleviated ANY diseases or conditions, and b), they have conflicts of interests riddled throughout, especially when their employees can march across the street and get high paying pharma jobs? Just saying? Shouldn't we ask congress why they continually fund genetic studies, when in their constant search, the genes for autism are either elusive, combined with many other disease conditions, and, clearly you can't have an epidemic of genetics changing this fast? The same should be done for GMO companies, gluten laced sugar laced food companies, companies that pollute, fluoride advocates, dental amalgams, and birthing practices known to contribute to autism? Why aren't we also asking disclosures of ties to pharma from media corporations who tout lies that the "frenzy" of parents saying autism is caused by vaccines is false? Who is the perpetrator of such continual deceptions? And lastly, let's ask congress people who they are often funded by and why they are told to not break the silence?

Kathy Blanco

Mother of two with autism

Researcher

**Note: Personally Identifiable Information (PII) has been redacted in this document**

**Laura Cellini**

April 2, 2014

Dear IACC Members,

I used to have a recurring dream that our son was drowning in the ocean, slipping just under the waves before I could reach him. This was during the period he was regressing more each day, slipping away from us prior to his second birthday. Our younger son, [PII redacted] was born in August of 1998. By all accounts he was a beautiful, happy baby, but around two months of age [PII redacted] developed his first ear infection.

For the next year and a half he was frequently ill with twelve upper respiratory infections, ear infections and was diagnosed with gastro-esophageal reflux disease at four months. At six months we took him to Mayo Clinic where they ruled out Cystic Fibrosis but found aspiration pneumonia. He was on numerous medications for reflux, allergies and antibiotics for constant upper respiratory infections. At eighteen months he was tested for HIV. I was at a loss as to why I was visiting the pediatrician almost on weekly basis. I was breastfeeding, he was not in daycare we were diligent with hand-washing and were up-to-date on all vaccinations. Yet, none of the numerous physicians we saw had any answers.

Contrary to his physical health, [PII redacted] was developing in other areas just fine. He loved it when his big brother would play with him and had an array of words around his first birthday. Between 15 and 24 months we started down what I would describe as the slippery slope of regressive autism. He stopped talking so we tested his hearing. His startle reflex disappeared and he started looking through you rather than at you. I can distinctly remember the day when he was in his high chair trying to say "mama" as he had been for months but no longer could utter those two precious syllables. I dropped to my knees. The head banging, extreme tantrums, spinning and hand flapping soon followed. I knew then something had gone terribly wrong.

By the time he was 18 months old, we enrolled [PII redacted] in our state's Early Intervention Program for speech therapy. He also had tubes placed in his ears for chronic ear infections but the infections continued. By this time he was on antibiotics prophylactically and regressing further into autism. He was no longer interacting with his older brother, [PII redacted], who asked, "Why doesn't [PII redacted] see me anymore?"

In July of 2000, right before [PII redacted]'s second birthday we had a preliminary diagnosis of PDD-NOS, a mild form of autism. We were traveling to the best hospitals in the Midwest from Chicago to St. Louis to see numerous physicians to seek answers. It was exhausting traveling from one doctor to the next. Finally, through serendipity, we were able to bypass the two year waiting list and get into the University of Chicago for a diagnostic evaluation that would classify him as having severe to moderate autism and indicated that his receptive and expressive language scores had regressed to that of a six to nine month old; he was twenty-six months old. He had lost nearly two years of development. It was devastating. However, when I mentioned how ill he had been I was told that I was "just more sensitive" and my concerns were dismissed.

In 2004, we were fortunate enough to find a physician who specialized in biomedical treatments. He stated that we must have had an angel looking over our shoulder because we had already done so much

that had helped [PII redacted] such as removing gluten, casein and artificial dyes. We started him on essential fatty acids at age two. In 2007, after [PII redacted] contracted RSV we checked his vaccine titers, it seemed he had failed to develop antibodies to almost every disease he was vaccinated against. We finally took [PII redacted] to see a leading Immunologist who diagnosed him with a primary immune deficiency after appropriate testing. It was when we began treating his underlying immune disorder that [PII redacted]'s symptoms of autism dissipated.

The prognosis for [PII redacted] at age two was that he would eventually need residential care, now at age fifteen, we're thinking about what he'll study in college. We were told he was incapable of love. Every night before bed, he says, "Love you, mom." He's learning Italian along with Geometry and Biology. He loves to read and says maybe he'll be a writer one day. He's a big fan of movies so he doesn't rule out a future in directing. All of this possibility eluded him at one time and I didn't even dare to hope for such normalcy.

There isn't a day that I'm not cognizant that we are extraordinarily fortunate and that this would not have happened had we listened to the advice of many prominent doctors who discouraged the path we took in getting him better. In truth, the doctors who are helping provide the most promising treatments for children like [PII redacted] are also parents of children affected with autism. The problem is we need more medical professionals to handle this epidemic and that are aware of underlying medical conditions co-occurring with ASD. How can best practices be implemented when most physicians are ignorant of the biological pathologies associated with ASD? Why haven't more fishnet studies distinguishing sub-cohorts to help elucidate clearer treatment protocols been prioritized?

The IACC should immediately undertake efforts expediting the translation of biological discoveries from emerging science into clinical practice. With ever increasing numbers, it's imperative that we transform how medicine views and treats persons with autism. The present standard of care for ASD is inadequate and needs to be updated to reflect the myriad of underlying and co-morbid medical conditions that scientific investigations have elucidated:

- Allergies
- Automimmune Conditions
- Gastrointestinal Disturbances
- Immune Dysregulation
- Metabolic Abnormalities
- Mitochondrial Dysfunction
- Neuroinflammation
- Oxidative Stress
- Seizure Disorders

For far too long autism has not been well understood by the medical community and far too often underlying medical conditions are ignored. Recent meta-analyses and numerous peer reviewed publications confirm these findings. It's no longer sufficient to simply define "autism" as a disorder affecting behavior, social and communication. Scientific inquiry has provided many answers to the mystery, it's time we acknowledge them.

Sincerely,  
Laura Cellini  
[PII redacted]