# Written Public Comments

IACC Full Committee Meeting

July 19, 2016

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

#### Dr. Eileen Nicole Simon

July 19, 2016

Eileen Nicole Simon, PhD, RN [PII redacted] Cambridge MA [PII redacted]

I would appreciate hearing the issues below discussed by members of the IACC:

#### **#1 WHAT CAUSED THIS TO HAPPEN?**

How disappointing the Science Updates presentation was at the IACC meeting on April 19.

What caused this to happen, could have been understood more than 40 years ago.

Before lauding "historical" viewpoints in recent books by journalists, the history of discoveries in neurology should be included in every science update on autism. Before citing just two papers on (1) maternal obesity and diabetes plus (2) spacing of births, research on all hazards during pregnancy and birth should be cited.

Prenatal exposures to rubella virus, valproic acid, and alcohol should be discussed.

The danger of rubella infection became apparent in the 1970s, and this should not now be forgotten and discarded as "old" data. Evidence that valproic acid (Depakote) disrupts development of the brainstem auditory pathway was published in 2011. It is wrong that the papers by R Lukose and his colleagues have not been included in recent IACC Summary of Advances publications.

Premature birth, and complications at birth, have been reported for decades as predispositions for developing autism. How can publications discussing these factors be omitted?

Oxygen insufficiency is the greatest concern associated with premature birth and complications during birth.

In 1972, RE Myers confirmed the findings by WF Windle during the 1960s, that a brief period of asphyxia at birth leads to damage within the brainstem auditory pathway. This research from the past should have been cited along with the article by Marina Sarris on what we know about noise sensitivity in autism.

I would like members of the IACC to read the following papers, and discuss their clear significance for understanding auditory system dysfunction in autism:

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

2. Myers RE. Two patterns of perinatal brain damage and their conditions of occurrence. Am J Obstet Gynecol. 1972 Jan 15;112(2):246-76.

3. Sarris M. What do we know about noise sensitivity in autism? online at: https://iancommunity.org/ssc/noise-sensitivity-autism

#### #2 NEW LAW?

My son has been very unhappy at his group home. He was discharged from Westborough State Hospital (in Massachusetts) to this group home 13 years ago, in 2003. He has run away many times.

In 2009 he was gone for 7 weeks and 2 days. He was finally located in Harvard Square. The police took him to Cambridge Hospital. After examining him, the hospital discharged him to the Quincy Mental Center, where he was admitted for psychiatric evaluation. He remained at QMH as an inpatient for several weeks. QMH was closed a year later, despite huge public protests.

Over the past year, 2015 and 2016, my son has run away on three occasions:

(1) A week after he disappeared last September I was called by the police in Belmont. I was told the law has changed; they could not transport him to a hospital. They released him to me.

I took him to Cambridge Hospital. This time he was asked if he felt like hurting himself or anyone else. His response was "No," and on this basis he was discharged without further examination. I was told if he could not return to his group home, or stay with my husband and me in our small apartment, they recommended several local shelters. I took him back to the group home.

(2) He ran away again on March 16. He was found by the police in Concord on March 31. Staff from the group home drove to Concord, and took him to the Emerson Hospital. Again he replied "no" to questions whether he would harm himself or others. Again he was discharged, and this time taken back to the group home by staff.

On Saturday, April 2, I asked him to write about how he had spent his time during the previous two weeks. That account is below, #4 DANGER TO SELF OR OTHERS? Note that this account describes his visits to three hospitals. I believe he was seeking help; but he is autistic, and seems not to know how to ask for help.

(3) Monday morning, April 4, he ran away again. Two days later the state police at Logan Airport found him, and had him taken by EMS to the Massachusetts General Hospital. Again he was asked whether he would hurt himself or others, and immediately released based on responding "No," to both questions. The police re-instated their all-points-bulletin (APB) for him.

#### **#3 PSYCHIATRIC EVALUATION?**

Wednesday, April 20, the state police at Logan Airport called me at 9:30pm, and asked me to get to Mass General Hospital as quickly as possible, to meet the EMS team on arrival. I requested a medical checkup in addition to a psychiatric evaluation. His blood pressure was 200/100, and blood glucose over 400. At 11pm he was given BP medication and insulin. At my request he was allowed to remain overnight in the ER overflow area.

I returned to the ER just before 8am, and was relieved to find he was still there. His BP was normal, but glucose over 300, and again they administered insulin. I was told they had many more urgent

psychiatric evaluations to do. I could take him or wait. I called the DMH site director for the Southeast MA area, who explained the shortage of inpatient beds for psychiatric evaluation.

I asked why there should be such a shortage? Unfortunately the money required for "community" placements led to closure of state hospitals ahead of schedule. How well thought out were these community placements? My son has been warehoused for 13 years (since February 2003) in a shabby group home with 5 other men who all hate each other.

My son has been bullied and scapegoated in his group home. When he can no longer take it, he runs away.

Just before 7pm a psychiatrist appeared, and took my son off to another area. He never returned to speak with me. He discharged my son. The bag of dirty clothes my son had worn the previous two weeks were brought to him, and as soon as he had his shoes on he vanished.

I am grateful to the security officers who found him. He told them he had to have a cigarette (or two), then forgot his way back into the area of the ER from which he departed. Where did he get the cigarettes? He bummed them off another smoker outside the door.

I did not have my car. I had taken public transportation into Mass General Thursday morning. Security called EMS to take my son back to his group home.

Saturday, April 23, I took my son out, and asked him to write about what he had been doing during the past two weeks. His report was far less coherent than what he wrote on April 2. It was primarily lists of train stations and cities on commuter rail lines.

#### #4 DANGER TO SELF OR OTHERS?

[PII redacted]

Sat 4/2 March 17 to April 1st of this year

Starting on Wednesday, March 17, I was on a Leave of Absence from [PII redacted] in Randolph. I left at about 7am and got to Peabody Square in Ashmont in the town of Milton about 8am.

Then I took the **T** Redline into Boston, then to Alewife in Cambridge and then back to Boston where I took the **T** Greenline to Wellesley, Newton Wellesley Hospital. Then I walked to Wellesley Hills and stayed there for awhile and then to Wellesley Square where I eventually got on a **T** commuter train to Worcester from Wellesley Square late afternoon.

In Worcester I walked over to St. Vincent Hospital where I had supper at the cafeteria and stayed awhile until about 9pm and then caught a train to Boston about 9:45pm.

When I got to Boston I took the Silverline bus to Logan Airport where I stayed overnight and then returned to Newton/Wellesley Hospital Thursday morning where I stayed throughout the morning and arrived at Wellesley Hills around 1pm.

I saw some trains go by around 1:15pm and then walked to Wellesley Sq. where I had lunch at a place called "AL & Ethan House of Pizza." I had 2 slices of pizza for lunch.

I took a **T** train to Worcester around 5:15pm and stayed in Worcester until the 10:30 pm **T** train came and went into Boston where I took the Silverline Bus to Logan Airport, where I stayed overnight from 12am to 7am.

Most of the weekend I spent at Mass General Hospital in Boston and Worcester between Saturday and Monday morning.

the following week I spent mostly in Boston Worcester, and Wellesley. One afternoon I spent in Framingham and later in the day took a **T** commuter rail train from Framingham to Worcester and spent one night at St. Vincent Hospital in Worcester, and then returned to Wellesley the next morning.

#### **#5** Wernicke's Encephalopathy

RE Myers in 1972 confirmed the finding by WF Windle that a brief lapse in respiration at birth (6-10 minutes) causes damage in the brainstem auditory pathway. Windle admitted that he almost missed finding this damage, because the acoustic relay centers are small and almost unnoticeable.

SS Kety pointed out to Windle that blood flow is higher in way stations of the auditory pathway than anywhere else in the brain. Kety's paper is free online, and illustrated by autoradiographic pictures from his research on cerebral blood flow.

Kety's research also provides an explanation for the pattern of bilaterally symmetrical damage within the brainstem described by Wernicke in 1881. Wernicke's cases were two chronic alcoholics and a woman who committed suicide by drinking sulfuric acid.

The damage described by Wernicke was hemorrhagic. The damage described by Myers and Windle was ischemic (blocked blood flow).

Substance use (alcohol, sulfuric acid, opiates, etc.) disrupts aerobic metabolism. Thiamine (vitamin B1) deficiency likewise disrupts metabolism; thiamine is an essential co-enzyme for several steps in the aerobic metabolic cycle. Ischemic asphyxia affects the same brainstem centers of high aerobic activity. The damage is similar, whether by asphyxia, thiamine deficiency, or substance abuse.

Signs of brainstem damage should be looked for in autistic children and adults.

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#### #6 Korsakoff's Encephalopathy

Without treatment, Wernicke's encephalopathy progresses to Korsakoff's dementia, with deterioration of connections within the cerebral cortex. Progressive involvement of structures within the cortex reveals the lifelong importance of trophic neurotransmitters produced in brainstem pathways.

Signal processing in the auditory system relies on interplay of excitatory and inhibitory transmitters within every relay center along the way: cochlear, trapezoid, superior olivary, inferior colliculi, geniculate, and thalamic nuclei. Hearing is the earliest of the senses to suffer the ravages of age or unhealthy lifestyle.

Ischemic damage of the inferior colliculi by asphyxia at birth has been dismissed over the past 5 decades, as part of "minimal" brain damage. Over the past 50+ years "patterning" exercises and other treatments have been used to promote neural plasticity. Neural plasticity? Isn't that a modern myth? Could spinal paralysis by polio be reversed by therapies based on principles of neurological regeneration?

Until embryonic neurotransmission is understood and made applicable to reversal following injury, avoiding injury must be the goal. Loss of trophic neurotransmission from the brainstem auditory system should be investigated as a factor in failure of the language areas to develop. Maturation (myelination) of the language areas continues during the first 4 to 5 years of childhood.

Before citing epidemiology research on autism and obese, diabetic mothers, or close spacing of births, how these factors are predispositions for brain injury must be considered.

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#### **#7 COMMENTS SUBMITTED IN APRIL**

I submitted 6 comments (April 26 and 29), first to express my disappointment with the update to the Strategic Plan question What Caused This To Happen? It was beyond belief that only 2 citations, on maternal obesity and spacing of births, were provided.

Thus again I tried to point out the many known causes of autism, prenatal exposures to rubella virus and valproic acid, premature birth, and oxygen insufficiency at birth. Also the evidence of auditory system injury caused by prenatal exposure to valproic acid, and asphyxia at birth.

Then I described recent horrific experiences with trying to get help for my 53-year-old son. Who cares? Is there any member of the IACC with any comprehension of the life-span problems faced by children diagnosed with autism? More than early recognition and early interventions are needed.

#### **#8 A REQUEST FOR DISCUSSION OF BRAIN INJURY IN AUTISM**

Could a panel of medical experts be made part of the IACC meeting schedule to discuss public comments relevant to brain injury? The "traits" of autism should be discussed as neurological signs: (1) language disorder, (2) repetitive movement disorder, and (3) diminished level of consciousness.

Brain damage is the result of all causes of autism. "Social disorder" is a euphemism that must be discarded. "Social disorder" is a euphemism for diminished level of consciousness. Autism is a life-long neurological disorder. Early intervention and special education do not provide a cure. Prevention must be the priority.

Brain injury in autism might have been understood 40 to 50 years ago. I will continue to try to point this out. Comments I have submitted to the IACC over the past 13 years (since 2003) have only been mentioned in summaries of written public comments.

I submitted written comments (April 29) on Wernicke's and Korsakoff's encephalopathies. I would especially appreciate discussion of these well-known brain disorders and their relationship to: (1) brain damage caused by asphyxia at birth, and (2) failure of brain maturation following perinatal injury.

If my comments are not worthy of discussion, please explain why.

#### **#9 AUTISM'S MANY CAUSES**

Autism is the result of brain damage, and there are many known causes of autism. Some of these causes are: prenatal rubella infection, prenatal exposure to valproic acid (Depakote), genetic enzyme disorders like PKU (phenylketonuria) or adenylosuccinate lyase deficiency, as well as the genetic structural disorders tuberous sclerosis and neurofibromatosis [1-7].

Autism has also been reported in some children with fetal alcohol syndrome [8]. The brain pathology caused by alcohol has been known for 135 years, first described by Wernicke in 1881. Wernicke described symmetric bilateral damage of nerve centers in brainstem sensory pathways in two cases of chronic alcohol abuse and one case of sulfuric acid poisoning [9].

Abnormal (and toxic) metabolites are produced by faulty enzymes in genetic disorders like PKU and adenylosuccinse deficiency. The effects of these toxic metabolites may be similar to the effects of alcohol, sulfuric acid, and many more substances. Wernicke-like damage has been reported in poisoning by pyrithiamine, methyl bromide, carbonyl sulfide, alpha-chlorohydrin, anti-cancer drugs, as well as lead and mercury [10-16].

Birth complications have been investigated more often than any other cause of autism, for at least the last four decades [17]. Low Apgar scores are reported in most of the research articles, but then often attributed to some unidentified pre-existing problem with the infant or mother [18-20].

Brain damage as the cause of autism might have been understood more than 50 years ago. William F. Windle conducted experiments with monkeys on asphyxia at birth. His aim was to create a primate model of cerebral palsy, then seek ways to prevent this horrific disability [21]. At birth asphyxia was inflicted by delivering the head into a saline-filled sac, then clamping the umbilical cord [22]. In later experiments cesarean deliveries were performed; the umbilical cord was clamped and the infant monkey left in the amniotic sac.

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#### **#10 NIMH RESEARCH PRIORITIES**

Below are perspectives on mental illness research, which I submitted June 17, 2016 in response to a Request for Information (RIF) from NIMH. I don't know if these will appear in a "Public Record" of responses received. I do want my ideas discussed. Autism is my primary interest, thus I am resubmitting my comments to the IACC.

As explained below, my education was in science. I have been attending writers' workshops to improve my skills in communicating my ideas. A recent suggestion in one of these workshops was to make it absolutely clear why I believe the inferior colliculus (plural colliculi) is so important. Thus each of the (500 word or less) essays #2-#14 include the inferior colliculus in the title.

#### NIMH #1 Mental Illnesses are Neurological Disorders

This is the first of several 500-word-or-less comments I plan to submit in response to the NIMH Request for Brief Perspectives on the State of Mental Illness Research:

- 1. Mental illnesses are neurological disorders: The brain and function of its anatomical components must be the focus of all research on mental illnesses. This should especially be the case for mental illnesses treated with medications.
- Childhood autism, in particular, is a neurological disorder: The three defining "traits" of autism are in fact neurological signs: (1) Language disorder, (2) repetitive (choreo-athetoid) movements, and (3) diminished level of consciousness (LOC), which should not be dismissed as a "social disorder."
- 3. Claims of autism not diagnosed until adolescence or adulthood should be verified by review of pediatric records to determine if language development was delayed or abnormal in any way. Schizophrenia, not autism, should be a diagnosis to consider for people who exhibit signs of "social disorder" not associated with developmental language disorder.
- The inferior colliculus (plural colliculi) in the midbrain tectum should be a focus of research on: (1) Language development in childhood, (2) loss of speech understanding in adulthood, (3) auditory hallucinations in schizophrenia, and (4) the conscious state.
- 5. The obstetric protocol to clamp the umbilical cord immediately after birth must be stopped. Enough research evidence has been gathered that surgical termination of placental blood flow is dangerous. Increased prevalence of autism, ADHD, dyslexia, schizophrenia, premature puberty, gender identity confusion, and other anomalies of development should be investigated as the result of this brutal and wrongful procedure.

I am submitting more comments (2-14) shortly, and may send more before June 30:

- #2 Autism, Asphyxia at Birth, and the Inferior Colliculus
- #3 Language and the Inferior Colliculus
- #4 Blood Flow in the Brain and the Inferior Colliculus
- #5 Deoxyglucose Measurements and the Inferior Colliculus
- #6 Brain Maturation and the Inferior Colliculus
- #7 Metaphorical Speech and the Inferior Colliculus
- #8 Placental Respiration and the Inferior Colliculus
- #9 Neonatal Circulation and the Inferior Colliculus
- #10 Apgar 10 and the Inferior Colliculus
- #11 Male Vulnerability and the Inferior Colliculus
- #12 Neonatal Resuscitation and the Inferior Colliculus

- #13 The Conscious State and the Inferior Colliculus
- #14 Schizophrenia and the Inferior Colliculus

#### NIMH #2 Autism, Asphyxia at Birth, and the Inferior Colliculus

My first two sons suffered head injury and asphyxia at birth. Both were diagnosed as autistic because: (1) Their speech consisted of phrase fragments (echolalia) rather than rearrangement of words according to rules of syntax. Both exhibited (2) involuntary (choreo-athetoid) movements, and (3) diminished environmental awareness (level of consciousness, LOC).

For 50+ years I have been reading everything I can find on these three neurologic signs (or traits) of autism. In 1969 I was accepted into the Medical Sciences program at the Boston University School of Medicine, and with funding from NIMH and other sources, and received a PhD in biochemistry in 1975. I am most grateful for the support I had from NIMH. I gave up laboratory research and returned to my former profession of computer science mainly because computer work was easier to manage with day-care and after-school programs for my four children.

In October 1969 I read the article by WF Windle on asphyxia at birth in the Scientific American [1]. He reported damage in the midbrain auditory pathway, the inferior colliculus (plural colliculi) caused by 6 to 10 minutes of asphyxia at birth. RE Myers in 1972 reported the same selective injury of the inferior colliculi [2]. Myers reproduced the more extensive brain damage characteristic of cerebral palsy by inflicting partial disruption of placental circulation late in gestation.

Injury of the inferior colliculi and other relay centers in the auditory pathway, might be expected to: (a) prevent hearing of syllable and word boundaries, and (b) disrupt postnatal maturation of the language areas of the cerebral cortex.

Faro and Windle described disrupted maturation in the brains of monkeys subjected to asphyxia at birth [3].

Complications at birth have been documented more than any other factor in the etiology of autism. Injury of the auditory pathway should long ago have been considered as a possible reason for the language disorder of autistic children.

I will submit subsequent comments on language disorder as a possible result of damage within the brainstem auditory pathway.

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#### NIMH #3 Language and the Inferior Colliculus

Windle suggested that damage within the inferior colliculi and other brainstem centers caused by asphyxia at birth might underlie what was then referred to as minimal cerebral dysfunction (MCD) [1, 2].

However, loss of the ability to understand spoken language following injury of the inferior colliculi has been documented in several case reports [3-15]. How much more serious this should be for an infant with damage of this auditory processing center in the midbrain caused by asphyxia at birth.

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# NIMH #4 Blood Flow in the Brain and the Inferior Colliculus

A seminal paper by Seymour S Kety sits in the medical literature [1], just as forgotten as the papers by Windle and Myers on brain damage caused by asphyxia at birth [2, 3]. Windle and Myers documented damage by asphyxia at birth in the inferior colliculi.

Kety injected a radioactive substance into the circulation of cats. One minute later the cats were decapitated, and the brains frozen in liquid nitrogen. Slices of the brain were then placed on

photographic plates. The inferior colliculi were found to be most intensely radioactive. Nuclei in the superior olivary complex and the lateral lemniscal tract were only slightly less prominent in these (autoradiographic) images.

Roth and Barlow also used the method of autoradiography to investigate distribution of drugs in the brain [4]. Some drugs were found in highest concentration in the inferior colliculi. Distribution of other drugs occurred in areas where they combined with receptor sites.

In 2011 Kulesza and Lukose found damage in the superior olivary complex in brains from 9 people who were autistic from childhood [5]. Malformation of the superior olives had been described in a paper by Rodier et al. [6]. Lukose et al. then exposed laboratory rats to valproic acid (Depakote) during gestation, and found similar derangement in the superior olives [7].

What is the significance of high blood flow in relay centers of the auditory pathway? British audiologist Ladislav Fisch pointed out that the auditory system is constantly active, even during sleep, and that it is the "vigilance center" of the brain [8].

The inferior colliculi show up as bright dots on fMRI scans [9]. The inferior colliculi should be looked for in fMRI scans of people who were autistic from early childhood.

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#### NIMH #5 Deoxyglucose Measurements and the Inferior Colliculus

Sokoloff et al. (1977) extended the research on blood flow in the brain by using an analogue of glucose (Carbon14-deoxyglucose) as the radioactive tracer [1,2]. Uptake of deoxyglucose was greater in the inferior colliculus (plural colliculi) than anywhere else in the brain, as measured by radioactive intensity:

"The highest values were clearly in the structures involved in auditory functions with the inferior colliculus the most metabolically active structure in the brain." [1, p912]

Thus high blood flow in the inferior colliculus and other auditory centers supports greater need for glucose as well as oxygen for aerobic metabolism.

The deoxyglucose method has been used extensively for research on the effects of various substances in the brain. These research papers list deoxyglucose uptake in many brain regions, including the inferior colliculus, as well as particular regions of interest, and uptake in the inferior colliculus is always highest [3-7].

It should be of interest to determine why this small nucleus in the midbrain auditory pathway is constantly so highly active.

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#### NIMH #6 Brain Maturation and the Inferior Colliculus

As for prenatal growth of organs and limbs, brain development follows an orderly course. Disruption at any stage by prenatal exposure to alcohol, viral infection, or other teratogenic factor leads to malformations. The tragedy of babies born with stunted limbs to mothers who took Thalidomide during pregnancy will hopefully never be forgotten.

Maturation of the brain continues after birth. Myelination within the language areas continues during the first three to four years of childhood, and as language development takes place [1, 2].

Damage of the inferior colliculus by asphyxia at birth was viewed in the 1960s as a possible cause of "minimal cerebral dysfunction" (MCD). The damage was almost missed, because the inferior colliculi are small. But trophic neurotransmitters produced in these small midbrain centers appear to be crucial for development of their target areas in the cerebral cortex [3].

More research should be conducted on the importance of small subcortical sites affected by perinatal drug use or oxygen insufficiency. Their role in ongoing postnatal maturation of the cerebral cortex should be a priority.

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#### NIMH #7 Metaphorical Speech and the Inferior Colliculus

Language is the defining characteristic of the human species. Aphasia, loss of language in adulthood, is regarded as among the most serious of all neurological disorders [1, 2].

Language disorder must be recognized as the most serious handicap of autistic children. Claims of a late autism diagnosis in people whose language development was normal are about something other than the disorder described by Kanner.

Kanner's 1946 paper on metaphorical speech, described the use of "irrelevant" phrase fragments by the children he described in his first paper [3]. Kanner had to ask parents for the meanings of these phrases. He learned from parents that these were verbatim recitations of things heard in earlier situations, then later used badly out of context.

"What's the matter? Did your wagon get stuck?" was my son [PII redacted] stock exclamation in any situation of frustration.

Normal language development begins with monosyllabic approximations of single words. Research has revealed that monosyllabic speech is based on a child's comprehension of syllable boundaries [4]. The ability to detect syllable boundaries diminishes during the first decade of life. This is why learning a second language becomes increasingly more difficult.

Use of phrase fragments rather than monosyllables reveals an earlier than usual difficulty with detecting syllable boundaries. This is the echolalic speech disorder of early infantile autism, and includes the characteristic reversal of pronouns, use of "you" rather than "I" to refer to self [5].

Language has for centuries been a focus of scholarly research. Loss of language has been a focus of neurological research at least since the discoveries by Broca and Wernicke in the 19th century. Language development is an area of recent research that should be viewed as most important for understanding Kanner autism.

The idea that autism is a "social disorder" is horrifically imprecise. This was promoted as a euphemistic way to avoid talking about brain damage. That lack of "shared attention" prevents language development provides no more a meaningful insight.

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# NIMH #8 Placental Respiration and the Inferior Colliculus

In 10th grade biology I remember learning embryonic development. Cells that form the placenta are among the earliest to differentiate. The heart is the first permanent organ to become functional, circulating yolk-sac blood cells to the placenta to receive oxygen from the mother.

Aerobic metabolism is essential for formation and function of later developing organs. I learned these things back in the 1950s.

Perusing old journals and textbooks I see the 1950s were when episiotomy was thought to be essential, for all women giving birth. Repair of the episiotomy requires a "sterile field" and this was maintained by clamping the umbilical cord immediately after birth and removing the infant from the surgical area [1].

Not all babies breathe immediately after birth. Thus Apgar developed her scale for assessing the need for resuscitation, and she commented, "A satisfactory cry is sometimes not established even when the infant leaves the delivery room" [2].

Before the mid 1980s, textbooks of obstetrics all taught that the umbilical cord should not be tied or clamped until pulsations in it have ceased [3]. Pulsations of the cord are an indication that fetal heart valves have not yet closed. Blood flow to the placenta does not cease at the moment of birth.

Clamping the umbilical cord terminates postnatal blood flow to and from the placenta. If respiration by the lungs has not yet been established, the infant will suffer a period of oxygen insufficiency. Damage of the inferior colliculi is then likely, as reported by Windle and Myers, who inflicted asphyxia by clamping the umbilical cord, and preventing onset of respiration in newborn monkeys [3, 4].

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#### NIMH #9 Neonatal Circulation and the Inferior Colliculus

When should placental respiration cease?

The earliest description I have found for use of a clamp on the umbilical cord was published in the Lancet, May 1899. This instrument was introduced as a hygiene measure, with instructions to wait for pulsations of the umbilical cord to cease before applying the clamp [1].

For several days in 2004 I sat on the 4th floor of the Countway Library at Harvard, and pulled one old obstetrics textbook after another off the shelf. The instruction until the mid 1980s was to wait for pulsations of the cord to cease before tying or clamping it. Why?

Pulsations of the cord are evidence that the ductus arteriosus has not yet closed; the infant's heart is continuing to pump blood back to the placenta. These pulsations diminish as the baby takes its first few breaths and begins to cry. Research from the late 1800s to the 1930s documented that pulsations of the cord can persist for 30 to 50 minutes after birth [2].

I found two research papers (more recent than those of Windle and Myers) on models for producing perinatal asphyxia in experimental animals based on clamping of the umbilical cord [3, 4]. In how many human births is some degree of oxygen insufficiency being inflicted by clamping the umbilical cord immediately after birth? Some degree of injury to the inferior colliculi should be expected in infants who have not begun breathing before the umbilical cord is clamped.

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#### NIMH #10 Apgar 10 and the Inferior Colliculus

Before pulmonary respiration can begin, the capillaries surrounding the alveoli must be filled with blood to receive oxygen.

Mercer and Skovgaard (2002) described the research of Finnish scientist S Jäykkä back in the 1950s [1, 2]. In experiments with un-inflated lungs from stillborn infants, Jäykkä discovered that ventilation produced only patchy opening of alveoli, and only those nearest the bronchial airway. Injecting India ink into the pulmonary artery led to "erection" of the alveoli throughout the lungs.

The alveoli develop during gestation, but remain un-inflated until blood begins to flow into the pulmonary artery, in sufficient amounts to fill the capillaries that supply the alveoli. Volume expanders are sometimes given to newborn infants to promote circulation to the lungs and overcome respiratory distress. But volume expanders do not contain hemoglobin, which is needed to take up oxygen from the alveoli [3].

The lungs take priority at birth. An infant may not appear to be in distress if blood is drained from other organs to jump-start the lungs. An infant may have an Apgar score of 10, but if blood is drained from the brain, ischemic damage of vulnerable systems like the inferior colliculus may occur.

How can clamping the umbilical cord immediately after birth not be considered one of the most serious medical errors of all time? [4]

Sudden amputation of the placenta is likely to lead to the characteristic pattern of damage to the auditory system and basal ganglia reported in experiments on asphyxia at birth [5, 6]. This pattern of damage should be investigated as a likely cause of language disorder, repetitive movements, and diminished level of consciousness in children who develop autism.

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# NIMH #11 Male Vulnerability and the Inferior Colliculus

Metabolism is higher in males than females. Muscle strength is greater in males than females, and athletic ability of males is superior to that of females. Women do not compete with men in most sports. Separate records are kept for running, swimming, and skiing competitions. Even events like figure skating, gymnastics, and springboard diving are separate for men and women.

During the process of birth, the aerobic needs of males are greater than females. I remember this being a topic of discussion at a meeting of the Fetal and Neonatal Physiological Society meeting I attended in 2006, as part of a discussion of cooling caps for infants who suffered anoxic-ischemic encephalopathy during birth.

I requested discussion of this by members of the Interagency Autism Coordination Committee (IACC) on the greater number of males than females who develop autism. What alternative ideas are there that might explain the 5:1 male to female ratio of children who develop autism?

Following are citations to the medical literature on this subject, including my own dissertation research back in 1976:

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#### NIMH #12 Neonatal Resuscitation and the Inferior Colliculus

New guidelines for neonatal resuscitation were provided in a November 2015 Supplement for the journal Pediatrics [1].

According to this article:

1. Transition to extrauterine life is brought about by "initiation of air breathing" and "cessation of placental circulation." What? And,

2. "Approximately 85% of babies born at term will initiate spontaneous respirations within 10 to 30 seconds after birth." What about the other 15 percent?

The authors then state:

3. In the past 50 years, the umbilical cords of babies born preterm have been cut soon after birth, so that the newborns can be transferred immediately to the neonatal team.

The authors then acknowledge recent evidence that:

4. "A delay of clamping by 30 to 60 seconds after birth results in a smoother transition, particularly if the baby begins breathing before the cord is cut," and

5. "Parents favor delayed clamping, which has received strong popular support through social media and Internet sites." Good news!

An article on resuscitation published five years earlier (2010), also in Pediatrics, began with the statement, "Approximately 10% of newborns require some assistance to begin breathing at birth..."

That placental circulation continues after birth was mentioned (in 2010) only to the extent that pulsations of the cord continue. But then the statement was made, "There is insufficient evidence to support or refute a recommendation to delay cord clamping in babies requiring resuscitation."

Clamping the cord had become mindlessly routine. The fallacy of this childbirth intervention is finally being brought to light by a strong grassroots movement. Yes! And maybe what many of us learned in 10th grade (back in the 1950s) was all we needed. Then the articles by Windle and Myers in the following decades revealed the vulnerability of the inferior colliculi to asphyxia at birth, but this evidence was ignored and forgotten [2, 3].

How can "experts" continue to insist more randomized-controlled trials must be done? Enough evidence of harm has been reported [4, 5]. Further randomly assigning an infant to immediate clamping of the cord at birth is unethical.

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#### NIMH #13 The Conscious State and the Inferior Colliculus

Level of consciousness (LOC) is an important but not well understood component of neurological assessment [1]. Research on cerebral connections of the inferior colliculus might be useful.

Denny-Brown (1962) proposed that the midbrain tectum (superior and inferior colliculi) deserves consideration as the most vital for unitary function of the organism, that it merits consideration as the "physiological ego."

Denny-Brown compared the effects of removing the inferior colliculi in one monkey and the superior colliculi in five others [2]. The animal in which the inferior colliculi were removed survived for sixteen days, and was described as having a fixed doll-like appearance with complete absence of spontaneous movement.

Papers by Sprague et al. (1961) and Jane et al. (1965) described altered behavior in cats with lesions that isolated the inferior colliculi from the lower brainstem auditory pathway or its connections forward to the thalamus and temporal lobes.

Sprague et al. (1961) reported dramatic behavioral changes following bilateral lesions of the lateral lemniscal tracts. Their experimental cats became mute and presented a blank, staring, mask-like look, which they described as strikingly reminiscent of autistic children [3].

Jane et al. (1965) investigated the hierarchy of sensory stimuli that evoke attention in cats [4]. Bilateral lesions of the brachium of the inferior colliculus led to behavioral changes that went beyond identifying sound over light as the dominant sense; these animals resisted handling, did not groom themselves, appeared dazed, and were mostly mute.

Miller and Myers (1970, 1972) compared the effects of circulatory arrest in mature monkeys with asphyxia at birth. The inferior colliculi were prominently damaged. Monkeys that survived showed signs of "decerebration," like opisthotonus [5, 6].

Sherrington (1898) described "decerebrate rigidity" and "opisthotonic posturing" following removal of the cerebral cortex in experimental animals [7]. Sherrington later discovered that a cut in the midbrain between the inferior and superior colliculi also produced decerebrate rigidity and opisthotonus.

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#### NIMH #14 Schizophrenia and the Inferior Colliculus

Auditory hallucinations are a prominent feature of schizophrenia. Perinatal complications and developmental delay have been identified in people who develop schizophrenia [1]. Perinatal complications in most cases lead to at least a brief period of oxygen insufficiency (asphyxia), thus injury of the inferior colliculi is likely [2, 3].

Language is the defining characteristic of the human species. Even severely autistic children attempt to master language through use of phrase fragments (echolalic speech). Comprehension of spoken language is lost following severe injury of the inferior colliculi in adulthood. I listed citations to several case reports in my submission #3 for NIMH research, and pointed out how much more serious injury of the inferior colliculi should be for an infant.

What about lesser degrees of injury? If discrimination of syllable and word boundaries is not lost, language development should begin according to the stages described by Roger Brown [4]: (1) acquisition of words, and (2) syntactic rearrangements, If early maturation of circuits in the temporal lobes is not abolished.

Damage of the inferior colliculi by asphyxia at birth was viewed as a minimal defect, because much more extensive injury had been expected. However, maturation of the brain was impaired in monkeys subjected to asphyxia at birth; and patterns of maturational disruption were unpredictable and idiosyncratic [5].

MRI investigations of the brain in schizophrenia include reports of impaired structure and function in the inferior colliculus [6-8]. Perinatal damage of the inferior colliculus should be made a priority for research on schizophrenia.

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#### NIMH #15 The Blood-Brain Barrier, Kernicterus, and Autism

I submitted 14 comments earlier this month in response to the request for ideas on mental illness research at NIMH. I am submitting the following shortly:

- #16 Bilirubin-Induced Neurologic Dysfunction (BIND)
- #17 Bilirubin, Kernicterus, and the Inferior Colliculus
- #18 Bilirubin and the Blood-Brain Barrier
- #19 Repetitive Movement Disorder in Autism

These are in part based on excerpts of a letter-to-the-editor I submitted to a journal about 8 years ago: Autism, a Variant of Kernicterus? My letter was rejected for publication, but I continue to believe that the neurological signs of autism should be compared with those of kernicterus.

Bilirubin may not be involved in autism, but the effects of other toxic substances that may have a similar effect on the brain should be investigated. Most important is for research to be done on the blood-brain barrier.

In my earlier submissions for NIMH research (#1-14), I hope my concerns about oxygen insufficiency at birth will be considered. Umbilical cord clamping, and collection of placental blood for blood banks should be stopped. It is good to see a grassroots movement for return to tradition, and waiting for placental circulation to cease naturally.

Objections to clamping the umbilical cord immediately after birth have been raised since the 1930s [1], when placental blood was first harvested for blood banks [2, 3].

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#### NIMH #16 Bilirubin-Induced Neurologic Dysfunction (BIND)

The paper by Jerold F Lucey et al. published in January 1964 should be regarded as seminal [1]. This article does not show up in PubMed. I wrote to Dr. Lucey about this paper, and he asked me how I ever found it! I found it in the early 1970s, using the old paper version of Index Medicus.

What Lucey et al. found, in experimental monkeys, was that bilirubin even at high levels did not get into the brain except for monkeys subjected to asphyxia at birth. Asphyxia breaks down the blood-brain barrier.

Use of a surgical clamp on the umbilical cord immediately after birth became standard practice by the mid-1980s. Traditional textbooks taught that the cord should not be tied (or clamped) until pulsations in it ceased. Pulsations are evidence that the fetal heart valves remain open after birth, until blood flow is completely redirected to the pulmonary artery.

Clamping the cord before transfer of respiration to the lungs leads to a lapse in respiration, and asphyxia until breathing is established. Even the briefest period of asphyxia may cause break-down of the bloodbrain barrier. This should be made a priority for research on increased prevalence of kernicterus and autism since 1990.

Kernicterus, by the year 2000, was reported to be on the increase [2]. Autism spectrum disorders likewise have been on the increase since the 1990s. High bilirubin levels have been documented in infants who later developed autism [3-6]. The danger is from clamping the the umbilical cord immediately after birth, with abrupt termination of postnatal placental blood flow. Clamping the cord at birth must be stopped. Anymore randomized controlled trials are unethical.

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# NIMH #17 Bilirubin, Kernicterus, and the Inferior Colliculus

Asphyxia at birth was found to cause severe damage to the inferior colliculi in experiments with monkeys [1, 2]. The damage was found only after Seymour Kety pointed out that his research on cerebral circulation revealed higher blood flow in the inferior colliculi than anywhere else in the brain [3].

Experiments with monkeys on asphyxia at birth were intended to produce an animal model of cerebral palsy. But monkeys subjected to asphyxia did not develop cerebral palsy. They were developmentally delayed, and the damage found in the inferior colliculi was proposed to be the cause of "minimal cerebral dysfunction" [4].

Myers was able to produce a primate model of cerebral palsy by partial obstruction of placental blood flow near the end of gestation [2].

In the first report on asphyxia at birth Ranck and Windle noted, "The human neuropathologic entity most closely resembling the effects of asphyxia neonatorum in the monkey is kernicterus" [5, p153]. The most severe damage in the brains of monkeys subjected to asphyxia at birth was in the inferior

colliculi of the auditory pathway, and auditory dysfunction is a serious problem for children afflicted with kernicterus [6].

Lucey et al. injected monkeys with bilirubin "every 6 hours from 1 to 3 hours after birth for as long as 4 days" [7, p43], and neither kernicterus nor any neurological signs were seen. Monkeys subjected to asphyxia before being made hyperbilirubinemic, developed severe neurological deficits and were found to have kernicterus. The damage caused by bilirubin staining is shown in figure 5 between pages 50 and 51. Look at especially picture F, which shows the most intense bilirubin staining in the inferior colliculus (lower left).

Damage of the inferior colliculi by bilirubin (secondary to asphyxia) should be investigated as part of the audiologic impairment and developmental language disorder in children with bilirubin-induced neurologic damage (BIND), including autism. Effects of other toxic substances that may cross the bloodbrain barrier should also be investigated.

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# NIMH #18 Bilirubin and the Blood-Brain Barrier

Hemolytic disease of the newborn, caused by maternal antibodies that cross the placenta, is the best known cause of kernicterus. However, development of RhoGAM to prevent maternal antibody formation to Rh-factor has not eradicated the problem [1]. Hansen (2000) pointed to an increase in kernicterus since 1994, which he even referred to as a new "epidemic" [2, p1156].

Zimmerman and Yannet (1933) summarized a large number of case reports and concluded that injury by anoxia or sepsis often precedes bilirubin staining of subcortical nuclei, and stated, "This differs in no way from the well known fact that any intravital dye will localize in zones of injury and will leave unstained tissues which are not damaged," [3, p757].

The blood-brain barrier normally prevents bilirubin from getting into the brain anywhere, but if breached, according to Levine et al. (1982), "Other toxic substances may also enter the brain, but they could go unnoticed if they are colorless." [4, p258]. Thus substances other than bilirubin should be looked for that could result in kernicterus-like injury of subcortical nuclei.

Kernicterus has been reported in infants with very low levels of bilirubin [5], and kernicterus was found in newborn infants following treatment with synthetic vitamin K, or with sulfisoxazole antibiotic [6].

Factors that might trigger breakdown of the blood-brain barrier should be looked for as the real cause of kernicterus.

Lucey et al. (1964) injected monkeys with bilirubin "every 6 hours from 1 to 3 hours after birth for as long as 4 days" [7, p43], and neither kernicterus nor any neurological signs were seen. Monkeys subjected to asphyxia before being made hyperbilirubinemic, developed severe neurological deficits and were found to have kernicterus. Lou et al. (1977, 1979) also demonstrated entry of Evans blue dye into the brains of fetal sheep, but only after breakdown of the blood-brain barrier by asphyxia [8, 9].

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#### NIMH #19 Repetitive Movement Disorder in Autism

Choreo-athetoid movement disorder in kernicterus is the result of damage in the basal ganglia [1]. Motor "mannerisms" in children with autism also reflect impairment of the basal ganglia [2-4]. The basal ganglia are (slightly less than the inferior colliculus) among the rank order of the metabolically most active sites in the brain [5, 6].

Brainstem damage, with involvement of the basal ganglia, has been reported in neuropathological studies of human infants who died at birth [7-14]. Variability in sites of damage from case to case should be considered as explanations of the variability of the neurological signs both in kernicterus and the spectrum of autistic disorders.

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# **Pictures of the Brain**

(illustrating comments submitted for the IACC meeting to be held July 19, 2016)

Damage of the inferior colliculi caused by asphyxia at birth - 2 & 3

Damage of the inferior colliculi in a human infant - 4

High blood flow in the inferior colliculi - 5

High blood flow in the inferior colliculi in an fMRI scan - 6

Bilirubin staining occurred only in monkeys subjected to asphyxia at birth - 7

Early myelination of the inferior colliculi - 8

Diagrams of the brain and auditory pathway - 9 & 10

Brain maturation from prenatal life to age 30 - 11

Damage of the inferior colliculi in a monkey subjected to asphyxia at birth (Windle 1969)



Damage to the inferior colliculus in a monkey subjected to a brief period of asphyxia at birth and sacrificed at five years of age.



Appearance of the inferior colliculus in the brain of a normal monkey of the same age

Windle, W. F. (1969). Brain damage by asphyxia at birth. *Scientific American*, *221*(#4): 76-84.

Damage of the inferior colliculi in a monkey subjected to asphyxia at birth (Myers 1972)



Myers RE (1972) Two patterns of perinatal brain damage and their conditions of occurrence. *American Journal of Obstetrics and Gynecology* 112:246-276. Damage of the inferior colliculi in a human infant (bottom)



Leech RW, Alvord EC (1977) Anoxic-ischemic encephalopathy in the human neonatal period, the significance of brain stem involvement. *Archives of Neurology* 34:109-113. Blood flow is higher in the inferior colliculus than anywhere else in the brain



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

#### Human fMRI images show the inferior colliculi (IC) as tiny bright dots

(Note, the MGB are the medial geniculate bodies of the thalamus that relay sounds to the temporal lobes, the large bright areas)



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

Note: Dr. Budd contacted me after finding my website, conradsimon.org, searching on the internet for any explanation he could find for high blood flow in the IC.

# **Bilirubin Staining**

Bilirubin was found only in subcortical nuclei of high blood flow and metabolism, and only in monkeys subjected to asphyxia. Note intense staining in the inferior colliculi (lower left).



Lucey JF et al. Kernicterus in asphyxiated newborn monkeys. Exp Neurol 1964 Jan; 9(1):43-58.

# Myelin in the brainstem at 25 gestational weeks (gw)

SCol superior colliculus, ICol inferior colliculus TzB trapezoid body, SOl superior olive



Yakovlev, P. I. & Lecours, A.-R. (1967). The myelogenetic cycles of regional maturation of the brain. In A. Minkowski (Ed.), *Regional Development of the Brain in Early Life* (pp. 3-70). Oxford: Blackwell Scientific Publications.

Diagram of the brain, side view



From my website, conradsimon.org

Diagram of the auditory system



Simon EN (1975) *Long-term Effects of Neonatal Asphyxia in the Rat*. Doctoral Dissertation, Boston University, Boston MA, 1974, 193 pp. University Microfilms, Ann Arbor MI. Order No. 7505520. Available online at http://www.umi.com/umi/dissertations/ or http://wwwlib.umi.com/dxweb/gateway.


## Brain maturation continues through the first 3 decades of life

Yakovlev, P. I. & Lecours, A.-R. (1967). The myelogenetic cycles of regional maturation of the brain. In A. Minkowski (Ed.), *Regional Development of the Brain in Early Life* (pp. 3-70). Oxford: Blackwell Scientific Publications.

#### Comments on Respiration, for the IACC meeting on July 19, 2016

The biochemistry of respiration is clearly not part of common knowledge. It should be for at least two reasons:

- (1) How is respiration transferred from placenta to the lungs at birth?
- (2) Why is hypoxia different from asphyxia?

## Hemoglobin

As an undergraduate student, I was inspired by my chemistry teacher's explanation of hemoglobin as one of nature's most elegant mechanisms in support of life in multi-cellular organisms. In graduate

school (in the 1970s) we used White, Handler and Smith's textbook of biochemistry. Following is a description in this book (which cannot be improved upon) of the function and importance of hemoglobin:

"Primitive organisms rely on diffusion through their environmental media to provide the oxygen needed for their metabolism and to remove the carbon dioxide produced.

The active metabolism of mammalian tissues remote from the atmosphere is possible because of a mechanism which provides constant delivery of oxygen and removal of carbon dioxide. The magnitude of this task may be appreciated from the fact that a man oxidizing 3000 Cal. Of mixed food per day uses about 600 liters of oxygen (27 moles) and produces about 480 liters of carbon dioxide (22 moles).

Through the action of hemoglobin, oxygen is abstracted from the air, carried within a few seconds to the most distant parts of the body, and delivered to the tissues at a pressure only slightly less than that which it existed in the atmosphere.

The CO<sub>2</sub> produced daily by the tissues becomes  $H_2CO_3$ , an acid, in an amount equivalent to 2 liters of concentrated hydrochloric acid; yet all this acid normally pours from the tissues, through the blood, and out of the lungs with a change in the pH of blood of no more than few hundredths of a pH unit. " [White, Handler & Smith, p758 -- Chapter 32. Chemistry of Respiration]

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#### **Respiration at birth**

No one would suggest clamping the umbilical cord before birth. A tight cord around the neck is considered dangerous. What then is the logic that clamping the cord within seconds after birth is safe?

After birth un-oxygenated (blue) blood continues to be pumped to the placenta through the umbilical arteries. Pulsations of the umbilical cord continue until the fetal heart valves close and blood is redirected to the pulmonary artery. Traditional textbooks taught that pulsations of the cord should cease before tying or clamping it. Termination of blood flow is easier with a surgical clamp than a tying it with a string. But clamping the cord does not magically open the pulmonary artery.

Pulmonary respiration begins with blood filling the capillaries around the alveoli. This causes expansion of the alveoli. Hemoglobin reaching the alveoli is saturated with carbon dioxide, which is then released in exchange for oxygen. The first breath is likely preceded by an initial exhalation. Respiration (oxygen, in exchange for carbon dioxide) via the placenta must continue until the alveoli are fully able to take over this function.

In a previous comment I submitted for this meeting (NIMH #10) I described the research of Jäykkä, and its discussion by Mercer & Skovgaard [1, 2]. Jäykkä discovered that ventilation of un-inflated lungs (from

stillborn infants) produced only patchy opening of alveoli, and only those nearest the bronchial airway. Injecting India ink into the pulmonary artery led to "erection" of the alveoli throughout the lungs. Thus opening of the alveoli is also aided by the mechanical force of fluid (blood or india ink).

Ventilation has been the recent focus of newborn resuscitation [3, 4]. How can the understanding and teaching of the past have become so disregarded? Allowing full transfer of placental blood to the newborn lungs should be the priority.

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## Hypoxia versus asphyxia

The different effects of brief asphyxia and prolonged hypoxia are the result of how oxygen and carbon dioxide interact with hemoglobin. Hemoglobin delivers carbon dioxide to the placenta, then after birth to be exhaled from the lungs, in exchange for oxygen to be delivered to all organs of the body.

The mechanism of oxygen uptake and release were determined in experiments performed by C Bohr, and published in a seminal paper in 1904.

Oxygen is received from hemoglobin, in exchange for carbon dioxide [1, 2]. Highest blood flow to the inferior colliculi is a response to its highest rate of aerobic metabolism, thus highest production of carbon dioxide. During a period of oxygen insufficiency (or hypoxia), after the inferior colliculi force oxygen off of hemoglobin, less (or none) will remain for distribution to metabolically less active areas of the brain. The cerebral cortex will then be damaged.

The inferior colliculi are small, and their damage by sub-lethal asphyxia at birth was almost missed. Brainstem centers that control breathing and heart rate are even smaller, but likely even more metabolically active than the inferior colliculi. Under conditions of insufficient oxygen, these vital centers will also be spared.

#### REFERENCES

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#### Science is important

I have seen eyes roll when I appear at IACC meetings. I am sorry to be regarded as silly. But I am planning to attend the meeting on July 19, and present a Gettysburg Address length summary (3 minutes) of what I have submitted as written comments since the meeting in January.

The past year has been extremely difficult for my 53-year old son. This has been a large part of my anxiety-driven efforts to be heard. My son's physical health has suffered greatly from his frequent "leaves of absence" from his group home. The Department of Mental Health in Massachusetts (DMH) is broken. This has been the focus of an ongoing series in the Boston Globe newspaper, which describes exactly what we have faced trying to have my son evaluated in hospital emergency rooms.

The legacy of Dorothea Dix, the state hospital system, has been demolished, in large part through the efforts of psychiatric-illness imposters, the Mental Patients' Liberation Front. How does a group like this become so powerful, and completely defeat advances in science?

Ongoing disregard for science in understanding autism is most distressing. I have worked hard over the past 50+ years to understand what caused my first two son's disabilities. Why should that be so contemptible? Why can't my ideas be discussed at IACC meetings?

I went back to school, and with full funding from the NIMH obtained a PhD in biochemistry. With four children, I could not manage lab work, so returned to my earlier career as a software engineer. My understanding of circuits in the brain derives more from my experience programming interrupt trap software than from biochemistry and neuroscience.

For 13 years (since 2003) I have been attending IACC meetings, trying to participate in the conversation on brain impairments, and reasons for the increasing prevalence of severe disabling autism. My ideas could be wrong. If so explain my error.

I wish I understood how the neurodiversity movement has meanwhile come to be so well regarded. How do their goals contribute to understanding the serious life-span problems of people like my son? He needs help, not wishy-washy ideas about acceptance.

I want to see more effort put into neurological research, and how the brain can be injured during prenatal life, at birth, and during the neonatal period. Autism diagnosed in early childhood should be the focus of the IACC. I will continue to take this stand.

## **Bobbie Rahill**

I just wanted to let people know that the dsm 5 is so off my son who was diagnosed pdd nos under dsm 4 now 1 day he us on spectrum and the next he isn't so what help I can get for him varys on weather or not he is showing on the spectrum

#### Anonymous

Dear Dr. Daniels and Members of the IACC,

My wife and I both work as professionals in a university setting. Just prior to his third birthday our first child, a son, was diagnosed with an autism spectrum disorder. Prior to the diagnosis he was evaluated by a team of professionals with vast experience in evaluating young children suspected of having an autism spectrum disorder. The evaluation occurred approximately one month prior to his third birthday. We were told that his condition was severe. In particular, his overall language skills were evaluated as being at an age equivalent level below 24 months and he had similar deficits in other areas.

Around the time of the diagnosis I started to read both the popular and academic literatures on autism spectrum disorders. I had no prior knowledge of either literature. After just a little bit of reading I realized that I had grown up with a mild case of Asperger's Syndrome which I eventually grew out of as I got older. I also noted that our son had exhibited no developmental problems before a second child was born a few months earlier. At the time our second child was born there were significant changes in our son's family environment – much more television and much less parental attention. Another change was that after our second child was born our son got significantly less sleep.

I quickly developed a conjecture. My conjecture was that our son and I had similar genetics and that our son's severe deficits were due to an interaction between his genetics and the changes in the family environment after our second child was born. I also speculated that, since these deficits had developed over just a few months, the deficits could be eliminated if the changes in the family environment were reversed. I shared my ideas with the Psychologist who led the evaluation team. She told me in no uncertain terms that my ideas had no validity and that, although treatment might reduce the severity of his condition, his potential for improvement was quite limited.

I proceeded to look more at the academic literature to see on what basis she was so certain I was wrong. I found nothing in the literature to justify her certainty and I thus decided to ignore what she said. The result is that my son's life changed radically starting about three days after the official diagnosis. First, we turned off the television. Second, I dedicated my life for the next few months to helping him (I explained the situation to my bosses and they gave me the needed flexibility to do this). The result is that he had one-on-one adult attention from the time he woke up to the time he went to sleep every day for the following six months. The adult attention consisted of either me or my wife (mostly me because my wife was taking care of our infant daughter), various therapists (ABA, speech), and adults at a special pre-school he started attending approximately a month after the initial diagnosis.

The result of all these changes was rapid progress. Six months after the initial evaluation when he was 3 years and 5 months old he was assessed as having few language delays. In particular, he was given the Clinical Evaluation of Language Fundamentals – Preschool Test (CELF-Preschool) and his total language score was at an age equivalent of 4 years and 1 month. He did, however, still have significant articulation problems at that point in time and other non-language related deficits.

At that point I decided he was on the road to a full recovery and so I cut down how much time I was spending with him so that I could catch up on my professional responsibilities, but everything else continued including no television. He continued to show progress and by his sixth birthday he was judged to have fully recovered. Around the time of his sixth birthday a well-known autism expert who saw our son a number of times between the ages of 3 and 6 wrote "...has done remarkably well and is

appropriately served at this time with services for a youngster with pragmatic language needs. I am very pleased at the presence of an apparently typical social reciprocity, absence of obsession and stereotyped behavior, and resolution of early symptoms...I am extraordinarily pleased with his progress and follow-up can be as needed. The parents understand that with increased social demands in the future, it is certainly possible that some social differences may be evident that may require social language interventions. However, at this time, I would not anticipate significant difficulty given his dramatic progress." During the same time period the Chairperson of the Committee on Special Education in our school district wrote "...After careful consideration and review, the Committee has recommended that your child no longer meets the criteria to be classified as a student with a disability and does not require special education at this time." All this occurred a few years ago and our son continues to do well (lots of friends, multiple sports teams, high grades) and he shows no signs of behaviors associated with the autism spectrum.

In addition to my own experiences with our son, I am familiar with a number of other cases in which a child diagnosed with an autism spectrum disorder showed rapid improvement after television was eliminated and parental interaction was increased. Based on this and the recent publication in the journal *Medical Hypotheses* by Drs. Heffler and Oestreicher that puts forth a very plausible theory for how early exposure to electronic screen media could serve as a trigger for autism, I think it is very likely that early childhood television watching is a trigger for autism for genetically vulnerable children and that its removal has important positive effects on treatment outcomes. I thus feel it is of vital importance that the autism medical community begin to seriously investigate these possibilities.

Sincerely,

A Concerned Parent

#### Jim West

To the pertinent IACC constituents,

I would like to present the fact that most modern science already proves beyond doubt that ultrasound is the primary initiator for ASD.

The science is already in, conclusive for ultrasound.

I spent 2 years researching for a book on the topic, looking for irrefutable HUMAN STUDIES. I found 50 modern studies, high-tech, dose/response, *prenatal* studies. Now I have 3 years research, since 2013.

All ultrasound exposure causes fetal damage. I then present a Synergy Model, as ultrasound creates permanent increase in cell membrane permeability. It creates heritable cellular and hormonal damage. Empirically determined facts. 2,700 maternal-fetal pairs studied in total.

See details of research:

Ultrasound: A New Bibliography http://harvoa.org/chs/pr/pr\_details.htm

Regards,

Jim West New York, NY

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

#### Lori Frome

July 19, 2016

Hello,

My name is Lori Frome and I am writing to you as a concerned mother and early interventionist who specializes in helping children and families affected by Autism Spectrum Disorder. In February 2015, when my son was 3 1/2 years old, he received an ASD diagnosis after he was evaluated with ADOS and other standardized measures. I would like to share his story so you can understand the changes in his environment that I believe have greatly benefited him and rapidly changed his developmental trajectory for the better. I have also witnessed these same environmental changes help many other young children with ASD diagnoses whom I service in Early Intervention and I am bringing this to your attention as I feel it would be negligent not to let the committee know what is happening.

To build background, I will share some information about what occurred early in my son's life. Our son; [PII redacted] was born at a tumultuous time in my life as I suffered a horrible bout of postpartum depression after his birth. While coping with the PPD, I placed him in front of the television for about 3-5 hours a day just to survive daily life with three young children. As I felt better when he was 9 months old, I tried taking him away from the television, but he would fuss and scream until I either nursed him to calm him or put him back in front of the screen.

As [PII redacted] grew, he showed a delayed pattern of development very early, and began physical therapy within the first months of life for low tone, and then began speech services for expressive and receptive language deficits at 15 months of age. At 30 months, [PII redacted] began to show many sensory seeking behaviors that lead to perseveration and isolation such as repetitive spinning. He would often spin and use his peripheral vision to look behind him while he scripted from one of his favorite movies as he spun around in circles in isolation for long amounts of time. He also began to use echolalia and would repeat the last word he would hear others say to him. We were becoming more and more concerned by his behavior and it was at this time that we began to grow more suspicious of ASD. Because of our feelings that [PII redacted] was showing many of the red flags for ASD, we removed all screen media; television, DVD, tablet, and smart phones from his view due to an experience I had with a child whom I serviced a year prior.

This child was 2.5 years old and had documented red flags for ASD which included minimal eye contact, lack of response to name, few spoken words, lining up of objects, and isolated and repetitive play. He would often stare blankly out the window or at the wall. This child consumed 6 hours of screen time a day per parent report as the family thought it would help him learn language and academics. It was shortly after recommending to the family that he be officially tested for ASD that they decided to remove screens from his view as they felt that he was more interactive with them when the TV, DVD's and tablet were not on.

This child's mother replaced his screen time with reading, craft experiences with tactile media such as play dough and paint, and registered him for swim lessons and other extra-curricular activities with typical developing children his age. The family also removed several computer and light-up toys and replaced them with a ball pit, tricycle, and other developmentally appropriate toys and games. In my professional opinion and those of others, the child quickly transformed and followed a steady path away from a trajectory exhibiting the core features of ASD to that of a child only exhibiting a language delay in

just 6 months time, and then was discharged from all services only 18 months after his parent's removed screen media from his view. This child's rapid progress had always fascinated me, as it was like nothing I had ever witnessed and I prayed that I could have these same results occur in my own son.

So on January 2015, we turned off the viewing of screens for [PII redacted] and focused on intense social interaction with him in the same way as the child I had witnessed. I had always done these activities with him, but they did not have the same impact they had once the electronic screen media was removed. It is with abundant joy that I am able to share that this same type of trajectory change occurred for him as well. Within 9 months he presented with only a language delay, and no longer exhibited the core features of ASD per being retested with ADOS. Now, just 20 months after screen removal, he has been released of all therapies. Just last January, before removing screens, my son was receiving 2 sessions of occupational therapy, 3 sessions of speech, 1 session of physical therapy, and 1 session of therapy with a special instructor weekly. Within 6 months of this screen free socially interactive therapy that I began with him, he was only receiving speech 1 time a week and OT and PT were both discharged due to lack of necessity. This has been a rapid and dramatic change that we have never seen at any other time in his life despite his many therapies and I feel that it is significantly related to and an intense focus on social interaction and just being with him for a great part of his day and involving him in our day.

I'm writing to you today with a sense of urgency to encourage research in this area, as I have recommended these same strategies of electronic screen removal paired with intense social interaction provided by the parent or caregiver to many of the families of young children with ASD. All of the families that have tried this are seeing similar rapid and positive results, including their children wanting to be physically closer to them, using greater eye contact and joint attention, improvement in social reciprocity, decrease in sensory sensitivities and seeking behaviors, and an overall trajectory change that leads to more typical development and milestones being met in a developmentally systematic way instead of scattered skills and patterns of development. I thank you for your time and would be more than willing to answer any questions that could help your understanding of the contents of this letter.

Thank you,

Lori Frome

#### **Matthew Carey**

Dear IACC members,

In a previous comment I mentioned this study: Premature mortality in autism spectrum disorder (<u>http://bjp.rcpsych.org/content/208/3/232</u>).

One thing I know is that it is most helpful when a comment suggests actual actions to take, not just a call for action. Yes, I called for a rebalance of the Strategic Plan to include more emphasis on autistic adults. But what specifically could we be doing?

First off, we could use studies (plural) on how autistic adults are faring. A lot of attention was given to the "Optimal Outcomes" study on autistic children a few years ago. We need to see what sort of living conditions and supports have led to "optimal outcomes" in adults. It is so obvious as to sound sarcastic, but being alive is an "optimal outcome". It isn't everything, though. Autistics without intellectual disability commit suicide 9 times more often than non autistics. This means that a large fraction of adult autistics are contemplating suicide, maybe even to the point of failed attempts.

In discussing this paper, an adult autistic pointed something out to me I hadn't considered: some behavior we see in autistics with intellectual disability might be suicide attempts. For example, wandering. A great deal of attention has been focused on wandering, but relatively little on the motivation behind wandering. I'm not saying that wandering is often a suicide attempt, but we need to understand why autistics behave in the ways they do. We need to accept that autistics with intellectual disability and communication challenges can and do have many of the motivations that non disabled people do. And we need to accept that wandering, as just one example, is not just an issue with children.

We need to study adult autistics with self-injurious behavior and aggression. Again, with a goal as to understand "why", not just report on what fraction of the population exhibit these behaviors.

If we understand the "why", we can build the needed supports. By this, I mean we can understand how to help an autistic while respecting the individual. Too often the approach is, "this is an autistic behavior, we need to find a way to eliminate this autistic behavior." Suicide is not an autistic behavior.

"We", by the way, is all of us. Autistics and non autistics. Too often "we" is used in a context of "we" as in "we non autistics" talking about "those who are not we, the autistics". Even when studies focus on the needs of autistics with intellectual disability or limited verbal communication, involving autistic adults without these challenges is important. All too often the contribution from this segment of our community is either neglected or outright dismissed. Some of the strongest advocates I know for all on the spectrum are adult autistics. And the perspectives can be key. I know autistics who have been nonverbal children, been institutionalized, still have limited or no verbal communication. You non autistics on the IACC need only to look around the table during each meeting to see dedicated selfadvocates who, while they have different challenges, are great allies to children like mine.

The power of the Strategic Plan is in the specific goals and specific research projects that it calls for. When a new Plan is drafted, I don't want to see just a discussion of "we recognize the importance of research on adults". I want to see actual, specific projects recommended, with estimated budgets. And for emphasis, projects/budgets are plural. We need many. Respectfully Submitted,

Matthew J. Carey

#### Lisa Henderson

There need to be more services for adults like there are for children with autism. Many low functioning adults are left with zero recreational or therapeutic or educational activities once they age out of the school system . There are also very very few if any supervised safe living options for these same adults. When the parents die what will will happen to these low functioning adults with autism who are not capable of working but need things to do and places to go during the day?

#### **Kevin Wheat**

It is now past time to recognize the cause of autism. Please push congress to do an independent study, with trusted people running it, that compares unvaccinated to vaccinated populations. This one study will undoubtedly prove what we already know. Then we will be ready to find out much more such as genetic variances, treatment protocols, and most importantly prevention. Thank you.

#### **Lorraine La Pointe**

I can't speak from a researchers point of view but as a mom of an adult son with middle spectrum autism (graduated with cert if attendance language fluency problems and stims), I can tell you that he enjoys his group home his competitive eage jib at Walgreens and another at a place that does doors for new construction, attends a cooking class and a spin class and goes to two camps every summer.

I was fortunate to live in Chapel Hill and thankful to have met Eric Schopler and put his ideas to work.

I started with life skill goals in elementary school it is too late if you wait till HS to start.

I never made more than 10 IEP goals and most of them were consumer oriented and of these 10 we were working on 6-7 at home.

I am happy to say because if a great village of people he is able to use a debit card calculate his balances, shop and know when something is on sale, do laundry, get himself up In the morning and get ready for work, ride the buses around town, participates in his church, flues in airplanes solo.

He has a full life but none of that would have been possible if we didn't start as early as we did.

John Thomas who worked at TEACCH told me every child needs a chore per year of life. Chires are the building blocks to jobs...He was so right...

#### Sheila Stauffer

My son was supposed to be integrated into a residential home after H.S. His father went for guardianship so he could take the money from S.S.I and now my son sits at home doing nothing. No program or work. He is depressed and suicidal. I am concerned but I have no money for attorney. I worry about his welfare and what might happen if and when his father passes. Nothing is being done about his employment or future housing or community integration. The courts and attorneys both ignorant on these issues and look at who makes more money and when the case is over nothing is looked at for review. I am concerned and need help for advocacy for my son. Thank you

#### Dr. Susan M. Whitefeather

Autism does not go away after age 18. I spent the past year trying to find professional training for working with adults with Autism. It appears that all of the effort (and money) are concentrated in the schools and on kids and teens. That leaves adult service providers "out in the cold".

One severe problem is the total lack of training for professionals. I have been a mental health clinician for over 35 years. I never heard the word Autism in graduate school. All of the available training seems concentrated on children and teens. I work with adults. Last June I started a search for training focused on adults with Autism, and never found any. This is a serious problem.

## Toni Means

Peoe on the spectrum are so misunderstood in this country and there is not enough being done to educate the general population. This, should begin in the elementary schools, and continue through high school and secondary schools.

#### Gwen F. Wise

I have tried unsuccessfully for many months making phone calls, writing emails to try to get information about Ohio 's Interagency Autism Workgroup. By Ohio Revised Code this group of state agencies meet monthly behind closed doors. No minutes are taken or shared with the public. It is impossible to receive information or participate. I think this makes a mockery of community participation. Ohio receives a lot of federal monies for autism. This is a disgrace.

The State of Ohio receives federal monies. I just wanted to make you aware that in the State of Ohio the public, families and individuals with ASD, do not have access to the state interagency workgroup on autism. Perhaps the IACC can look at community participation and suggest a model for states to include the public. Because state policies, programs, rules and regulations will have a HUGE impact on the lives of our loved ones with autism.

Thank you, Gwen F. Wise

## Daphne Phillips

Please subpoena Dr.William Thompson. Parents of vaccine injured children want to hear the truth.

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

#### Anthony DeJerolme

#### July 19, 2016

FI don't know if you can help with a serious matter that we are dealing with, or if this is the right site. We have a 26 year old son who is in the Autism Spectrum/Aspergers Syndrome. On April 1, 2015 Deputies from the Stafford County Sheriff's Department came to our home with a search warrant for child porn. They took computers talked to our son and left. At the time the detective said that since everything went over our son's head he might just get some counseling.

Over a year later on April, 15, 2016, I had to bring my son to the Sheriffs office. He was indicted by a grand jury for downloading child porn.

He was incarcerated in the Rappahannock jail and we were on permitted to see him until six days later at bond hearing No bond was originally placed on him.

[PII redacted] as we call him has always been with either my wife or myself since birth. He is our grandson who we later adopted. He has extensive medical problems including Aspergers, Organic brain syndrome and many more. He has the maturity of about a 12 year old.

The Commonwealth attorney here in Stafford, Virginia apparently has no training with the Autism Spectrum and is believd by us to think it is not real.

We were able to get him out on bond on the 20th of April. His mental and physical health has deteriorated since each day awaiting trial. Even supplying the Commonwealth Attorney with documentation from Psychologist, Neurologists and other doctors, he has disregarded them.

This is very important to note that on his bond hearing, the Assistant Commonwealth attorney made a statement that "The Autism Spectrum and Aspergers is a smokescreen". Just reviewing the court transcript, his statement is missing. I have contacted the company that does the court reporting and have not heard back yet.

THIS A BATTLE TO SAVE OUR SON, A HELPLESS HUMAN BEING WHO CANNOT DEFEND HIMSELF FROM A PROSECUTOR WHO DOES NOT SEEK JUSTICE, BUT TO PERSECUTE AND INDIVIDUAL WITH A DISABILITY. THE SAME PROSECUTOR SENTENCE A BLACK YOUNG MAN WITH AUTISM TO TEN YEARS IN PRISON FOR ASSAULTING A DEPUTY. THE YOUNG MAN LATER PARDONED AFTER THREE YEARS BY THE GOVERNOR, AFTER MUCH PRESSURE BY THE AUTISM COMMUNITY.

I WOULD ASK YOU TO VISIT MY FACEBOOK PAGE UNDER (ANTHONY DEJEROLME) AND SCROLL DOWN TO THE BEGINNING. WE ARE COMMITTED TO KEEP WORKING ONCE WE FIND PEACE AND FREEDOM FOR OUR SON.

EVEN BEFORE A VERDICT IS RENDERED, WE ARE BEING PUNISHED.

ADVISE TO ALL PARENTS WITH A CHILD LIKE [PII redacted]. KEEP ALL OF YOUR IEP INFORMATION AND GET YEARLY DOCUMENTATION. YOU WILL NEED THEM IF YOU HAVE OUR NIGHTMARE.

## Laura Regalado

## July 19, 2016

Adults w/ Autism should be given employment opportunities in all fields. They can benefit from job modifications to fit their specific talent or ability. Employment opportunities such as office, technology, law enforcement/fire fighter/EMT ect., in political offices plus many more. No more maintenance only or bus boy jobs.

#### **Nathaniel Geyer**

As an adult who was diagnosed with an autism spectrum disorder (ASD) and a current Doctorate student, I am greatly impressed that the federal government is taking an interest in attempting to assist those with an ASD. I would be very interested in having the department recruit adults with ASDs to serve as mentors for successful integration in to medical care. I was diagnosed in 1990s when the disorder was first being documented and was not a candidate for ABA. However, I learned to socialize by having a strong supportive network of mentors, friends, and family. Additionally, as an child I was very active in social groups, such as choir, boy scouts, church, and after school activities. My concerns are that ASDs is not a one size issue fits all but rather a spectrum disorder that should be taught social skills, self-advocacy, and focused on setting reasonable and achievable goals. These learned characteristics are some of the reasons why I was able to graduate with a high GPA in both high school, undergraduate, and graduate schools. Unfortunately, there are confounding influences that lead to a poor quality of life, based on related experiences with other people who are on the spectrum who are friends:

Housing-many ASDs currently live with relatives and experience difficulty in living independently
Transportation-many ASDs are unable to get drivers licenses and rely on other for

transportation

3. Employment-90% of adults with ASDs are unemployed or underemployed

4. Relationships-many ASDs are single and are not in a dating relationship

However, I am a strong believer of early intervention programs that depending on the child can improve quality of life as adults on the spectrum. It is important to realize that persons with ASDs are a growing minority population that does not suddenly gets cured after age 18 but rather face an uncertain future. I chose to view my diagnosis as a gift and not a curse, and have conditioned myself to think positively and to choose hope over grief. However, I know many people on the spectrum that need to be reassured that everything will be okay. I am hoping that this intervention provides hope for individuals diagnosed with an ASD.

#### **Thomas Candelario**

Hello, my son was diagnosed with Asperger's in 1997, along with a comorbidity of an anxiety disorder. He is now 30 years old. He is very good with computers and has a associates degree in information technology. Mom and dad have been very actively supporting and advocating for our son from infancy through his current age. In 2012 our home was raided by a SWAT team because our son had downloaded child porn, (which is readily available on the internet). Even though very little was/is known about high functioning autism, our son recieved good support and good advocates up until he graduated from high school. After high school there was, and still is very little support for these individuals once they graduate high school. There is a growing body of evidence that is exposing a particular neurological vulnerability for those who have high functioning autism that leads them to actually fall victim to viewing and downloading child porn. Refer to NCCJD, (National Center on Criminal Justice and Disibility). The intersection of child porn and high functioning autism is turning into a national crisis mainly because this heinous material is allowed to be viewed on the internet without regard to, not only children, but the harm it might cause to those on the spectrum. The penalties are very harsh for someone who downloads this material. Please seriously consider funding organizations such as NCCJD as this national organization is still in it's infancy and needs the support of the autism community for defending those on the spectrum who are unwittingly thown into the harsh and punitive hold of our criminal justice system. Thanks!

#### **Karen Beck Pooley**

We were very happy to see, in the interventions section, so much discussion of developing strategies and technologies to assist minimally verbal individuals with communication. ("Remaining Gaps, Needs, and Opportunities: The field of research on non-verbal patients with ASD is growing, yet still requires significant work and future investment. ASD research has historically concentrated on verbal individuals and adults, which highlights the need for increased research on minimally verbal populations.")

When I read that section to our son, who is 7 and largely non-speaking (although fluent and able to communicate by writing), he responded with "I love it! How can I help?"

So thank you for stressing the importance of that type of research and those type of tools, and sign us up...

## Isbel Gonzalez

## July 19, 2016

I am begging to continue the research for the sake to my two children & my brother. For their future & answers to future babies for other families. I would like to have help on how to help them improve & get better every day.

## **Michael Smith**

## July 19, 2016

Recycling Newspaper Or Aluminum Cans from softdrinks do research for the cans and then do a National Call to Action.

Money paid can be donated to any worth while purpose. Or do a can roundup Nationally.

## **Dwight Zahringer**

## I have a 4-½ year old moderate / severe ASD boy with tics and PANs. My statement and public request of the IACC board is fourfold:

## 1.) Speak with parents more and focus research on their feedback. There is truth in the herd.

Over the past 19 months since his official diagnosis we have invested all free time, over \$50,000 out of pocket on ABA, OT, Speech, accessories, learning aids, medical tests and vitamins. In addition to 28-32 hours a week of ABA in-home he is also attending a special education class 5 days a week, 4 hours a day. We've done the EEG's, the genetics and had over

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

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

After 6 months we've seen great results in:

- response in ABA, verbal response and cognitive
- weight loss, 10 lbs of fat
- better sleeping
- better stool
- lower heavy metals in May (by 25%)

We also noticed:

- any gluten, any sugar causes extreme aggression and yeast flare

- any "normal" produce produces foul stool, changes behavior and increases stimms

- touching and playing with fruits, or gluten items causes flares and behavior changes (gluten free putty at school now = expensive)

What I also learned:

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

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

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

# 2.) Autism is an epidemic and needs the attention from you, our Government and the media. Autism needs to be treated with as much or more urgency than the ZIKA virus.

I live in a community outside of Detroit, MI. Since I've been given the "gift" as a parent, I see ASD disorders in children more and more frequently. Recently while at a local park playground out of the 40-50 children there I came across not one other, not two, not three but four other children with moderate to severe autism.

## Why is this happning?

The prevalence of autism in U.S. children has increased from 1-150 in 2000 to 1-68 in 2015. Autism is now the fastest-growing developmental disability in the United States.

I ask, as many have - why is this not being given the attention?

## Can the IACC please answer this clearly to us parents and caregivers in the fiscal year of 2016?

# 3.) Glyphosate. What are the affects on the human brain? What are the affects on the human ASD brain?

Why would a 4-½ year old child on the spectrum whop was breast fed for two years and ate a natural, healthy diet have over 3x the normal levels of Glyphosate in his blood? We do not live near a farm, he does not work in produce, nor a processing plant.

# <u>Can the IACC to investigate how Glyphosate is affecting children with ASD vs. Non-ASD in the fiscal year</u> of 2016?

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

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

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

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

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

## **Nancy Shaw**

I am requesting that the 2004 study by Dr.'s Thompson, DeStefano, et. al, concerning the MMR and autism vaccine be retracted immediately because of the unethical fraud in compiling the statistics of this study. I am also requesting that the CDC no longer be allowed to do vaccine studies.

### **Jilene Chivell Griffiths**

Adults with ASD need job coaches out in the workplace. We need to promote and elevate these individuals, usually with a high IQ and works entry level jobs. There is a whole new set of social skills needed for these individuals at that adult stage. I'm personally advocating for my son who works as a manager now and is struggling with social communication skills he has not yet learned. Intervention for people on the Spectrum is needed at adults stages of life.20's 30's & 40's? I look for a day when there are services available in Atlanta for adults with autism.

#### Jame Tillman

...I am here and now asking you to put away the conflicting myths that have run rampant through the scientific and medical industries regarding the cause(s) and/or remedies applied to the Asperger Spectrum of Disorders.

...We must seek practicle solutionss and open our eyes and minds to first (define and)find the "real" or true root-cause and second treat those inflicted with the proper procedural means at our disposal.

...I have made the above mentioned declaration my mission for the rest of my living years; I emphatically denounce all other "proofs" in stating that auto-immune neurological deficiencies in children starts with the 'sudden changes' in ones environment.

...I have thus far been made an otherwise distracting irritant and this supposed "nuisance" have struck a cord with those who've sought to gain financially from such deceptive practices.

...This being my 21st year in developmental research it has become clear to me that Autism, Downs Syndrome, Turretts, and even Schizophrenia are the side effects of gradual increasage of electromagnetic devices introduced in our society and the dramatic proliferation of its usage from the 1940's up til now.

...Pregnant women started out with short-band/short wave(A.M) radio, then onto Frequency-Modulation(FM) and later Transistor or Citizenz Band(CB radio) until the Cellular communicator(FRS)or Two-Way along with Television was born(UHF/VHF); which produced his son the Beta Video Transmission beside the MicroWave and the grand-chidren of Computer Desktop Terminals, Cordless Landline Phones, Fax/Facsimile, Digital Video Photography, WireLess Headphones and Transmittetrs up until we reach the digital world of networks and artificial intelligence devices we(or rather SHE) comes in contact every moment of the day(like the handheld SmartPhone being one example).

...I must say it took me years of trial and error but I am convinced(as I have proven by my technique)that what I have produced is the ONLY plan in existence that can be truely called a "means to a cure" for most cognitive abnormalities in the brains of toddlers borne with the weight of these disorders we struggle to understand and manage.

...E.C.Q.L. is a step by step therapeutic activity that combines restrictions and demands to both environments and diets along with structured guidelines on habits and interactions of which such patterns become "the new blue-print" for a healthy way of thinking. This "wheel" is the very key to my success in many clients(when reached at an early stage) ...I will not write further regarding this project or its algorithmic methods, theoretical practises,or scientific nor medical hypothetical conclusions without serious discussions among committed individuals and/or institutions seeking to honestly show interest in irradicating once and for all these diagnosis of embalanced neurons(caused by micro-wave) and chemical changes(exacerbated by too-early childhood immunizations) in the brain of our babies. ...Childhood immunizations after age 5 is highly recommended along with limited electro-magnetic interference(CAtScAN,x-Rays,etc.)while in the first tri-mester of pregnancy.

...COUNCSAUTISTICO.Org....Thanks You for the opportunity to express this my plea for help in advancing the vehicle down the road to cureus.

## **Russell Lehmann**

Hi,

My name is Russell Lehmann, I am 25-years-old and I have autism.

I have come a long, LONG way in life. 12 years ago, at the height of my distress, I was pretty much nonverbal. I was too afraid of the outside world to speak to anyone other than my parents. I stayed inside my house as much as possible, clinging to my parents? sides, terrified of any external stimuli, such as the doorbell ringing, the TV being on, or the microwave going off. I was a prisoner inside my own body. I would have multiple meltdowns every day, curling into a ball in the corner of a room, just crying for hours. I was extremely low-functioning, and could barely take care of myself.

Now, however, I am a public speaker and consultant who travels the country spreading hope, awareness and acceptance about autism. I happen to not only have autism, but anxiety, depression, OCD and a previous battle with anorexia.

I wanted to reach out to the IACC due to the fact that I have tremendous insight and experience to offer as an individual on the spectrum who has overcome so much.

I take pride in being a voice for the unheard, for I know how frustrating and challenging it is to go unnoticed. I?m honored and humbled to be able to give hope to families and parents who are concerned with their child?s future, just as my parents once were.

I am a member of the Nevada Governor's Council on Developmental Disabilities, I sit on the board for the Autism Coalition of Nevada, am the Youth Ambassador for Reno, Nevada Mayor Hillary Schieve, am affiliated with the renowned Kulture City organization which spreads awareness and acceptance about autism, and have written a book that earned an honorable mention at the NY Book Festival.

You can find much more information about me, including news stories, interviews, motivational videos, etc. at my website <u>www.theautisticpoet.com</u> and on my Facebook page <u>www.facebook.com/lehmann.russell</u>

I thank you very much for your time and I look forward to hearing back from you.

My Best, Russell

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

#### **Michael Battle**

#### July 19, 2016

I would like to stress the need for more informed businesses in regards to hiring adults on the autism spectrum. I have a 28 year old son, [PII redacted] who is educated with a B.S. In Civil Engineering from Brooklyn Polytechnic. [PII redacted] graduated in 2012 and there just weren't many job opportunities for him at that time. We lived in Brooklyn, NY for 17yrs. and always supported [PII redacted] in his dream of becoming a civil engineer. Although we as a nation experienced a recession during this period, we wondered how much [PII redacted] was affected by prospective employers' ignorance regarding individuals on the autism spectrum. [PII redacted] is on the mild autism spectrum, but does exhibit some shyness and, he also has a stutter. After several job interviews without getting hired, my wife and I began to wonder if his autism played a role in the non hirings, or was he just a small fish in a very big pond. We understand that the engineering field is very competitive, but we also believe that if given the opportunity, [PII redacted] can and will succeed! We recently relocated to the Birmingham, Alabama area, and [PII redacted] was given an opportunity with a small business (OnTime Electric Svcs.)who actively supports the autism initiatives in Alabama and elsewhere. [PII redacted] is now in charge of tool inventory for the company (a very important component of OnTime) and just received a very positive evaluation along with a pay raise. We pray that more businesses, both small and large, give autistic adults the opportunities they crave and need. They just need a chance! Thank you.

#### **Deborah Macalusa**

More activities and job or business opportunities are neede in rural areas for individuals with aspergers. My daughter is living on her own and has little contact with others unless it is her personal care workers and Me and her Dad. We are aging and medically fragile. She needs the ability to socialize without having to travel more than a half hour. Each region should have more sites if the regions are spread out and consist of multiple parishes.
## **Andrea Wherry**

It is my hope that my nation can uncover the true cause of autism spectrum disorders because millions are losing the ability to problem solve with verbal communication! Future generations will lose access to full inclusion in society due to genetic mutations that limit their development. How can a government sustain viability in our world, if it loses thousands to disability daily, while our government must commit millions to house, feed & care for our genetically injured! citizens? This committee directly impacts

# **Connie F. Burrows**

Hello,

I am an Intervention Specialist who teaches in an urban public school district that serves an evergrowing number of students who, possibly, qualify for identification/services on the Autism Spectrum. At this time in Ohio, the diagnosis for ASD must be made my a pediatrician, Intervention Assistance Team and the school psychologist (depending upon the age of the child).

Last year during a building-level meeting, our Special Education Consultant told us that Ohio is planning to re-assign the task identification children on the ASD spectrum to teachers. Personally, I find this idea not in the best interest of children and wanted and I wanted to know if this shift of responsibility is advocated by your committee and/or prevalent in other sates.

Thank you.

### Deanna Caver

Early intervention programs are vital. However, there is a need for programs that would benefit children assessed older than age 5. Programs that encourage behavior therapy, inclusion, general education & recreational activities would help make well rounded children. Although my son is 9, programs to foster independence with employment and housing is vital as well. The ability to access and have our children utilize them are scarce. More are needed.

## Michelle Patchett

### July 19, 2016

Protecting the rights of individuals on the Autism Spectrum, (especially those with intellectual delays, speech barriers or lack of having someone to care for their health and mental well being ). My daughter and I have had to learn through tragedy the truth about what really happens when you report a violent crime committed against you and you are 24 with Autism/Intellectual Delays and are your own legal guardian. After reporting a year n a half of repeated physical and sexual assaults to the local law enforcement in Arizona. My daughter and I have had to come to the devastating knowledge that law enforcement from the police officer to detective, the Police Captain all the way up to The Chief of Police and flowing into the forensic interviewers, District Attorney even the victims advocate and Family Crisis centers, therapist alike for rape and violent crimes and the Legal Court system have no knowledge on Autism, (grossly lack knowledge of Autism). There is no provision in place for the individual to protect their legal rights or to hold state officials, law enforcement and the courts responsible for up holding the law to protect all citizens from harm. How would one ever know that a language delay, slow processing time and a blank stare would for ever damage a wonderful individual with promise and potential. Or that the state of Arizona perhaps the entire USA looks way to lightly on matters of Rape and Physical Violence. Who protects the citizens on the spectrum ???? I mean really listen and respond ???? So far NO-ONE !!! Legislation has to change or be revised to meet the need of the people.

From : My title earned : Oh no, it's... " That Mom " Thank You Michelle and daughter [PII redacted].

# Patricia Robertson

Thank you for the documentary Vaxxed. Saw it last night in Edmonton AB. Had I have contacted numerous people to make sure they see it. No matter what their beliefs are. I had a client in that mentioned the movie otherwise I would not have known it was here in Edmonton. We are losing more rights here in Canada everyday and people are so complacent about it all.

# Dr. Kerry S. Lane

http://www.parentherald.com/articles/52707/20160704/pregnant-women-who-take-paracetamollinked-autism-adhd-children.htm

# Dr. Ann Z. Bauer

July 19, 2016

To the Esteemed IACC Committee,

I stood before you, in 2013, nervously making a public comment about the potential association of the use of acetaminophen (paracetamol, Tylenol) to the development of autism and ADHD. What has happened since then?

Have we done everything we could do to rule out the most common medication given to pregnant women and infants as a potential causal factor? Evidence is accumulating from other parts of the world of an association to prenatal use. This includes five prospective cohort studies, as well as, supportive findings from animal models. I implore all of you to review the research. https://www.facebook.com/AcetaminophenResearch/

Infant use remains largely uninvestigated. This could be where a strong US contribution could be made.

Ann Bauer

Ann Z. Bauer Sc.D. Post Doctoral Fellow - Children's Environmental Health University of Massachusetts Lowell [PII redacted] Lowell MA USA

# Ana Titus

Hello, I have an 8 year boy with autism. My big concern at this present time is the poor knowledge that public schools staff have in reference to autism.

My son had been abused, bullied and discriminated against the rights to a FAPE.

I had complaint but it seems like no one cares.

I not giving up because I am his voice.

He deserves an equal opportunity and to be treated with respect.

I had been fighting with the school for almost a year now and my son was ended with depression and suicidal thoughts do to all the bullying and not understanding of his needs.

He was receiving homebound services until the end of the school year, doesn't have a new placement for next year and definitely We don't want him back in the same school that caused him his present conditions.

Please help.

Thanks.

### **Brenda Klein**

I think that the biggest issue right now is for people with autism when they hit 22 years old and this needs to be addressed. At this point, they no longer qualify for any school/educational services. They will no longer get OT, PT, SLT. Regression will occur. There are no options for the families since they are hundreds or thousands of people on waiver waiting lists. Families cannot afford services on their own. Also, family members may have to quit jobs to take care of autistic adults. My biggest fear (my son is only 8 now), what do you do when the 22 year old is 250 pounds and violent/aggressive? there are no or very limited group homes to handle this and parents can't handle this also.

# Gail Elbek

To be reported to HHS Director Sylvia Burwell:

The HHS, FDA, NIH, NIEHS, NIMH, and IACC are well aware that there exist decades-worth of overwhelming amounts of reputable (NIEHS, FDA, NIH) published study evidence that concludes fetal, infant, and child neurodevelopmental exposure to endocrine disruptors can and do cause a host of adverse neurodevelopmental effects related to the cause of autism.

It is therefore past due that U.S. Health Organizations stop denying, stop publicly withholding existing mass research evidence concluding fetal, infant, and child exposure to soybean phytoestrogen endocrine disrupters, phytates, enzyme inhibitors, heavy metals, etc., etc, (in addition to GMO) are the cause of a wide range of neurodevelopmental poisoning as an established cause of innumerable adverse neurological disorders such as autism, until soy phyto-poisons can ever be proven as neurodevelopmentally safe, in accordance with U.S. food, formula, health, and child protection laws.

The falsifying of developmental exposure to soybean phyto-poisons as safe, while never FDA or NIH proven as physiologically, reproductive, or neurologically fetal, infant, or child safe is evidence of your cooperation with illegal adulteration and misbranding.

I remain hopeful for your promised moral and ethical duty to protect developmental body and brain health as your priority.

#### Dena L. Gassner, MSW

July 19, 2016

Dena L. Gassner, MSW Adelphi University Garden City, NY [PII redacted]

To Whom It May Concern:

My name is Dena Gassner and although I hold numerous board positions, I am writing today as a member of the community, I am a PhD student at Adelphi University and an autistic woman in fear for myself, my adult son who has autism and for my community.

Today I am writing to address the escalating difficulties that autistics and their families are experiencing in their interactions with TSA and airport security staff.

I realize that subjectively speaking, my disability is "invisible". As a result, I proactively prepare for travel taking full responsibility for my own needs. My strategies include: reporting that I have autism to airport staff and then TSA as I progress through the system, sharing laminated card from my doctor outlining my few needed accommodations, asking for (1) expedited screening and (2) pre-boarding privileges.

These accommodations limit my exposure to the visual and auditory stimulation of the people queuing up. Pre-boarding insures that my electronics are stored above me, reducing my anxiety about the status of the equipment. Pre-boarding also allows me extra time to gather the items I use in flight (book, headphones, gum, blanket, pillow). TSA Cares/airline disability services have been unhelpful.

These accommodations allow me to minimize the amount of energy involved with travel. The bleeding away of this energy due to poorly trained personnel diminishes my problem solving skills. I show that vulnerability on my face and this can be misunderstood by TSA, or the "lost" look could result in being victimized by others.

In the last year, I have repeatedly had my disability status questioned. I've been insulted, publicly humiliated, intentionally delayed, intentionally escalated and denied my very reasonable accommodations).

Airlines and TSA have suggested I lie and say I need a wheelchair, which I refuse to do for many ethical reasons. I've been repeatedly pressured to purchase the TSA for fee Pre-check which again, is unreasonable, and given my current student status, is cost prohibitive. Not to mention that no one should have to pay for reasonable accommodations.

I also have a physical condition and soon will need help for that as well; I am terrified having seen what happens to others who have wheelchairs that are destroyed, are left sitting on planes, and have to crawl off the planes when their chairs "disappear".

I wish I could say this was a unique experience but approximately 1 out of every 8 times I fly, something terrible happens. At this point, I can't approach Kennedy Airport without medication due to the

frequency and intensity of the trauma that happens to me there. I've written administrators, congresspersons, senators, the New York Times and TSA with no response.

The failure of TSA and airport administrators to properly and meaningfully equip their personnel to meet the needs of autistic families places individuals and families at risk.

My suggestion is that IACC enter into discussions with TSA about these issues and possibly suggest a special card that would be a no-fee alternative to the current pre-check program. I have one for New York City transit and there's no reason why we should be placed at risk.

I'm sure many of you are familiar with the recent story about Hannah Cohen, a 19 year old cancer patient who became overwhelmed with the security process and despite her mother repeatedly telling agents she was distressed and disabled, she was slammed to the floor and bloodied by the agents. Their response was that the family should have called ahead. Under the law, that is not required. This could have been me, or worse, my son.

The lack of accessibility with TSA has been an ongoing conversation by self-advocates and families nationwide. The Arc and the Autism Society have done incredible work with families to help them be more effectively prepared to cope with security but there seems to be only a small number of agents receiving training. The few kindnesses I've enjoyed have come from employees who live autism in their personal life; accommodation should not be a Roulette wheel of randomness.

Please note that this training should be provided not only with TSA personnel, but the contract security personnel and airport first responders. These issues place families and individuals at risk, limit quality of life and create isolation and disenfranchisement. For me, it is jeopardizing employment opportunities.

Please respond to this substantial need.

Dena L. Gassner, MSW PhD Student Social Welfare Adelphi University National Board Member Arc US National Board Member GRASP National Advisory Board Member Autism Society

## Meg Oberreuter

July 19, 2016

Dear Committee members,

From my standpoint of reading reviews of the workings of the IACC work it does not seem to be going anywhere near the direction of looking at the causes and treatments of ASD and its related disorders, ie vaccines, seizures, allergies, GI issues, etc, that plague many of our children and adults. I see a huge amount of money spent on chasing the elusive autism gene(s) to no real benefit. It is a huge multi gene complex overlap with the environment triggers. Everyone can fall under the diagnosis if they have an environmental insult that the body is not able to overcome.

I have a 36 yr old son with classical autism, onset when a few months old, knew he had problems by one year of age, first hearing test at 9 months, late on physical and social milestones. I have been around and active in the ASD world for over three decades. We do not get ANY better answers now than we got as new parents over 35 yrs ago. Please get independent folks to run this group, you cannot stay under the thumb of Big Government, Big Medicine, Big Pharma, etc. You have too much political capital to get independent oversight. There is a CDC WhisIteblower, Dr William Thompson, still at CDC, who has come forward and reports destruction of research data, manipulation of date for predicted outcome, changing of research criteria to hide the real evidence. He has federal protection and has yet, almost two years later, been called before Congress, why not? They are afraid to face the results. The movie VAXXED From Cover Up to Catastrophe is being seen across the nation and we will have thousands of more parents and professionals banning together to get vaccine reform. The whole program must be stopped until we get unbiased independent research into side effects and ingredients of the vaccine contents. We have the sickest generation of children, who will not outlive their parents generation for longevity, they have such compromising medical conditions already.

I have many more examples if you want more information, please contact me.

Meg Oberreuter Cedar Rapids, IA [PII redacted]

### **Carol J. Fruscella**

To the Members of the IACC Panel,

You have a new issue.

A parent that has written this group in the past, has now past away.

She literally wore herself down to the core.

She had a massive Heart Attack and she died.

She was only 61 years old.

Her son on the spectrum is 22 years old. He will more than likely need help for the rest of his lifetime.

Her husband had just been laid off from work.

There are few, to little, to no resources for this family to pull from.

There is was no savings account for this rainy day. When you live and care for severe autism daily, it rains non stop.

This family lost their home a few years ago.

Their medical bills and sons needs were more important than the mortgage.

There is not ONE place for us to call Nationally nor Locally to help this family at this moment.

What we HAVE is a network of Private non profits STARTED by other exhausted Autism Parents that MIGHT be able to help.

You failed to help this family. You are failing all parents as we watch ourselves and our children, who are now adults age daily. We do the math in our heads. If I pass at the same age as my friend just did, as I use the rate of my county placement average ( for those that are currently ON the list ) it will be 11 years, AFTER I pass, before a placement would be available for my son. That is only per the fact that NO ONE ELSE is deemed an emergency and placed BEFORE my son. Oddly, I do not wish for my son to be that emergency placement. I do not wish for my son to be placed AFTER my own demise. I would like to aide my son in his transition to a new location. Is that asking too much?

IACC you failed this family and there are countless others just like them.

You ignore our personal and compassionate pleas that TELL you what we need done DAILY by this group.

You are meeting about a topic and debate to no clear end. We live daily with your lack of response and lack of support.

Who among you sitting at this table live with LOW functioning, non verbal, Autism Daily and have done so for two and 1/2 decades? Having a loved one placed in residential services is NOT the same as providing daily 24/7 care. My son has not ONE real representative on this panel to speak or say his case. If for no other reason, my son can not speak to share his concerns. He can not advocate for himself. He can not type. He can hardly reply to yes and no questions on his best day.

Parents like myself and the woman who past are tied into an ENDLESS network of forms and paperwork while trying to care for our children daily. I am personally not even fully vested into social security due to the number of years that I have been at home caring for my son and without a paying job.

### There MUST be a better way!

Those of us lucky enough to have waivers in our states could NOT find housing BEFORE all the current CMS changes. We now contact agency's that are under staffed and that have their OWN waiting lists. As we hope and pray for help to find home staff that MIGHT help us, until the agency staff aide quits because the job was too demanding! The paperwork involved for them is WORSE in some cases, than the jobs they are ask to do.

In all seriousness, I would LOVE to bring my son to your meetings so he could present his own comments. Trust me when I tell you that his stim and loud echolalia and OCD that he presented within the last 24 hours, would allow this group to not even complete your roll call for attendance.

### And we wait.

We bury our allies and other autism parents one at a time as we wait.

While CMS says group homes are too restrictive, I wonder if this placement was? "<u>Autistic Woman Kept</u> <u>in Backyard Cage and Forced Into Prostitution, Say Police</u>" It is my understanding that this woman's mother past in December. Should we BLAME the woman that past? Do you THINK this was the outcome the mother, her care provider, hoped for?

You have spent over one Billion Dollars as I know ONE family that is scraping together just to have a memorial service for a loved parent.

#### Our Children's lives matter!

We have little to nothing once our loved ones age out of school services. What placements we had CMS is saying are now too limited, too restrictive and are too much like an institutional setting. YET, all the while THAT IS THE VERY SUPPORT and SERVICES that a very LARGE percentage of our community members need just to be safe! When those on the highest end of the spectrum can not find jobs, what will become of the people that are Non verbal and have Autism? Where will they work? My own son was not even able to work at our local Good Will due to his behaviors and NOW, his workshop is too restrictive? Are you kidding me?

I am currently looking at newly designed 'workshop' ideas in Ohio. None of those new choices would fully serve my sons needs nor replace what he has currently. My son hates change. My son loves routine. What is being offered to him for his betterment will be very difficult for him to adjust to. We recently painted the exterior of our home. It was long overdue and very much needed. That 'simple'

change, to freshen up the exterior of our home caused my son to yell and cry. This is the same son that the 'system' is now saying can or should be easily be placed in a job in his community. Sadly, even with one on one staff, my son who had countless hours of private treatments and private interventions so he could possibly function as an adult in a typical setting is still not able to do so. I tried. We all worked so hard. The progress came but NOT at the rate needed to function in a normal working world. Now, we are punished. We are all being punished for getting to this point and not gaining enough. I had one son recover from his Autism. Should my oldest son lose what he is able to do? With change, sadly comes regression for him. This panel will sit and sadly allow that to happen. To you he is a number. To me, he is my son.

Please ask yourself why you are part of this panel. Please ask yourself what ONE positive affect this group has served for the sickest and most ill of the Autism population. Adults with Autism that still need help toileting are going to find zero jobs in the main stream world.

Adult waivers DO NOT cross state lines. We are not even allowed to MOVE to a place that might have the natural support of family and friends or we will again start at the very bottom of the wavier waiting lists. There are now over 44,000 people waiting for waivers in the State of Ohio alone. What is that number nationally? Now add in all those DX under the age of 22 that have Autism and have no wavier.

As we are waiting for help the Autism Rate is growing daily. And now sadly, parents and natural care providers are passing. What will become of the sickest of our children that you and our government have now ignored and willingly choose to forget about for now over one full generation of children.

The quality of my sons life lays in your hands just as much as it lays in mine. I lost sleep while writing this letter. Most people you will never hear from. Most parents are so busy existing daily they do not even know this group exists. You will have your airfare paid for. If I would come to speak my mind in person I pay for that from what personal funds I do have. That is exactly why you have so few people attending your meetings and showing up to speak to you.

I will be donating the value of my airfare to a family that I personally know that just lost their mother. What matters in the end, my money will help another Autism family. We are all we have. I gave that airfare money value instead of talking in person to people who are just going to ignore my plea.

Please, feel free to prove me wrong.

Carol J. Fruscella

# Ada and Rafael Sepulveda

July 19, 2016

To whom it may concern:

On behalf of our non-verbal 17year-old son [PII redacted], diagnosed with "autism," and so many others affected in our population, we thank you for attending to this important matter. Fifteen years ago, during the Christmas holiday season, our son no longer recognized us. This was reciprocal. We no longer recognized him. He was not the happy, healthy, precocious child that filled our home with joy. He had deteriorated physically and mentally after having met all his developmental milestones. This regression journey followed a "well baby" visit for immunization.

Our son had fever, limping, rash, excessive drooling, and hand tremors accompanying body rigidity. His eyes lost all luster and appeared opaque. He had vomiting, diarrhea alternating with constipation, photosensitivity, and restriction of the visual field, hypotonia, and high pitch screaming every night with no sleep. He looked pale, jaundiced, and was just not thriving. He would jump if you coughed near him, yet not respond to his name. His little hands could no longer hold any object. His words became less and less, until no longer any. He stopped playing with tspanned, stared at ceiling fans, rocked, and head banged. He walked the periphery of Gymboree and would crawl between people's legs at home, only to resume a catatonic state on the floor. He no longer responded to the human voice. He no longer looked at anyone. However, the skin peeling, rashes, allergies, constant respiratory infections, sinus infections, and gastrointestinal pathology continued. My son was no longer with us.

This regression is not psychiatric. This is medical, biological, without a doubt. This is vaccine related, without a doubt. The vaccine studies are just not there. Can we honestly assure that the benefits of immunizations outweigh the risks? Where are the studies that address the synergy and interactions of this aggressive vaccine protocol? Where are the follow up long term studies? How utilized is the VAERS system? How effective and just is our Vaccine Injury Compensation system? Who is adjusting for genetic and environmental variability seen in our population, as should be done with pharmacological agents used in medicine? We did not hear any answers from the CDC or NIH experts. Now fraud being committed by CDC scientists?

My family is extremely grateful to those who "hear us well." Today, many are asking the right questions and getting ambiguous, substance empty responses. Accountability and transparency are imminent. An investigation of the CDC is mandated. We really envision the beginning of a new vaccine paradigm emerging that will really serve the "public good." This can realize when our political representatives listen to "the people;" all this because of the initiative of some ethical men. Please keep in mind that in so many cases, like our son, "autism is really a misnomer for so many individuals that are suffering from vaccine injury." You must call the CDC whistleblower Dr. William Thompson to testify in Congress! Thank You.

# Sincerely,

Ada and Rafael Sepulveda [PII redacted] Kissimmee, Florida [PII redacted]

### Marianna Esposito

### Hello,

Research has proven how providing early childhood education can help children on the Autism Spectrum achieve age appropriate developmental goals. Early intervention is helping children with Autism and their families achieve there goals and guide them with difficulties they cross daily. Depending on the state you live in it is not easy for children with Autism to receive the services they need to succeed. In some states your child needs to be diagnosed to obtain services from Early Intervention, but Doctors will not diagnose a child unless they are close to three years of age. These same children will not qualify because they are high functioning and don't meet the criteria for services. The earlier we start with children with Autism the better are the outcomes.

### Karen Kain

### July 19, 2016

We need to really push informed consent with the vaccination schedule. Parents must know the risk of vaccines. My daughter was injured in 1994 and we settled with the Vaccine Injury Compensation Program in 1998. They never disputed the cause of injury. My daughter [PII redacted] Kain died at the age of 15 from complications from a life of uncontrolled seizures and severe brain damage from the vaccine. We must look at vaccine injury and find out why some children have injuries and some do not. We must educate doctors on what vaccine injury looks like. We know that vaccines are unavoidably unsafe and a certain percentage of children will have reactions that may alter their lives forever. We can no longer turn away from families who are living with chronic illness. Please address these issues and the many more that parents are now dealing with as 53% of our children are living with chronic illness.

## Laura Cellini

July 19, 2016

Dear IACC Members,

The present statistics from the CDC estimate that 1 in every 68 children and 1 in 42 boys, are diagnosed with autism across the U.S. A 2012 phone survey by the CDC indicated for school age children, this rate may be as high as 1 in every 50 children. These rates have grown by 120% since 2002.

Numerous scientific studies have now shown that co-occurring medical conditions can occur more commonly with persons diagnosed with autism, and when properly diagnosed and treated, not only do their medical issues improve but their symptoms of autism are ameliorated.

While autism spectrum disorders have primarily been diagnosed in measuring deficits in the areas of communication, socialization and behavior, recent clinical and scientific investigations have determined that co-occurring pathophysiological conditions may occur more commonly in persons also diagnosed with autism, the symptoms of which may be overlooked and mistakenly be attributed to behavior.

Individuals with autism have a mortality rate that is 10 times that of their peers without autism. In many cases, this is due to their inability to get proper diagnosis and treatment for their co-occurring and underlying medical conditions. It is not uncommon for health care providers to dismiss their underlying medical symptoms as "autism" and miss the opportunity to adequately evaluate and treat them.

These underlying conditions include but are not limited to; allergies, autoimmune conditions, gastrointestinal diseases, immune dysregulation, metabolic disturbances, mitochondrial abnormalities, oxidative stress, neuroinflammation, and seizure disorders. Scientific inquiry is increasingly providing evidence of biological markers. These include single nucleotide polymorphisms, indications of cellular inflammation, increased cellular oxidation and damage, and abnormal DNA methylation, that may be clinically significant in the provision of appropriate medical care for persons also diagnosed with an autism spectrum disorder.

A search of peer reviewed publications on Pub Med with the various terms generated the following number of results;

Autism + seizures = 878 Autism + Epilepsy = 1760 Autism + metabolic = 621 Autism + immune dysfunction = 495 Autism + immune = 729 Autism + T cells = 71 Autism + lymphocytes = 172 Autism + neuroinflammation= 127 Autism + neuroinflammation= 127 Autism + microglia = 106 Autism + mitochondrial dysfunction = 153 Autism + gastrointestinal disorder = 575 Autism + microbiota = 97 Autism + genetics = 6802 Autism + oxidative stress = 312 Autism + allergies = 242 Autism + autoimmune = 237

While there is an incredible amount of scientific evidence establishing the various comorbid and underlying conditions which occur more often in persons with autism, the medical standard of care does not reflect these and most medical professionals remain uninformed and lack the appropriate training. The IACC should promote the translation of scientific findings into medical practice. From a stakeholder's perspective, considering the numerous advances in this area, the most recent publication from the IACC "Summary of Advances in Autism Spectrum Disorder Research: Calendar Year 2015", was a disappointment.

Individuals with autism deserve to have proper medical assessment, diagnosis and treatment of underlying and comorbid conditions. Health care providers need immediate training in recognition and treatment for the numerous pathologies and abnormalities that occur more often in children with autism than the general population. Parents need to be provided with information on the symptoms that may indicate their child may have one of these co-occurring conditions and what they should discuss with their doctor. I am hopeful that the IACC will do more to address these discrepancies in future strategic plans and workshops and that they will encourage more research in these underlying conditions.

Sincerely,

Laura Cellini Springfield, Illinois [PII redacted]

## Stepahanie Stock

### July 19, 2016

If autism rates continue 1 out of ever 2 children will be on the spectrum by 2032. This is catastrophic. At what point will you ask that CDC scientists Dr. William Thompson be subpoenaed for his allegations of CDC FRAUD in the 2004 MMR- Autism study?? Thousands of documents are sitting on Representative Posey's desk! What does HHS plan to do about this???

#### Dr. Karen F. Heffler

Karen F. Heffler, MD

Associate Professor of Ophthalmology, Drexel University College of Medicine

There is an area of science with tremendous promise for both prevention of autism spectrum disorder and early intervention which has been overlooked and requires attention from the IACC as an area of research focus. Extensive research in both animals and humans shows that brain development in infancy and early childhood is highly dependent on early sensory experience (1-15). What the child sees, hears and feels determines brain connectivity and behavior, a concept called neuroplasticity. Research in autism has ignored the science of neuroplasticity, which may explain the brain development of many children with genetic risk who develop ASD.

Before the late 1980s, infants and young children were not exposed to extended hours of fast-paced, repetitive TV/video and other screen viewing. Infants were not interested in the slow paced "real-life" shows such as Mr. Rogers and largely ignored adult programming. Prolonged and repetitive viewing became available with VCR (16), cable (16), and the introduction of children's television stations (17).

Watching TV/videos at an earlier age (6 months vs 12 months of age) and more hours of viewing is associated with developing an ASD diagnosis (18). Brain alterations and attention mechanisms (19) in ASD are largely auditory (20-23) and visual (24-28), exactly what we would expect from heightened early audiovisual exposure. TV viewing interferes with parent-child interaction (29), joint attention (29), toy play (29), (30), and verbalization of both parent and child (31). More hours of screen viewing at a young age is associated with multiple developmental problems including language delay (32), ADHD (33), cognitive delay (34) and behavioral problems (35). Young children do not learn well from TV or video (36, 37). Joint attention and eye contact appear to be critical in early learning (38). Having the TV on even in the background interferes with joint attention, parent responsiveness to the child, and toy play (29), all critical factors in promoting social (39), cognitive (40), and language development (41). Children with ASD spend more time watching non-social TV and videos than all other leisure activities (42).

There are very many reasons to suspect that TV and video viewing may be contributing to developing ASD in children at risk. I hope that the members of the IACC understand that environmental factors such as TV, video and other screen watching in young children is a risk factor that requires research to fully understand the impact on autism. Parents deserve to know the impact of early screen watching on ASD as this is a modifiable risk factor with tremendous potential to impact future generations of children at risk.

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#### **Christine Conway**

There are so many areas that need improvement. I will bullet the areas I think are critical to our children's future.

- education/schools- all the tools to improve our kids' lives are at school. However, the resources are terribly under utilized.
- Focus groups- Ask the parents, therapists, teachers and individuals with ASD and other disabilities meet regionally to discuss these issues. We are the ones who need to make the decisions. Value this group and turn to them for discussion. Provide a stipends to these individuals to meet to come up with solutions!
- There should be peer groups with typical peers, shadowing, extracurricular involvement with buddies and academics expectations need to be increased. School shouldn't just be a place where we dump our kids off for 6 hours and get daycare for them.
- Teens- services! There is not adequate pre-vocational and vocational and life skills programming for our children in this age range. As a result, many become even more isolated, anti-social, regress and tune out to real life. We need to be preparing them for life as a productive, social adult.
- innovative or experimental services- allow us a sum of money to use how we want to use it. There are lots of cutting edge therapies that we want to try and allow our kids to enjoy- pet therapy, music therapy, vision therapy, auditory processing therapy, etc. Our schools can't and don't give us these therapies. Give grants to private practices to allow such therapies.
- Family support- our other children are having issues. Because of the isolation of families we are suffering along with the rest of the families. We take on our children's issues and still have to work, mow the lawn, pay the bills, clean the house and have no support. We are experiencing health and medical issues because of all the added stress to our families. We are financially drowning in debt too?.because of all of the added expenses for our children that typical families don't experience.
- Adult and parent assisted living- Keeping our children safe from predators and financial cons is a priority for our families. If our children can't reach the level of independence, then we should have the option of other 'sheltered' living options. I love the idea of adult disabled children living in assisted living centers with or w/o their adult parents! There would be daily activities, therapy, meal and medication management. It could be a place where the adult children hold jobs of maintaining the center and have jobs?.maintenance, lawn care, working in on-site restaurant and coffee shop. It would give peace of mind to parents and a place where everyone is accepted and included. It could be an upscale assisted living facility that includes living and working and is a gated safe community that includes a walking/bike path, gardens, family areas, pond with fishing, and a gym for daily therapies. Vocational therapies and learning could take place here. It would be a combination of medicaid and medicare funding plus private pay for an upgraded singe family housing units with yards etc.

## **Kristen and Brian Festa**

Dear members of the committee:

We follow the research on medical comorbidities of autism very closely, but a recent study in The British Journal of Psychiatry left us stunned. Hirvikoski, et al., looked at mortality rates in nearly 30,000 individuals. Those with ASD only lived to an average of 54 years. Lower functioning individuals only lived an average of 40 years. Individuals who were lower functioning demonstrated particularly higher mortality rates related to endocrine, nervous, respiratory systems, mental and behavioral disorders and congenital malformations.

Our focus and research funding priorities must change. The body of research regarding the medical nature of autism can no longer be denied. We have 1 in 68 children suffering from a disease that will significantly decrease their lifespan. AUTISM IS A DEADLY DISEASE. We need to treat it as such and get a hold of this epidemic.

No more inaction. No more politics. Please shift your priorities to funding medical research into understanding the biological nature of autism and medical treatments. We will not solve this tragedy without research funding.

The good news is that there is some excellent pioneering researchers already tackling this problem. Please help fund their work. Most notably is Dr. Robert Naviaux?s team at UC San Diego. He has been studying the cell danger response in autism and has used the drug suramin to reverse autism in mice. His team is nearing completion of their first stage of suramin clinical trials in children. Please work to secure funds for a large multi-center clinical trial.

Another pioneer is pediatric neurologist Dr. Richard Frye at the University of Arkansas Medical Center. His research into mitochondrial and autoimmune disorders in children with autism is already improving the lives of many children, including our own son. Please give him the funding he needs to support his work.

We can change the medical trajectories of children suffering from autism, but we need to focus our efforts and funds prudently. Please make discerning the underlying biology of autism and developing treatments the focus of your mission.

Sincerely, Kristen A. Festa, BA (molecular biology), RN, BSN Brian D. Festa, Esq.

Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte. ?Premature mortality in autism spectrum disorder.? The British Journal of Psychiatry. Mar 2016, 208 (3) 232-238; DOI: 10.1192/bjp.bp.114.160192 User Name: Kristen Festa

### **Nonya Business**

I have ADHD as co-morbid with autism spectrum. Recently, the DEA has begun to drug test ADHD prescription users to make sure that we are using our medicine as some people abuse drugs. I think this is an invasion of my privacy and it makes me uncomfortable. I pay high fees out of pocket to go to my Dr. and for that relationship and I feel that the government is interfering with it, for a lessor good. I have a job that works within and gives back to the community and I do not believe that I should have this invasive thing done in order to receive my needed medication.

# Synopsis of the Article - Measles Vaccine Scandal: World Governments Have Known It Can Cause Neurological Disorders Since 1970's

by Research and Author Christina England

As I am sure you are fully aware, in 2004, Dr. Andrew Wakefield revealed that, during telephone conversations between biochemist Brian Hooker and a CDC (Centers for Disease Control and Prevention) whistle-blower, later named as Dr. William Thompson, Thompson admitted that the CDC had deliberately withheld crucial evidence proving that the MMR (measles, mumps and rubella) vaccine caused autism.

However, I am sure that the majority of you will be less aware, that for many years, the Joint Committee for Vaccination and Immunization (JCVI), an organization equivalent to the CDC that sanctions the vaccinations for use in the UK, also appears to have deceived the public and have also put vaccination policy above the health and safety of UK's children.

Not only, has this organization been found to sanction unsafe and potentially dangerous vaccinations but they have also been proven to change the name of the vaccination to mislead the general public.

If this was not bad enough, the JCVI have been fully aware since the 1970's, that both the single measles vaccination and the MMR have the potential to cause neurological conditions in children.

In 1972, the UK Government had serious concerns about the measles vaccine's potential to cause vaccine-induced Subacute Sclerosing Panencephalitis (SSPE). SSPE is a degenerative neurological condition, which affects a person's behaviour, memory and coordination, leading to fits, blindness and eventually death.

Due to these concerns, it was decided that a group called the *Expert Group on the Surveillance of SSPE* was needed to study the problem in more detail. On February 9, Medical Officer F.C. Stallybrass wrote a request to UK's leading professionals asking them to attend a meeting on Monday, March 13, 1972, in room D1001 of the Alexander Fleming House.

The members of this group were listed on a separate JCVI (Joint Committee of Vaccination and Immunisation) document titled *Proposed Membership of Expert Group on Surveillance of SSPE*. These same professionals were seen to attend that meeting on March 13<sup>th</sup> 1972. The meeting was titled *Surveillance and Registration of Subacute Sclerosing Panencephalitis*. (6)

Around the same time, a memo, titled *Copy Of Notice To Be Circulated To ABN – Measles Vaccine And* **Subacute Sclerosing Encephalitis** was also sent out, which stated that:

"There has been some concern recently about the suggestion that measles vaccines **might occasionally** give rise to Subacute Sclerosing Encephalitis. Professor Sir Charles Stuart-Harris, as chairman of the Joint Committee on Vaccination and Immunisation, has asked whether members of the Association would be prepared to notify cases we see." (own emphasis added)

As the wording on this particular document differs slightly from the other two, using the words Subacute Sclerosing **Encephalitis** as opposed to Subacute Sclerosing **Panencephalitis**,

Are these professionals speaking about the same disorder?

Also note the words *might occasionally*. Were these words chosen specifically to cover the fact that this was a growing problem?

This document, along with many others that have been uncovered, suggests that the measles vaccine was proving to be problematic from as far back as 1972, and has been associated with neurological adverse outcomes for many years.

If this was the end of the matter, then it would be easy to assume that these problems had been overcome. However, the problem of vaccine-induced SSPE continued to persist even when the measles vaccination was combined with the mumps and the rubella vaccination to form the MMR triple vaccine.

A staggering 15 years later, during the ARVI (Adverse Reaction to Vaccination and Immunization) meeting 6<sup>th</sup> July 1987. The minutes of that meeting stated:

"The correspondence was submitted for member's information. Dr Cavanagh reminded the Committee of **an SSPE-like syndrome** reported from rubella virus infection and noted the 'reported' (added in hand) maternal viraemia and transmission of rubella virus in breast milk.

Could the SSPE-like condition being reported at the ARVI meeting, be autism? I say this because Dr. Rebecca Carley M.D. has been convinced that it is for over 14 years.

In 2009, Dr. Carley wrote the following on the Abundant Hope website:

<u>"The way that the true etiology of autism is hidden from doctors is by changing the name of the vaccine induced disease.</u> For example, SUB ACUTE SCLEROSING PAN ENCEPHALITIS (SSPE) has been changed to AUTISM, as is demonstrated in the 10th edition of Harrison's Principles of Internal Medicine where, on page 2096, the following information about SSPE is included:

"...The disease affects boys 3 to 10 times as frequently as girls...Characteristically, they are entirely well until the disease begins. The onset of usually insidious mental deterioration, often expressed by a decline in the patient's schoolwork, is the presenting symptom. Incoordination, ataxia, and myoclonic jerks develop within a few months along with abnormalities of the pyramidal and extrapyramidal motor systems....Elevated levels of measles antibody are found in the serum and CSF....Measles virus is the etiologic agent....Staining of brain tissue from patients with the disease demonstrates measles virus antigen in the inclusions....A few reported <u>cases have been related to measles vaccination</u>."

It appears that Dr. Carley was absolutely spot on because Dr. Cavanagh did state *"a SSPE–like syndrome reported from rubella virus infection,"* indicating that this was a condition similar to SSPE, which is exactly what Dr. Carley has stated all along, without the benefit of seeing these papers that had been tucked away for all these years.