

Written Public Comments

**IACC Full Committee
Meeting**

January 14, 2014

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Eileen Nicole Simon

December 15, 2013

Developmental language disorder is the most severe handicap for children with autism. The Strategic Plan must include this. Also, neurological disorder is a clear-cut biomarker for autism. This includes language and movement disorders.

When my son (now 51) was young, he exhibited clear choreo-athetoid movement disorder. He has this in good control, but under stress he cannot control writhing of his hands.

My son was not allowed to attend public school because he could not speak. No, there were not a lot of other non-verbal children going unrecognized. I read the paper by Brugha, who used standard checklists, but could not find information on early "communication" disorder. That this shifts autism away from being just a childhood disorder is silly. Autism is not a problem that was widely overlooked in the past. Autism in children is far more prevalent than it was 50 years ago.

My son is higher functioning than most, but auditory processing disorder is still his major handicap.

Nuclei in the brainstem auditory pathway are susceptible to damage in the perinatal period from oxygen insufficiency and toxic substances. This evidence has been in the medical literature for decades. If members of the IACC believe this evidence is not important for mastery of language, then provide the counter-evidence, and allow some back-and-forth discussion on this issue. Refusal of the IACC to discuss the concerns of grieving parents like me is despicable.

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

Eileen Nicole Simon

December 30, 2013

I noticed the Core Values statement on the IACC Events page. Of greatest interest to me is the statement, "We will treat others with respect, listen to diverse views with open minds, discuss submitted public comments, and foster discussions where participants can comfortably offer opposing opinions."

I would therefore like to request that my views on auditory system injury be discussed by members of the committee. When time to discuss public comments finally arrives, members of the committee are asked if there are any comments they want to discuss. I am clearly not good at making public presentations, which is why I continue to submit ideas as written comments.

My ideas may be wrong. Then please point out the counter-evidence. Time should also be scheduled for back and forth discussions.

Attached to this email is the short statement I made on my website in April 2000. Also, I have included links to my Viewpoint paper, plus notes on the auditory system, the inferior colliculus, hemoglobin and its role in oxygen delivery to the brain, concepts of autism and the autism spectrum, and social responsibility. I stand by what I wrote in 2000. Only the recent papers on malformation of the superior olive in autism, and in laboratory rats subjected to valproic acid during gestation, are as significant to me. See references 1 and 2 below.

Am I wrong, or unreasonable? If I am wrong, then please allow time for discussion of why I am wrong, and why the papers on the superior olive were not included in the bibliography of significant advances.

I have not been treated with respect, and I am angry. The autism epidemic is every much as tragic as the polio epidemic decades ago. Would anyone have told parents of children with polio that they should just be accepting of what their child had to look forward to in the future?

I am angry for good reason. I try to mind my manners, but I am angry! The neurological basis of developmental language disorder could have been understood decades ago.

Please let me know that this email and attached file have been received, and included in the Public Record. Thanks.

Sincerely,
Eileen Nicole Simon
[PII redacted], Lexington MA
[PII redacted]

References:

[1] Kulesza RJ Jr, Lukose R, Stevens LV. Malformation of the human superior olive in autistic spectrum disorders. Brain Res. 2011 Jan 7;1367:360-71.

[2] Lukose R, Schmidt E, Wolski TP Jr, Murawski NJ, Kulesza RJ Jr. Malformation of the superior olivary complex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.

Views posted on conradsimon.org, April 2000

Eileen Nicole Simon

Working paper: [Viewpoint on the brain disorder](#)

Notes: [The auditory system](#) | [The inferior colliculus](#) | [Hemoglobin and the brain](#) [Concepts of autism](#) | [Autism spectrum](#) | [Social responsibility](#)

[Photo Redacted]

[PII Redacted] 1963-1995

Infantile autism is a serious disorder clearly recognizable by age three, but it is defined (or diagnosed) in terms of a set of behaviors, not yet by any known impairment of brain function. Failure to learn language is the most serious aspect of the disorder, at least for parents who must cope day by day with a non-communicative child.

The prevailing opinion is that autism is caused by an obscure and mysterious combination of bad genes. Currently there is more research on chromosome loci associated with autism than on which systems of the brain might be affected.

Many genetic disorders have been found among children with autism, including phenylketonuria, tuberous sclerosis, and fragile X syndrome. But children with autism are also found among those with prenatal rubella infection, and autistic behaviors have been observed in children with prenatal exposure to alcohol, thalidomide, the anti-seizure medication valproic acid, and drugs of abuse.

I will argue here that asphyxia at birth can sometimes be another cause of autism - a most disagreeable notion for the medical establishment. I would like to solicit discussion pro and con on this subject. Send me email at: [PII redacted]

The focus of research should be to look for areas of the developing brain vulnerable to any and all factors that can impair function whether these might be genetic, infectious, or due to toxic substances, or asphyxia. [The auditory system](#) has been found to have the greatest blood flow and metabolism in the brain, and to be vulnerable to many factors such as alcohol, lead, mercury, infections and asphyxia at birth. Impairment of auditory function deserves greater emphasis in research on failure of language development.

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

Gene Bensinger

December 15, 2013

In order for the essential work and initiatives of the IACC to continue beyond 2014, the Combating Autism Act of 2006 (CAA), which created and controls the continued existence of the IACC, will require a second reauthorization by Congress. The effort to achieve the first reauthorization of the CAA, the Combating Autism Reauthorization Act of 2011 (CARA), was successful, but only barely. The future appears equally uncertain for the next scheduled CAA reauthorization in 2014. It will likely require an “all hands on deck” effort on the part of the broad autism stakeholder community to be successful. I will be one of the many volunteers across the country leading this significant effort in the year ahead.

It greatly troubled me that least one member of the IACC publicly spoke out in opposition to CAA reauthorization legislation in 2011, apparently without consequence. Going forward, other IACC members may choose to speak out in opposition to an active CARA bill, without risk of being held accountable for their words and actions. Whatever issue or issues an individual member may have regarding some specifics in the ultimate bill, I believe that they must, as a member of the IACC, support reauthorization.

Debate and disagreement on issues among IACC members, including any reauthorization bill, is expected, invited, proper, and absolutely welcome, but an IACC member broadcasting public opposition to this enabling legislation while it's before Congress is harmful to the autism community and, in my view, completely unacceptable behavior. When negative, partisan, and misleading statements about CARA were widely circulated by a sitting IACC member in 2011, it reflected poorly on the IACC's overall work and caused damaging distraction and confusion about the IACC itself and the CARA legislation. I think strong action should be taken by the IACC to avoid any chance of a repeat in 2014.

Therefore, I strongly urge the IACC to adopt a policy that any current member who publicly states their opposition to the reauthorization of the CAA, and by implication the IACC's existence and mission (as well as their own duty as member to “combat autism through research, screening, intervention, and education”), should be asked by the Chair to resign their appointment to the IACC. If those circumstances occur, the Chair should also be compelled to formally recommend to the Secretary the termination of the member(s) appointment.

Going a step further, I think it is also essential for all IACC members to go on the record in the months ahead, at a minimum in the IACC minutes, stating their support for reauthorization of the Combating Autism Act. Going on the record should pose no conflict whatsoever to any member and will help advocates convince Congress and the public of the necessity for the Act's reauthorization. It's really unfortunate that I find it necessary to make these comments and suggestions to the IACC, but I think it's essential for advocates like myself to be able to clearly communicate to both the Congress and

the public that the IACC strongly and *unequivocally* supports *its own* continued existence and mission, and not risk encountering, as we did in 2011, harmful, counterproductive, and undermining evidence to the contrary. Thank you for the opportunity to make these comments to the Committee.

Gene Bensinger, Parent Advocate [PII redacted]
[PII redacted]

Anne Bauer

January 6, 2014

Subject: ACETAMINOPHEN (TYLENOL) RESEARCH SHOULD BE A TOP PRIORITY!

There is new, strong, evidence supporting the plausibility of acetaminophen use as a causal factor in autism spectrum disorder (ASD). Studies of the effects of this commonly used over-the-counter medication on neurodevelopment are limited yet warranted. In the U.S. about 65% of women will take acetaminophen at some time during their pregnancy and it is the drug given most frequently to young children (1, 2). The first published cohort study looking at this relationship, found that children exposed to long-term acetaminophen use during pregnancy had substantially adverse developmental outcomes at 3 years of age (3). Additionally, there are two new animal studies supporting a causal association (4, 5).

The Brandlistuen et al. prospective cohort study reported in the International Journal of Epidemiology, found that children prenatally exposed for more than 28 days had poorer gross motor development, communication, externalizing behavior and internalizing behavior. They also displayed hyperactivity (3). These are typical autism phenotypes (6). This study finds a strong association, with the results suggesting that prenatal exposure to acetaminophen for more than 28 days increases the risk of adverse psychomotor and behavioral outcomes by almost 70% and double the risk of language problems. Children exposed prenatally to short term use of acetaminophen had poorer gross motor skills but these effects were smaller. These researchers, importantly, also looked at the relationship to ibuprofen and found no associations.

The animal study by Viberg et al. found that acetaminophen exposure during critical times of brain development can act as a neurotoxic agent inducing long-lasting effects on cognitive function at doses below the recommended daily doses limit (4). The second animal study found that the long term administration of therapeutic doses of acetaminophen significantly changed the concentration of amino acids essential for the proper functioning of the brain. The researchers stated that “so pronounced a decline in amino acids level may significantly affect the metabolism and transport of other neurotransmitters causing cognitive and behavioral impairments” (5).

Prenatal exposure to other medications- valproic acid, thalidomide and misoprostol has been shown to be associated with an increased incidence of autism (7). This alone should be reason to investigate acetaminophen. It is known that acetaminophen freely crosses the placenta and the adverse effects of acetaminophen are numerous (8). Acetaminophen is the nation’s leading cause of acute liver failure (9). Prenatal exposure has been associated with maternal preeclampsia and offspring development of asthma and cryptorchidism (10-12).

Acetaminophen has a narrow safety margin so for individuals who are ill or otherwise vulnerable the conversion to the toxic metabolite of acetaminophen N-Acetyl-p benzoquinone-Imine (NAPQI) may occur even at recommended doses (13). NAPQI has been shown to be a neurotoxin and to cause atrophy of cerebellar Purkinje cells in rats (14-16). Purkinje cell alteration is a consistent finding in ASD (17). A recent paper in Nature stated “chemicals and genetic mutations that impair topoisomerases could commonly contribute to ASD and other neurodevelopmental disorders” (18). NAPQI is a topoisomerase poison and likely inhibitor (19).

Acetaminophen is a prevalent, causally plausible and modifiable exposure. Further research, particularly epidemiologic, is urgently warranted to replicate and extend these findings.

References

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3. 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.
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5. Blecharz-Klin K, Joniec-Maciejak I, Piechal A, Pyrzanowska J, Wawer A, Widy-Tyszkiewicz E. Paracetamol impairs the profile of amino acids in the rat brain. *Environ Toxicol Pharmacol*. 2013 Nov 13;37(1):95-102.
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18. King IF, Yandava CN, Mabb AM, et al. Topoisomerases facilitate transcription of long genes linked to autism. *Nature.* 2013;501(7465):58-62.
19. 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;43(12):3731-3739.

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

Eileen Nicole Simon

January 7, 2014

[PII redacted]

I want to suggest that an addendum be made to the Strategic Plan. The focus of research should be the brain, and impairments that prevent normal language development.

Autism is a neurological disorder, a disorder of brain maturation that impedes language development. Myelin formation in the language areas of the cerebral cortex continues for the first four to five years after birth [1]. Factors that can disrupt maturation of the language areas of the cortex must be sought. One such factor has been in plain sight for many decades. It is the pattern of damage caused by oxygen insufficiency at birth [2].

Difficult birth resulting in low Apgar scores has been documented in many epidemiological investigations of predispositions for autism. Most of the reports of autism in children who suffered complications at birth propose that difficult birth is the result of some problem with the mother or her infant. No evidence of presumed “problems” is provided.

William Windle’s research with monkeys on asphyxia at birth provided evidence that nuclei in the brainstem auditory pathway are susceptible to injury. The monkeys used in this research did not have any predisposing problems. The unanticipated breech birth of one monkey led to difficulty extracting the head, and this monkey suffered asphyxia and damage of brainstem auditory nuclei. The pattern of brain damage was identical to that caused by clamping the umbilical cord and preventing the onset of breathing.

Maturation of the brain did not follow a normal course in monkeys subjected to asphyxia at birth [3]. No one expects a monkey to learn to speak, but the target destination of the brainstem auditory pathway is the language receptive area of the temporal lobes.

Maturation of the cortical centers for hearing is dependent upon transient neurotransmitters produced in brainstem auditory nuclei. If these are damaged, development will be curtailed [4].

The effects of difficult birth in children who develop autism should be compared with the disrupted maturational process observed in monkeys subjected to asphyxia at birth. If the evidence provided by Windle is considered out-of-date. The experiments with monkeys should be repeated. Development of the brain can now be followed with MRI, without the need to “sacrifice” the monkeys to look for neuropathology.

Research on the effects of oxygen insufficiency on the brain should be added to the current strategic plan. I suggested this five years ago, in November 2008, but my ideas were not discussed by members of the committee then. I have continued to suggest need for research on how the brain is affected by asphyxia, and asphyxia caused by clamping the umbilical cord before the first breath.

Don't tell me my citations are too old. Autism like polio should have been understood and prevented decades ago.

Autism will not be understood until the underlying brain pathology is found. The effects of asphyxia at birth cannot reasonably be dismissed. I will continue to try to bring this up for discussion. The refusal of members of the IACC to discuss the ideas presented by stakeholders like me is indefensible, and an obstacle to progress.

REFERENCES

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[2] Windle WF. *Scientific American*. 1969 Oct;221(4):76-84.

[3] Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Exp Neurol*. 1969 May;24(1):38-53.

[4] Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity- dependent and activity-independent processes. *Cell Tissue Res*. 1999 Aug;297(2): 187-95.

PICTURES:

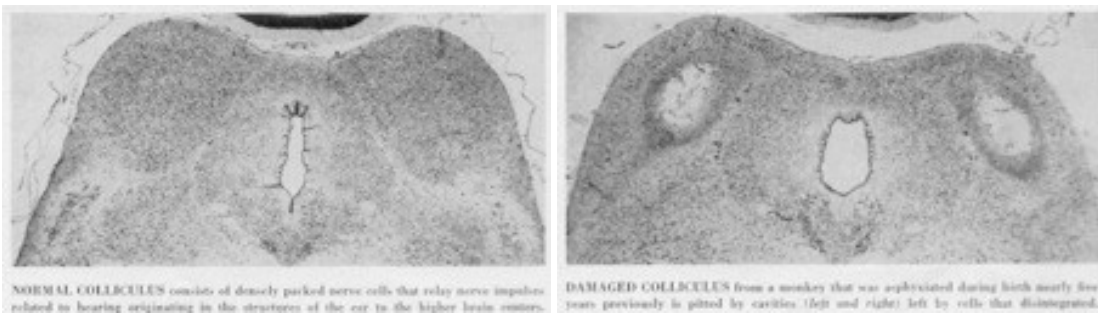
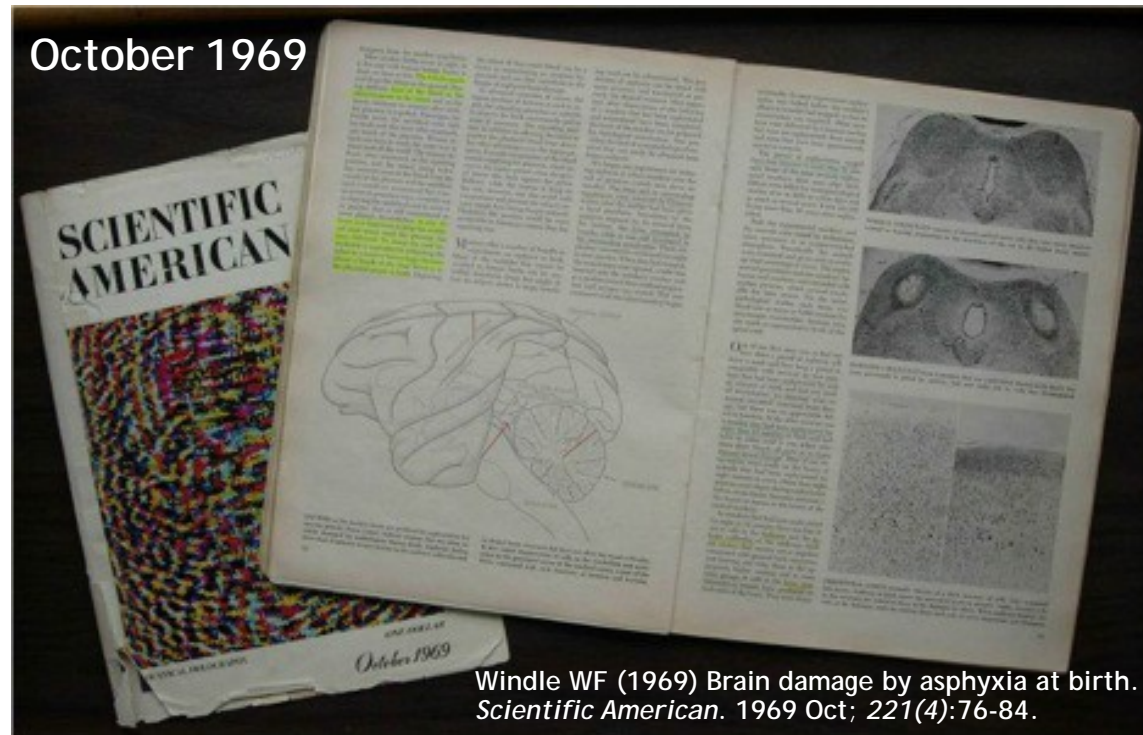
- My first two sons were both born full term but suffered trauma and oxygen insufficiency at birth.
- The October 1969 issue of the *Scientific American* provided evidence of the injury both my children suffered at birth, damage of nuclei in the auditory pathway.
- Blood flow is higher in nuclei of the auditory pathway, making them susceptible to injury from oxygen insufficiency and/or toxic substances
- Nuclei of the auditory pathway are fully myelinated before birth. They produce trophic neurotransmitters that guide maturation of the language areas of the cerebral cortex.
- I returned to school and earned a PhD in Biochemistry. Autism research has been the sad focus of my entire life.
- MRI now provides evidence that loss of speech comprehension follows injury of the inferior colliculi.
- Clamping the umbilical cord at birth is a clear medical error. There is no health benefit from clamping the cord. Clamping the cord before the first breath causes a lapse in respiration that will injure nuclei in the auditory pathway.

[Photo redacted]

[PII redacted] reading stories to [PII redacted], which [PII redacted] learned to recite verbatim. We came to believe that [PII redacted]'s traumatic anoxic birth had not affected his development, but then at age 3 his nursery school teacher suggested we have him evaluated for autism. He fit the description of classic Kanner autism. – more at www.conradsimon.org

Before we had heard of autism, we knew [PII redacted]'s language development was not normal. We also knew he was hypersensitive to some sounds, and oblivious to others.

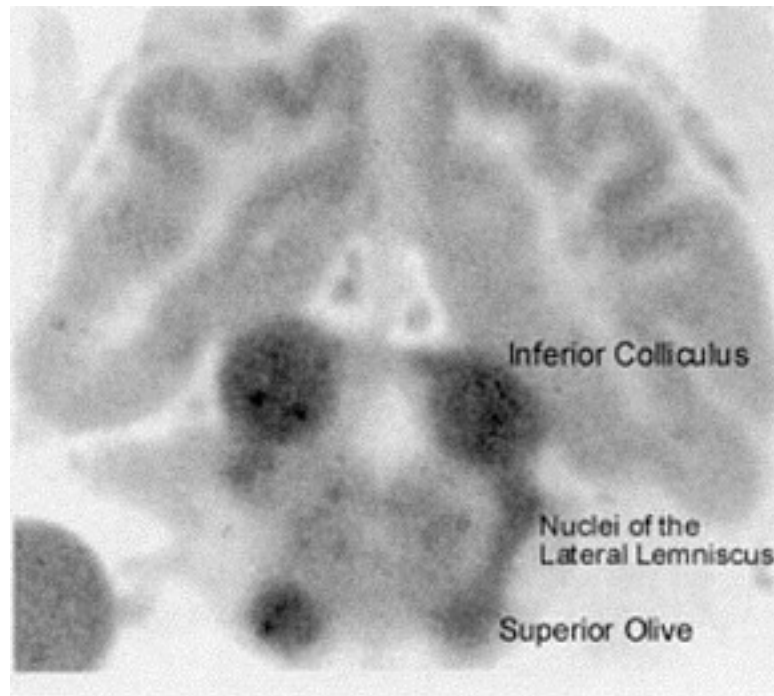
The article by William F. Windle on brain damage caused by asphyxia at birth provided a logical explanation. We knew that oxygen insufficiency at birth was the reason for [PII redacted]'s problems.



The inferior colliculus: Normal appearance (left), ischemic damage (right). Pictures originally published in Faro and Windle, *Exp Neurol*. 1969 May;24(1):38-53, reproduced with permission.

Nuclei in the brainstem auditory pathway have higher blood flow than any other area of the brain. This is why the inferior colliculi and other brainstem auditory nuclei are vulnerable to ischemic injury.

The picture below is an autoradiogram showing distribution in the brain of a radioactive tracer 60 seconds after injection into the circulation of a cat.



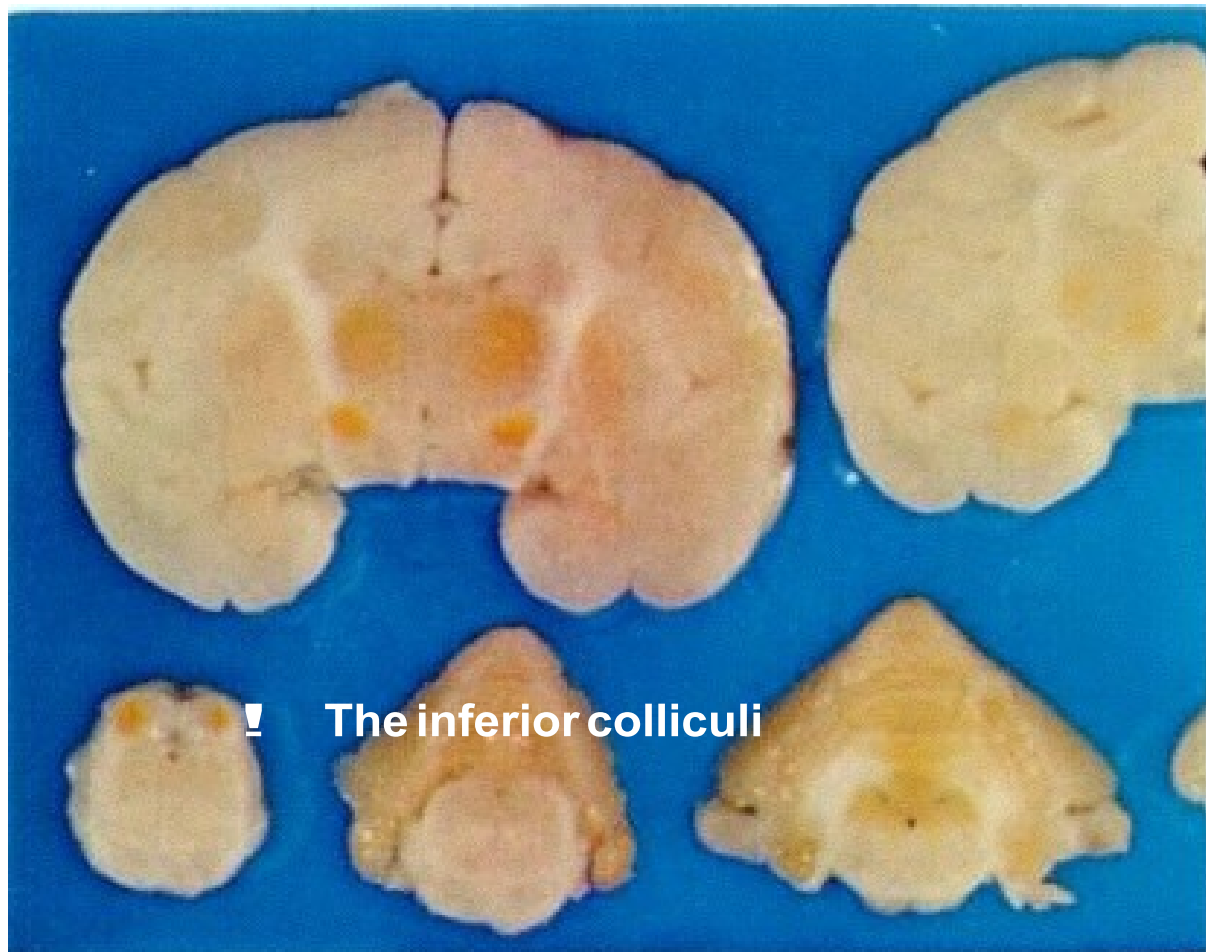
From: Kety SS. Regional neurochemistry and its application to brain function. In French, JD, ed, *Frontiers in Brain Research*. New York: Columbia University Press, 1962. pp 97-120.
With permission from Columbia University Press.

This seminal paper by Seymour Kety was reprinted in the *Bulletin of the New York Academy of Medicine* 1962 Dec;38:799-812, and is available free online at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed>

High blood flow makes nuclei of the auditory pathway susceptible to injury from toxic substances in the circulation.

Ischemic injury caused by asphyxia at birth also injures the blood-brain barrier and makes these brain centers of high blood flow even more vulnerable to infiltration of anything in the circulation.

The pattern of ischemic damage caused by asphyxia is the same as that found in infants who suffer kernicterus (bilirubin staining of nuclei in the auditory pathway and the basal ganglia). Further investigation by Windle and his research team revealed that kernicterus (bilirubin staining) occurred only in the monkeys subjected to asphyxia, as seen in the following picture:



From: Lucey JF, Hibbard E, Behrman RE, Esquivel FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. *Exp Neurol* 1964 Jan; 9(1): 43-58, with permission.

Nuclei of the auditory pathway, in addition to having higher blood flow than any other area of the brain, are among the earliest centers of the brain to be fully myelinated. The auditory pathway is myelinated before birth, and trophic neurotransmitters produced in brainstem auditory nuclei guide postnatal maturation of the language areas of the cerebral cortex. See Friauf & Lohman (1999) below, and the citations to Moore et al. (1995, 2007).



Early myelination of the auditory pathway

Myelin formation in brainstem auditory structures of a human fetus at 25 gestational weeks.

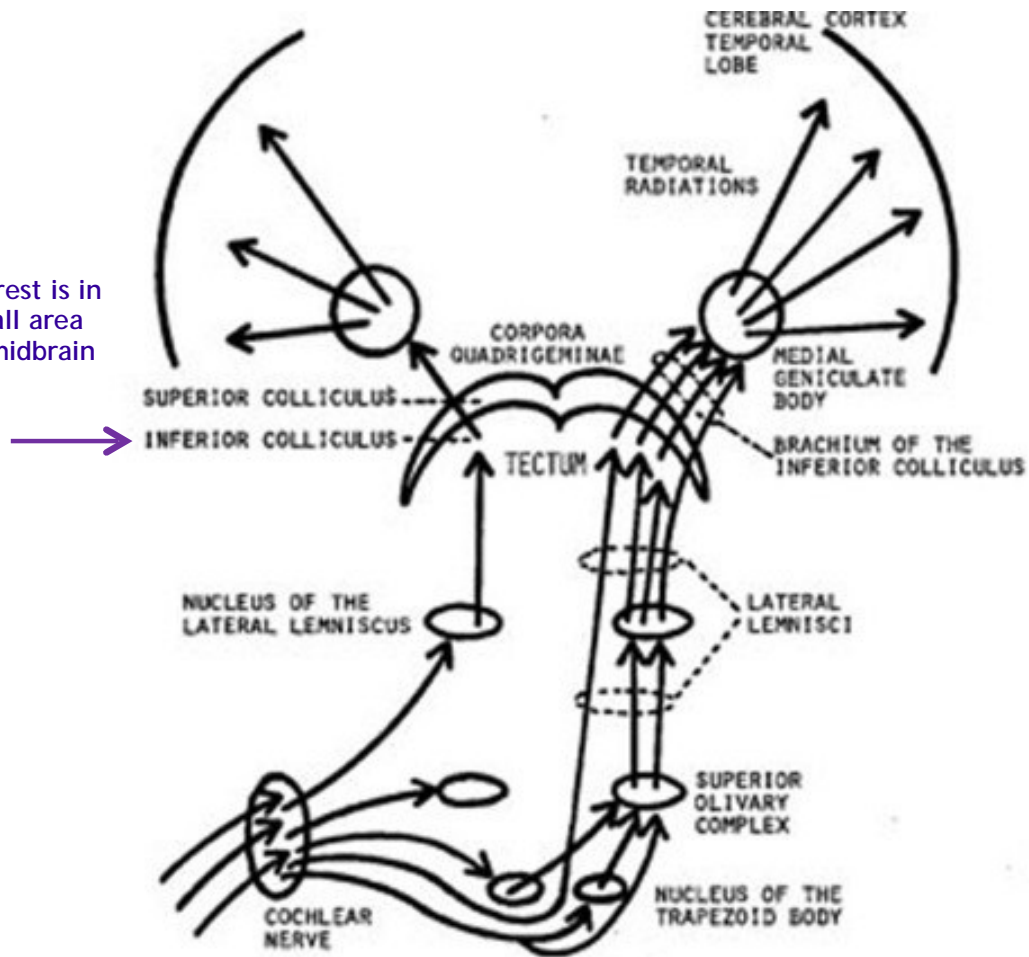
ICol = inferior colliculus Sol = superior olive TzB – trapezoid body

From Yakovlev and Lecours (1967) with permission from Blackwell Scientific Publishers.

See also:

- Moore JK, Perazzo LM, Braun A. Time course of axonal myelination in the human brainstem auditory pathway. *Hear Res.* 1995 Jul;87(1-2):21-31.
- Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity-dependent and activity-independent processes. *Cell Tissue Res.* 1999 Aug;297(2):187-95.
- Moore JK, Linthicum FH Jr. The human auditory system: a timeline of development. *Int J Audiol.* 2007 Sep;46(9):460-78.

My interest is in this small area of the midbrain



Question: could brainstem impairment lead to developmental language disorders?
From insults such as: Prenatal exposure to alcohol? Prenatal infection? Asphyxia at birth? Toxic exposure in infancy?

Dissertation Research

Simon N (1975) Echolalic speech in childhood autism. Consideration of possible underlying loci of brain damage. *Archives of General Psychiatry*. 1975 Nov;32(11):1439-46.

[Photo redacted]

Simon N, Volicer L (1976) Neonatal asphyxia in the rat: greater vulnerability of males and persistent effects on brain monoamine synthesis. *Journal of Neurochemistry* 1976 May; 26(5):893-900.

Note: Greater vulnerability of males was an unexpected finding

[PII redacted] and [PII redacted] with mom and baby rat pups, Boston University School of Medicine, 1971.

Language development depends upon intact auditory processing.

Loss of the ability to comprehend spoken language has been described in several case reports following injury of the inferior colliculi:

1. Howe JR, Miller CA. **Midbrain deafness following head injury** *Neurology*. 1975 Mar;25(3):286-9.
2. Jani NN et al. **Deafness after bilateral midbrain contusion: a correlation of magnetic resonance imaging with auditory brain stem evoked responses.** *Neurosurgery*. 1991 Jul;29(1):106-8.
3. Nagao M et al. **Haemorrhage in the inferior colliculus.** *Neuroradiology*. 1992;34(4):347.
4. Meyer B et al. **Pure word deafness after resection of a tectal plate glioma with preservation of wave V of brain stem auditory evoked potentials.** *J Neurol Neurosurg Psychiatry*. 1996 Oct;61(4): 423-4.
5. Hu CJ et al. **Traumatic brainstem deafness with normal brainstem auditory evoked potentials.** *Neurology* 1997 May;48 (5):1448–1451.
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8. Vitte E et al. **Midbrain deafness with normal brainstem auditory evoked potentials.** *Neurology* 2002 Mar 26;58(6):970–3. -- 2 cases
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10. Musiek FE et al. **Central deafness associated with a midbrain lesion.** *J Am Acad Audiol* 2004 Feb; 15(2):133-151.
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12. Kimiskidis VK et al. **Sensorineural hearing loss and word deafness caused by a mesencephalic lesion: clinicoelectrophysiologic correlations.** *Otol Neurotol*. 2004 Mar;25(2):178-82.
13. Pillion JP. **Speech processing disorder in neural hearing loss.** *Case Report Med*. 2012, Article ID 206716. Epub 2012 Dec 6.

How much more serious injury of the inferior colliculi should be for an infant!

Obstetric error?

"Immediately after the delivery of the neonate, a segment of umbilical cord should be double-clamped, divided, and placed on the delivery table pending assignment of the 5-minute Apgar score."

ACOG Committee Opinion No. 348, November 2006

ACOG Committee on Obstetric Practice. ACOG Committee Opinion No. 348, November 2006: Umbilical cord blood gas and acid-base analysis. **Obstet Gynecol. 2006 Nov;108(5):1319-22.**

How many prospective parents are told that placental respiration is to be cut off so abruptly at birth, possibly before the first breath?

There is no health benefit from use of a clamp on the umbilical cord.

This should be investigated as one possible cause of the autism epidemic.

John Erb

January 8, 2014

To the members of the IACC Committee, and more importantly to the Individuals and families affected by Autism Spectrum Disorder.

This year marks a turning point in research into understanding what has become a Global Epidemic.

Almost seven years ago I stood before this Committee in the Reagan Rotunda of Washington D.C. The minutes from the November 30th meeting state:

"Finally, **John Erb** said that he has been working with autistic individuals for more than 20 years. Four years ago, while doing research on monosodium glutamate (MSG), he developed a hypothesis that the compound causes neurons to grow more rapidly than they would otherwise. Mr. Erb said that he is going to demand that the FDA remove MSG from the food supply, which he hopes will cause a drop in autism."

Weeks after presenting this at the IACC I launched the Petition to Remove the Generally Regarded as Safe status of Monosodium Glutamate. The FDA avoided answering this petition until an Audit from the Government Accountability Office in 2010 forced their office to respond. The FDA's response to the petition failed to include a single article citing that MSG was safe for children. To quote Michael Landa, Director of Center for Food Safety and Applied Nutrition

"We note, however that whether adding a substance to foods provides benefits is not relative to the GRAS status of a substance. The FD&C Act does not direct the FDA to consider the potential benefits of a substance in determining whether a use of a substance is GRAS."

Today is January 14th, 2014. The birthrate in the United States for Autism is now one in 88.

The FDA and food manufacturers are dragging their feet on admitting that the Genome Project which pointed to Glutamate could actually connect with MSG in food and vaccines.

The government itself has some skeletons in the closet when it comes to knowing MSG affected the brain. Just check the Journal of Mental Deficiency April 1951 Volume 55 number 4. "Glutamic Acid and Mental Deficiency- A Review"

This review reported on several studies showing IQ gains (between 5 and 15 points) of mentally handicapped children being fed MSG in their diet.

What happened to this line of experimentation? Evidence was found that MSG affected the minds of children and then set aside for Sixty years?

But now, in 2014, the internet and the explosion of available educational resources to individuals, families and the support people around those with Autism can have renewed hope for a greater understanding of the mystery that is the Autism Spectrum.

People will research for themselves to find the best approaches on this journey in a world painted by the brilliance of Autism.

Advances in Melatonin regimes and THC derivatives are giving people more options for positive and empowering therapeutic approaches.

Thank you to everyone here and watching around the globe. United States is leading the world in understanding and investing into answering the riddle of Autism.

Sharing the pieces will give us all a better look at the puzzle unfolding before us.

References:

Gadson EJ. Glutamic acid and mental deficiency; a review. *Am J Ment Defic*. 1951 Apr;55(4): 521-8.
[PMID: [14819083](#)]

John Erb's attachment can be viewed here:

[Attachment](#) (PDF – 89 KB)

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

Michelle Guppy

January 8, 2014

Subject: Of [offensive language redacted], Indifference, & the IACC...

[Photo redacted]

Warrior Mom's of Autism are pretty potent. Everything about them multiplied over typical moms. You could probably get by with lame excuses of being too busy in not helping with a bake sale or something, but with warrior mom's and advocacy, that ain't gonna fly. When warrior moms ask you to do something, you don't tell them you're too busy. They'll laugh at you if they don't smack you upside the head first. No, when a warrior mom asks you to do something above and beyond the above and beyond you already do, - you simply find a way to do it.

[Photo redacted]

That's what the warrior moms who went to Washington, D.C. did. They asked me to go to Washington, D.C. with them to give oral testimony at the IACC. I went over my list of excuses why I couldn't, then abruptly had to quit because they had the same ones, they're autism moms too, yet they were going. Then I came to a big one that I thought would for sure get me out of it "smacked-upside-the-head" free.... Money. I simply had none to even justify using to go. So I told them I simply couldn't afford to go. Even that didn't stop them though. They proceeded to plan our trip. In my brilliance I thought I would play chicken with God, I guess you would call it. I told Him that if He wanted me to go, He would have to send me a ticket to go. Note to self: Never play chicken with God. He'll call your bluff.

A business person in the Autism community who I have met at different conferences and resource fairs over the years, bought me a ticket. So, off we went to Washington, D.C. I want to share that though I am writing this from my perspective only, there were other parents who made the sacrifice to be there and who shared their testimony:

[PII redacted]

[PII redacted]

[PII redacted]

[PII redacted], who read the written testimony of [PII redacted]

What was so surreal for me in even being there in Washington, D.C., is that the last time [PII redacted], [PII redacted], and I were there together, was for the 1st Autism Rally & Congressional Hearings on Autism. Thirteen years ago. That we even had to be back there still fighting the same exact fight, was very sobering. Depressing, really. Will the next time we all converge there be when we're in wheelchairs? I pray not. **But make no mistake, the caliber of women I was with that day in April 2000, and that day on November 15, 2013 -- is that if need be, we will be.**

That's what gives me HOPEISM. Knowing that despite any differences we each may have in what our

child needs - we will find a way *to join together, putting all those differences aside*, to collectively fight for our children.

Our adults.

When I was last there, my son was a child.

In January 2014, he will be twenty years old.

Which is precisely what saddens me most regarding the autism community. How lately so many are attacking "their own" so to speak. Using their brilliance and talent to repetitively attack a select few over and over, accomplishing absolutely nothing but further weakening, further dividing, a weakened and divided autism community. I sat in that room at the IACC meeting wishing that person were there with us, truly investigating each person in that room who needed to be investigated. Which was most of them. Using his time, talent, and brilliance in writing to help in the battle of us against them. Not pitting us against us.

So much time spent in "An Open Letter to" Then because some other organization didn't agree, their own "An Open Letter in Response to....." How such waste of time saddens me. The clock is ticking in my life on earth to care for my son; and for groups that claim to represent us to spend such time in wasted effort just tips me closer to the edge of insanity. **I want this to be my "Open Letter to All Y'all's" that says "STOP"**. Stop wasting time and effort. We have an autism crisis. To sit there and nit pick to cover all politically correct bases is a waste of time. There is room on this autism battlefield to accommodate *all* who need what they need. If someone wants a cure, they deserve it. If someone doesn't, it doesn't need to be forced on them. "Life with Autism" for my son is a silent, painful disorder. One that yes, has brought such joy and meaning to our life, but one where my son is very much in need of medical treatment. Medical healing for him to have the chance one day to talk. To advocate for himself! Autism for him isn't an alternate lifestyle where people must simply accept him and adapt to his quirks. I do not want to, nor will never, view burning hot lava spewing out of his ass as something to accept. I will never think that in advocating for my son, that he would rather me just accept his seizures that have split open skin, broken bones, shattered teeth, and landed him in the emergency room more times than I can count, as part of who he is. No, I will watch how he must suffer and know in my heart that that is *not* the lifestyle he would choose to live.

What I share is my perspective of being at the November 15, 2013 IACC Strategic Planning meeting. If you want facts and numbers and specific people who said what - I urge you to watch that meeting. It was truly eye-opening to me, someone who has never been to one before. And as much as I hated to go and give oral testimony, I honest to God want to be at all further meetings. If for nothing else than to be a presence of truth in a room full of lies. Someone representing our truth must be at each of those meetings giving oral comments and sharing the truth they refuse to see. All of us, for every meeting, must make the time to submit written testimony.

That's perhaps the short version of my take from the trip.

The IACC...

To find out what that stands for and what the role of this committee is, [click here](#).

Parents who care for children, youth, and adults who have an autism spectrum disorder diagnosis, I beg

of you to familiarize yourself with this committee. Take some time to browse through their website and listen to previous meetings. Read about who is on this committee. And always, always submit written testimony to be included in the meeting. So very many of you said that you submitted written testimony, but it wasn't included in the handouts each member received. You must clearly indicate in your submission to them for specific meetings, that you want your written comments included in public input as written testimony to be made available to each member of the committee.

IACC Website

Public Comment Guidelines

I think one of the first observations was from my friend [PII redacted]. She wrote in my little Mickey Mouse notebook, "We are sitting at an IEP Meeting for this committee and no one can agree on how to write the goal."

What they were trying to accomplish is to put together their strategic plan that would justify their thirty minutes of wasted time in introducing themselves to each other when the meeting started, and the millions upon millions of dollars spent in doing absolutely nothing of value.

Please [click here](#) to read all seven questions they are to answer in that strategic plan. I kid you not when I say that the five of us parents who were there that day, could have answered those and found studies already done that illustrate our points. Most autism advocates and parents could, and that was so depressing to hear them all go back and forth among each other and all their fancy titles, and know that they are the ones in charge of helping my son. When each of us parents in that room knew more than them regarding those questions.

Perhaps to me, the most poignant illustration of that is their "**Question Three**" -- which is:
What causes this (autism) to happen and can it be prevented.

Not.One.Mention. of toxins, poisons, GMO's, the nutritional deficiency of non-food fast food, vaccinations.

Not.One.Mention.

I wanted to cry. This committee with millions of dollars to truly make a difference, truly help, and not one mention of any of the things that have been proven independently to trigger the biological dysfunctions that cause a diagnosis of autism for so many.

You know what IACC, here's your answer to that question... Toxins in vaccinations, Poisons in our environment, Genetically Modified Food, fast-food, processed food, multiple vaccinations at once -- all contribute to the epidemic of autism. To prevent the possibility of your baby being adversely affected -- remove all toxins from vaccinations. No multiple vaccinations at once. I would say to not vaccinate, but we'll start with baby steps. Ban GMO's, eradicate Monsanto's poisons in our environment.

Parents -- not one mention of any of those things were spoken.

Not one.

I hope this puts fear in each person reading this. Parents must stand up for the health of their children as we did that day. If we were each not there and in some way mentioning those things, it would not have been mentioned at all. And that scares me. Tremendously.

Parents whose children are receiving special education services in the public school, the person representing the Department of Education wasn't even at the meeting. All of you who are battling schools, who have children who have been in some way bullied or abused in schools, no one was there to represent you. Not one mention of special education services.

This is where I beg God to have me win the lottery. I want to be able to be at every IACC meeting to answer their "Question Three" over and over again. All of you must be submitting written testimony if you can't be there in person, in answer to questions three.

I think at one point in the discussion of the cause of autism, Insel shared about an App for Parkinson's that helps diagnose it based on speech patterns. He wanted to know if there could be an "App" developed that would diagnose autism.

I can see it now. *"Autism, there's an App for that!"*

You know what Insel? The "App" for that would be that any mother going to her Pediatrician's office to vaccinate their baby - would have an alarm sound that would say, "Danger! Autism potential! Tear the consent form in two and walk away!"

There's your "App" for Autism.

It only got worse after that. One highly initialed 'expert' suggested that we could track mother's based on their cell phone to see where they go -- as some way to determine the cause of autism.

The only tracking that must be done, is who is vaccinated, who is not, and who is healthier. That question has been asked, and answered, in other countries, with the result being that the unvaccinated are healthier.

That is the tracking parents in this country must demand before they ever consent to another vaccination ever again.

Insel also asked what yard line they are on in identifying autism. He asked if we are on the 30, 40, etc yard line....

Insel, you, and the IACC, aren't even on the field.

In identifying it, treating it, let alone doing all that can be done in helping to prevent the biological devastation to a child's body from it.

You have no clue.

It was then oral testimony time, and all five of us did very well in the delivery of our comments. I was so

proud to be among such women of strength who stood up and spoke the truth. Who made the sacrifices to be there. The teamwork of one person who could be there, sharing the testimony of someone who couldn't be there. God gave me the strength to get through mine, and the boldness to stare down Boyle and Insel during parts of my testimony.

[Click here to view my testimony.](#)

I couldn't take any more after that. I was physically drained from being in the presence of such disdain and disregard for our children's health. There was a presence of such lies and corruption in that room. It's hard to put into words.

My friend [PII redacted] stayed until the bitter end, and from her recap I know I didn't miss much. When she shared that one of the members made reference to how perhaps our children could "grow out of it" - I knew I would have been arrested had I been in that meeting. That [PII redacted] shared that studying adult issues or services for autism was underfunded by that committee tells me that they even further have no clue.

As I said in my testimony, there's an entire generation who will "age out" of public school/services and who will have nowhere to go.

I don't want this to be a feel good blog. It's not. It must be sobering to each who read it because there is much work to do and there are no excuses for anyone not contributing some part to doing it.

That committee must have parents there at each meeting to be that elephant in the room.

To speak the truth.

Those handouts they receive must be in the hundreds with regard to public comment received as written testimony.

Congressional Hearings are coming up the first of December, from now until then each parent must be writing to their Congressman or woman with regard to that "Question Three" in what causes autism and what must be done to help prevent it.

Please, I beg of you, **[CLICK HERE](#)** and make your voice heard. Please support the efforts of so many who are working together for our children.

That night after the meeting, [PII redacted], [PII redacted], and myself went on a monument tour. We needed to just do something fun and for me, try to put aside the depressing reality that is the [offensive language redacted] and indifference of the IACC.

But the whole time we were on that tour, I kept wondering if it was worth it to even have been at that meeting. We were but five in a room full of so many who out initial us and who have the funds to outspend our truth and perpetuate their lies.

Then we came to the last memorial. The wall. That sobering wall with endless names etched in it. It was fitting that it was dark, and cold, and raining. It fit my mood after being in the presence of such

dark and cold indifference.

[Photo redacted]

I just stood there and could do nothing but touch the names. I don't know anyone listed on that wall. I will never be able to relate to what any of those names went through, except in wondering if they thought their sacrifice was worth it. I was sure pondering if my insignificant compared to theirs sacrifice to attend that meeting was worth it if what I said would make any difference. When they left to go fight a war that perhaps they never wanted to fight, did they wonder if anything good would come from it? Did they think they should just stay home and let someone else do it? If they could come back and stand there as I stood there and touch their own name, would they be proud of how they gave their all, or simply regret that they did? If they could do it all again knowing their outcome would be the same if they did, would they?

I just wanted to cry as I am now in writing this.

I honor them by saying yes. It is worth it. Fighting a battle worth fighting is always worth it, no matter what the odds, opposition, or outcome.

We honor them by *never forgetting* their war.

We honor our children by *Never Quitting* our fight.

[Photos redacted]

The November 15, 2013 IACC battle is over.

The next battles are just beginning.

Please be a part of them.

Congressional Hearings on Autism

January IACC Meeting

To HOPEISM!

HOOYAH!

~

written by Michelle M Guppy

Kerri Sellers

January 8, 2014

Dear IACC Committee Members:

I am the mother of an autistic child and have watched the previous meetings on line. I have some questions for you. I would very much appreciate very detailed and specific answers so that I may understand very clearly your answers.

The committee came up with seven questions to answer:

1. Diagnosis-When should I be concerned? Specifically what is your answer to that question and could you provide us with research that you did that gave you the answer that you came up with? Who was the research done by? Thank you
2. Biology-How can I understand what is happening? Again, very specifically what is your answer to that question and may I please see the research that brought you to your answer? Who was the research done by?
3. What caused this and how can it be prevented? I again would like to know the answer to that question and specifically what research was done that gave you this answer? Who was the research done by?
4. Which treatments and interventions will help? Did you come up with answer to that question? There is not a "cookie cutter" approach to this, so what research was done that brought you to your answer?
5. Where can I turn for services? What is your answer to that? How did you come to your answer? Was research done? Who did it?
6. What does the future hold particularly for adults? What's your answer to that? How did you come up with that answer? Was research done? Who did the research?
7. What other infrastructure and surveillance needs to be met? Your answer to that? Was there any research done in regard to any of these questions and if so, who did the research?
8. Lastly I would like to know very specifically where 1.4 million dollars that was set aside for this committee to help families living with autism went?

I appreciate your time.

What I will appreciate even more, is results!

Sincerely,

Kerry Sellers

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

Chita Raman

January 8, 2014

As you prepare for the upcoming IACC meeting to review progress and calibrate your action plan going forward, I would like to add my thoughts for consideration. I am among the growing number of parents deeply worried by what we perceive as the lack of tangible, observable benefits to the autism community emanating from the reported expenditure of some **\$1.4 billion** in Federal funds on Autism projects between 2008-2012. We are further alarmed by the newly released report by the US Government Accountability Office (GAO) that points to wasteful research expenditure on duplicated or similar projects. The report seems also to suggest that there is a lack of attentive hands-on project coordination from the IACC, an agency specifically created for that purpose.

From my personal experience as a parent and a member of more than one committee involving disparate agendas, I completely appreciate the vast challenges involved in steering a course to a desired outcome. I just hope that the IACC likewise understands the consequences of remaining indefinitely adrift on an ocean of good intentions.

Forgive my bluntness in framing the following analogy: the intent is not to offend, but to illuminate. Imagine one is tasked with responding to a potentially explosive device placed in a building. How might one set priorities? Does one turn to discussing how surveillance systems might be improved to better spot the bad guys who planted it, or how better to police access points, or how to isolate the genetic markers of mass murderers? Perhaps these are all worthy objectives to address at some point. But in that scenario, I think we would all agree that **our first priority** would be to **maximize the safety and wellbeing of anyone likely to be impacted** by that device.

Now imagine that the device in that scenario is Autism, ticking down the hours, days and years to adulthood, when the individuals affected by it will have to fend for themselves. They will need safe transportation and appropriate housing, employment, assistance in daily living depending on their abilities, and recreational options.

I do not dismiss the importance of early diagnosis and intervention. But cute toddlers with autism do eventually grow into adults with autism. They may be less desirable subjects from the media's perspective unless they do something extraordinary, but they are no less valuable to their parents and caregivers. Not all of them are magically transformed by crushingly expensive interventions; not all of them are mathematical savants or musical geniuses. All of them are however, without exception, deserving of recognition for their innate worth. They deserve support and nurture from the wider community when their parents are no longer around to advocate for them. Accomplishing this is more about changing attitudes and perceptions than it is about spending money on personal iPads and people in lab coats.

Here is my personal story in brief. I am the parent of a 22-year-old girl with autism. She represented her high school as a solo vocalist at the statewide Solo & Ensemble competition over three consecutive years. She earned first division at the District level in all three years and first division at State level in her

second and third year. She participated in several piano festivals earning the highest possible grade over four consecutive years, winning a gold cup. She was held to the same standards in all these competitions as her neurotypical peers. She has traveled extensively. She is good at mental math and enjoys algebra. Although she struggles with receptive and expressive language, she reads and spells superbly.

But was all this predetermined by my daughter's abilities? Hardly. On the contrary, her progress was stymied at every turn by those who saw only her disabilities. It started with the neurologist who, in handing me the diagnosis, told me she might never speak. Then there was the elementary school teacher who told me she could not be taught to use a computer mouse. Another elementary school teacher said she could not comprehend the difference between addition and subtraction. A music therapist said she could never be taught to play the piano. And a high school choir director consistently withheld appropriate supports despite recognizing her talent, perhaps subconsciously hoping that if my daughter appeared obviously "autistic" on stage then she, the director, would seem all the more magnanimous for including my daughter in her sublimely perfect choir.

So how was all this overcome? By going outside the system and finding teachers who would work in partnership with us in making that critical investment of belief. By hiring private voice and piano teachers, paying for private math lessons, and finding an outstanding language instructor. And through it all, by my daughter's own determination to succeed.

I recall my own experience in school when I was intimidated by math and thought I would never be any good at it. That "disability" was not addressed by putting me on vitamin supplements and herbal remedies, but by my father's intuitive and inordinately patient teaching methods which targeted the scariest mental roadblocks and transformed them into a series of stepping stones. When I was unable to read signs at a distance, my parents did not assume that I could not read beyond a certain level. They took me to an optometrist and fitted me with a pair of glasses.

Why should the approach to autism be any different? With all the resources at this country's disposal and a comprehensive law guaranteeing free and appropriate public education, the education of children with autism is largely a travesty -- an exercise in justifying the presumption of failure. The laws keep many teachers more preoccupied with filling out paperwork than on refining and applying what they learn on their jaunts to various conferences and seminars.

In summation, unless **meaningful and productive** school education is made as much a fundamental requirement for children with autism as it is for any child, those children grow up needing more support than they might otherwise.

I respectfully submit that the IACC needs to take a much closer look at how funds for Autism Education are utilized and give this sector prime importance. It also needs to ensure that both priority and resources are assigned to the housing and employment needs of the burgeoning population of adults with autism.

Thank you so much for this opportunity for public comment, and for your thoughtful consideration of my input.

Sincerely,
CHITRA RAMAN
[PII redacted]

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

Donna Knepple

January 8, 2014

My name is Donna Knepple and I have two sons, ages 24 and 21, and a daughter age 15.

My daughter [PII redacted], born in [PII redacted], has received all of her routine vaccinations as set forth by the American Academy of Pediatrics for Infants and Toddlers. Since November of 2000 to date, she is diagnosed with PDD.NOS/Autistic Spectrum Disorder, Anxiety Disorder, ADD, ODD and OCD along with Medical Comorbidities based on lab investigations; she has immune dysregulation, mitochondrial dysfunction, unspecified metabolic disorder, autonomic nervous system dysfunction, polymorphism of MTHFR enzyme leading to detoxification problems, heavy metal toxicity, moderate to severe food and environmental allergies. In addition to the INFAMOUS BOWEL DISEASE, also known as Autistic Enterocolitis, in which she was diagnosed with in February of 2002, at the early age of 3 1/2 and continues to suffer from to date. You know the BOWEL DISEASE no one believes in which is completely DISREGARDED!!!

The very same inflammatory bowel disease as described in the 1998 Lancet paper, Ilea! Lymphoid-Nodular Hyperplasia Non-Specific Colitis and Pervasive Developmental Disorder in Children. I am sure you have heard the news about one of the authors, [PII redacted]. You know, [PII redacted] from England who was declared in 2009: "WORST PERSON IN THE WORLD" as reported by the media. The [PII redacted], who in the year 2010, made every media channel and headlines around the world; for him being a FRAUD, losing his medical license and the retraction of his 1998 Lancet paper, Jleal Lymphoid-Nodular Hyperplasia Non-Specific Colitis and Pervasive Developmental Disorder in Children, as ruled by the GMC in England. The [PII redacted] who challenged the medical system on behalf of our injured children back in 1995 and wrote to tell about it in his book Callous Disregard Autism and Vaccines - THE TRUTH BEHIND A TRAGEDY. - UNBELIEVABLE TRAVESTY OF JUSTICE!!!

Due to my daughters vaccine injury, I filed for compensation under the National Vaccine Injury Compensation Program dated May 21, 2003, Federal Register Volume 68, Number 98, Page 27834, #506, Court of Federal Claims #02-1890V. My petition was set forth in a list of an additional 666 petitions received by HRSA on October 1, 2002 through December 31, 2002. At the end of April of 2012, I received my dismissal papers after waiting 9 1/2 years; however, the attorneys representing us were paid in excess of \$3,900.00. Not only did the NVICP pay attorneys for dismissing thousands of cases they have paid out millions of dollars to a number of children just like my daughter and her fellow petitioners who they grouped under the Autism Omnibus ... only they did not mention AUTISM. Now let's add up all the money NVICP paid out on dismissing claims, money paid out to petitioners and the 7 million dollars it cost to try the Autism Omnibus test cases. - UNBELIEVABLE TRAVESTY OF JUSTICE!!!

I have been advocating for my daughter since she entered Early Intervention at the age of 2. have been trying to get an appropriate education with related services for my daughter since the very beginning. Our school district recently preferred to throw away approximately one-half of a million dollars in tax payer money arguing over my daughter's educational needs. In all actuality the Board of Education has no ACCOUNTABILITY for any of their wrong doing! The State, County and Town=

NO HELP AT ALL. After all of the wasted years I finally have my daughter in an appropriate placement, however, it is only for a very limited time and I need to start the process all over again for the same placement this year!!! - UNBELIEVABLE TRAVESTY OF JUSTICE!!!

Helping my daughter overcome her vaccine injury has caused me and my family to lose everything. Needless to say, everything my daughter has had to endure on a daily basis. I can't even find the words to describe this nightmare that we are unable to wake up from and have to live with each day. For the past 7 years I have been a single parent taking care of my daughter, struggling from paycheck to paycheck, living in small apartment on top of a store front, on a main avenue in my hometown. My saving grace has been the wonderful people in the Autism Community that I have connected with from around the world since 2001. Unfortunately, my story is not all that unique and neither is my daughter's VACCINE INJURY AND INFLAMMATORY BOWEL DISEASE!!!

So here we are again at another Interagency Autism Coordinating Committee Meeting and each year since 2006 we... MEET ... TALK. .. WASTE TIME ... WASTE MONEY ... DO BOGUS STUDIES ... and raise AUTISM AWARENESS. Game over... you cannot continue to stall nor hide from the TRUTH ... each year you have wasted since the 1990's the more and more children who have become affected and their families ... now 1 in 88 which can be as low as 1 in 50! THIS IS NOT A GENETIC EPIDEMIC; THIS IS AN UNBELIEVABLE TRAVESTY THAT HAS BEEN BESTOWED UPON OUR CHILDREN AND THEIR FAMILIES!!!

ONE CAN ONLY HOPE AND PRAY THAT THE JANUARY 14, 2014 MEETING WILL BE WHAT THIS COMMITTEE WAS SET FORTH TO DO AND THAT IS TO COMBAT AUTISM!!!

In loving memory of [PII redacted] and all of the other children whose lives were lost to

Autism. Respectfully Submitted on July 15, 2013 by,

Donna M. Kemple

Amended document on 8/19/13 (reflects my son's age on his birthday [PII redacted])

Amended document on 10/20/13 (reflects my son's age on his birthday [PII

redacted]) Amended document on 10/30/13 (10/29/13 - IACC Meeting Cancelled)

Amended document on 11/18/13 (reflects next IACC meeting 1/14/14)

Amended document on 1/6/14 (amended next year to this year)

[PII Redacted]

MY DAUGHTER [PII Redacted] IS 1 IN ?? CHILDREN DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER. I AM NOT ANTI-VACCINE AS YOU WILL SEE I FOLLOWED THE AMERICAN ACADEMY OF PEDIATRIC'S AND OUR PEDIATRICIAN'S RECOMMENDATIONS. MY BABY GIRL, [PII redacted], RECEIVED ALL OF HER ROUTINE VACCINATIONS ON SCHEDULE. I WAS INFORMED VACCINES ARE SAFE AND REACTIONS ARE RARE. MY DAUGHTER PAID THE ULTIMATE PRICE FROM MY CONSENT TO VACCINATE. WE WATCHED [PII redacted] SUFFER FROM ILLNESS TO ILLNESS AND REGRESS INTO AUTISM FROM THE VACCINES THAT WERE GIVEN TO PROTECT HER. MY DAUGHTER AND HER FELLOW PETITIONERS WERE DISMISSED FROM THE NATIONAL VACCINE INJURY COMPENSATION PROGRAM WITH THE REALITY OF CALLOUS DISREGARD TO THEIR VACCINE INJURY. OUR FAMILY DIVIDED OVER THE CONTROVERSY THAT SURROUNDS VACCINES, AUTISM AND BOWEL DISEASE. IT IS THESE FACTS THAT HAVE CHANGED MY LIFE INTO ONE OF A WARRIOR MOM ON A MISSION FOR TRUTH AND JUSTICE ON THE MALFEASANCE WITHIN THE UNITED STATES GOVERNMENT AGENCIES, DEPARTMENTS AND PROGRAMS. THE VERY SAME UNITED STATES GOVERNMENT AGENCIES, DEPARTMENTS AND PROGRAMS WHO ARE SUPPOSED TO PROVIDE THE AMERICAN PEOPLE WITH SERVICES AND REGULATIONS THAT ARE NOT ONLY FOR THE PUBLIC GOOD BUT IN WHICH PROTECT ITS CITIZENS FROM HARM.

“IN GOD WE TRUST”

CURRENT CDC DATA AND STATISTICS IDENTIFIED PREVALENCE OF AUTISM SPECTRUM DISORDERS

CURRENT YEAR 2014 = 1 IN ??

SURVEILLANCE YEAR 2008 = BIRTH YEAR 2000 = 1 IN 88
SURVEILLANCE YEAR 2006 = BIRTH YEAR 1998 = 1 IN 110
SURVEILLANCE YEAR 2004 = BIRTH YEAR 1996 = 1 IN 125
SURVEILLANCE YEAR 2002 = BIRTH YEAR 1994 = 1 IN 150
SURVEILLANCE YEAR 2000 = BIRTH YEAR 1992 = 1 IN 150

BIRTH YEAR 1985 = 1 IN 2500

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

Kristine Lewis

January 8, 2014

Please accept this as my public comment.

IACC committee:

Please consider funding research that investigates:

1. Subgroups of ASD- this important step was missed. My son has participated in many studies where they were studying what effect X treatment had on "autism". This is of course nonsense because autism is heterogeneous. These subgroups should be delineated by biomarkers, not necessarily functioning level! One example would be studying dietary interventions- why not study those exclusively in people w/ ASD who comprised the huge % of those with GI symptoms!?

2. Disorders of metabolism and mitochondria and their effect on the BRAIN. Dr. Richard Frye gave an incredible presentation to the IACC about his research into mitochondrial autism and disorders of folate metabolism. Why aren't you plowing a bunch of money into this promising area? My son, who is low-functioning, had a lumbar puncture to measure his folate in his CSF upon my insistence to the neurologist after showing her Frye's work on Cerebral Folate Deficiency. My son had all of the biomarkers that matched up with kids w/ LF autism and CFD. The neurologist only agreed to do this as a favor to my husband who is a pediatric specialist. My son's CSF folate came back at 31 (ref range 40-120, mean of 75) showing that he indeed has SEVERE CFD. This is a treatable cause of autism if caught early enough. Unfortunately my son was 7 years old and damage had been done to his brain. Nevertheless he has improved his functioning- mostly cognitive, language, and speech- tremendously since his metabolic disorder was identified and TREATED. This is just one example of treating underlying DISEASE and how "autism" symptoms can improve! Autism is treatable!

I watch/listen to the IACC meeting as time permits and follow the actions of the committee as I feel this group has enormous impact on my son and his health and life, our whole family, and society as a whole. Millions of kids with autism will grow up to be adults with autism. If you don't get serious about treatment, CURE, PREVENTION, then these people will absolutely bankrupt the country's resources. If no other child developed autism starting today, then we would still have a crisis of monumental proportions. Please stop funding nonsense eye gaze studies. Stop with the "recognize the signs" as there are not even services to give those who recognize the signs. I can't help but notice the parents/professionals/autistics who comment during public comment and how their messages and warnings are like a totally different language than that of the committee. What is your focus? Congress has charged you with "Combating Autism" COMBATING. Get to it.

Kristine Lewis
Mother of [PII redacted]

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

Jill Rubolino

January 9, 2014

Dear Committee Members,

I am writing to you as a mother of a ten year old son who is recovered from autism. I officially request that my public written comments be just that, public. I request that they be made available on the IACC website so that concerns and issues raised by individuals and families affected by autism, those that you are in existence to serve, are available to everyone.

Accountability and transparency are imperative as this committee controls funding of research that should translate into real and relevant help for those affected by this disability. In addition, I request that the GAO be aware of the tremendous disconnect in dollars spent related to productive interventions and improvement in outcomes for those affected by autism. I will forward this comment along with an account of my personal interaction with the IACC and its ineffectiveness in serving this population. Funding should be directed towards research and programs that address the complex medical needs of this patient population and improve their access to appropriate health care.

It was at the July 9th meeting that Dr. Timothy Buie and Dr. Richard Frye, both experts in their fields, both invited by this committee, stated that children can greatly improve and even recover with proper diagnosis and treatment of, underlying medical problems. By not incorporating this important information into the strategic plan, you are essentially eliminating the chance of greatly improved outcomes for potentially thousands of children and adults on the autism spectrum. You are dismissing this extremely important factor brought to light by the very individuals you invited as experts. This is akin to calling an expert witness in a court case to give testimony, and then having it stricken from the record. This absolute neglect of attention to this important factor not only creates a population of individuals who cannot access a medical standard of care, but it exponentially decreases their chances of improving both their health as well as their functional status. From a cost benefit perspective, you are actually increasing the cost of services across all venues including, but not limited to medical costs, costs to state programs, educational systems and federal Medicaid dollars by denying these individuals their opportunity to improve their outcome. I request an immediate review of the information presented and discussed at that committee meeting, which indicated that medical issues, an appropriate diagnosis and treatment should be at the forefront of the new strategic plan. I request that coordination with the AAP to develop a plan to disseminate this information to all practicing physicians, pediatricians, primary care practitioners, and specialists occur as also previously discussed at that meeting.

This committee has a moral, ethical, financial and legal obligation to utilize the funds available to serve this community in the most appropriate fashion. It has been supported by countless studies and is even noted in the AAP recommendations, that serious health issues including but not limited to gastrointestinal dysfunction, seizure activity and mitochondrial disorders are prevalent in this patient population. Proper diagnosis and treatment of these conditions can and does greatly improve both health and functional status, decreasing autistic behaviors. Dietary changes and interventions are

promoted and prescribed for every chronic health problem that affects our population. It is appalling that dietary intervention is not at the forefront of the plan for research and implementation as well.

We will hold our agencies that serve our children and adults with autism accountable at every level.

Regards,

Jill Rubolino, RN, PCCN
Sugar Land, Texas
[PII redacted]

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

Lisa Ackerman

January 9, 2014

My purpose in writing this letter is to help with planning the next steps for the IACC. It is my objective to communicate urgent needs while echoing the sentiments of others. The next steps should include:

1. Based on CDC autism estimates, declare autism an epidemic and public emergency. We need to treat autism with the urgency it warrants: 1 in 88 or 1 in 50 children are living with autism in the United States. To know the true numbers and need we need to define and collect a true census of individuals affected by autism. It is important to indicate that four year old estimates based on surveys do not work. Real numbers and details such as age groupings are urgently needed. (1.)
2. Consider a more diverse board at the IACC to include some of the world's researchers in cause and innovative treatment such as: Dr. Martha Herbert, Dr. Jill James, Dr. Richard Frye, and Dr. Dan Rossignol. It is my opinion that the current IACC board lacks in ground-breaking research and medical treatments happening today.
3. Collaborate with families via support groups in identifying needs for those living with the condition today. It is clear from the 2013 public comments from each committee meeting that the IACC committee does not address the realities of families or individuals living with autism and their needs.
4. Outside traditional therapies, medical treatments are helping individuals with autism live healthier. Based on new research, co-morbid medical issues do exist with autism. Where are the initiatives addressing these concerns to define answers? (2.)
5. Identify a task force to address the current and future needs of adults living with autism.
6. Prioritize and evaluate all possible environmental causes of autism.
7. We need to research autism subtypes to provide treatment and support paths needed. One subtype should not own the discussion or direction for all. Each subtype should be represented by the IACC committee members.
8. We have such little money available for research. The IACC needs to be efficient with those funds and check for research redundancy. The recent US Government Accountability Office (GAO) report shows gross negligence and what appears to be no oversight.
9. Require mandatory attendance of IACC members for meetings or they should not be allowed to serve on the committee.
10. Operate with a sense of urgency in your strategic plan. We cannot waste another moment. We must drive for answers.

Nothing has changed since the inception of IACC but more kids with an autism diagnosis, more adults needing services and less money to help. The IACC has little success to share. It is time to change direction and focus on driving help for families living with autism.

Sincerely,

Lisa Ackerman
Parent of a child diagnosed with autism
Email: [PII redacted]

References

1. What constitutes an emergency: <http://www.tacanow.org/blog/what-constitutes-an-emergency/>
2. Many children with autism have other health problems: <http://health.usnews.com/health-news/news/articles/2012/09/25/many-children-with-autism-have-other-health-problems-study-says>

Mary Cavanaugh

January 9, 2014

To Whom This May Concern:

Since January 2008 my life has changed dramatically. A few months prior to this my daughter received the diagnosis of "Autism". It changed when I learned the connection found in research with monkeys, autism, and vaccines. My daughter was 11 at the time. Prior to this diagnosis she had been given the ADHD diagnosis in 2nd grade.

Spring forward to 2013. What is my daughter's health like today? What does "Autism" look like in her body. After taking her to a Dr. who specializes in nutrition, German Biological Medicine, Acupuncture, and Homeopathy I found out my daughter who is now 17 is hypoglycemic, has parasites, h pylori, toxoplasmosis, has trouble absorbing her food, has trouble detoxifying her liver, and is STILL full of mercury. This Doctor is not covered by insurance because she requires tests the insurance will not cover. With the current system of "health" insurance they would have had to test her blood. Because my daughter is in a high state of anxiety all the time you would have had to sedate her to get this done if you could even get her to a hospital. What are you doing to assist parents with a child like this?

My daughter is currently very close to dropping out of high school because she feels like a failure. How are you helping these kids? The schools are in crisis! Is this going to be the norm in this country? One fourth of high school seniors in my state do not graduate. Is this acceptable to you? Why are our kids so sick? One out of two kids today have a chronic health condition.

My daughter at a very young age was not able to fight the toxicity in her body and her body did not have the ability to process it therefore a lot of blockages have occurred and compromised her primary reflexes causing multiple problems cognitively, visually, with balance, muscle tone, and a mitochondrial dysfunction.

Is it your intention to keep spending money on "research" when it is obvious to all what has caused this dumbing down of our children.

Thank you.

Mary Cavanaugh

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

Carolyn Gammicchia

January 8th, 2014

Dear Chair Insel and members of the IACC,

Today we are writing in concern for many reasons. As parents of a son with autism and members of the autism community, we have made attempts at the last two meetings to provide information to the IACC regarding our concerns via oral comments. Having provided information for your consideration via oral testimony and within written comments at both the July 9th meeting and November 15th meetings, we still have feel there is a lack of response from the committee regarding our concerns as well as others who provided testimony, especially in response to meeting the overall health needs of those with autism. However our main concern now is what is transpiring since the GAO report has been released. As we have indicated within our concerns, we do not feel the IACC is meeting its intended mission. The GAO report only confirms our concerns in indicating that there is a lack of coordination within what is transpiring within research and ensuring unnecessary duplication of research by governmental agencies does not occur. Additionally there seems to even be a lack of ability for IACC members to be able to adequately access the information they need to properly serve on the committee and be active representatives for the autism community. Additionally steps the IACC have taken in the past, to close doors on environmental effects related to vaccine injury, medical considerations and choice for individuals living with autism, as well as denying the ability to re-establish a Safety Committee, further show that the intended purpose and mission of the IACC is not being realized.

We are writing today for one reason, to ask that at this point that the IACC become more transparent within your coordination efforts by taking into consideration the following:

1. Disclose how the selection process occurred for current sitting IACC membership and the conflict of interest statements that those individuals completed upon consideration for sitting on the IACC. Also make available to the public the list of those who were nominated for consideration for appointment to the IACC.
2. Ensure that all written comments for public record are made available to the public as part of the public record for the IACC via the IACC website and are done so in an accessible form.
3. Ensure that all oral comment testimony, provided to the IACC in written form, be provided to the public via the IACC website including all accompanying materials in an accessible form.
4. Ensure that all committee meetings be recorded and are available via recording on the IACC website and made available in an accessible form.
5. Ensure that there is no conflict of interest by those presenting to the IACC during IACC meetings. We have seen many presentations specific to organizations that are either directly benefitting from funds from commercial enterprises or those who have a self-interest via their own organizations and have been in collaboration with for profit agencies that have collaborated with non-profits who have either BOD members on the IACC.
6. Reconsider the current subcommittees of the IACC and how those are currently meeting the needs of the entire autism community. Currently there is a lack of representation within applied research, especially in the area of services and meeting the needs of adults with autism. Since

this is a growing concern, and an area where research funding did not meet expectations from the IACC's past Strategic Plans, we ask that a specific committee within the IACC oversight be convened to address this topic. Our son is now an adult and will live the majority of his life as an individual over the age of eighteen. There is much to be done to assist in meeting his future needs as well as ours as a family. As was mentioned by a parent at the last IACC meeting, and something that we have broached for many years as parents, our son's Medicaid supports are not transferrable from state to state. This not only denies him his rights under the Olmstead decision, but denies our ability to live where we may desire within our retirement years as well as to properly support our son if we needed to move due to our own personal employment requirements. This seemed to fall on deaf ears at the meeting, as did oral comments provided on experiences on health care discrimination base on an individual having autism. This has been an area we've been very happy to see addressed at recent meetings, with both Dr. Buie and Dr. Frye's presentations. However in the same breath we were exposed to inane commentary on "catatonia" with treatment by ECT that seemed as those we stepped back rather than progressed in looking at how medical conditions produce behavioral challenges and illness in individuals living with autism. Again we need to look at why a presentation of such content was provided at an IACC meeting when it was obvious, especially to Dr. Frye who also commented on this and Ms. Redwood an RN, that an individual's medical needs should be addressed first rather than looking at behaviors as only psychologically based, especially when they are used as a means of communication for those who cannot do so via verbal means or by other methods.

7. Consider reconvening the IACC Safety Committee. This is an area of daily need that has not been addressed and needs to have a focus and specific research guidelines realized. The IACC taking a limited, privately funded study on only children and less than 900 participants over a limited six week time frame, shows lack of coordination to ensure unbiased research and research that is reflective of the entire autism population, not only a very small segment within a very limited time frame and done to focus on wandering which brought responses from those most likely to have a child that wanders. That research study, one very limited study, as used to develop a "wandering" code. This all accomplished in a very short time without public input, but guided by special interest groups who may financially benefit from its use such as long term care facilities or those who may deny access to a child with this behavior due to liability. It seemed too, during the consideration for the IACC to be once again funded; that this was done to show the IACC was indeed being proactive. However this did not meet the needs of all individuals who may elope or wander, including those less likely to be in the care of parents, adults living with autism.
8. Reconsider the make-up of the current committee. There currently is no representation from organizations that actively have assisted families in the past such as TACA or the National Autism Association. We feel that these organizations have the most active means of addressing the current needs of the autism community, since they are meeting those needs via volunteer mentor parents and their chapters across the country as well as their conferences offered in many venues. Additionally they are the only national organizations who are doing so by being fiscally responsible and not paying donated funds to their administration, but to provide programming options and supports for individuals living with autism and their families.
9. Respond to the public with a comment, via an open meeting of the IACC, at which members of the public can comment. Allow for at least a thirty day notice to the public on this meeting, and allow it to be accessible as well.

10. The meeting on November 15th displayed the lack of foundational understanding of the current IACC and the Strategic Plan as well as of the research that has been conducted in relation to the seven questions being asked within the plan. On several occasions things we mentioned by members as needs to new research to be conducted, however if the research resource provided for the meeting had been reviewed by those members, they could have seen research has been done in each of those areas. All except one however, one that four members of oral comment mentioned, and that is vaccines and their possible link to causation. Three comments were provided by parents that they witnessed their child's injury and then subsequent autism diagnosis after their child had been born healthy. This should be of concern to IACC members, now more than ever, since environmental factors have been shown to be related to neurological injury. Additionally it is the only research yet to be conducted, a study of vaccinated vs unvaccinated children diagnosed with autism. Why within the vast possible duplication of research by governmental agencies, up to 84%, and 1.4 billion dollars spent since 2008 has this not been brought to the table by the members of the IACC, even when members themselves have mentioned it? This is also not about individuals being skeptics, this is about science, and ruling out any area of scientific research shows a bias that the IACC at this time should reconsider, especially since you have members who have benefitted financially due to the vaccine industry or have members of their organization BOD who have. This is a direct conflict of interest and should be of consideration made at the time of any type of vote on vaccine content (unnecessary neurotoxins) and research needed to eliminate causation of a subset of individuals diagnosed with autism.

In closing we'd like to refer back to Carolyn's oral comments at the November 15th meeting. Currently there are individuals with autism being discriminated against to allow medical choices in health care treatment. This should be a foundational right of any individual and should never be something that is not realized by someone who may need it more due to the complications which may arise as an individual living with autism. Additionally choices for self-determined lives that are free of abuse, victimization, and discrimination should be of concern of the committee members and are within the scope of what your role is defined as serving members. We as a community are tired of hearing this is not within your scope, especially after the GAO's findings and the lack of translation of the majority of research completed to actual application for those living with autism and their families and those who supported them daily.

Please also feel free to contact us if you have any concerns regarding our letter or for further discussion which we welcome. We do feel the public oral comment sessions of the meetings also need to be revised to allow longer comment periods with questions allowed by the IACC members to ensure that those taking the time to do so are heard and their concerns realized. At this point that does not seem to be the situation.

With much appreciation for your consideration,

Andrew and Carolyn Gammicchia
[PII redacted]
Shelby Township, MI 48317
[PII redacted]

Dawn Loughborough

January 9, 2014

Dear Chairman Insel and Agency Members,

I respectfully submit this email requesting that the IACC include environmental causation research and physiological medical treatments in its strategic plan for 2014. Children who regress into autism are often helped by physiological medical interventions that use a whole body/multi-system approach.

Our children with regressive Autism represent perhaps the most environmentally affected children in society. Further research into toxins, pollution, vaccines, insecticides, and genetically modified foods must be investigated if we are to make progress with overall health.

Throughout several 2013 IACC meetings, physicians presented medical information on autism and gastro-intestinal, neurological, mitochondrial, and immunological concerns with the aim to help recover children with regressive autism. If 10% of children who regress into autism were recovered medically, it would be a great service to their lives and their families.

Please include these two important topics - environmental causation and physiological medical recovery interventions - in the strategy as part of the advisory function of IACC.

Best,
Dawn Loughborough