Written Public Comments

IACC Full Committee Meeting

January 12, 2016

List of Written Public Comments

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

Eileen Nicole Simon **November 12, 2015**

I don't have that much to say, but will continue to try to say it in ways that might lead to meaningful discussion. I will continue to ask especially for discussion of vulnerable brain systems, and how these may be injured by all known causes of autism.

Sincerely,
Eileen Nicole Simon, PhD, RN
[PII redacted]

#1 THANK YOU
Thank you, John Elder Robison and Alison Singer, for reading and responding to the Public Comments many of us submitted during the past year while we awaited resumption of meetings by the IACC. Alison Singer, thank you for acknowledging the focus on the severe affliction most parents are requesting of the IACC, especially the lifelong problems that result from minimal language competency. John Elder Robison, thank you for discussing all of the comments submitted. However, I would like to have engaged in a back-and-forth conversation with you, and other members of the committee. You did misinterpret my use of the word acceptance. No one except for me is accepting of my son. He is 53 years old, and we face the abyss. I am consumed with stress and anxiety over his future. What I cannot accept is the attitude of the present day acknowledged research experts. I would have liked to submit an abstract or two or more for IMFAR in Baltimore next spring. But the instructions specify that only data-driven research will be considered. My data, gathered from life-long (50+ years) milieu observations would not be accepted. I know this from having submitted 14 proposals for oral or poster presentations at IMFAR 2012. I may submit these for discussion by members of the IACC.
I am near the end of a long sad life dedicated to dealing with and trying to understand autism. In retirement, my focus is now trying to learn to write and communicate my ideas as clearly and concisely as possible. I hope some of the comments that follow will be read and discussed by members of the IACC.

#2 AUTISM DIAGNOSIS
Neurodiversity is something different from the neurological disorder referred to as "autism" over the past 70 years. The syndrome of autism described by Kanner is the result of perinatal brain damage, by a number of different causes. Kanner autism is not something that can be missed, and only discovered when a person is in college. The syndrome described by Asperger is likely the result of a lesser degree of neurological impairment. Gilberg & Cederlund's 2004 and 2005 articles pointed out that boys with Asperger syndrome were late learning to speak, suffered complications at birth, and had high levels of bilirubin. This information was obtained from pediatric records in Sweden. Isn't this kind of information available in pediatric records everywhere? Pediatricians are reluctant to discuss delayed development with parents. My husband went with me to see the pediatrician after our son [PII redacted]'s diagnosis of autism. The pediatrician told my husband he had recognized [PII redacted]'s problems with speech development. He then commented, "What could I say to a middle-American mother sitting there with her baby?" My husband jumped up with [PII redacted] in his arms and ran out through the crowded waiting room yelling, "We are going to find a pediatrician who knows how to talk to a middle-American mother."

The book Neurotribes by Steve Silberman does not discuss the language handicap of Kanner autism in adequate depth. Language handicap in Kanner autism has to be experienced up close and on a day-by-day-basis. I wrote about echolalic speech as part of my dissertation research back in 1975 (N Simon, Archives of General Psychiatry, November). My paper (like many others) has become part of forgotten history.

#3 METAPHORICAL SPEECH

Language disorder must be recognized as the most serious handicap of autistic children. Claims of late diagnosis 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. 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]'s 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. 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. 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 meaningful insight.

#4 LIFESPAN CARE

My oldest son, [PII redacted], made a miraculous recovery from autism. He learned to speak just before his sixth birthday. In the 1980s I read Lorna Wing's papers on Asperger Syndrome, then those of Tantam, Szatmari, Gilberg & Cederlund, and others. My son does not quite reach the criteria for Asperger Syndrome.

Sadly, I have to acknowledge he remains severely handicapped, though he is a savant, especially in automotive history, movies, music, and figuring out if money in his pocket (plus sales tax) is sufficient for a purchase. He lives in a group home for schizophrenic men and attends a day program, where no effort has been made over the past 13 years to prepare him for employment. He is capable of doing useful work, but no one listens to me anymore than at an IACC meeting.

I don't know if he could earn enough money to pay for rent, groceries, or to own and operate a car? No "professional" effort has gone into thinking about this, or trying to put a plan of action in motion. Who am I (silly mother) to pose such heretical questions? My son is currently at risk of being denied housing by the Department of Mental Health (DMH) in Massachusetts, because of his inability to obey the rules of his current group home, from which he has repeatedly run away.

The DMH motto "recovery is real" means substance abuse is their primary focus. The most seriously mentally ill people in Massachusetts too often end up homeless without attention to basic needs, or myriad health problems from diabetes to scabies.

#5 FORGOTTEN EVIDENCE

I have often been demeaned for pointing to "cherry-picked" old out-of-date data. I can only respond with a really old quote from Cicero: "If no use is made of the labors of past ages, the world must remain always in the infancy of knowledge."

Autism research is an example of knowledge that has remained in its infancy. I will continue to try to point out there is much research published decades ago that remains relevant to understanding the brain disorder in autism:

(1) Research on ASPHYXIA AT BIRTH (1959-1972) revealed that relay nuclei in the brainstem auditory pathway are selectively damaged by a brief (8 to 12 minutes) of asphyxia at birth.
(2) Research on BLOOD FLOW AND METABOLISM in the brain (1955-1981) revealed that blood flow and aerobic metabolism are higher in nuclei of the brainstem auditory pathway than anywhere else in the brain.
(3) Research on BRAIN MATURATION (1933-1967) revealed that myelination (or maturation) of the brainstem auditory pathway is complete earlier than any other sensory system.
(4) Research on TRANSIENT NEUROTRANSMITTERS produced in the brainstem auditory pathway revealed that these guide maturation of target language areas of the cerebral cortex.
(5) Research since the 1970s on the AUDITORY BRAINSTEM RESPONSE (ABR) has revealed abnormalities in autistic children and adults.
(6) Research on LANGUAGE DEVELOPMENT revealed that children begin using stressed syllables (word fragments), in contrast to use of phrase fragments (echolalic speech) by autistic children.
(7) Research on bilingualism revealed that AUDITORY INTRICACIES of language become increasingly incomprehensible during early childhood. A second language is rarely learned in adulthood without an accent.

#6 RESEARCH BACKGROUND

Parents seek information, and want to discuss what they uncover. As a young mother, I was told by a pediatrician that I didn't have the technical expertise to understand the medical literature. Fifty years later my understanding of autism is being discredited, and now by people who have far less technical expertise than I do.

I returned to school, and in 1975 earned a PhD in biochemistry. My dissertation was on the long-term effects of neonatal asphyxia in laboratory rats. The most immediate effect was growth retardation, which was more pronounced (visibly so) in male rats. This was a totally unanticipated result. After maturation, serotonin synthesis was disrupted, and only in male rats. (Lookup N Simon & L Volicer, J Neurochem 1976). I considered doing research in genetics, but for a biochemist genetics research involves study of enzymes that transcribe the genetic code, messenger and transport RNAs, and enzymes that assemble proteins from the RNA message. Research of this kind led to discovery of transcription error and a faulty enzyme responsible for PKU (phenylketonuria). But neurotoxic metabolites were identified, and dietary treatment of PKU established before discovery of the nucleotide components and structure of DNA. How silly in comparison is research that attempts to associate "gene loci" on chromosomes to autism traits in parents of children afflicted with autism, a "broader autism phenotype" (BAP).

#7 HEARING WORDS

Language is the defining characteristic of the human species. Euphemistic attempts to dismiss the seriousness of the language disorder in autism are not helpful. "Social disorder" is the result of the language disorder.

Human social interactions are based on language. "Shared attention" is likewise a function of language, comparable to vocal signaling in other primates, birds, and lower species.

"Shared attention" and social orientation are very much impaired following loss of hearing in the elderly. Language is learned through the auditory sense. Sign language is used by the deaf community, but the cochlear implant is now viewed as preferable by most, and the cochlear implant is most beneficial when received at the youngest possible age.

The book Thirty Million Words, by cochlear implant surgeon Dana Suskind, should be read by all researchers investigating language development. Autistic children need instruction in hearing words as much as children with cochlear implants.

Autistic children need instruction on hearing syllables in words. I think starting with the last syllable, then the last two, then three helped my son figure out how to hear words.

#8 SEROTONIN WHAT?

Everyone knows the terms "selective serotonin re-uptake inhibitors" and SSRIs. But what is it that everyone knows? What about post-synaptic cyclic-amp (second messenger) activation? Why is that not part of common knowledge about serotonin?

"Inferior colliculus" might be a better term for everyone to know. This is the nucleus in the midbrain auditory pathway that has higher blood flow and metabolism than any other area of the brain. This is where sound signals are processed, and modulated in part by serotonergic neurons, and gamma-amino butyric acid (GABA) neurons; and who knows yet how many other neurotransmitters might be involved? Modulation of auditory signals is clearly impaired in autistic children who suffer hyperacusis, who are unable to dismiss the sound of a vacuum cleaner as background noise. Similar failure of modulation may impair hearing syllable boundaries.

After early childhood we all become impaired in hearing syllable boundaries, which is why it becomes more difficult to learn or follow a conversation in a foreign language.

As adults we use foreign language phrase handbooks, which make us echolalic like an autistic child. We rely on peculiar-sounding phrase fragments in a desperate effort at basic communication. Forget about trying to participate in a conversation about feelings.
We also become socially impaired in trying to communicate in a foreign language. We lose the ability to maintain "shared attention" in a foreign country. It is far easier to ignore responses from a foreign speaker, unless that person suddenly demonstrates a remarkable fluency in English. English is taught from an early age in many European schools. The earlier a second language is learned, the more likely life-long fluency will be gained.

#9 WRONG IDEAS?

Autism has been my life's work. For more than 50 years now I have been reading everything I could find on autism, language development, neurological disorders, and the brain. I returned to school and earned a PhD in biochemistry.

I have published a few papers, many letters, and most recently six eBooks on autism. My autistic (savant) son co-authored two of these eBooks. Why should I agree with critics that autistic self-advocates are in a better position to guide autism research? Do I have any right to feel angry? What do members of the neurodiversity movement want to teach me about severely disabling language handicaps? Can they inform me on how better to promote shared attention or social awareness in children and adults who are minimally verbal? What are their research insights that make their conversations with researchers more meaningful than mine?

My ideas may be all wrong. Then please discuss why. Do I come across as belligerent? I sometimes feel I am being attacked in a belligerent manner.

I would like to request discussion of my ideas in terms of neurology, physiology, and biochemistry. Why did any of us put great effort into higher education? Please at least point out where I have gone wrong, and perhaps allow me to respond.

#10 SYSTEMS PERSPECTIVE

I majored in chemistry at Barnard College. I was inspired by my freshman professor, who drew a small rectangle in the upper right-hand corner of the blackboard, then she gestured across the rest of the board saying, "If this is everything we could know about chemistry, all I can teach you during the year is this much," and she pointed again to the small rectangle she had drawn.

I worked for two years in a research laboratory, and put up a huge poster over my desk with the Krebs cycle (steps of aerobic metabolism), and other well-known interfacing metabolic cycles. Even what was known in the small rectangle my professor drew on the blackboard was enough to fill the large complicated poster over my desk.

In 1960 I was hired to work in the Satellite Tracking Program at the Harvard Smithsonian Astrophysical Observatory. I started with learning to program the IBM 704 computer with 32K core memory!!! The large programs I worked on required much more memory, for which I designed "overlays" to swap in and out program sections and data from magnetic tape.

Wizards at MIT designed the first time-sharing (multi-tasking) system for the follow-on IBM 7094. Instead of submitting programs on punched cards, users at display terminals could load programs from tapes or disks. This was an interrupt-driven system, responding to keystrokes from user terminals and signals from disk and tape storage devices.

My view of the brain derives from my work on operating system design (TOPS-10 and 20, VAX/VMS, & UNIX). In graduate school we learned the anatomy of the occipital, parietal, frontal and temporal lobes, the pre-central gyrus, angular gyrus, amygdala, hippocampus, thalamus, basal ganglia, reticular formation, cranial nerve nodes, and the visual, auditory, and somatosensory pathways. We also learned the anatomy of neurons and synapses. These anatomical components were for me like the components of a computer system, interacting via traps and interrupts, and interface with the outside world via multi-plexed pathways for hearing, vision, and touch.

#11 PLACENTAL RESPIRATION

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. 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." 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. 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.

#12 FIRST BREATH

Also back in the 1950s, my 10th grade biology teacher taught us that the anatomy of the heart must change at birth. Two fetal heart valves must close (the ductus arteriosus and foramen ovale), before blood flow to the placenta stops. Incomplete closure of these fetal valves causes problems that can persist into adult life. Football player Tedy Bruschi wrote a frightening account about suffering a stroke that was triggered by a patent foramen ovale.

Before birth blood receives oxygen from the placenta in exchange for carbon dioxide, the end product of metabolism in the fetus. Blood returning to the placenta is laden with carbon dioxide. Blood flow to and from the placenta does not stop at the instant of birth, but fairly quickly must be redirected to the lungs. Capillaries surrounding the alveoli must be filled with blood before they can begin to receive oxygen. Our teacher told us that exhalation of carbon dioxide precedes the first breath!

Blood that would have flowed through the ductus arteriosus back to the placenta with carbon dioxide begins instead to flow to the lungs as the pulmonary artery becomes functional. Then carbon dioxide is exhaled in exchange for intake of oxygen with the first breath. Receipt of oxygen into the newly expanded alveoli triggers an initial movement of the diaphragm for expansion of the chest cavity. From this moment on, brainstem centers begin sending signals to initiate lifelong movement of the diaphragm at regular intervals.

#13 AUTONOMIC FUNCTIONS

Respiration, heart rate, intestinal peristalsis, and more are controlled by centers in the brainstem that do not require conscience attention. Here I would especially appreciate discussion, and correction, by members of IACC who have more training and experience in Medicine than I do. I have cited (often) the research of S Kety and L Sokoloff on blood flow and metabolism in the brain. Blood flow and metabolism were shown (by their autoradiographic methods) to be higher in nuclei of the brainstem auditory pathway than anywhere else in the brain.

The auditory pathway has been described as the "vigilance center" of the brain. The auditory system is continually active, even during sleep. This is why we use alarm clocks. However, centers of autonomic control must be even more metabolically active than relay nuclei in the auditory pathway, but too small to show up in the autoradiograph images that revealed high blood flow in the auditory pathway.

I have discussed over and over why I think auditory system impairment is a primary affliction of autistic children. But many parents have expressed concerns over disrupted intestinal motility in their children. Many believe a "leaky bowel" is responsible for the brain dysfunction of their children, and fervently hope that treatment for bowel disorder can reverse (or cure) the brain disorder. Is blaming bowel disorder as the primary cause of autism a reasonable starting assumption?

Maybe damage that affects centers of autonomic control should be investigated as part of the neuropathology of autism. Could the same etiologic factors that affect the auditory system also be involved (prenatal drugs or infection, asphyxia at birth, neonatal jaundice)? Repetitive movement disorder (chorea and athetosis) most likely are also the result of direct (not secondary) injury of subcortical structures like the basal ganglia, in the brain.

#14 NUCLEUS TRACTUS SOLITARIUS

I responded (Dec 10) to Manuel Casanova's review on corticalchauvinism.com (Nov 18) of NeuroTribes. Dr. Casanova pointed out the research of Steve Edelson, which I then looked up in PubMed. Wow!!! I found the article by WR McGinnis et al. on their proposed vulnerability of the nucleus tractus solitarius (NTS) to toxic and anoxic impairment in autism. Yes! This area of the medulla fits the description of a site in the brain more metabolically active than the auditory pathway, but likely too small to show up on brain images made following injection of a radioactive tracer. In PubMed this morning (Dec 11) nucleus tractus solitarius deoxyglucose brings up 56 citations dating back to 1980, which I will begin to look up.

#15 NEONATAL CIRCULATION

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. 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.

I found two fairly recent research papers on models for perinatal asphyxia based on clamping of the umbilical cord:

(1) van Dijk AJ et al. Umbilical cord clamping in term piglets: a useful model to study perinatal asphyxia? Theriogenology. 2008 Sep 1;70(4):662-74.
(2) Juul SE et al. Prenatal cord clamping in newborn Macaca nemestrina: a model of perinatal asphyxia. Dev Neurosci. 2007;29(4-5):311-20.

In how many births is some degree of oxygen insufficiency being inflicted by clamping the umbilical cord?

#16 CORD CLAMPING

The obstetric standard of care published by the American College of Obstetricians and Gynecologists, ACOG (2006) mandates:

“Immediately after the delivery of the neonate, a segment of umbilical cord should be double-clamped, divided, and placed on the delivery table pending assignment of the 5-minute Apgar score.....If the 5-minute Apgar score is satisfactory and the infant appears stable and vigorous, the segment of umbilical cord can be discarded.” [Obstet Gynecol. 2006 Nov; 108:1319]

Not just one clamp, but two are applied, and the purpose is to analyze the blood trapped in the clamped segment for signs of an abnormal oxygen/carbon dioxide ratio.

If the infant has not yet begun breathing, carbon dioxide should be high in the umbilical arteries and oxygen (en route to the baby) should be high in the umbilical vein. The infant cannot receive this oxygen once the cord has been clamped.

The following more recent paper indicates that 8 years later, little thought has been given to possible detrimental effects of clamping the cord immediately after birth:
Jelin AC et al. Obstetricians' attitudes and beliefs regarding umbilical cord clamping. J Matern Fetal Neonatal Med. 2014 Sep;27(14):1457-61.

#17 PULSATING CORD

With the now nearly universal practice of immediate cord clamping, how many doctors trained in the last two to three decades have ever been in attendance at what Apgar would (by the 1950s) refer to as a "slow birth," waiting for pulsations of the cord to cease? We therefore need to go back to historical accounts, as in the case of vanishing diseases like smallpox, neurosyphilis, tuberculosis, leprosy, or polio.

The paper by Frischkorn and Rucker [The relationship of the time of ligation of the cord to the red blood count of the infant. Am J Obstet Gynecol 1939; 38:592-594] would be as useful to include in a Cochrane Review as any of the randomized-controlled trials of "delayed cord clamping" so highly valued today. Frischkorn and Rucker provided a description of postnatal umbilical cord function that perhaps even in the 1930s was not waited for or witnessed by many obstetricians:
"If a cord be watched immediately after delivery the umbilical vessels can be seen to pulsate strongly throughout their entire length. In a varying length of time the pulsations cease in the more distal part and as this occurs the umbilical vessels collapse. This process of cessation of pulsation and collapse of the vessels proceeds toward the umbilicus until finally there is no pulsation even at the navel. The vessels are then entirely collapsed. If now the cord be tied and cut very little blood will escape from the placental end." [p 593].
Frischkorn and Rucker (1939) noted that with use of anesthesia, pulsations of the umbilical cord continue longer than in infants born without use of anesthesia. In one case they observed pulsations to continue for 50 minutes after birth. Did prolongation of pulsations perhaps have had something to do with an increasing tendency to tie off the cord early? After introduction of the clamp, ligation of a taut pulsating cord would certainly be easier.

#18 BLOOD BANKING

By the 1930s it became possible to store blood for transfusions, and umbilical cord blood was believed to be especially desirable [Starr, DP. Blood: an epic history of medicine and commerce. New York: Alfred A Knopf, 1998]. Collecting umbilical cord blood led to the practice of clamping without waiting for full transition from placental to pulmonary respiration [Goodall JR et al. An inexhaustible source of blood for transfusion and its preservation. Surgery, Gynecology and Obstetrics 1938; 66:176-178].

The eleven children described by Kanner in 1943 were all born in the 1930s, and most were from families of high educational achievement. It would be hard to trace the medical centers where these children were born, but it might be of interest to determine if some were among those whose avant garde parents allowed umbilical cord blood to be collected for banking. Banking of umbilical cord blood is now widely encouraged, and early clamping yields more blood. Why then aren't all children autistic? Most infants breathe right away at birth, and appear to suffer no ill effects from early termination of placental circulation after birth. However, what about the increasing prevalence of autism, most dramatic since the mid 1990s? Some infants may be more vulnerable, like those born prematurely. Male infants may be more vulnerable to oxygen insufficiency at birth than females.

#19 MALE VULNERABILITY

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.

Again, I would appreciate discussion by members of the IACC with medical education and experience more extensive than mine. 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:

(1) Dunn L et al. Gender specific intrapartum and neonatal outcomes for term babies. Eur J Obstet Gynecol Reprod Biol. 2015 Feb;185:19-22.
(2) Diepeveen FB et al. Among perinatal factors, only the Apgar score is associated with specific language impairment. Dev Med Child Neurol. 2013 Jul;55(7):631-5.
(3) Nagy E et al. Sex-differences in Apgar scores for full-term neonates. Acta Paediatr. 2009 May;98(5):898-900.
(4) Simon N, Volicer L. Neonatal asphyxia in the rat: greater vulnerability of males and persistent effects on brain monoamine synthesis. J Neurochem. 1976 May;26(5):893-900.

#20 NEONATAL RESUSCITATION

New guidelines for neonatal resuscitation are provided in a November 2015 Supplement for the journal Pediatrics*.

According to this article:

(1) Transition to extrauterine life is brought about by "initiation of air breathing" and "cessation of placental circulation." What?
(2) Then, "approximately 85% of babies born at term will initiate spontaneous respirations within 10 to 30 seconds after birth." What about the other 15 percent?
(3) The authors then state:
(4) 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.
(5) They then acknowledge recent evidence that:
(6) "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
(7) "Parents favor delayed clamping, which has received strong popular support through social media and Internet sites."

An article on resuscitation published five years ago (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 was all we needed.

Meanwhile, the "experts" continue to insist more randomized-controlled trials must be done...

*To be cited as: Perlman JM et al. on behalf of the Neonatal Resuscitation Chapter Collaborators. Part 7: neonatal resuscitation: 2015 International Consensus on Cardiopulmonary Resuscitation and Emergency Cardiovascular Care Science With Treatment Recommendations. Circulation. 2015;132(suppl 1): S204–S241.

#21 MEDICAL ERROR?

Throughout the nine months of prenatal life, respiration takes place in the placenta. No evidence supports any health benefit of umbilical cord clamping. Clamping the cord immediately at birth instantaneously cuts off oxygen arriving from the placenta. The lungs are forced to take over, and if the response is not immediate, the baby will be left in a state of respiratory distress. Clamps are surgical instruments. Beginning in the early 20th century clamps came into use in obstetrics, but always with the instruction to wait for pulsations of the cord to cease. By mid-20th century, clamping the cord quickly after birth was advised by some obstetric surgeons to preserve the sterile field for surgical repair of the incision made for cesarean delivery, or episiotomy. Gradually it became the norm.

Throughout subsequent decades, many obstetricians have attempted to show that respiratory depression and hyaline membrane disease could be avoided by allowing circulation to and from the placenta to continue after birth.

Investigation of outcomes by school age, of infants who suffered respiratory distress at birth is quite recent. Research with monkeys should be resumed to evaluate long-term outcomes. Are more "randomized-controlled trials" with human infants justifiable? No! Clamping the umbilical cord immediately at birth should be stopped.

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

Jeffrey Brown **December 15, 2015**

Subject: IACC Priorities

I am very pleased that the committee is reconvening in 2016. As a parent and brother to people on the ASD spectrum, I have a great interest in the role that the IACC plays in our community.

It is my great hope that the important work of the committee will not be derailed by individuals and groups with agendas that go against well-established research in medicine, public health and behavioral science. I do believe these people have a right to express their concerns, but not to the point of wasting the limited time and resources of the committee. I know these issues have been brought to committee in the past, but extremist in these groups do not listen to reason and are often conspiracy minded and do a great deal of harm to our community.

I, of course, have my own agenda :) and I hope these issues will be near the top of the IACC priorities:

1. Early childhood identification and intervention available regardless of income
2. Increased, earmarked funding for public schools to ensure all students (not just ASD) receive a free and appropriate public education
    a. I use the term "earmarked" as it was rumored that a local school used special education funds for advanced placement programs and special education at the school suffered as a consequence
3. Encourage 2 year community colleges to offer or increase the number of specialized programs for people on the spectrum. Our community has a great deal to offer if the right training is available.

The overall goal of my agenda is to help people with ASD become as self-sufficient as they can be. I know some young adults on the spectrum, and those who work are much happier than those who don't. They also contribute to, rather than take from federal and state taxes.

Early investments in our community will pay both financial and social dividends. People with ASD are a largely untapped resource of many talents and skills. Many people are unaware of how creative and productive they can be given the right training and accommodation for sensory or other sensitivities.

Thanks to all of you for taking on this challenging work!

Best regards,

Jeffrey Brown
[PII redacted]

John Best **December 15, 2015**

You are hereby ordered to tell the truth. Autism is caused by mercury, most of it from the thimerosal in vaccines. Autism is cured by using alpha lipoic acid to chelate mercury out of the brain.

Asperger's Syndrome is not autism. You are ordered to make that distinction perfectly clear and cease your efforts to obfuscate the truth about the abject horror of autism. The [offensive language redacted]. People with autism cannot speak, read, write or perform any useful function. Stop lying to the public.

For The People,

John Best
Londonderry, NH

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

Eileen Nicole Simon **December 28, 2015**

#22 SOMETHING TO CELEBRATE?

"The transfer of respiratory function from the placenta to the lungs at birth stands out as the most dramatic, complex and important event in our lives. How does this transfer take place? We know that there is often a delay after delivery before breathing commences and that a further interval must pass before pulmonary respiration meets the requirements of the newborn infant. What of the placenta during this time? Does its respiratory function cease at the moment of delivery, or is it maintained until the lungs have assumed their new responsibility?" [from Peter M. Dunn. Developmental Medicine and Child Neurology 1966 Oct; 8(5):607]

Soon after I put up my website conradsimon.org in April 2000, I received many email messages asking how soon after birth [PII redacted]'s umbilical cord was clamped. [PII redacted] was on the other side of the delivery room with a team of specialists trying to help him begin to breathe. Remembering that still causes me much anguish. I was told [PII redacted] was stillborn; but at 8 pounds 11ounces, and kicking strongly during labor? No! He did not breathe immediately after birth. So they clamped off the umbilical cord, and took him to the other side of the room. He did not respond quickly enough. He was pale as a ghost. His blood was all left behind in the placenta. Then he developed severe jaundice, a well-known cause of hearing problems and choreo-athetoid movement disorder. Asphyxia at birth destroyed [PII redacted]'s chance for a normal life. [PII redacted] came into the world physically perfect, but because of injuries at birth developed a classic case of Kanner autism. This is something to celebrate?

#23 APGAR 10

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. 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. 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 auditory pathway may occur. How can clamping the umbilical cord immediately after birth not be considered one of the most serious medical errors of all time? 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. 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.

#24 CITATIONS:

#2 Autism Diagnosis

- Kanner L. Autistic disturbances of affective contact. Nervous Child. 1943; 2:217-250. Reprinted in Acta Paedopsychiatr. 1968;35(4):100-36.
- Rapin I Autism. N Engl J Med. 1997 Jul 10;337(2):97-104.
- Cederlund M, Gillberg C. One hundred males with Asperger syndrome: a clinical study of background and associated factors. Dev Med Child Neurol. 2004 Oct;46(10):652-60.
- Gillberg C, Cederlund M. Asperger syndrome: familial and pre- and perinatal factors. J Autism Dev Disord. 2005 Apr;35(2):159-66.
- Silberman S. NeuroTribes; The Legacy of Autism and the Future of Neurodiversity. New York: Avery Books, 2015.
- Simon N. Echolalic speech in childhood autism. Consideration of possible underlying loci of brain damage. Arch Gen Psychiatry. 1975 Nov;32(11):1439-46.

#3 Metaphorical Speech

- Kanner L. Irrelevant and metaphorical language in early infantile autism. 1946. Am J Psychiatry. 1994 Jun;151(6 Suppl):161-4.
- Broca P. Remarques sur la siège de la faculté du langage articulé; suivies d'une observation d'aphemie. Bulletin de la societé anatomique de Paris 1861; année 36, serie 2, tome 6:330-357. Translated by Bonin G von (1960) in Some Papers on the Cerebral Cortex. Translated from the French and German. Springfield, Ill.: Thomas.
- Wernicke C. Der aphasische Symptomencomplex. Breslau: Franck und Weigert, 1874. Translation: The symptom complex of aphasia, in Cohen RS & Wartofsky MW, eds (1969) Boston Studies in the Philosophy of Science, vol 4, pp 34-97.

#4 Lifespan Care

- Wing L. Asperger's syndrome: a clinical account. Psychological Medicine 1981; 11:115-129.
- Tantam D (1988) Lifelong eccentricity and social isolation. I. Psychiatric, social, and forensic aspects. British Journal of Psychiatry 153:777-782.
- Tantam D (1988) Lifelong eccentricity and social isolation. II: Asperger's syndrome or schizoid personality disorder? British Journal of Psychiatry 153:783-791.
- Szatmari P, Bartolucci G, Bremner R (1989) Asperger's syndrome and autism: comparison of early history and outcome. Developmental Medicine and Child Neurology 31:709-720.

#5 Forgotten Evidence

(1) Asphyxia at birth

- Ranck JB, Windle WF. Brain damage in the monkey, Macaca mulatta, by asphyxia neonatorum. Exp Neurol. 1959 Jun;1(2):130-54.
- Windle WF. Brain damage at birth. Functional and structural modifications with time. JAMA. 1968 Nov 25;206(9):1967-72.
- Lucey JF, Hibbard E, Behrman RE, Esquival FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. Exp Neurol 1964 Jan; 9(1):43-58.
- Myers RE. Two patterns of perinatal brain damage and their conditions of occurrence. Am J Obstet Gynecol. 1972 Jan 15;112(2):246-76.

(2) Blood flow and metabolism in the brain

- Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed
- Sokoloff L. Localization of functional activity in the central nervous system by measurement of glucose utilization with radioactive deoxyglucose. J Cereb Blood Flow Metab. 1981;1(1):7-36.

(3) Maturation of the brain

- Langworthy OR. Development of behavior patterns and myelinization of the nervous system in the human fetus and infant. Contributions to Embryology, 1933; no. 139 24:1-57.
- Yakovlev PI and Lecours A-R. 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, 1967.
- Moore JK, Perazzo LM, Braun A. Time course of axonal myelination in the human brainstem auditory pathway. Hear Res. 1995 Jul;87(1-2):21-31.
- Moore JK, Linthicum FH Jr. The human auditory system: a timeline of development. Int J Audiol. 2007 Sep;46(9):460-78.
- Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity-dependent and activity-independent processes. Cell Tissue Res. 1999 Aug;297(2):187-95.

(4) Auditory brainstem response

- PubMed: auditory brainstem response autism

(5) Language development

- Brown R. A First Language: The Early Stages. Cambridge, MA: Harvard University Press, 1973.
- Conboy BT, Kuhl PK. Impact of second-language experience in infancy: brain measures of first- and second-language speech perception. Dev Sci. 2011 Mar;14(2):242-8.

#6 Research Background

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

#7 Hearing Words

- Suskind D. Thirty Million Words; Building a Child's Brain. New York: Dutton, 2015.

#8 Serotonin What?

- PubMed: inhibitory neurotransmitters

#10 Systems Perspective

- Van Vleck T. The IBM 7094 and CTSS. http://www.multicians.org/thvv/7094.html

#11 Placental Respiration

- Apgar V, Holaday DA, James LS, Weisbrot IM. Evaluation of the newborn infant – second report. JAMA 1958; 168(15):1985-9.

#12 First Breath

- Bruschi T, with Holley M. Never give up : my stroke, my recovery, and my return to the NFL. Hoboken, N.J. : John Wiley & Sons, 2007.

#14 Nucleus Tractus Solitarius (NTS)

- McGinnis WR, Audhya T, Edelson SM. Proposed toxic and hypoxic impairment of a brainstem locus in autism. Int J Environ Res Public Health. 2013 Dec 11;10(12):6955-7000.

#17 Pulsating Cord

- Frischkorn HB, Rucker MP. The relationship of the time of ligation of the cord to the red blood count of the infant. Am J Ostet Gynecol 1939; 38:592-594.

#21 Medical Error?

- Morley GM. Cord closure: Can hasty clamping injure the newborn? OBG Management, July 1998: 29-36.

#22 Something to celebrate?

- Dunn PM. Postnatal placental respiration. Dev Med Child Neurol. 1966 Oct;8(5): 607-8.

#23 Apgar 10

- Mercer JS, Skovgaard RL. Neonatal transitional physiology: A new paradigm. J Perinat Neonatal Nurs. 2002 Mar;15(4):56-75.
- Jäykkä S. Capillary erection and the structural appearance of fetal and neonatal lungs. Acta Paediatr. 1958 Sep;47(5):484-500.
- Hsia CC. Respiratory function of hemoglobin. N Engl J Med. 1998 Jan 22;338(4):239-47.
- McAdams RM. Time to implement delayed cord clamping. Obstet Gynecol. 2014 Mar;123(3):549-52.

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

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

Yadira Calderon **January 2, 2016**

[Attached PII redacted]

Once again I write to share our story as we handle, survive and manage 5 years of autism in our household.

This month is the fifth anniversary of my daughter's full blast regression - ATEC was about 150... about 12 now...

2 developmental peds diagnosed June 2011 (Puerto Rico) - both said autism is medical, treat the medical issues and your child will come back... and my child is coming back!!

Highlights-

- health --- 2 months now and NO barking cough, no getting sick, no drastic behavior changes/aggression/screaming and no fever during full moon - this is huge... for 6yrs this was our reality... ** she sleeps 9-10hrs every night
- social: even more receptive to changes... being out, doing 4 stops and with reminders and motivators we survive them beautifully and she has fun, so do I...
- academic - more reading of sight words - full sentences; big effort being made to sound out words and figure out the mechanics of reading not memorizing; counting backwards from 20, adding bigger numbers
- Verbal - 10 word sentences, more correct verb/pronoun usage; great ideas being shared-imagination galore, very logical at times; continuity of conversation; joker - big time... (her joke: A horse stepped on an egg, [offensive language redacted]!!!) \physical: climbs, jumps, loves to climb fences/poles, learning to do cartwheels - very strong

Sharing what has worked for us last 4 mths - on and off...

1. Attacking individual lyme coinfections with homeopathy -- mycoplasma, bartonella, borrelia, babesia. Also attacking clostridia with homeopathy (used those remedies - Lemke's page has them http://www.sourcehomeopathy.com/[PII redacted])
2. This was a jewel....http://www.iherb.com/Lumina-Health-Cellfood-NuScience-…/7431
3. Another jewel: http://www.iherb.com/Life-Extension-Brain-Shield-60-V…/55651
4. Gaia's tinctures - super jewels.... parasites came out and helped immensely with behaviors-morning and night - before full moon: goldenseal, lemon balm and licorice root
5. Prepared concoction with turmeric, honey, lemon and apple cider vinegar when sick and to support immune system - strong flavor and oh so good...
6. Energy healing with [PII redacted]
7. Gave Lymphonest - on and off last 3mths
8. Cheap probiotic - on and off
9. Herbalogic - Quiet Mind and Fixed Focus with this: Polygala Polygaia Tenuifolia from Herbalist Alechemist ([PII redacted] recommended this one)

** Aug 2014-Sept 2015 - did and loved Cease homeoapthy - with [PII redacted] (detoxed metals, vaccines, ultrasound, labor, steroids, progesterone --- and supported with essential oils, burbur and

anything else that helped with die off (that was [offensive language redacted] intense) this helped big time: http://www.onlynaturalpet.com/…/Newton-Homeopa…/161012.aspx…
* also did ionic foot bath - cheap one from ebay -- tons of [offensive language redacted] came out...
* Key interventions prior to that -- essential oils for 6+ mths; gave cryptolepis for babesia for 3+ mths – [offensive language redacted]; biomed at the beginning for less than 6mths... it was a mess...
* Nutrition - not 100% strict but GFCFSF and everything and their mother free... once in a while take to Chick fil A - french fries, grilled nuggets and their cheapo ice cream -- 90% of the time no tummy/behavior reaction
** between Aug. 22 and Dec. 20 - grew 2 inches and gained 7 pounds

My concerns and plan of action for 2016:
remnants of brain inflammation; mild self-chatter; mild night terrors; dyslexia; night urination; social skills - she's intense, wants interaction in her terms, some kids respond others don't - helping her understand/accept it's OK and keep trying
Hoping finances get better... would love to do Brain Balance or Neurofeedback or Cranial or another kind of Energy/Brain healing...

Videos of how things were:
3yrs ago: https://youtu.be/csbOUvaqGiA
Almost 5yrs ago - full blown regression - awake from 3-5am, jumping
https://youtu.be/nZuxpUDGNgY
Reaching milestones: https://youtu.be/exYmqgDP-os
Our present efforts -- share our survival skills: https://www.youtube.com/channel/UCXZ6lHYL-eg5_5MKLWP8YFg

Future initiatives to address autism must involve all efforts and interests and address parental emotional and physical health.
I was told from the get go... Autism is Medical.... not that Autism is a Mental Illness....
My child is doing incredible because of that message and the country needs to hear from people like us.

Sincerely,

Yadira Calderon and Thomais Moshopoulos

[PII redacted]

Sharing this event:
https://www.facebook.com/events/1492697921025014/
Please join us!

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

Eileen Miller **January 3, 2016**

Subject: Autism-Missing- Method for Searching

In light of the recent death of the autistic boy found in the canal, I would like to propose a plan of action when searching for an autistic child. My name is Eileen Miller, mother of autistic individual [PII redacted]. My daughter was a wanderer/eloper/escape artist. I won't give all of the details, but my husband was also a police officer. This is the method I propose that communities and law enforcement should adopt when searching for a child/adult with autism.

There needs to be a plan of action when a child who has autism, is missing.

There needs to be a 3 pronged approach for searching for an autistic child. 3 different teams with 3 different functions.

#1. Look for/in bodies of water---Look at mud puddles, ditches, canals, lakes, streams....etc.
What common denominator do we have when looking for missing children and they end up dead? WATER!!! WATER!!! WATER!!! What are autistic children/individuals attracted to?? WATER!!!
What is the most IMMEDIATE threat to a child with autism when missing? WATER!!
Their first priority should be the closest bodies of water and work their way outward from there.

#2. The 2nd team should be looking in the immediate area for the child who could possibly be hiding or wandering in neighborhood. Usually reports are not of a child "hiding" but wandering or distracted by something like objects or animals (cat/dog). They should look and listen for clues. That is what an autistic person is doing as they are wandering, what catches their attention!!!

This team should work quickly.

#3. The 3rd team should be searching in a ring further out from the immediate neighborhood to look for wanderer...this team will have more time to look thoroughly and work inward toward the neighborhood where child became missing. Do we read of missing autistic children being abducted? NO!!! Do we read that they were dead because they were hiding? NO!!! We read that they either are dead from exposure (wandering) or the most dangerous threat, WATER!!!

I apologize for being passionate. My daughter is now 30 years old and no longer escapes. We had to have several locks, door alarms on our doors until the threat of her escaping had passed. Over the decades, it tears my heart out to read of missing autistic children often found dead. I think the method of searching for these children is far and away outdated and we need to revise and set a standard for such searches...to be conducted in a manner that eliminates the most serious threats first.

Please consider this, it is such a simple concept that could save lives.

Thank you for your time, attention and consideration

Sincerely,

Eileen Miller- author
The Girl Who Spoke With Pictures
Behind the Pictures
www.thegirlwhospokewithpictures.com
www.autism_behindthepictures.com

[PII redacted]
Eileen Miller
[PII redacted]

Christine Matovina **January 3, 2016**

Subject: Autism Topic

I saw this and thought one of the key issues for autism is for after the age of 18. What then? Employment and housing would be great to focus on for the conference.

Thank you for your time

Christine Matovina

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

Gizelle Tolbert **January 3, 2016**

I am going to send just a "brief" bio about myself and I why I am so passionate and zealous about Autism. I am a single mother of three and my youngest teenage son is autistic. I have had many battles and struggles along the way however have been blessed with assistance from the schools and other services. Is it great, yes, could it be better, of course, however comparing to others, I can't complain.

I am also one of the facilitators of the Facebook page, Bring Avonte Home, which was primary, dedicated to the search and rescue for Avonte Oquendo but three months later his remains were found not far from his school (where he wandered off). That was two years ago and we still kept his page up in his honor so we could have Congress pass the Avonte's Law to provide new grant program within the Department of Justice that will be available to local law enforcement, schools and non-profits that aim to assist children with Autism. The bill will authorize $10,000,000 federal dollars in order to help fund the purchase of voluntary tracking devices for children with ASD, education and training for parents, schools and local law enforcement, as well as other innovative methods that will assist families of children who "wander" with ASD. With this additional funding, families and local entities can work together to find the best possible solution for each individual child with ASD.

Unfortunately, this bill has been sitting in Congress for over a year now and while its sitting there we are losing are kids due to wandering. So the points I would like to be discussed in this committee is the following:

- Make sure Congress passes AVONTE'S LAW ACT OF 2015 (S.163) this year.
- All 50 states need to implement alerts when children and adults who may wander off. Higher want issue the Amber Alert because on was not kidnapped but they need to issue some kind of alert.
- If child or adult to wanders the first place first responders need to search are near waterways, train stations etc. for
- Since time is off the essence send out alerts quickly, first responders and need to be fully equipped. If and when volunteers help to assist with the search and rescue need to use everyone to the fullest and need to be organized (Whether it's in the big cities or the small country towns).
- We also need to address the issues with children with Autism also becomes adults with autism. There are tons of services for the little ones but not enough for when they grow older.
- And last but not least, the next thing besides wandering that has bothered me is how the lack or no training of police official dealing with people who may have mental or disabilities issues and their use of unnecessary deadly force when there are other ways to handle such situations.

FRIGHTENING STATISTICS:

AUTISM & WANDERING

- 49% of children with autism engage in wandering behaviors
- 35% attempt to wander at least once per week
- More than one third of children with autism who wander are never or rarely able to communicate their name, address, or phone number
- 29% of wandering happens from a classroom or school
- 53% of those who exhibited elopement behavior, went missing long enough to cause concern

- 42% of cases involving a child with autism 9 and younger end in death
- Accidental drowning accounts for approximately 90% of lethal outcomes

I would like to thank you for this format and if you need my assistance or have any questions I would be more than happy to do so. I will put my contact information at the bottom of this email.

Gizelle Tolbert
[PII redacted]

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

Donna Jo Kazee **January 3, 2016**

The deaths of autistic adults and children weighs heavily on the minds and hearts of myself and other parents right now. It has been a year of fatal wanderings/elopements and police encounters. We need more training for parents, teachers, therapists, respite workers, and police officers in de-escalating and managing behaviors when dealing with autistic children and adults. Development of this training should include input from individuals with autism, ideally those who have had problematic interactions. We need technologies to assist with wandering and elopement that enable prediction of it and quick recovery of the missing person.

There is an overwhelming need for services. We are hearing about kids who might have autism being diagnosed with Global Developmental Delays, and people with PDD being denied services because they are not deemed "severe" enough. Further, states have incredibly long waiting lists for getting support services and some (like Ohio, our state) are eliminating many programs for adults with autism. We have to have these services to provide as positive an outcome as possible for autistic people, many of whom will need support their entire lives. Parents are facing choices they shouldn't have to face: placing their adult children in residential care or providing full-time care to their adult children who cannot maintain employment. People who do not have the resources to set up trusts and create innovative employment and living circumstances are facing a horrible future for their autistic children.

All this leads to the issue of why there are so many autistic kids in the first place. We have a huge problem that no one wants to fully acknowledge, and it's not getting better. While I could be selfish and ask that all resources go to supporting the current population with autism, I realize that if we can't figure this out, we realistically don't have a future. Please leave no stone unturned in finding out the causes of autism. Subpoena the CDC Whistleblower William Thompson. Investigate the role of vaccines, environmental toxins, and genetic vulnerabilities in this catastrophic situation.

Sincerely,

Donna Jo Kazee
[PII redacted]

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

Kathy Blanco **January 4, 2016**

Subject: Autism, is it caused by glycophosphates, vaccines and nagalase?

As a parent of two adult children with autism/seizures in their thirties and late twenties, I would like to ask the panel if they are prepared to imagine a world where one in two children with autism exists?

For over three decades, Stephanie Seneff, PhD, has researched biology and technology, over the years publishing over 170 scholarly peer-reviewed articles. In recent years she has concentrated on the relationship between nutrition and health, tackling such topics as Alzheimer's, autism, and cardiovascular diseases, as well as the impact of nutritional deficiencies and environmental toxins on human health.

Stephanie Seneff's Home Page - People | MIT CSAIL
[PII redacted]
Stephanie Seneff is a Senior Research Scientist at the MIT Computer Science and Artificial Intelligence Laboratory. She received the B.S. degree in Biophysics in 1968 ...

At a [recent] conference, in a special panel discussion about GMOs, she took the audience by surprise when she declared, "At today's rate, by 2025, one in two children will be autistic." She noted that the side effects of autism closely mimic those of glyphosate toxicity, and presented data showing a remarkably consistent correlation between the use of Roundup on crops (and the creation of Roundup-ready GMO crop seeds) with rising rates of autism. Children with autism have biomarkers indicative of excessive glyphosate, including zinc and iron deficiency, low serum sulfate, seizures, and mitochondrial disorder.

- See more at: http://healthimpactnews.com/2014/mit-researcher-glyphosate-herbicide-will-cause-half-of-all-children-to-have-autism-by-2025/#sthash.ys3Q9hKf.dpuf
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“At today’s rate, by 2025, one in two children will be autistic.” - See more at: http://healthimpactnews.com/2014/mit-researcher-glyphosate-herbicide-will-cause-half-of-all-children-to-have-autism-by-2025/#sthash.ys3Q9hKf.dpuf

In a recent conference, Dr Seneff of MIT told members this exact quote stating by 2025, one in two children will have autism. Her belief is that the synergistic affect of the use of glyphosate glycophosates and vaccinations at today's current schedules will create this disastrous result. For over three decades, her research interests have always been at the intersection of biology and computation: developing a computational model for the human auditory system, understanding human language so as to develop algorithms and systems for human computer interactions, as well as applying natural language processing (NLP) techniques to gene predictions. She has published over 170 refereed articles on these subjects, and has been invited to give keynote speeches at several international conferences.

Her contact information is as follows.
Stephanie Seneff
[PII redacted]

I had my kids before the age of this pesticide which does not explain this synergy to me personally. However I acknowledge all toxic substances can induce an autism synergy inducing affect, when applied at the right time in the right combinations in the right levels, during utero, birth, and infancy. All of which has not been studied in combination, or what I call, and many others call, the perfect storm. The shikamate pathway, described in her lectures were never explored in regards to the gut physiology of a child developing. That pathway, is crucial in the gut for maintaining crucial amino acids in the gut and brain. When not supplied, the brain starves in essence for crucial amino acids and proteins and enzymes. This then, depletes the synthesis of methione, which leads to shortages of neurotransmitters, folate, and other key nutrients for proper brain formation. Vaccines slam the brain, as the last step in ruining many more pathways in the brain including the much needed blood brain barrier and brain stem.

I am asking you invite an FDA member and Dr Senoff to listen and participate in the discussion of such of that synergy. Starting with the FDA at minimum, who admitted thimerosal was toxic and other ingredients in vaccines as key toxicants. We need a toxicity rating scale so parents know what things to avoid in those critical time windows of development.

Secondly, I would like to have a panel explore the nagalase enzyme in vaccines. Doctors are dying, being murdered over what they are revealing! One has to wonder why doctors, who were using GcMAF in the USA and getting dramatic improvement-to-cure rates with patients, have been found DEAD. Without GcMAF, the entire cascade of immune actions cannot be initiated including crucial immune neurological formations. So getting rid of Vitamin D AND introducing Nalgalase assures, absolutely guarantees, that there will be huge numbers of cancers, autism cases and illness and death at every hand from viral and other diseases. Nagalase becomes involved with creating cytokine storms after vaccinations, inflammation, and a host of other chronic diseases like Diabetes, Lupus, Lyme disease, Multiple Sclerosis—especially cancer and heart disease.

Is it any wonder why parents feel your committee has not addressed the concerns of the public, when these two concerns are not brought up, discussed, and a plan of action ensue? This means your committee now has to satisfy this question.

Cocurrently, to reverse that damage, many kids benefit from the use of GcMAF. I would like to have your committee explore this as a viable therapeutic option for newly diagnosed children, and children currently with the autism diagnosis. Are we going to sit on our hands knowing this information, and letting children suffer for their entire lifetimes? I am not along with that program. My kids deserve better!

Apparently, heath 'authorities' really don't want us well; that's an anathema to their string pullers agenda, I guess.
Vaccines and Brain Inflammation
http://www.vaccinationcouncil.org/2011/06/01/vaccines-and-brain-inflammation/
Basics of the Human Immune System Prior to Introduction of Vaccines: Are Vaccines Turning Our Children's Immune Systems Inside Out?
http://www.vaccinationcouncil.org/2011/06/10/basics-of-the-human-immune-systen
Basics of the Human Immune System Prior to Introduction of Vaccines: Are Vaccines Turning Our Children's Immune Systems Inside Out? Part 2
http://www.vaccinationcouncil.org/2011/06/21/risks-damage-basics-of-the-human-immune-system-prior-to-introduction-of-vaccines-are-vaccines-turning-our-childrens-immune-systems-inside-out-part-2/
Do childhood Vaccines Cause Subdural (Brain) Hemorrhages, Currently Diagnosed as Shaken Baby Syndrome, and Other Health Anomalies?
http://www.vaccinationcouncil.org/2011/10/23/do-childhood-vaccines-cause

Please use due diligence in this committee...to actually have a battle plan on how to confront autism.
In summary

1. Lead this council into "how to prevent mode" of autism
2. Lead this council into proper information to parents on toxicity scales
3. Lead this council into proper experts who can stop this epidemic, actual experts who will find a way OUT of autism

Kathy Blanco
Ione California

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- See more at: http://healthimpactnews.com/2014/mit-researcher-glyphosate-herbicide-will-cause-half-of-all-children-to-have-autism-by-2025/#sthash.ys3Q9hKf.dpuf
For over three decades, Stephanie Seneff, PhD, has researched biology and technology, over the years publishing over 170 scholarly peer-reviewed articles. In recent years she has concentrated on the relationship between nutrition and health, tackling such topics as Alzheimer's, autism, and cardiovascular diseases, as well as the impact of nutritional deficiencies and environmental toxins on human health.

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

Holly H. Masclans **January 4, 2016**

Subject: Enough with Genetic Reasearch, Eye Gazing Studies and Awareness

I would like to see the following:

Vaccinated vs Never Vaccinated study with respect to autism
Vaccination's effect on micro-biome
Thimerosal concentration and mitochondrial disease
Listening Therapy's effectiveness for treatment of Auditory Processing Disorder
Magnetic Resonance Therapy for learning, processing and attention
GcMaf's effect on immune system
VICP – justice for all vaccine injured children

Holly H. Masclans
Mother of [PII redacted] and [PII redacted]

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

Michael Kazee **January 4, 2016**

As our son enters high school, I am troubled by the realities of his future and the lessons that seem to have gone unlearned from his past. It seems as if little is being done to provide services to people with autism at all ages, and more and more kids are being diagnosed with it!

I can remember the years we dealt with eloping and wandering. They were some of the most stressful ones, and we had to finally even put locks on our doors to prevent his escape -- something that is totally not OK with emergency and law enforcement. But it kept him in after many sprints into a nearby woods or toward the highway. We need parent education and support and technology to address these and other behaviors that affect some people with autism. We seem to be stuck with the same old unsatisfactory band aids to these situations. Parents have to be able to sit down or go to the restroom and not have to worry that their kid has managed to get away. They need tools to find the kids (and adults) quickly before catastrophe strikes. This is a live-saving, critical technology similar to ventilators and wheelchairs for the people who need it.

Similarly, we need to know why autism rates are increasing, and not just due to better diagnostics. Shouldn't we be carefully tracking how many are being diagnosed with it, severity, expected prognoses, effectiveness of various therapies, and long-term outcomes? Shouldn't we be finding out why there is such a huge increase in a relatively short amount of time? I ask that you look at all factors that might be contributing to autism prevalence, including increased vaccination and environmental factors. Press for Congress to subpoena Dr. William Thompson of the CDC.

Sincerely,

Michael Kazee
[PII redacted]

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

Donna Knepple **January 4, 2016**

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

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

Due to my daughters vaccine injury, I filed for compensation under the National Vaccine Injury Compensation Program dated May 21 , 2003, Federal Register Volume 68, Number 98, Page 27834, #506, Court of Federal Claims #02-1890V. My petition was set forth in a list of an additional 666 petitions received by HRSA on October 1, 2002 through December 31, 2002. At the end of April of 2012, I received my dismissal papers after waiting 9 ½ years; however, the attorneys representing us were paid in excess of $3,900.00. Not only did the NVICP pay attorneys for dismissing thousands of cases they have paid out millions of dollars to a number of children just like my daughter and her fellow petitioners who they grouped under the Autism Omnibus... only they did not mention AUTISM. Now let's add up all the money NVICP paid out on dismissing claims, money paid out to petitioners and the 7 million dollars it cost to try the Autism Omnibus test cases. - UNBELIEVABLE TRAVESTY OF JUSTICE!!!

I have been advocating for my daughter since she entered Early Intervention at the age [PII redacted]. I have been trying to get an appropriate education with related services for my daughter since the very beginning. Our school district recently preferred to throw away approximately one-half of a million dollars in tax payer money arguing over my daughter's educational needs. In all actuality the Board of Education has no ACCOUNTABILITY for any of their wrong doing! The State, County and Town - NO HELP AT ALL. After all of the wasted years I finally have my daughter in an appropriate placement, however, it is only for a very limited time and now she is back in the New York State public educations system! ! ! - UNBELIEVABLE TRAVESTY OF JUSTICE!!!

Helping my daughter overcome her vaccine injury has caused me and my family to lose everything. Needless to say, everything my daughter has had to endure on a daily basis. I can't even find the words to describe this nightmare that we are unable to wake up from and have to live with each day. For the past 10 years I have been a single parent taking care of my daughter, struggling from paycheck to paycheck, living in a small apartment. My saving grace has been the wonderful people in the Autism Community that I have connected with from around the world since 2001. Unfortunately, my story is not all that unique and neither is my daughter's VACCINE INJURY AND INFLAMMATORY BOWEL DISEASE!!!

On the morning of July 29, 2015, on the floor of the House of Representatives, Congressman Bill Posey testified that CDC vaccine safety researcher Dr. William Thompson had reported to Posey's office that he was present for a meeting in which he and his colleagues, all CDC senior-level vaccine and autism staffers, destroyed data which demonstrated a clear link between the MMR vaccine and autism. Dr. Thompson, believing this to be illegal, retained copies of these documents and turned them over to Rep. Posey, along with thousands of others which reportedly show that the CDC has committed extensive and pervasive fraud in its vaccine safety research. Rep. Posey testified to the House, which was broadcast on CSPAN, that he has the documents and will make them available to any member of Congress who asks for them.

These documents have been in possession of the House for more than a year. It is time for a full investigation. - **UNBELIEVABLE TRAVESTY OF JUSTICE!!!**

So here we are again at another Interagency Autism Coordinating Committee Meeting and each year since 2006 we.... MEET. .. TALK... WASTE TIME... WASTE MONEY... DO BOGUS STUDIES and raise AUTISM AWARENESS. Game over... you cannot continue to stall nor hide from the TRUTH... each year you have wasted since the l 990's the more and more children who have become affected and their families... now 1 in 68 which can be as low as 1 in 45! THIS IS NOT A GENETIC EPIDEMIC; THIS IS AN UNBELIEVABLE **TRAVESTY THAT** HAS BEEN BESTOWED UPON OUR CHILDREN AND **THEIR FAMILIES!!!**

ONE CAN ONLY HOPE AND PRAY THAT THE JANUARY 12, 2016 MEETING WILL BE WHAT THIS COMMITTEE WAS SET FORTH TO DO AND THAT IS TO COMBAT AUTISM! !!

In loving memory of Alex Spourdalakis and all of the other children whose lives were lost to Autism.

Respectfully Submitted on January 5, 2016 by,

Donna Knepple

Amended document on 08/19/13 (reflects my son's age on his birthday [PII redacted])
Amended document on 10/20/13 (reflects my son's age on his birthday [PII redacted])
Amended document on 10/30/13 (10/29/13 - IACC Meeting Cancelled)
Amended document on 11/18/13 (reflects next IACC meeting 1/14/14)
Amended document on 01/06/14 (amended next year to this year)
Amended document on 01/04/16 (amended ages, school, apartment location, autism rates and added WHISTLEBLOWER)

Bill and Karen Fuller **January 4, 2016**

Subject: 1 in 45 While you meet

1 in 45 American children are affected by Autism. While you meet. When will it be an emergency? Another young child affected by Autism and drawn to water drowned last week... while you meet. What were the numbers of affected children when this committee was put together? The tsunami of affected are becoming adults...while you meet. Our son has aged out of the school system....while you meet. Meet....Meet....Meet....As the children fall.

Bill and Karen Fuller.

1 in 45 American children are affected by Autism, including our son. Not born with it.

Kristen Festa **January 4, 2016**

I am a mother of a four year old child with ASD who displays some wandering tendencies. I am appalled by the lack of action on the part of the IACC and the government in regards to wandering deaths. We are experiencing a crisis, which will only get worse as more and more children are afflicted with autism. Please address this epidemic. Please work to pass Avonte's law.

Sincerely,

Kristen Festa
Bristol, Connecticut

Heather Price **January 4, 2016**

This is my fourth written comment to the IACC. Because the last IACC meeting was so recent, I am choosing to keep my letter the same with this addition: THANK YOU for having another meeting so soon. The more you meet, the more you will accomplish. The more you accomplish, the more points I can remove from this letter (I don't want to send the same letter next time). Additionally, as far as point 7 goes, please note that the first death of 2016 related to a child with autism wandering has already happened. Moving quickly is crucial. Children with autism are getting older and stronger and more violent. Parents are getting less support, less help, and are more confused about our options.

---

1. The increasing numbers of autism diagnoses among the lowest functioning are not related to better diagnosis or to wider understanding of the condition. Where were the multitudes of nonverbal adults just one generation ago? Where were the folks who couldn't provide the most basic self-care for themselves?

2. To bring about tolerance and understanding, we need more awareness of the dirty, often shunned type of autism. You have the power to make people see ALL types of autism, not just the high functioning.

3. Medicaid waivers need to have portability between states. Parents waiting for residential treatment for their children or placement in group homes for their children are locked into their state. Medicaid waiver wait lists are FAR, FAR, FAR too long. My nine year old son bites strangers, family, and even friends and teachers at school. I want him to have ABA for this and so much more. He's been waiting YEARS. YEARS.

4. There is too much infighting between the vaxers and anti-vaxers. The vaxers wave away any concern about vaccines because "Wakefield was discredited". What about the over ONE HUNDRED studies that DO show a link between vaccines and autism that are NOT discredited? Where is the study that will PROVE that vaccines do not cause autism---- if you as a panel are so certain of it (I count very few people on your panel who are not pro-vaccination)--- then PROVE it with a double blind study that pits the rate of autism in the non vaxed community versus the rate of autism in the vaxed community. While we're at it, why not pit the general health of the vaxed community against the non vaxed community? Where will we see more auto immune illnesses, more type 1 diabetes, more adhd? MMR has been studied somewhat. Thimerosal has been studied somewhat. What about aluminum? What about the HUGE increase in the NUMBER of vaccinations on the current CDC schedule? What about studying the effects of environmental factors on children who have MTHFR? Mitochondrial issues? What about studying the fact that mercury was found in hair samples of children recently diagnosed with autism? Do all diabetics need the same amount of insulin? Do all cancer patients need the same amount of radiation? Then why is it acceptable to give the SAME vaccination, and the same vaccination schedule to a 4 pound newborn and an 8 pound newborn? The last time I wrote I gave you a link showing a study that every time a new vaccine with human DNA was introduced, the autism rate went up starting with children born that year. We need more studies along those lines. EVEN IF WE WILL NOT LIKE THE RESULTS and the entire vaccination schedule needs to be completely revamped. Far too many parents of children with autism have stopped vaccinating. Vaccines are far too dangerous until we can PROVE that vaccines are NOT the cause of the horrendous infant mortality rate in America, along with autoimmune diseases, type 1 diabetes, adhd, and yes…. Perhaps AUTISM.

5. I would like to see parents of those severely affected with autism on the IACC.

6. We need access to hbot, GcMAF, immune therapies, and ABA. Why is insurance coverage so limited for the wealth of treatments we COULD be utilizing? Far too many parents are paying out of pocket for what WORKS to recover our children. Why can't insurance pay for a wealth of options when our children are young and their brains are most malleable? We need cannabis legal in every state, as a valid option for families dealing with autism.

7. Autism is dangerous. Too many autistics are drowning and having daily seizures. Too many autistics are putting their parents and caregivers in the hospital. Treating autism with politically correct "neurodiversity" serves no one. Recognize that it is an epidemic, and recognize that it must be STOPPED. We don't wave away cancer patients with the wand of "physical diversity". We don't want people living with cancer. We want cancer stopped. Same thing.

8. The last percentage I saw showed that 84% of autism research was duplicative in nature. You don't know what parents want to see you research? ASK US! How about an online survey--- one for parents. One for high functioning autistics. One for teachers of those with autism. ASK US what you should be doing.

9. We need more places for young adults to go, as our children age out of the school system. There are more and more children aging out each year. Eighteen through twenty five year olds have limited options. Where are the short term treatment centers where supplements are respected (and prescription drugs aren't PUSHED)? Where parent/autistic chosen diets can be followed? Where individual treatment plans can be made? Where there are NO WAIT LISTS? Aggressive episodes don't patiently wait for the wait list. Daily seizures don't wait for the wait list. We and our children need help NOW. For those able to work, where are the supported work options? Where are the group homes? YES--- there are work options and there are group homes but again----- the wait lists don't help a couple in their sixties in poor health who need to know that their child has a SAFE place to live BEFORE they can no longer care for him.

Thank you for your consideration.

Heather Price
Cleveland, OH
Parent to nine year old twins on the spectrum

Joseph Jackson **January 4, 2016**

My son would not currently have severe "autism" had I not agreed to inject his tiny body with the MANY poisonous cocktails recommended by the CDC. I'm waiting on this committee to get their [derogatory language redacted] and do SOMETHING ABOUT IT. How many times will you hear the SAME STORY over and over again before you do something PROACTIVE and start PREVENTING this [derogatory language redacted] nightmare for other families? What will it take? Maybe when you watch it happen to your child....your grandchild? I hope that is not what it will take for you to come to appreciate your position on this committee and get busy. Start LISTENING to the broken record being played at EVERY SINGLE [derogatory language redacted] MEETING.

"I would like 2016 to be the year when people remember that science is a method of investigation, and NOT a belief system." John Cleese

Yours Truly,
Joe Jackson

Jill Rubolino **January 4, 2016**

AIM
Autism Is Medical
Jill Rubolino
Jeanna Reed
Nikki Tomczak

Our nonprofit organization respectfully requests our public comments be added to this meeting's agenda and disseminated to the committee members, as well as posted on the IACC website for viewing.

AIM, Autism Is Medical, is a nonprofit organization that works diligently to bring awareness to the complex medical needs of the autistic patient population. We have personally attended this committee meeting in the past to provide oral comments, as well as submitted public comments. Moving forward, we will be addressing this committee and its members as an organization that is actively seeking accountability for all agencies contributing to determination of funding, research and development of a strategic plan to address the exponentially growing numbers of children and adults with autism. The emergent need for appropriate standards of care to address their complex medical needs and appropriations of funding directed to relevant research and initiatives to accomplish this goal is our primary directive.

Our action items in addressing the committee members focus on accountability and the urgent need for the development of a medical standard of care.

Accountability

Accountability and transparency are imperative as this committee controls funding of research that should translate into real and relevant help for those affected by autism. Dollars spent should relate to productive interventions and improvements in outcomes for this large patient population. Programs to improve access to appropriate medical care are nonexistent and research dollars continue to be funneled into areas that cannot provide the support in any area of health care that is so desperately needed by all affected by autism.

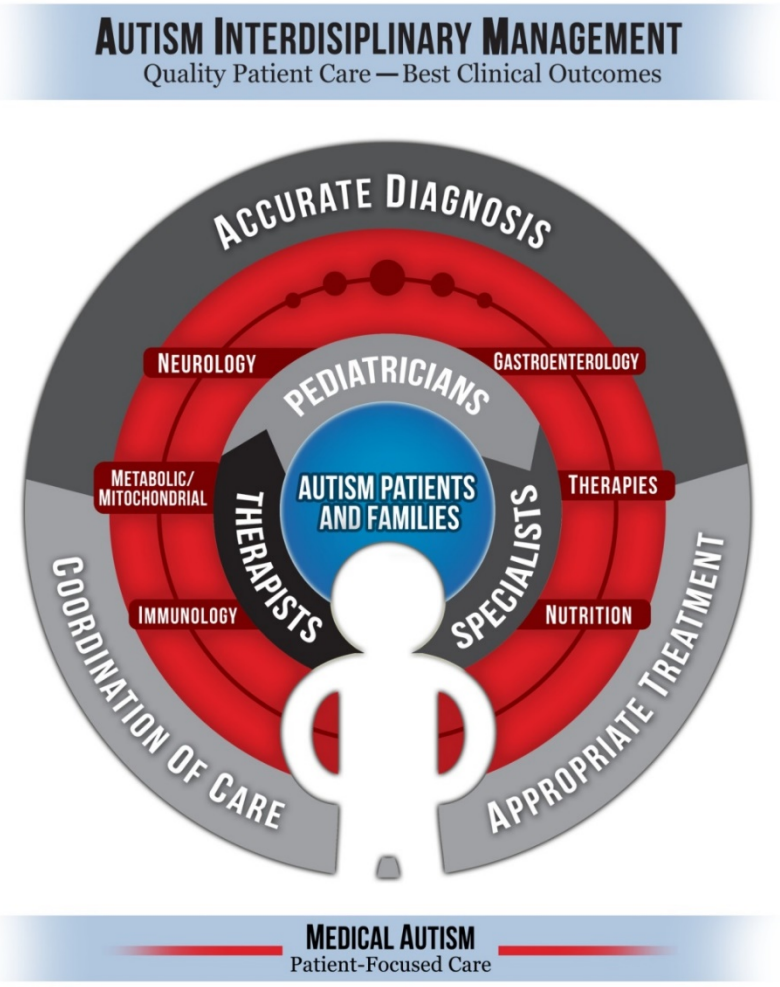
This committee exists to serve these very same individuals and will be held to that standard by our organization, as well as thousands of parents who support this desperate call for real help, right now. By participating as a committee member, you are willingly declaring your commitment to serving this community in a way that is needed most by the individuals that are affected, and that is your only priority. Accountability of members of this committee as individuals, is to serve with the best interest of these individuals at the forefront of all that they contribute. This committee has a moral, ethical, financial and legal obligation to utilize the funds available to serve this community in the most appropriate fashion. Misappropriation of funds directed towards research in areas that are oversaturated with previously funded studies will not be tolerated by the thousands of children and adults that you serve. Please make this a priority for you personally. May you internalize this fundamental commitment to serving the **entire** community of individuals affected by autism.

We at AIM, make a commitment to holding this committee accountable to its primary directive and have an expectation that their strategic plan, and activities throughout the year, include a focus on the

desperate need for an appropriate medical standard of care, and open access to health care by all persons affected by autism.

Medical Standard of Care

"Autistic patients should have the same access to an appropriate diagnostic investigation of their health problems as all other patient populations. Patient centered focused care is the standard of practice in all settings and we will continue to promote the inclusion of this large group of medically complex individuals." – Autism Is Medical



The urgent need for a medical standard of care for all people affected by autism is the driving force for our organization. This committee has, in the past, hosted multiple medical experts as well as members of the American Academy of Pediatrics, who have presented comprehensive information indicating that early medical diagnostic testing, accurate diagnosis and appropriate medical interventions greatly improve both the health outcomes and functional status of these individuals. We are adamant in requesting that research and program dollars be allocated to develop this medical standard of care and that it be disseminated to all practicing physicians, pediatricians, primary care practitioners, and

specialists. It is imperative that this patient population have **the same access** to **the same health care** as all other patient populations. Many children and adults with autism have complex medical conditions that go undiagnosed as they are labeled on the "autism spectrum", and are not appropriately assessed by practitioners. They are not given any diagnostic evaluation for their health issues and these undiagnosed medical problems are left untreated while the child or adult has a decline in health and worsening of their autistic symptoms. Many of these medical conditions have treatment protocols that would greatly improve and even reverse both their health issues as well as their autistic symptoms. By not incorporating this important information into your strategic plan, you are essentially eliminating the chance of greatly improved outcomes for potentially thousands of children and adults diagnosed with autism.

Most practitioners are uneducated in the underlying, sometimes complex, medical problems affecting this patient population. Failure to diagnose and failure to treat is medical negligence and malpractice by all standards of care and can and will be litigated appropriately. A mitochondrial disorder that remains undetected while the child's health declines and their "autistic" symptoms spiral out of control, will no longer be tolerated as acceptable losses while the AAP and this committee turn a blind eye to the thousands of children that suffer from mitochondrial disorder induced autism. The basic initial step of comprehensive medical assessment made for EACH AND EVERY PERSON WITH AUTISM, must not be replaced with complacency in the medical neglect of this exponentially growing patient population.

Our organization exists today as a result of this very failure of our system and we are committed to ensuring that this medical standard of care is developed and utilized for all persons diagnosed on the autism spectrum.

Comprehensive diagnostic evaluation and appropriate medical treatment is the standard of care. It can and will be utilized for every patient with autism. Common medical problems include gastrointestinal disorders, immune dysfunction, neurological disorders and mitochondrial/metabolic disorders. Patient focused care is the national standard and is endorsed by every federal and state agency and every private practitioner association. Development of a medical standard of care and implementation of the patient centered care model for these individuals is every patient's right. It is the responsibility of this committee to allocate funds and identify this as a priority.

Respectfully,

Jill Rubolino, RN, PCCN
Co Founder/ Co Director
Autism Is Medical
www.autismismedical.com

Chanda Jackson **January 4, 2016**

When will this committee make a real effort? This committee has clearly wasted a great deal of time.

PLEASE DO NOT spend another year blowing $50 million on early diagnosing and early behavioral intervention research. We are NOT going to early diagnose our way out of this man-made nightmare. Even with an excellent early interventions, only 17% lose their diagnosis. Early behavioral interventions are highly effective for kids ALREADY high-functioning to begin with. There are 11,000 studies on learning the signs and early intervention. MOVE ON.

I want to see this committee invest in comprehensive environmental prevention science and biomedical autism research and treatment trials. Research aimed at finding purely genetic causes for autism is a WASTE of resources, especially after William Thompson's released statement regarding his involvement in a cover-up at the CDC omitting data that showed African American boys who receive the MMR vaccine before 36 months had an alarming increased autism rate.

I'm a broken record every time I submit a comment to this committee and based on your lack of action, I know my comments fall mostly on deaf ears. I recall Colleen Boyle stating at one meeting (after a young lady poured her heart out about her brother's vaccine injury), "Sometimes people hear something over and over again and they start to believe it." I'm still waiting for that from this committee. VACCINES ARE LEADING OUR CHILDREN TO AN "AUTISM" DIAGNOSIS.

We can stop calling it autism and start calling it by its real name. Vaccine injury. My son was vaccine injured. I will continue to educate families of the risks of following the CDC's recommended schedule ……vaccine induced autism. It's real whether you like it or not. The truth doesn't care what your opinion is.

1 in 45. One in forty-five.

Chanda Jackson

Wapakoneta, Ohio

Shannon Primer **January 5, 2016**

Subject: Autism

As a parent of a 14 year old with autism, I am saddened by this committees lack of doing ANYTHING to help families like mine. We are now at 1 in 45 children have autism. 50% of our kids wander and the number one way they die is by wandering.

What is it that this committee does?

What is the plan for the future when the nonverbal children like mine need housing and taken care of after their parents and siblings are gone? My child with autism is the youngest of 4, he will most likely be left to his nieces and nephews to be cared for. That fact scares me since the stats say by 2025 we will have 1 in 2 people with autism. Who will care for them, who will foot the bill? How will you leave your legacy on this committee on helping families like ours? Doing the hard this is never easy, but you each still have a choice to be part of the solution or continue to be part of the problem. I am asking you to step up and actually do something.

Shannon Primer

Mary Bornstein **January 5, 2016**

I have a 14 year old nonverbal child with autism. He is always on the run! I have a 6-foot fenced in yard for the back of my house. I have put keyless locks on my doors. I am on high alert all day and night but there are still instances that he gets out and runs to the neighbor's house. We have gotten him within 30 seconds. I have alerted my neighbors that he may wander. We just moved because we lived close to the highway and we were afraid he would go there. Listening to the stories of the 30 children who have died this year since June 2015 makes me totally paralyzed with fear. What if my son is next? Please help us keep our children safe. For those without a child with autism one might think we are just not keeping a close eye. Quite the opposite. However, children with autism many times wander and most importantly don't respond to their names, or calls for help. They don't go ask for help instead they sit and hide and most often die by drowning or frost bite. I have been talking with my child saying that he should ring someone's doorbell if he is ever lost. Would he? And even if he did if no one answered would he just sit down and hide in a small space and no one would find him. Please support gps technology for our kids before another one is gone.

Thank you,

Mary Bornstein Tolland, CT

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

Eileen Nicole Simon **January 5, 2016**

#25 NEW NORMALS?
Precocious puberty? Perusal of PubMed shows this is often associated with brain injury. Not just autism, but childhood obesity, allergies, attention deficit disorder, school failure (dyslexia) seem to be on the increase. Why? What is causing so many childhood disorders and disabilities?

Again I would appreciate the opinion of members of the IACC who are pediatricians, neurologists, or medical researchers. Parents (like me) cannot be stopped looking for answers, and we hope for genuine discussion, not a brief brush-off.

Gastrointestinal disorder is a priority issue. But isn't the leaky-gut theory simplistic? Brain pathology in autism is specific for: language disorder, repetitive movements, and diminished level of awareness. Distinctive circuits are affected, not the brain as a whole. What circuits and why?

The nucleus tractus solitarius (NTS) in the medulla appears to regulate autonomic functions like heart rate, breathing, and intestinal peristalsis. Another brainstem site controls satiety, and prevents overeating. Hypothalamic circuits are activated with maturation of the sex organs. But where is the neurologic damage that is causing premature development of the reproductive system, as early as age 6 or 8? There must be metabolically active brainstem control centers (in addition to the NTS) that are less visible than relay nuclei in the auditory pathway.

In a previous comment (#23) I described how brain damage might occur with an Apgar score of 10. Clamping the umbilical cord immediately after birth leaves a large volume of blood behind in the fetal respiratory system (the placenta). Blood must then be drained from other organs to fill the capillaries surrounding the alveoli. After birth the lungs have highest priority. Subsequent brain pathology is less predictable.

#26 MONKEY EXPERIMENTS?
If the research of WF Windle and RE Myers is considered to be too old, can I suggest trying to replicate their findings in a new series of experiments on asphyxia at birth? Animal rights protesters may object, but asphyxia at birth involves little more than what obstetricians are doing in delivering human infants. Windle began by delivering the infant head into a saline-filled surgical glove, then clamping the umbilical cord. In later experiments he performed Cesarean section, but left the newborn monkey in the amniotic sac, and clamped the cord. Asphyxia could not be prolonged for more than 8 to 12 minutes, or resuscitation failed to revive the infant monkey.

We all learn in CPR class that resuscitation must occur within 4 to 6 minutes at most. The idea is false that infants can withstand longer periods of oxygen deprivation.

MRI scans can now be done to examine the short- and long-term effects of asphyxia on the brain. Sacrificing the experimental animals is no longer necessary. All aspects of development can now be observed and correlated with changes in MRI scans of the brain.

Windle and his colleagues made many movies of monkeys allowed to survive for months or years before being sacrificed to look for neuropathology. These movies are kept in an archive at the University of

California at Los Angeles (UCLA). I have spoken to Dr. David Amaral about this archive, and urged him to go there and view the movies.

I hope Dr. Amaral will attend the IACC meeting in January, and that he will discuss my comments. I hope he will consider trying to replicate Windle's research.

#27 MORE CITATIONS:

- Ming X, Patel R, Kang V, Chokroverty S, Julu PO. Respiratory and autonomic dysfunction in children with autism spectrum disorders. Brain Dev. 2015 Jul 30. pii: S0387-7604(15)00134-5.
- Odd DE, Gunnell D, Lewis G, Rasmussen F. Long-term impact of poor birth condition on social and economic outcomes in early adulthood. Pediatrics. 2011 Jun;127(6):e1498-504.

#28 SEASON OF SORROW

I hoped to come to Bethesda for the IACC meeting on January 12, and therefore began to prepare a 3-minute presentation. My husband pointed out a few years ago that a 3-minute talk would be about the length of the Gettysburg Address. The Gettysburg Address is 274 words long, and with this in mind I began work on a comment of about this length. But then I had more to say than would fit into one comment...

After the IACC meeting in November I entered my annual season of sorrow. December 20 would have been my son [PII redacted]'s 52nd birthday. My mother died on Christmas day in 1994; [PII redacted] died not quite 3 weeks later from Thorazine prescribed by a psychiatrist at 1500 mg per day (at 3pm, 7pm, and hour of sleep). He refused to take the pills, so they crushed them (a no-no) and mixed them in his favorite dessert, chocolate pudding.

The "neurodiversity" movement is for me the last straw!!!

It is incomprehensible to me that medically trained pediatricians, psychiatrists, and even neurologists could in any way acknowledge or embrace this movement.

Claims of an autism diagnosis made only when someone is in college is preposterous, unless pediatric records can be obtained that reveal a delay in language development.

Schizophrenia in the past was a romantic diagnosis feigned by admiring imposters. But then their complaints about care led to the "Mental Patients' Liberation Front" movement, and eventual closure of asylums for people with severe debilitating mental illnesses. Where are the most severely mentally ill people now? Homeless and on the streets?

"Social disorder" without language delay is a different kind of "autism" than what the IACC was intended for. Funding for a separate federal committee should be sought to address the completely different problems of this group of people.

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#29 THE INFERIOR COLLICULUS

Everyone in the whole world should know the importance of the inferior colliculus (plural colliculi). Why? The inferior colliculi are a small pair of auditory relay centers in the midbrain. How could this hidden area possibly be compared in importance with the evolutionary pinnacle of the language circuits in the cerebral cortex?

For starters they are, during gestation, the earliest structures of the brain to become fully myelinated, and into neonatal life and early childhood they produce neurotransmitters that guide maturation of the language areas.

Loss of the ability to understand spoken language has been described following injury of the inferior colliculi in several case reports. This is referred to as "verbal auditory agnosia" or "word deafness" in the reports cited below. How much more serious this should be for an infant who has suffered damage to the inferior colliculi during a difficult birth.

Isabelle Rapin referred to the language disorder in some cases of autism as "verbal auditory agnosia" based on an inability to comprehend syllable and word boundaries.

William Windle, in experiments with monkeys more than 50 years ago, discovered selective severe injury of the inferior colliculi caused by a brief period of asphyxia at birth. This damage was not immediately evident, but found only on the advice of Seymour Kety.

In experiments with radioactive tracers, Kety had discovered that blood flow in the inferior colliculi is higher than anywhere else in the brain. His student, Louis Sokoloff, used a radioactive analogue of glucose, which confirmed that aerobic metabolism is higher in the inferior colliculi than in any other anatomical structure of the brain. The papers of Kety (1962) and Sokoloff (1981) are both free online. Ladislav Fisch pointed out that the auditory system is the vigilance center of the brain. Fisch, and audiologist also wrote many papers on language comprehension.

Derek Denny-Brown proposed that the midbrain tectum, superior (visual) and inferior (auditory) colliculi may comprise the seat of the physiological "ego" or the conscious state. The paper by Denny-Brown (1962) is free online.

#30 VERBAL AUDITORY AGNOSIA (WORD DEAFNESS)

(1) Case reports

- **Poliva O**, Bestelmeyer PE, Hall M, Bultitude JH, Koller K, Rafal RD. Functional Mapping of the Human Auditory Cortex: fMRI Investigation of a Patient with Auditory Agnosia from Trauma to the Inferior Colliculus. Cogn Behav Neurol. 2015 Sep;28(3):160-80.
- **Kimiskidis VK**, Lalaki P, Papagiannopoulos S, Tsitouridis I, Tolika T, Serasli E, Kazis D, Tsara V, Tsalighopoulos MG, Kazis A. Sensorineural hearing loss and word deafness caused by a mesencephalic lesion: clinicoelectrophysiologic correlations. Otol Neurotol. 2004 Mar;25(2):178-82.
- **Pan CL**, Kuo MF, Hsieh ST. Auditory agnosia caused by a tectal germinoma. Neurology. 2004 Dec 28;63(12):2387-9.
- **Musiek FE**, Charette L, Morse D, Baran JA. Central deafness associated with a midbrain lesion. J Am Acad Audiol. 2004 Feb;15(2):133-51
- **Hoistad DL**, Hain TC. Central hearing loss with a bilateral inferior colliculus lesion. Audiol Neurootol. 2003 Mar-Apr;8(2):111-3.

- **Vitte E**, Tankéré F, Bernat I, Zouaoui A, Lamas G, Soudant J. Midbrain deafness with normal brainstem auditory evoked potentials. Neurology. 2002 Mar 26;58(6):970-3. (2 cases)
- **Masuda S**, Takeuchi K, Tsuruoka H, Ukai K, Sakakura Y. Word deafness after resection of a pineal body tumor in the presence of normal wave latencies of the auditory brain stem response. Ann Otol Rhinol Laryngol. 2000 Dec;109(12 Pt 1):1107-12.
- **Johkura K**, Matsumoto S, Hasegawa O, Kuroiwa Y. Defective auditory recognition after small hemorrhage in the inferior colliculi. J Neurol Sci. 1998 Nov 26;161(1):91-6.
- **Hu CJ**, Chan KY, Lin TJ, Hsiao SH, Chang YM, Sung SM. Traumatic brainstem deafness with normal brainstem auditory evoked potentials. Neurology. 1997 May;48(5):1448-51.
- **Meyer B**, Kral T, Zentner J. Pure word deafness after resection of a tectal plate glioma with preservation of wave V of brain stem auditory evoked potentials. J Neurol Neurosurg Psychiatry. 1996 Oct;61(4):423-4. Free PMC Article
- **Nagao M**, Kita Y, Kamo H. Haemorrhage in the inferior colliculus. Neuroradiology. 1992;34(4):347.
- **Jani NN**, Laureno R, Mark AS, Brewer CC. Deafness after bilateral midbrain contusion: a correlation of magnetic resonance imaging with auditory brain stem evoked responses. Neurosurgery. 1991 Jul;29(1):106-8; discussion 108-9.
- **Howe JR**, Miller CA. Midbrain deafness following head injury. Neurology. 1975 Mar;25(3):286-9.

(2) Verbal auditory agnosia in autism

- **Rapin I**. Autism. N Engl J Med. 1997 Jul 10;337(2):97-104.

#31 VIGILANCE CENTER, SEAT OF THE PHYSIOLOGICAL "EGO"?

(1) Vigilance center of the brain

- **Fisch L.** The selective and differential vulnerability of the auditory system. In: Sensorineural hearing loss. Ciba Found Symp. 1970:101-26.

(2) Seat of the physiological ego (or élan vitale)?

- **Denny-Brown D**. The midbrain and motor integration. Proc R Soc Med. 1962 Jul;55:527-38. Free PMC Article

(3) Asphyxia at birth, brain metabolism, and brain maturation (listed in #24):

- Ranck & Windle (1959), Windle (1969), Lucey et al. (1964), and Myers RE (1972).
- Kety SS (1962) and Sokoloff (1981).
- Langworthy OR (1933), Yakovlev PI & Lecours A-R (1967), Moore JK et al. (1995), Moore JK & Linthicum FH Jr. (2007), and Friauf E & Lohmann C (1999).

#32 COMMENT SUMMARIES

#1 Thank you to John Elder Robison and Alison Singer for responding to my comments.

#2 Autism diagnosis and even Asperger syndrome are disorders of language development.

#3 Metaphorical speech was Kanner's description of echolalic speech, which he understood only by asking parents.

#4 Lifespan care will be required for my savant son, but he does not fit the "recovery is real" goal of psychiatric care, and is at risk of becoming homeless.

#5 Forgotten evidence includes neuropathology caused by asphyxia at birth, metabolism in the brain, brain maturation, and auditory dysfunction in autism.

#6 Research background of a parent viewed by professionals as lacking in technical expertise.

#7 Hearing words is the basis for language development, the defining characteristic of the human species.

#8 Serotonin what? And what is it that everyone thinks they know about this neurotransmitter?

#9 Wrong ideas? And what do "neurodiversity" experts want to teach me about disabling developmental language disorders?
#10 Systens perspective is the background I bring to understanding the brain as an interrupt-driven seat of consciousness to multiplexed signals from the outside world.
#11 Placental respiration is the fetal respiratory system, which does not cease at the moment of birth.
#12 First breath after birth cannot be accomplished until blood from the placenta fills the capillaries surrounding the alveoli.
#13 Autonomic functions are controlled from brainstem centers that are among the metabolically most active sites in the brain.
#14 Nucleus tractus solitarius controls heart rate, respiration, and perhaps intestinal peristalsis.
#15 Neonatal circulation includes blood flow to and from the placenta, which is abruptly terminated by clamping the umbilical cord.
#16 Cord clamping is now a standard protocol, although traditional textbooks taught that pulsations of the cord should cease before tying the cord.
#17 Pulsating cord indicates that blood flow to and from the placenta is ongoing after birth, and that the fetal heart valves have not yet closed.
#18 Blood banking has been an industry since the 1930s. Could the avant garde parents of Kanner's 11 first cases of autism have consented to cord blood banking?
#19 Male vulnerability to asphyxia at birth is because aerobic metabolism is higher in males than females.
#20 Neonatal resuscitation is required for about 15% of all newborn infants, and is accomplished by external ventilation of the lungs.
#21 Medical error? No evidence of health benefit can be put forth for clamping the umbilical cord before placental circulation has completely ceased.
#22 Something to celebrate? Transfer of respiration from the placenta to the lungs is the most dramatic, complex and important event in our lives.
#23 Apgar 10 provides evidence of satisfactory onset of respiration at birth, but after amputation of the placenta, may be achieved by blood drained out of other organs.
#24 Citations to the medical literature, old and new, on autism diagnosis, language development, brain maturation, and metabolic hierarchies in different brain areas.
#25 New normals? Precocious puberty, obesity, allergies, hyperactivity disorder, difficulties in school are epidemic, and should be a cause of concern.
#26 Monkey experiments? New experiments on asphyxia at birth should be undertaken, and MRI used to examine the brain.
#27 More citations on autonomic disorders in autism, and long-term outcomes of poor birth condition.
#28 Season of sorrow. The "neurodiversity" movement is undermining the original goal of the IACC, to uncover causes of autism and its increasing prevalence.
#29 The inferior colliculus metabolically the most active site in the brain, essential for comprehension of spoken language. Seat of the conscious state?
#30 Verbal auditory agnosia case reports.
#31 Vigilance center of the brain, site of the physiological "ego"?
#32 Comment summaries for topics submitted for discussion by members of the IACC.
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Nicole Cassidy **January 5, 2016**

I am writing on behalf of my daughter, [PII redacted] who is a [PII redacted] diagnosed with Autism Spectrum Disorder. [PII redacted] was diagnosed with Autism four days before her [PII redacted]. During the past year she has gone from being nonverbal and still in diapers to being verbal albeit with severe apraxia and somewhat toilet trained. The reason for her success thus far is due to all of the members of her team from Early Intervention, her private school, teachers, therapists, family and friends.

Autism is an epidemic with an incident rate of 1 in 45. Girls are still underdiagnosed and no research has been done on girls with autism as the focus has been on boys. We really need the agency to do something about the rate of autism, improve access and funding for vital therapies (not just ABA but PLAY Project and Floortime as well). There is an incredible gap in services for adults with autism as well. Medicaid waiver wait lists are extremely long. We were told by the county and state DD that our daughter would have to wait 25-30 years before she could get a waiver. If we had waiver funding now it could cover intensive therapies not covered by our health insurance and school system. The earlier the therapy the more successful the child is as an adult.

Thank you for your time,

Nicole Cassidy

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Dwight Zahringer **January 5, 2016**

As a "newer" parent of a child of autism I need help. Over the past 18 months I have been on a roller coaster of a ride locating resources, navigating insurance and providers trying to get my son the support I "think" would help him. I've been through 6 doctors now and have been told that we should plan on the reality of him being placed in a home in the next 10 years. This same Dr, an accredited pediatric neurologist in metro Detroit, now relocated in Providence, RI also tried to comfort my wife and I by saying not to worry, the homes are much better and most are not institutional. He then recommended for my son to take a medication that has a side effect of stroke. So much for empathy.

Autism should not be a new-found business model made for profit.

New parents of autism need help. We need resources. We need a guide and compassion, empathy to help get to a point of acceptance and reality at which I am just now entering after 18 months.

We need answers as to what could of happened and who to see to get the bio tests, blood tests, DNA tests and other neurological tests to establish a REAL baseline of what could be going on. We do not need to be preyed upon by big Pharma or businesses who's only real reason to befriend us is to maximize the insurance benefit they can get in a calendar year.

In November I watched the entire meeting via webcast and was disappointed for a few reasons. I am happy there is now a group in place ready to work however, are they ready to work for the public, parents like me and my son or geared more towards their own personal motives. I sat for the second half after public comments and listened as each board member introduced themselves and ⅔ of them gloated about personal and professional backgrounds. It appeared more like the seat they were on was to secure more credibility and disability for individual causes or to publicize a grant or monetary gain for research. I believe more time could of been spent on collectively discussing what areas the collectively think need real focus and budget associated with.

I would also like to see the foundation of accountability and complete transparency in regards to the funding and research they are proposing. I want to see this committee become the advocate for my son and others on the spectrum working to improve appropriate medical care and services for the entire autism community. This is your obligation by sitting on this committee.

All of you are to be accountable for the actions of the committee, the execution of the strategic plan and the use of all funding provided by the federal government.

Comprehensive diagnostic evaluation and appropriate medical treatment needs tone the standard of care for the autism community. It can and will be utilized for every patient with autism. Common medical problems include gastrointestinal disorders, immune dysfunction, neurological disorders and mitochondrial/metabolic disorders. Patient focused care is the national standard and is endorsed by every federal and state agency and every private practitioner association. Development of a medical standard of care and implementation of the patient centered care model for these individuals is every patient's right. It is the responsibility of this committee to allocate funds and identify this as a priority.

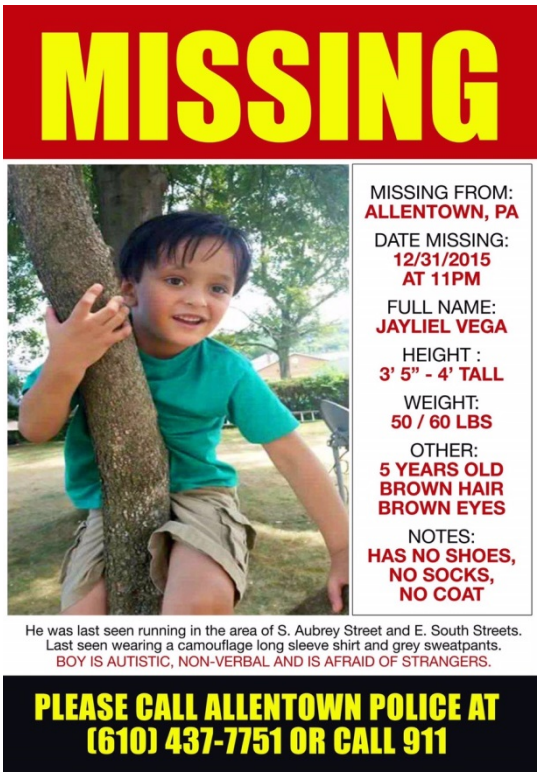
Lastly, I challenge the IACC committee to uncover the truth of information from the whistleblowers that worked at the CDC in relevance of autism being linked to vaccines. The public needs the truth and would also allow more pathways to understanding why and how autism occurs.

Dwight Zahringer
[PII redacted]

Lea Googe **January 5, 2016**

Subject: IACC Needs to address wandering

The autism community has also experienced tragedy. Individuals with autism are wandering and dying. Already in 2016, Jayliel Vega Batista wandered on New Years Eve and died. He was only 5.This could have easily been my [PII redacted] with autism.



Avonte's law needs to be passed. Avonte's law is named for another child diagnosed with autism, wandered and drowned (8.) Avonte's law is an important bill that needs to move forward. In summary, it is a proposed Federal bill that would allocate $10,000,000 to work towards education and prevention of autism and wandering. More details on the bill can be found here: https://www.congress.gov/bill/114th-congress/senate-bill/163 http://autismsafetycoalition.org/take-action/

Regards,

Lea & Joey Googe
Plano, TX

Lisa Ackerman **January 5, 2016**

We kicked off the new year with another autism and wandering death. Jayliel was only 5 years old. 49% of individuals with autism wander from safe environments. Every life matters. Children with autism need protection. We need the IACC to act on behalf of families living with autism and keeping children safe. Please take the initiative to help families by pushing support of Avonte's Law and demanding action for the families you serve (1.)

The IACC committee needs to be aware they have a lot of catch up to do. Families are not impressed with efforts (2.)

Once again, I will ask the IACC to activate committees to perform work on the most pressing issues facing families. After serving the autism community for 15 years and working with over 45,000 families, I see areas of needs that can and should be addressed. Here is a summary of changes that can help families living with autism:

- Based on CDC autism estimates, declare autism an epidemic and public emergency. We need to treat autism with the urgency it warrants: 1in 68 children are living with autism in the United States. With the new 1in 45 parent survey we know this number is sadly outdated (3.)
- Define and collect a true census of individuals affected by autism. It is important to indicate that four year old estimates based on survey samplings do not work. Real numbers and details such as age groups and severity are urgently needed to review and address their unique needs.
- Push for subtyping to determine appropriate treatments and therapies to meet the unique needs of each individual (4.)
- Since 2006, over $2 billion has been spent on the IACC. Families are not experiencing any changes to services or help for these costs. No innovative treatments have been found. I would like to propose the following changes to the IACC:
    - Consider a more diverse board at the IACC to include some of the world's researchers in cause and innovative treatment such as: Dr. Martha Herbert, Dr. Jill James, Dr. Richard Frye, and Dr. Dan Rossignol. It is my opinion that the current IACC board lacks in ground-breaking research and medical treatments happening today
    - Push the U.S. Dept. of Human Health (HHS) and IACC to collaborate and recognize the needs for services and support for families. We cannot operate in a vacuum.
- Collaborate with families via support groups in identifying needs for those living with the autism today.
- Outside traditional therapies, medical treatments are helping individuals with autism live healthier. Based on new research, co-morbid medical issues exist with autism. Where are the initiatives addressing these concerns to define answers? (5.)
- Identify a task force to address the current and future needs of adults living with autism.
- Prioritize and evaluate all possible environmental causes of autism.
- Operate with a sense of urgency in your strategic plan and committees. We cannot waste another moment. We must drive for answers.

We need help for families and individuals living with autism. We can no longer afford the status quo.

We now need to strive to drive positive change for families living with autism. They need you to step up and make a difference.

Sincerely,

[PII redacted]

Lisa Ackerman

TACA

References:

1) https://www.congress.gov/bill/114th-congress/senate-bill/163
   http://autismsafetycoalition.org/take-action/
2) IACC TACAnow biogs:
   http://tacanowblog.com/2016/01/04/the-iacc-needs-to-address-autism-and-wandering-how-can-parents-help/
   http://tacanowblog.com/2015/08/07/why-would-a-government- panel question-universal-autism-screening/
   http://www.tacanow.org/blog/what-the-iacc-must-consider/
   http://www.tacanow.org/blog/the-iacc-reconvenes/ http://www.tacanow.org/blog/what-constitutes-an-emergency/
   http://tacanowblog.com/2013/12/31/if-the-iaccs-strategic-plans-were-ieps-would-they-be-in-non-compliance/
   http://tacanowblog.com/2013/09/09/iacc-jul y-2013-meeting-recap/
3) Autism prevalence http://www.tacanow.org/news/cdc-releases-autism-prevalence/
   http://tacanowblog.com/2015/11/13/autism-is-now-1-in-45-wil/-anyone-listen/
4) Subtypes in autism http://tacanowblog.com/2014/04/11/science-and-subtv pes-in-autism/
5) Children with autism have other health problems http://tacanowblog.com/2012/10/15/man y-children-with-autism-have- other-health- problems/

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

Heather O'Neill **January 5, 2016**

My name is Heather O'Neil and I am a parent to a 4 year old boy with autism. Since his official diagnosis in [PII redacted], I have immersed myself in literature, studies, advocacy groups, etc. in order to learn more about the neurological illness that my son was suffering from. I write to the committee today in order to voice our support for passing S.163 Avonte's Law, which will reduce the risk of injury and death relating to wondering behaviors in individuals with autism and other disabilities. Recently I became aware that although many of our children and adults with autism suffer from the same symptoms as those individuals with Alzheimer's, there is no federal support to prevent deaths.

This past November, the CDC estimated that 1 in 45 American children have autism. Due to the ever increasing prevalence rate, the federal government needs to enact changes and programs now that will prevent injuries and deaths amongst the autistic community. Not only does Avonte's Law need to be passed, but autism itself should be declared what it is, an epidemic. My son's care is a full time job, constantly fighting for services that should be no issue for coverage. However, these are the services that allow him to function within "our" world – including safety measures written by me for his IEP so that he doesn't wander or get left unattended. It isn't so easy for these safety measures to be taught – kids on the spectrum need assistance over a long term period. Consider the following autism scenario, given by Gihan Ramadan (Arab News, May 17, 2002):

"Imagine you were in a foreign, noisy and crowded city at night, not understanding the language spoken, recognizing only a few words but not really comprehending situations taking place around you, wanting to express a need for help but not being able. This experience may begin to help you relate to what a child with autism feels like on an ordinary day."

This is why these kids bolt, this is why they run away from safe places, and this is why they have trouble expressing their needs in their environment. My son closes the world out when things get too much for him – he will retreat to another location, and it scares me to death to think that that place may be water or a busy street. I can never let go of his hand, I can never let him run free – I am taking away his personal freedom just to keep him safe.

According to a 2012 study in Pediatrics, an estimated 49% of our children wander or bolt from safe settings. Twenty nine percent of cases happen from a classroom or school. Cases involving a child with autism 9 and younger end in death 42% of the time. Sadly, these children die alone, scared, and without the ability to call out for help.

With extensive search and rescue efforts that have cost as much as $2 million for just one search, taxpayers are already reactively paying for this issue. Please support a proactive investment in saving priceless lives by passing S.163, Avonte's Law.

Warm regards,
Heather & Tom O'Neil
[PII redacted]

Deanna L Mulvihill R.N., Ph.D. **January 5, 2016**

I want to again draw attention to the nonverbal or minimally verbal children with the diagnosis of autism especially the ones who have evidence of digestive and/or neurological disorders. Many of these children are untreated because their primary physician or even their pediatrician do not recognize these symptoms or ask about them as they are not educated that correction of these issues can bring great relief to the child and their families as the child can then be comfortable in their own bodies and begin to understand the outside world.

Also I need to again draw attention to the sensory issues as many education and health professional believe that it is simply a matter of hyper or hypo sensitivity. It is far more complex than this. In autism the sensory system development is altered. It could be with the visual, tactile, olfactory or oral or a combination of two or more. One or more of these senses could be isolated and not integrated. This sense may interfere with the direction that we are trying to give the child in ways that we do not understand. Sometimes when one sense becomes dominate than others become isolated. Piaget gives us some insight into how this happens when he explains assimilation and accommodation. This sensory system development can be understood and modified by an occupational therapist who has been educated or specialized in this area or other professional who has been trained in Rapid Prompting Method (RPM).

Once the internal issues have been eased by proper diet, supplements or medication then the integration of the sensory system can begin and the child can begin to learn in a manner that we can understand and alternate forms of communication can begin. Many professional make the assumption that nonverbal or minimally verbal children are less intelligent that those who are highly verbal. I do not believe that autism has anything to do with intelligence as I have met many intelligent nonverbal persons with autism. I believe it has to do with two things: how the sensory system has developed and if the speech center in the brain has been damaged.

We do not expect blind or deaf children to learn the same way that hearing or seeing children learn. Our system needs to learn how to teach these children, we have a moral obligation to provide them with an education. Applied Behavior Analysis (ABA) is not working because it has nothing to do with intentional behavior. Ask yourself how much education is actually taking place? What are these children learning that will be helpful to them. RPM is a teaching method that every teacher could learn and even the most disabled child can take in the information and demonstrate that they understand it. It is also a method where they can learn to read and write or type. Once they have learnt to communicate many children have told us that even when they know what we want them to do, they have trouble making their body do it.

Yes, ABA has tons of research about teaching children to behave. It has tons of evidence because it was born out of a university where research is paramount. RPM was born in a home with a dedicated mother and a nonverbal child with autism. We need some researcher to champion it and given it the credentials to move it from individual children at home, from after school program, from private office of speech therapist and into our classrooms so that all children have the opportunity to learn and not just those children whose parents can afford these extras.

Respectfully submitted by
Deanna L Mulvihill RN PhD
RPM trained
Grandmother of two grandchildren with regressive autism

Kerry Lane **January 5, 2016**

- Attachments can be viewed in OneDrive
- Evidence that Increased Acetaminophen use in Genetically Vulnerable Children Appears to be a Major Cause of the Epidemics of Autism, Attention Deficit with Hyperactivity, and Asthma

The evidence is now abundantly clear ***ACETAMINOPHEN aka TYLENOL IS THE TRIGGER FOR AUTISM!!!!*** When is IACC/FDA going to act on this information? The inactions of IACC/FDA will not be judged lightly when historians write about this Pediatric Epidemic of this Century...

Best Regards,

Kerry Scott Lane M.D.
Palm Beach Autism Institute

Evidence that Increased Acetaminophen use in Genetically ...
www.greatplainslaboratory.com/home/eng/Acetaminophen.asp
by W Shaw - Evidence that Increased Acetaminophen use in Genetically Vulnerable Children Appears to be a Major Cause of the Epidemics of Autism, Attention Deficit with ...

Acetaminophen as a cause of the autism pandemic? It ...
www.safeminds.org/.../acetaminophen-as-a-cause-of-the-autism-pandemi...
by W Parker - Sep 11, 2015 - Acetaminophen rapidly gained traction as a great suspect. First, Schultz found that the rise in autism corresponded to the rise in acetaminophen ...

Did acetaminophen provoke the autism epidemic?
www.ncbi.nlm.nih.gov/...National Center for Biotechnology Information, by P Good - 2009 - Cited by 38 - Related articles
Schultz et al (2008) raised the question whether regression into autism is triggered, not by the measles-mumps-rubella (MMR) vaccine, but by acetaminophen ...

Could A Common Painkiller Cause Brain Inflammation ...
.../could-a-common-painkiller-cause-brain-inflammation-and-e...
Sep 8, 2015 - What if it's acetaminophen, NOT vaccines? Researchers tie America's most popular painkiller to brain inflammation and autism. My husband's ...

Just say "NO" to Tylenol! (Acetaminophen causes autism ...
naturopathicpediatrics.com/.../just-say-no-to-tylenol-acetaminophen-caus...
Jul 15, 2013 - So this is why Tylenol could possibly trigger autism in kids who are genetically susceptible. Please understand me on this one – not every child ...
Acetaminophen & Autism - Facebook
https://www.facebook.com/acetaminophenandautism/?fref=nf
Acetaminophen & Autism. 600 likes · 3 talking about this. Exploring the connection between the popular drug, Acetaminophen, and Autism.
Acetaminophen's Deadly Scourge - Facebook
https://www.facebook.com/autism.and.acetaminophen
Acetaminophen's Deadly Scourge. 1619 likes · 16 talking about this. Autism, ADHD, asthma and allergies...all on the increase in recent years...is there...

Tylenol, Inflammation and Autism - AGE OF AUTISM
www.ageofautism.com/2015/09/tylenol-inflammation-and-autism.html
Sep 12, 2015 - "Acetaminophen as a cause of the autism pandemic? It makes absolutely no sense … at first." Dr. William Parker My research looks at what ...

Is acetaminophen behind autism epidemic? OTC meds ...
www.autismsupportnetwork.com/.../acetaminophen-behind-autism-epide...
Study finds links between increases in autism and ADHD coincide with the replacement of aspirin by acetaminophen in the 1980s.

Julie Clymer **January 5, 2016**

I am the mother of a nine year old daughter on the autism spectrum. I am unable to hold down a job because of my daughter's various medical needs. I have the following questions:

In 2014 the Autism Collaboration, Accountability, Research, Education and Support Act, or the Autism CARES Act of 2014 was passed. What has been done to ensure that activities are not unnecessarily duplicated? Do you have current reports focused on funding implementations to confirm there has been no overlap which has the potential to impact one of four strategic areas? The four areas are as follows:

1. What are the causes of ASD?
2. How can we improve diagnosis of ASD?
3. What are the most effective treatments, and how can we create more effective ones?
4. What are the best practices for helping people already diagnosed with ASD?

UC Davis health economists have for the first time projected the total costs of caring for all people with autism spectrum disorder, or ASD, in the United States for the current calendar year. Costs also were projected 10 years of if effective interventions and preventive treatments for the condition are not identified and widely available.

Their forecasts for ASD-related medical, nonmedical and productivity loses are $268 billion for 2015 and $461 billion for 2025. The researchers noted that these estimates are conservative and, if ASD prevalence continues to increase as it has in recent years the costs could reach $1 trillion by 2025.

The study is published online in the Journal of Autism and Developmental Disorders.

What are you doing to reduce the multibillion-dollar totals? Do you have a research investment in ASD? What is the current annual budget for funding ASD by the National Institutes of Health? How are those funds allocated? How is funding determined?

Today, Hillary Clinton rolled out her proposed new initiative directed at boosting autism screening, treatment and research. That sounds wonderful and similar to what has been proposed by IACC but again as I stated above I don't see how that can be implemented without knowing how it will be funded.

On a side note, there have been many children that have wandered and died. Why isn't anyone from National Autism Association appointed to the Interagency Autism Coordination Committee?

Those are my biggest concerns and I would appreciate a response and immediate action.

Sincerely,

Julie Clymer

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

Gail Elbek **January 5, 2016**

PURPOSE- Evidence Reveals A Cause Of Autism Worthy Of Lawful Public Disclosure, While Never Proven As Neurodevelopmentally Safe.

As an investigative researcher into the cause of autism, I very much appreciate your due diligence to review this public comment related to the epidemic of Autism Spectrum Disorder. I request that the following factual information be seriously focused upon and dutifully reviewed, without bias, by responsible and respectable IACC Committee members.

It is well-known that fetal, infant, and child brain development is a most delicate and critical timeframe that largely relies upon the successful assembly of hard wired brain cells, brain systems, and brain circuitry of which must NOT under any circumstances be breached**.** Unquestionably, it is overwhelmingly research study established that interruptions in multiple developing brain systems are caused by accidental fetal, infant, and/or child exposure(s) to poisonous environmental estrogenic hormone disruptors with resulting severe and irreversible developmental adverse brain effects such as behavioral disorders to include autism.

As fact, the NIH NIEHS includes *"Soy Infant Formula"* on their poisonous list of *"Environmental Agents."* This NIH NIEHS toxic list confirms: *"Environmental Agents- Air Pollution, Allergens, Arsenic, Dioxins, Endocrine Disruptors, Formaldehyde, Lead, Mercury, Mold, Pesticides, Radon,* ***Soy Infant Formula,*** *Styrene, and Water Pollution."* http://www.niehs.nih.gov/health/topics/agents/index.cfm

While each of the above are confirmed estrogenic hormone disruptors, it is only one, "Soy Infant Formulas" that contain developmentally toxic phytoestrogenic hormone disruptors that are withheld from an innocent and trusting American public. Which of the above NIH NIEHS confirmed brain-toxic "Environmental Agents," will you choose to place into the mouth of your baby, or your grandbaby all day and night for the long-term…arsenic, dioxins, lead, mold…or Soy Infant Formula?

As equal to ALL developmentally poisonous estrogenic endocrine disruptors, NEVER are the ***unknown fluctuating dosage levels*** of several soybean phytoestrogenic endocrine disruptors: genistein, daidzein, glycitein, and the unknown number of people who metabolize daidzein to equol, proven as developmentally body- or brain-safe.

1999, **FDA Federal Register confirms, "*GRAS status of soy did not include a thorough evaluation of the safety of potentially harmful components, e.g. lysioalanine, nitrites and nitrosamines, trypsin inhibitors, phytates and isoflavones. Trypsin inhibitors are responsible for hyperplasia and formation of (pancreatic) nodules seen in animal studies. Further...high levels of trypsin inhibitors in humans can evoke this mechanism."***

As fact, there is no established fetal, infant, or child soybean benefit: no nutritional value, no evidence of safety, or survival. As fact, soybeans contain unknown fluctuating dosage levels of a multitude of toxic fetal, infant, and child brain-poisons to include: 1. Several toxic soy phytoestrogenic endocrine disruptors **2**. Highest food-toxic levels of Phytic Acid- block the absorption of essential developmental minerals i.e., calcium, magnesium iron, zinc. **3.** Toxic Trypsin Inhibitors- that inhibit digestion and absorption of nutrients, and proven to prevent normal growth also involving the brain and nervous

system. **4**. Inhibits topoisomerase- an essential enzyme involved in DNA replication, (studies also report as a cause of childhood leukemia). **5.** Multiple dangerous heavy metals (in detail below). **6.** Additional soybean phyto-brain poisons- lysioalanine, nitrites, nitrosamines… and more!

Also without evidence of developmental brain-safety additional poisons are added to soy infant formulas, such as dangerously high levels of: GMO Soy, Corn Syrup- 40.8 -55%, GMO Corn, and Sugar- 10.2-11%!

And corn syrup is processed through reagents that are generated by chloralkalide plants. Chloralkalide plants use a mercury cell process in which **laboratories have identified levels of mercury within high-fructose corn syrup**. **Add mercury to the growing list of soy phyto-poisonous developmental neuro-toxicants.**

Never proven as developmentally safe: Innumerable soybean plant-poisons placed into soy infant formulas, soy-contaminated infant "milk" formulas and foods are repeatedly and increasingly NIH Pubmed study concluded as deleterious to fetal, infant, and child physiological, reproductive, and neurological health, thus defining "adulterated" food. (21 U.S. Code 342).

Never proven as developmentally safe: Soybean product labels neglect mention of toxic chemical contents of these several soy phytoestrogenic endocrine disruptors plus additional soybean poisons that are established developmental body- and brain-poisonous, thus defining "misbranded."

Following are renowned NIH, FDA, U.S., and worldwide scientifically researched publish studies, as well as U.S. Health Official testimonials of which repeatedly and increasingly conclude that fetal, infant, and/or child exposure to the innumerable soybean phyto-poisons have established capabilities to severely disrupt, and irreversibly damage several developmental brain systems that are directly related to the cause of autism.

This is an **urgent request** that you, the U.S. appointed IACC Committee will righteously, responsibly, equally, and lawfully alert a trusting American public, and loving parents, to the following overwhelming accumulative evidence that proves soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisons as a possible, probable, and absolute cause of multiple fetal, infant, and child adverse behavioral effects, to include autism, until otherwise proven as developmentally brain-safe.

LOOK AT THE ESTABLISHED FACTS:

NIH NIEHS reports, ***"Why are people concerned about soy infant formula? The safety of soy infant formula has been debated because it typically contains a class of compounds called isoflavones. These isoflavones are referred to as phytoestrogens because they are found in plants (phyto) and because of their ability to act like the hormone estrogen in the body. ...infants are more likely than adults to be vulnerable to the estrogen-like effects of the phytoestrogens in soy. ...it is recognized that infants go through developmental stages that are sensitive to estrogens. Therefore, infants are more likely than adults to be vulnerable to the estrogen-like effects of the phytoestrogens in soy. In some cases, the health effects resulting from a soy-based diet may not be apparent until years later."***
http://www.niehs.nih.gov/health/topics/agents/sya-soy-formula/index.cfm

2013, **"Soy Infant Formula may be Associated with Autistic Behaviors," CJ Westmark confirms,** ***"Medical record data were analyzed from Simons Foundation Autism Research Initiative Simplex***

Collection.... This study provides preliminary data that the use of soy-based infant formula may be associated with specific autistic behaviors."
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4229689/

Nearly a thousand NIH Pubmed published studies concur with this 2010, Bar-El DS and R. Reifen report, ***"Soy as an endocrine disruptor: cause for caution? Endocrine disrupting compounds (EDCs) alter the function of the endocrine system and consequently cause adverse health effects. Phytoestrogens, natural plant compounds abundantly found in soy and soy products, behave as weak estrogen mimics or as antiestrogens."*** Journal of Pediatric Endocrinology and Metabolism. 2010 Sep:23(9) 855-861.

2009, **Water Environment Research Foundation** (WERF) reports, ***"Study Contaminates, (or emerging contaminates) of Endocrine Disrupting Chemicals. The classes of EDC included: steroids/sterols naturally occurring synthetic; phytoestrogens…. The term 'emerging contaminates' refers broadly to those synthetic or naturally occurring chemicals,… that have not been commonly monitored in the environment but which are increasing concern because of their known or suspected adverse ecological or human health effects."***

Throughout prior decades and to present day, NIH researchers consistently report as the following to the FDA. This time it is renowned NIH soy researchers Sheehan and Doerge who back in 1999 report, ***"Subsequently, this same group showed a significant dose-dependent risk (up to 2.4 fold) for development of vascular dementia and brain atrophy from consumption of tofu, a soy product rich in isoflavones (White, et al., 1996b). This finding is consistent with the environmental causation suggested from the earlier analysis, and provides evidence that soy (tofu) phytoestrogens causes vascular dementia."***
https://www.seleneriverpress.com/historical/scientists-protest-soy-approval/

Without HHS, NIH, or FDA established evidence of fetal, infant, and child soy phyto-toxic safety, it must be equally understood by all American people that soybean phytoestrogenic endocrine disruptors and additional multiple soybean phyto-poisons are severe and irreversible developmental body- and brain-poisons. What causes dementia in adult men can cause brain disorders, to include autism, in exposed fetus, infants, and children, until proven otherwise, until ever proven as developmentally body- and brain-safe…which in fact, has never been done!

2002, **"Global Assessment of the State-of-the-Science of Endocrine Disruptors," is an expert document prepared on behalf of World Health Organization (WHO) that states,** ***"'In this document, Endocrine Disrupting Chemicals (EDCs) have been defined as exogenous substances that alter function(s) of the endocrine system and consequently cause adverse health effects in an intact organism, or its progeny, or (sub) populations.' The diversity of chemicals includes natural and synthetic hormones, phytoestrogens, pesticides, and a variety of industrial chemicals and by-products. The ubiquitous presence of natural hormones and plant estrogens poses difficult analytical issues because these natural EDCs may be more potent than environmental EDCs. One of the most important issues that complicate assessing exposure to EDCs in both wildlife and humans is the level, timing, and duration of exposure relative to the developmental stage of the organism. Exposure during fixed time frames in development when programming of the endocrine*** **system is occurring may result in permanent changes..." http://www.who.int/ipcs/publications/new_issues/endocrine_disruptors/en/**

In regards to developmental exposure to soy phytoestrogens the **World Health Organization** expresses, "***Major concern.***"

U.S. Health Official Adverse Soy Testimonials:

1. 2010 **NIH NIMH Deputy Director Ms. Daniels states**, ***"Dr. Insel,*** *(former IACC Director)* ***is aware of the endocrine disrupting properties of soy, as he has personally done research in this area.... Soy may indeed be one of many environmental factors that contributes to various disorders and deserves further study."***

2. 2015, **NIH NIEHS Officer of Communications**, **Ian Thomas confirms,** ***"...our scientists study things in the environment that could potentially make people sick. This might include chemical agents like formaldehyde and pesticides or natural agents like mold and arsenic. This also includes the study of soy."***

3. NTP NIEHS Director Linda Birnbaum reports, ***"We know that young children are especially vulnerable to adverse health consequences of a wide variety of environmental exposures. …the active growth of children's organs and tissues enhances their susceptibility to environmental damage…. We also know much more about the linkages between environmental exposures and specific diseases and dysfunctions- not just childhood diseases, but effects of prenatal and childhood exposures can show up years later for example, as reproductive problems or cancer. The neurological and cognitive development of children is especially vulnerable to some environmental effects. A major area of study is the role of chemicals in the environment, with a primary focus on hormonally active agents (endocrine disruptors). The types of chemicals measured include…phytoestrogens found in foods…. Soy formula use is common, and there is public health concern about its effects on infants and young children. Other NIEHS programs are also looking at soy formula. Soy-fed infants have much higher exposure to endocrine-active compounds in their diets…. Soy-fed infants may be the group with the highest exposure to any environmental estrogen. Normal endocrine signaling involves very small changes in hormone levels, yet these changes can have significant biological effects. That means subtle disruptions of endocrine signaling is a plausible mechanism by which chemical exposures at low doses can have effects on the body. Endocrine signaling governs virtually every organ and process in the body. …effects of exposure to endocrine disruptors can be observed long after the actual exposure has ceased. This is especially true for growth and development, processes that are very sensitive to endocrine regulation. "*** http://www.hhs.gov/asl/testify/2009/09/t20090929e.html, and /2010/02/t20100225a.html

4. 2008, **FDA, Center for Food Safety and Applied Nutrition (CFSAN) Deputy Director Janice Oliver reports,** ***"FDA acknowledges that "concerns" have been voiced about possible effects of isoflavones in soy infant formulas on sexual development, neurobehavioral development, immune function, and thyroid disease."***

5. FDA includes soybeans on their "Poisonous Plant Database" stating- ***"Phytoestrogens: toxicants of plant origin."*** **The FDA Poisonous Plant Database also includes hundreds of studies reporting adverse developmental soybean phyto-poisonous effects.**

6. 2015, **NTP Senior Scientist, John Bucher reports,** ***"The larger issue of just how significant exposures to potential (soy) endocrine disruptors are to public health is still a subject of intensive research. To date it appears that exposure to the developing fetus are more potentially harmful than those after birth."***

7. In-depth history of MedWatch, and CAERS (CFSAN "Adverse Events Reporting System")- **reports are flooded with alarmingly numbers of guilt-ridden parents in despair as they detail a variety of adverse health effects caused to their soy-exposed child(ren), while without public disclosure!**

8. 1997and revised in 2013, The (U.S.) Endocrine Society reports, *"We conclude that (soy) phytoestrogens exhibit physiological effects in humans."*

9. Toxic transplacental or fetal contamination caused from maternal exposure to endocrine disruptors such as: alcohol, plastics, pesticides, pollution, etc., all carry legitimate "Warning" labels during pregnancy, with the ONE exception being soy! Transplacental transfer of poisonous soy phytoestrogenic endocrine disruptors carry no law-abiding "Warning" labels! Why Not?
http://www.ncbi.nlm.nih.gov/pubmed/11875621

10. 2000, EPA "Final Report: Developmental Effects of Soy Phytoestrogens," (Project period, 1996-1999)- ***"However, an increase of soy consumption in the North American diet has resulted in increased exposure to dietary estrogen mimics by reproductive-aged women raising concern regarding possible effects on the fetus and neonate."***
http://cfpub.epa.gov/ncer_abstracts/index.cfm/fuseaction/display.highlight/abstract/140/report/F

AUTISM- Multiple Soybean Phyto-Poisons Are Proven To Cause Multiple Adverse Neurological Effects Directly Related to the Cause of Autism:

It is critical that the developing brain is formed though a most intricate genetic blueprint of balanced hormones, essential minerals and nutrients that must not be disrupted or dismantled. Never proven as brain-safe, several hundred times over and over again, soy phytoestrogenic endocrine disruptors plus additional soybean phyto-poisons are NIH Pubmed study concluded to dangerously disrupt, dismantle, and destroy multiple developing brain systems that are directly related to adverse brain development and the cause of brain disorders to include autism. There is no evidence proving a child's brain is able to survive soy phyto-poisonous exposure(s):

How are the unknown, fluctuating dosage levels of soybean phytoestrogenic endocrine disruptors plus additional soybean phyto-poisons related to the fetal, infant, and/or child cause of autism? Innumerable studies, largely NIH Pubmed published studies, repeatedly and increasingly conclude:

1. Autism is caused by an imbalance of excitatory and inhibitory neurotransmitters- **Soy phyto-poisons** are the study concluded cause. **2. Autism** is caused by oxidative stress and metabolic perturbations- **Soy phyto-poisons** are the study concluded cause. **3. Autism** is caused by environmental perturbations- **Soy phyto-poisons** are the study concluded cause. **4. Autism** is caused by interruptions in neural pathways- **Soy phyto-poisons** are the study concluded cause. **5. Autism** is associated with additional physiological conditions: gastrointestinal distress, immune deficiency disorders, thyroid dysfunction- **Soy phyto-poisons** are the study concluded cause. **6. Autism** is caused by gene disrupting mutations- **Soy phyto-poisons** are the study concluded cause. **7. Autism** is caused by mitrochondrial dysfunction- **Soy phyto-poisons** are the study concluded cause. **8. Autism** is caused by heavy metal poisoning- **Soy phyto-poisons** are the study concluded cause. **9. Autism** is caused by inhibition of tyrosine kinase MET gene signaling- **Soy phyto-poisons** are the study concluded cause. **10. Autism** is caused by inhibition of RET receptor- **Soy phyto-poisons** are the study concluded cause. **11. Autism** is caused by methionine deficiency- **Soy phyto-poisons** are the study concluded cause. **12. Autism** is caused by inhibition of

tryptophan deficiency- **Soy phyto-poisons** are the study concluded cause. **13. Autism** is caused by inhibition of astrocytes neuroglial cells- **Soy phyto-poisons** are the study concluded cause. **14. Autism** is caused by Fragile X syndrome, **Soy phyto-poisons** are the study concluded cause! http://causeautism.blogspot.com

*** Autism is caused by fetal, infant, and/or child disruption in neurotransmitter systems. Soy phytoestrogenic endocrine disruptors are repeatedly NIH Pubmed study concluded to dangerously interfere and manipulate *several* neurotransmitters: vasopressin, oxytocin, serotonin, dopamine, GABA, glutamate, and cholinergic!**

*** Autism is caused by essential mineral imbalance- Soybean heavy metals and/or phytic acid are study reported to cause: zinc deficiency, iodine deficiency, calcium overdose, calbindin D28k overdose, iron deficiency, copper deficiency, thiamin (B1) deficiency, selenium overdose, phosphorus overdose, magnesium deficiency or manganese overdose.**

*** Autism is caused by fragile X syndrome- Soy phytoestrogens are NIH Pubmed study reported to increase the risk of Fragile X syndrome that affects the Fragile X mental retardation gene on the X chromosome that results in failure to express the fragile X mental retardation protein which is required for normal neural development.**

*** Autism is caused by heavy metal contamination- Soybeans are NIH Pubmed study confirmed cause heavy mental contamination: aluminum contamination, cadmium contamination, thallium contamination, and lead contamination. Increasing soybean lead levels are also reportedly caused by GMO soy, as most often marketed in the soybeans used in infant formulas and foods, without right-to-know labeling!**

*** The Office of Environmental Health Hazard Assessment (OEHHA) website reports, *" ...manganese exposures in childhood are associated with impaired neurodevelopment including decrements in intellectual function. Some infant formulas and foods are high in manganese. Soy formula may contain 200-300 micrograms, compared with 6 micrograms in breast milk. High dietary soy intake can put infants at greater risk of manganese toxicity. The newborn's brain is still developing, myelination is incomplete, and the blood-brain barrier is not fully formed. These conditions facilitate manganese uptake into the central* nervous system and increase the risk of attaining toxic levels."**

*** Soybeans are repeatedly NIH Pubmed study concluded to contain high levels of manganese, an established cause of adverse or impaired neurodevelopment.**
*** EPA reports, "Formula fed infants have been shown to absorb greater amounts of manganese than breast-fed infants. Recent California study reported a modest increase in incidence of autism was associated with highest manganese concentrations. Manganese concentrations were higher in soy and rice drinks, and in soy formulas, than in cow's milk formulas. Exposure to high concentrations of manganese exposure can be detrimental to health. The primary targets of manganese toxicity are the brain and central nervous system. Manganese…exposure to high concentrations…was associated with permanent (brain) damage, with symptoms of impaired neurological and neuromuscular control, mental and emotional disturbances, muscle stiffness, lack of coordination, tremors, difficulties with breathing or swallowing and other neuromuscular problems."**

*** With EPA confirmation of high levels of manganese in soy infant formulas, NIH NIEHS Director Birnbaum also confirms, "…manganese levels… were associated in a dose-dependent fashion with**

decreases in intelligence."

* **Soy phytoestrogens are a cause of mitochondrial deficits and multiple NIH Pubmed studies conclude: 1.** Soy Phytoestrogens inhibit mitochondrial activity. **2.** Mitochondria are important targets of estrogen action, soy disrupts estrogen action and mitochondrial dysfunction is a primary event in glutamate neurotoxicity**. 3.** Soy phytoestrogen genistein can inhibit FoFI-ATPase activity in rat brain mitochondria. **4.** Soy phytoestrogens interrupts ATP synthase… **5.** Soy phytochemcials should be included in the examination for potential cytotoxicity. **6.** Genistein a major soy isoflavone,...causes mitochondrial deficits.

* **HHS and NIH *CHARGE*** (Childhood Autism Risks From Genetics and the Environment) ***Study*** at U.C. Davis, **"News and Updates"** reports, ***"Study confirms mitochondrial deficits in children with autism."*** **Soy phytoestrogens are repeatedly study proven to cause mitochondrial deficits.** http://causeautism.blogspot.com

* Soy phytoestrogens are study proven to **lower the cholesterol necessary for developmental formation of brain cells**. Lowering cholesterol levels in babies is repeatedly proven to result in adverse body and brain effects. Kaayla T. Daniel's book, **"The Whole Soy Story,"** offers a graph exposing- After one month, the level of soy phytoestrogens in premenopausal women that cause hormonal changes- **45mg, or 0.75 mg per kg of body weight. The FDA recommended amount of soy phytoestrogens for adults to lower cholesterol- 25mg, or 0.40mg per kg of body weight**. **After just one month, babies fed soy infant formulas have toxic phytoestrogen levels that measure a most frightening: *"38mg isoflavone (phytoestrogens, or 6.25 mg per kg of body weight,"* which largely surpasses the FDA danger zone of low cholesterol levels, (and highly toxic phytoestrogen levels) that are proven to cause adverse developmental brain effects, to include autism.**

* **2009 the Karolinska Institute reports**, ***"A derivative of cholesterol is necessary for the formation of brain cells, according to a study from the Swedish medical university Karolinska Institutet. The study was led by Professor Ernest Arenas and demonstrates that the formation of dopamine-producing neurons during brain development in mice is dependent on the activation of a specific receptor in the brain by an oxidised form of cholesterol called oxysterol. Dopamine-producing nerve cells play an important part in many brain functions and processes, from motor skills to reward systems and dependency. They are also the type* of cell that dies in Parkinson's disease."**

* **GreenMedInfo.com reports-** "***Cholesterol is needed to: Prevent Aggression, Fight Cancer, Prevent Hemorrhagic Stroke, For Longevity…prevent DNA damage associated with cellular aging, and to help fight infection. Particularly for fetus, infants, and children cholesterol is essential for life and cholesterol-lowering drugs have over 300 adverse health effects."*** http://www.greenmedinfo.com/blog/underreported-dangers-low-cholesterol

* 2014**, T. Sehm et al report**, ***"In this study we investigated the impact of (dietary) isoflavonoids on glioma morphology and function. Genistein (soy phytoestrogen) is very effective in inducing glioma cell death, it is highly toxic for primary astrocytes."*** http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4303154/

* **Autism is caused by glioma cell death, and the poisoning of astrocytes and fetal, infant, child exposure to soy phytoestrogenic hormone disruptors is the cause.**

* 2010, **Sofroniew and Vinters report**, ***"Over the past 25 years it has become clear that astrocytes are responsible for a wide variety of complex and essential functions in the healthy Central Nervous System, including primary roles in synaptic transmission and information processing by neural circuit functions."*** http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2799634
In addition to causing adverse synaptic transmission and neural circuit functions that are related to the cause of autism, the soy phytoestrogen-cause of astrocyte toxicity via glioma cell death is also reported to cause**: intestinal dysfunction, diabetes, autoimmune disease, specific tumorigenesis, diabetes, Alzheimers disease, and more. Many of which are the very disorders diagnosed in autistic children.**

* Back in February 18, 1999**- Renowned NIH soy experts, Drs. Sheehan and Doerge together wrote directly to the FDA stating, *"...there is abundant evidence that... isoflavones found in soy... demonstrate toxicity in estrogen sensitive tissues and in the thyroid. ....this is true for a number of species, including humans. Development is recognized as the most sensitive life stage for estrogen toxicity because of the indisputable evidence of a very wide variety of frank malformations and serious functional deficits in experimental animals and humans. Taken together, the findings presented here are self-consistent and demonstrate that genistein and other isoflavones have adverse effects in a variety of species including humans. The health labeling of soy protein isolate for foods needs to be considered just as would the addition of any estrogen…to foods. Our conclusion... no dose is without risk..."*** https://www.seleneriverpress.com/historical/scientists-protest-soy-approval/

* **Autism- Decades of NIH Pubmed published studies repeatedly conclude soybean phyto-poisons cause severe thyroid dysfunction that cause any variety of dangerous developmental immune deficiency disorders and diseases. Thyroid disorders are study established cause of irreversible damage to the developmental hypothalamic-pituitary-thyroid axis that lead to brain and behavioral disorders to include autism!** http://www.ncbi.nlm.nih.gov/pubmed/19942155, http://www.ncbi.nlm.nih.gov/pubmed/17651757, http://soyhypothyroidism.blogspot.com

* 2004, **Renowned NIH NIEHS researchers, Chen and Rogan confirm, *"Both ingestion and injection of (soy) genistein can affect development of the reproductive system, decrease thymic weight... modulate immune response, or reduce thyroid peroxidase. This highlights the urgent need to evaluate the effects of isoflavones in soy infant formula…"***
http://www.annualreviews.org/doi/full/10.1146/annurev.nutr.24.101603.064950

* **Seizures are common in autistic children, and seizures are caused by exposure to soy phyto-poisons! These NIH Pubmed studies report, *"Seizures experienced by autistic children can be triggered by soy phytoestrogenic disruptions in estrogen receptor-dependent signaling mechanisms of the brain."***
http://www.ncbi.nlm.nih.gov/pubmed/24622158, http://www.ncib.nlm.nih.gov/pubmed/23034522.

* **AUTISM- Look at this TRUE soy phyto-toxic exposure history**: **1.** Nine months of fetal transplacental transfer of soy phyto-poisonous contamination due to maternal soy consumption. **2.** Maternal consumption of soy phyto-poisons are again repeatedly transferred to nursing baby. **3**. Baby is also soy phyto-toxic infant formula fed, all day and night for the long-term! **And by age 3 this baby girl is diagnosed with autism! And how many more children fall prey to soy phyto-poisons has never been righteously investigated with autism numbers established!**
LOOK At This Example, Out of Several Hundred ALARMING Soy Phyto-Poisonous Published Studies Concluding the Soy Phyto-Poisonous Cause Of Autism:
Awaiting responsible U.S. public disclosure, soy phytoestrogenic endocrine disruptors plus additional developmental soybean phyto-poisons are well-known throughout scientific literature as active

"**developmental neurotoxicants"** with the capabilities to: target, attack, and irreversibly disrupt, dismantle, and permanently damage multiple developing brain systems that are related to the cause of brain disorders such as autism. http://causeautism.blogspot.com

(Worth Repeating) 2013, **"Soy Infant Formula may be Associated with Autistic Behaviors," CJ Westmark confirms,** ***"Medical record data were analyzed from Simons Foundation Autism Research Initiative Simplex Collection.... This study provides preliminary data that the use of soy-based infant formula may be associated with specific autistic behaviors."***
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4229689/

Renowned researcher C.J. Westmark also reports, ***"We utilized medical record data from the Simons Foundation Autism Research Initiative to assess seizure incidence in autistic children fed soy-based versus other infant formula. There were data available for 1949 subjects (87% males). We found a 2.6-fold increase in the incidence of febrile seizures and a 4.8-fold increase in the incidence of simple partial seizure in autistic children fed soy formula. There was a 2.1-fold increased incidence in epilepsy. In aggregate, these data demonstrate that a soy-based diet is associated with increased seizure incidence in …autistic children. These data raise important questions regarding the neurological side effects of a soy-based diet during postnatal development. We did find exploratory associations between the consumption of soy-based infant formula and several autistic behaviors…"***
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4153031/

* 1990's **Renowned soy researcher Dr. Kenneth Setchell confirms,** ***"Because these bioactive phyto-oestrogens possess a wide range of hormonal and non-hormonal activities, it has been suggested that adverse effects may occur in infants fed soy-based formulas. The daily exposure of infants to isoflavones in soy infant formulas is 6-11- fold higher on a body weight basis than the dose that has hormonal effects in adults consuming soy foods. Circulating concentrations of isoflavones in the seven infants fed soy-based formula were 13,000-22,000 times higher than plasma oestradiol concentrations in early life, and may be sufficient to exert biological effects, whereas the contribution of isoflavone from breast-milk and cow-milk is negligible."*** http://www.ncbi.nlm.nih.gov/pubmed/9217716

1997, **renowned soy researcher Setchell et al also confirm,** ***"In placental mammals, the fetus is continuously exposed to high levels of estrogen from the placenta and the mother. Environmental exposure to (soy) phytoestrogens during this period is expected to disrupt the function of the natural steroid hormones."***

2014**, C. J. Westmark concludes,** ***"Soybeans are rich in phytoestrogens, "plant estrogens' which can be transferred to offspring through the placenta as well as maternal milk. Soy protein is rich in a type of phytoestrogens called isoflavones, which are bioactive compounds structurally similar to the female hormone estrogen. Isoflavones can exert biological activity by mimicking the effects of mammalian estrogen and thus disrupt the endocrine cycle. It should be noted that infants can efficiently digest, absorb, and excrete genistein and daidzein from soy-based infant formulas. At high doses genistein and daidzein are toxic to primary neuronal cultures."***
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4153031/

2004**, Renowned soybean researcher Setchell again confirms,** ***"Soy-derived isoflavone are the most abundant and in many ways the most studied phytoestrogens, and phytoestrogens are known endocrine disruptors. Daidzein can be further metabolized to the potent and abundant molecule***

***equol.... The specific influence of dietary soy phytoestrogens on consumptive, learning and memory, and anxiety-related behaviors is identified*."** http://www.ncbi.nlm.nih/gov/pumben/15454683.

Never proven as fetal or neonate safe, the EPA confirms the fact*, "However, an increase of soy consumption in the North American diet has resulted in increased exposure to dietary estrogen mimics by reproductive-aged women, 'raising concern' regarding possible effects on the fetus, and neonate."*

"CDC.gov, National Biomonitoring Program on Phytoestrogens" confirms, *"Ingested daidzein is further metabolized to…equol by intestinal bacteria. Equol, …has estrogenic activity. About 30% of adults can be characterized as equal producers…. The relevance of equol-producer status to potential health related effects is unclear. Equol has more potent estrogenic activity than its precursor, daidzein. Equol also has been shown to have anti-androgenic activity in animals. Genistein binds ER(Estrogen Receptor) -beta with greater affinity than equol (Doerge and Sheehan, 2002). …phytoestrogens can be present in concentrations 100 to 1000 times greater than the endogenously produced estrogens. Soy-based infant formula can result in plasma concentrations of isoflavones in infants that are 13,000- 22,000 times higher than endogenous estrogen concentrations in infants, (Setchell et al., 1997). "*

Yet the CDC will NOT lawfully alert the American public of developmental soy phytoestrogenic poisons! Likely because the CDC is heavily funded by Pharmaceutical soy formula profiteers!

USDA Ag-Magazine reports, *"Soy-based infant formulas contain soy protein isolate (SPI). Isoflavones are bound to soy proteins in high amounts. One controversial aspect of soy-based formula involves isoflavones because they're believed to act similarly to the female hormone estrogen. Critics suggest that isoflavones in soy formula might disrupt or impair development in infants."*

Yet the USDA will NOT lawfully alert the American public of developmental soy phyto-poisons! Likely because the USDA is heavily connected to Monsanto GMO soybean profiteers!

Beginning on page 27 of **"Pros and Cons of Phytoestrogens"** review the **"Cons"** as reported by **renowned NIH soy researchers H. Patisaul and W. Jefferson:** Their in-depth developmental soy exposure report is a parental nightmare while loaded with deleterious developmental brain and body effects. Patisaul and Jefferson report, ***"A possibility of increasing concern is that phytoestrogen may interfere with organizational role of estrogen in the developing brain and reproductive system. ....manipulation of estrogen during specific critical windows of development throughout gestation and early infancy leads to a myriad of adverse health outcomes including malformations in the ovary, uterus, mammary gland and prostate, early puberty, reduced fertility, disrupted brain organization, and reproductive tract cancers."*** http://www.ncbi.nlm.gov/pmc/articles/PMC3074428/

Yet the NIH will NOT lawfully alert the American public of developmental soy phyto-poisons! How many at the NIH have ties with the powerful U.S. Soybean industry?

Dedicated researchers at the **"Academics Review" report, *"When hormonal effects are undesired these compounds could well be regarded as dangerous or unhealthy. A potential undesirable effect of (soy) phytochemicals is disturbance of brain development in the unborn child. Remember, chemicals in the diet can promote or reduce cancer risks and can affect brain development and normal organ development in unborn children, and there is no doubt that foods such as soybeans, flaxseed and mung-beans contain such chemicals. These effects have been known to science for 50-years but it is***

only relatively recently that the general public have started to hear about them. Their decisions to manage diet hormone-like chemicals should be based on their particular health circumstances, stage of life, whether they are pregnant or are breast-feeding." http://academicsreview.org/reviewed-content/genetic-roulette/section-6/6-3-endocrine-disruptors

Innumerable NIH Pubmed published studies also report the same conclusions as **Kalkbrenner et al, *"....it is now understood that environmental factors play a larger role in causing autism than previously thought..."*** http://www.ncbi.nlm.nih.gov/pubmed/25742515

Throughout decades, the NIH NIEHS has repeatedly established ***"Soy Infant Formula"*** as brain and body-contaminating to fetus, infants, and children. And now establishing a toxic list called, ***"Environmental Agent"*** that includes **"Soy Infant Formula,"** because soybeans contain multiple developmentally-polluting estrogenic endocrine disruptors, (plus several additional developmental poisons). For several prior decades and continuing to this day, multiple NIEHS researchers consistently report horrific evidence of extreme and outrageous developmental soybean body- and brain-poisoning. But at the same time, the NIH NIEHS chooses to remain publicly mute. Why? Can it possibly be to save soy-industry profits, while knowingly jeopardizing the body- and brain-health of American fetus, infants and children? Why?

"Autism and the Environment," Dr. Slotkin reports, *"...there is always a critical period in which any disruption of input, positive or negative, will permanently alter (brain) function. If you send the wrong signal, it's going to produce the wrong outcome. It is going to teach the cell to respond incorrectly to the wrong kind of input. It will make that change permanently. What kinds of things will do that? Any drug of chemical that is neuroactive...reinforcing or blocking the actions of a neurotransmitter. ....drug abuse or therapeutic agents... environmental contaminants,... all of these can lead to misprogramming of responsiveness."* http://www.ncbi.nlm.nih.gov/books/NBK54333/

2003, **Journal of Agriculture and Food Chemistry; 51, 2193-2199, Stephen Boue et al report, *"Given the significant interest in the estrogenic activity of phytoestrogens, particularly isoflavones in soybean, this study was undertaken to determine the estrogenic activity…. Phytoestrogens act through both ER (estrogen receptor)-dependent and -independent mechanisms. By mimicking 17b-estradiol, phytoestrogens bind to estrogen receptors in different body tissues with estrogenic activities…. These data were consistent with previous data indicating isoflavones preferentially bind ERb, and transcriptional activation of phytoestrogens for both ERa and ERb was observed. However, the effects could be significant because phytoestrogens may be present at high concentrations compared to that of endogenous estrogen. …the isoflavones contents of different varieties, crops, and harvest years vary considerably. Much research has been conducted on the quantitation and estrogenic activity of the isoflavone daidzein and genistein found in high concentrations in soybeans."***

* 1998, **FDA Director of National Center for Toxicological Research (NCTR) Dr. Sheehan repeatedly confirms, *"These considerations suggest that much closer study in experimental animals and human populations exposed to phytoestrogen-containing products, and particularly soy-based foods is necessary. Among human exposure, infant soy formula exposure appears to provide the highest of all phytoestrogen doses and this occurs during development, often the most sensitive life-stage for induction of toxicity."*** http://www.ncbi.nlm.nih.gov/pubmed/9492351

Yet neither the FDA or NCTR will lawfully alert an innocent and trusting American public of their equal acknowledgement of developmental soy phyto-toxicity!

* 2003, **USDA reports, *"Methanol extracts were prepared from soybean…. These results show that several legumes are a source of phytoestrogens with high levels of estrogenic activity."***
As fact, since the 1950's to present day, there are nearly one thousand NIH Pubmed published studies that consistently report developmental soy phyto-poisonous conclusions as relative to this study; **2014, Singh et al, confirms**, ***"These results suggested that the higher dose of genistein (soy phytoestrogen) can produce several undesirable effects by affecting multiple cellular pathways."*** http://www.ncbi.nlm.nih.gov/pubmed/2467385

2010, **Renowned soy researchers Dinsdale and Ward confirm**, ***"Soy isoflavone are phytoestrogens with potential hormonal activity due to their similar chemical structure to 17B-estradiol. While much of this research has focused on adult populations, infants fed soy protein based infant formula are exposed to substantial levels of soy-based foods. Infant exposure, through soy formula primarily occurs from birth to one year of life, a stage of development that is particularly sensitive to dietary and environmental compounds."*** http://www.ncbi.nlm.nih.gov/pubmed/222540003

Although Illinois is the #1 U.S. State (out of 33 States) that largely profits from soybean production, in **2010 a study from University of Illinois, Urbana concludes**, ***"Soy-based infant formulas... contain high levels of the estrogenic isoflavone genistein leading to 'concern' that neonatal genistein exposure could cause acute and/or long-term adverse effects on reproductive and other organs. The immediate and long-term effects in this neonatal animal model raises 'concerns' that high serum concentrations of genistein are estrogenic and could potentially impact the* development *of human infants fed soy formula."*** http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2888966/

2015, **NIH, National Center for Complimentary and Integrative Health (NCCIH) reports**, ***"Side Effects and Cautions- The safety of long-term use of soy isoflavones has not been established. Until more is known about soy's effect on estrogen levels, women... who are at an increased risk for developing breast cancer, or other hormone-sensitive conditions should be particularly careful about using soy.... Minor stomach and bowel problems such as nausea, bloating and constipation are possible. Allergic reactions such as breathing problems and rash can occur..."***

That the NIH, NICCIH, also admits that the safety of soy isoflavone estrogenic endocrine disruptors "has NOT been established," while at the same time allowing an enormous population of trusting and loving American parents to participate in this undisclosed and undocumented fetal, infant, and child soy-poisoning U.S. experiment seems nothing less than HHS, NIH, and FDA criminal!

Louisa Barkla, Communications and Resources Officer, UNICEF UK Baby Friendly Initiative, reports, ***"Soya formula is made from soya, not cow's milk. Soya formula contains high levels of a chemical called phytoestrogen which may have negative effects on babies and so should only be used in exceptional circumstances and only under the recommendation of a doctor."***

2013, **"CDC.gov National Biomonitoring Program- Phytoestrogens" reports**, ***"Diet is the source of human exposure to phytoestrogens. The absorption and metabolism of phytoestrogens demonstrate large interindividual variability. After hydrolysis to the aglycone forms, phytoestrogens can weakly bind to estrogen-beta receptors which are expressed in arteries and smooth muscle. Individual phytoestrogens may be either estrogen agonists or antagonists. Numerous studies of either dietary soy or phytoestrogens and health outcomes have demonstrated inconsistent or inconclusive results. Results of chronic feeding studies in pregnant animals suggest that high doses of phytoestrogens alter the fetal hormonal environment (Cornwell et al., 2004)."***

2000 the **EPA "Final Report" confirms, *"There is widespread concern that developmental exposure to endocrine active chemicals (EACs) may adversely affect reproductive, neurobehavioral, and immunological development or predispose those towards various cancers later in life. For some of these endpoints, (soy) daidzein and genistein mimicked DES; however, unique or opposite responses were also evidence for each of the phytoestrogens, including low dose of genistein. The window of exposure also was important for type of response elicited by the treatments; that is, in utero and lactational exposure often had different effects. Altered outcomes… indicated that treatment effects continued to be evident after the end of the exposure window (birth or weaning). Therefore, exposure of human fetus, and/or nursing baby to these isoflavones has the potential to influence immediate and future reproductive development. …EACs at levels of exposure that mimic those found in humans in North America produces target effects that indicate changes in cell function."***
http://cfpub.epa.gov/ncer_abstracts/index.cfm/fuseaction/display.abstractDetail/abstract/140/report/F

EPA also confirms, *"An 'environmental endocrine disruptor' has been defined as 'an exogenous agent that interferes with the production, release, transport, metabolism, binding, action or elimination of natural hormones in the body responsible for the maintenance of homeostasis and the regulation of developmental processes. In addition to the so-called 'environmental estrogens'… the term includes agents that affect the thyroid and pituitary glands and other components of the endocrine system."*

EPA again confirms, *"In our study, 50% of the 49 chemical compounds tested exhibited estrogenic activity in the two bioassays: …and phytoestrogens. Because the endocrine system plays a critical role in growth, development and reproduction, even small disturbances in endocrine function can have profound and lasting effects. It is known that impacts of endocrine disturbances in humans or animals can be particularly damaging if exposure occurs during the highly sensitive prenatal."*

1996, **and again the EPA confirms**, ***"Phytoestrogens are naturally occurring non-steroidal plan chemicals with estrogen-mimetic properties."***

1998, **and again the EPA confirms, *"Consideration should be given to ensuring that existing programs such as NHANES (National Health and Nutrition Survey) include monitoring of the important classes of EDC's such as phthalates, phenols, (soy) phytoestrogens, organochlorines, and other pesticides and herbicides."***

2002, **and the EPA sponsored workshop, called "Endocrine Disruptors Program Review Workshop" report by Claude Hughes et al also confirms, *"For some of these endpoints, (soy) daidzein and genistein mimicked DES; however, unique or opposite responses were evident for each of the phytoestrogens including the low dose of genistein."***

Yet the EPA will not lawfully ensure American public disclosure of equal knowledge of the estrogenic activity in soy phytoestrogenic endocrine disurptors (whether transplacental or fed from soy infant formulas and foods), of which mimic DES, an established developmental poison, of which **both DES and soy phytoestrogenic endocrine disruptors are never proven as neurologically fetal, infant, and child safe.**

1990's NIH soy researchers such as **Drs. Doerge and Sheehan repeatedly warn**, ***"Although safety testing of natural products, including soy products is not required, the possibility that widely consumed soy products may cause harm in the human population via either or both estrogenic and***

goitrogenic activities is of concern." .
http://www.jstor.org/stable/3455387?seq=1#page_scan_tab_contents

Several renowned NIH and FDA soy phyto-toxic researchers such as: Doerge, Sheehan, Newbold, Patisaul, Jefferson, Chang, Delclos, and countless others, have for several decades and to this day, continue to repeatedly study report that soybean phytoestrogenic endocrine disruptors, and/or additional soybean phyto-poisons are capable of causing severe and irreversible adverse developmental body and/or brain effects to once healthy fetus, infants, and children. Absent heartedly, NEVER is there public disclosure.

Soy infant formulas and infant soy foods, as majority of soybean products contain GMO's of which are again NOT proven as neurologically fetal, infant, or child safe. **Proposition 65 recently includes this popular Monsanto soybean glyphosate herbicide on their list of carcinogens.**

Norway, 2013, T.Bohn et al report, *"Compositional differences in soybeans on the market: Glyphosate accumulates in Roundup Ready GM soybean. …soybeans were planted on about 30 million hectares in the USA, with (Monsanto) Roundup Ready GM soy contributing 93-94% of the production. However we argue that compositional studies that have overlooked (not measured) pesticide residues contain serious shortcomings. Chemical residues… may add toxic properties to the final plant product either by itself or by affecting the plant metabolism. This is particularly relevant for herbicide-tolerant varieties. USDA data document dramatic increases in the use of glyphosate-based herbicides and GM soy is a major driver for this development. A reduced body size of juveniles was even observed at exposure to Roundup…. …conclusion that the weight of evidence indicates that glyphosate itself is a teratogen and that adjuvants commonly used in conjunction with glyphosate amplify this effect."*

It is no secret that the U.S. USDA maintains a Monsanto "Revolving Door," a loaded gun that targets all healthy American people. And infant soy formulas contain soybean plant-poisons that are also saturated with GMO glyphosate. All without evidence of developmental body- or brain-safety!

Again without public disclosure, soy isoflavone phytoestrogenic endocrine disruptors are study proven as increasingly poisonous in combination with: *1. A second endocrine disruptor: pesticides, plastics, lead, mold, water or air pollution, etc., 2. Estrogenic and/or endocrine disruptor prescribed drugs.*

Soy is also reported as capable of disrupting the potency of some vaccines. There are also three vaccines (Influenza-Afluria, Hib/Hep B-Comvax, and Pnemococcal-PCV13- Prevnar 13) that contain soy**.** How dangerous to babies is this direct shot of soy phytoestrogenic endocrine disruptors, has never been investigated.

Is it legal that at the very same time that the HHS, NIH, and FDA refuse to post lawful "Warning" labels on developmental exposure to soy phyto-poisons, they withhold the fact that they continue to actively plan and organize an assortment of taxpayer multi-million dollar never-ending studies to investigate adverse soy phyto-poisonous developmental body and brain effects? SEAD, SEED, IFED, EARLI, MARBLES, CHARGE, National Children's Study, Beginnings Study...and how many more?

At the same time a million or more innocent and loving parents are unknowingly feeding their babies soy phyto-poisons because they trust the NIH and FDA, it is an outrageous undisclosed example of which

the NIH NIEHS describes the SEAD soy study, ***"To establish methods for future larger studies on the estrogenic effects of soy infant formula on the developing infant."***

And frightfully sad, the soy "Infant Feeding and Early Development" study (IFED) reports**, *"…looking for evidence of the infants' response to the estrogen exposure from soy as well as other putative 'endocrine disrupting' chemicals."***

Although heavily under the influence of Soy Industry/Pharma funding the **"Beginnings Study" reports:** ***"Nonetheless, questions remain regarding potential long-term adverse health effects of soy protein-based formula consumption due to the isoflavone content in the soy protein isolate used as the sole protein source in these formulas. Soy isoflavones have been shown to interact with estrogen receptors and therefore could have an effect on the reproductive system and other hormone sensitive tissues including… development, adult fertility, hormonally sensitive cancers...and bone development."***

In spite of the fact that the Arkansas Children's Nutritional Center and/or researchers working on the **"Beginnings Study"** are saturated in soy interest funding, they report soy formulas are, ***"...some reasons to be 'concerned' about possible drawbacks of soy proteins."***

Too often developmental soy phyto-toxic studies, involve soy industry, and/or Pharmaceutical, or Monsanto interests: funding, consulting, contracts, grants, review, etc. Tragically, ongoing U.S. Health Organization soy phyto-poisonous studies, funding, and results are NOT publicly disclosed while millions of American babies are fed soy phyto-poisonous infant formulas, or soy contaminated infant "milk" formulas and foods.

With decades of existing mass study evidence that describes the soy phyto-poisonous cause of developmental body, brain, behavioral disorders to include autism, there are NO parental health questionnaires that justifiably question the child's history of exposure to soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisons of health-damaged children. Why not?

NO Developmental Soy Infant Formula Phyto-Poisonous BENEFIT:
To date, the ONE soy infant formula benefit was as a replacement for lactose intolerance or milk allergies of which had become obsolete. Soybeans *are* high level allergens. To date, **"Lactose-free" infant formulas are in truth beneficial: safe and nutritional. Soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisonous infant formulas remain popularly U.S. marketed… without benefit, and without evidence that any normal infant is able to body- and/or brain-survive**. This is reason why soy infant formulas are forbidden for pre-term babies…no safety, no nutritional value! It is once healthy American babies who become prey, placed directly into the path of unnecessary adverse body- and brain-effects to suffer from for a lifetime.

Soybeans encourage dangerous peanut allergy reactions! Asthma and Allergy Resource Center reports, *"Soy induced anaphylaxis in children with asthma and peanut allergy. What you may not know is that infants and children with peanut allergies can have an allergic reaction after eating a food that contains soy..."* http://allergyware.wordpress.com/2007/04/22/if-your-child-has-peanut-allergy

Allergy Kids Foundation confirms, ***"Ten years ago, in 1996 soy was genetically engineered with chemical toxins to make it a more profitable crop. That same year, there was a 50% increase in soy allergy..."*** http://www.allergykids.com/defining-food-allergies/soys-role-in-peanut-allergy/

"Codex Alimentareius" (book of food) **contains food health standards set by the World Health Organization** and the **Food And Agriculture Organization of the United Nations that are to be respected by the USA. The *Codex Alimentarius* contains strict safety requirements for infant formulas, *"All ingredients shall be...of good quality, safe and suitable for ingestion by infants…and shall not contain any other poisonous or deleterious substances in amounts which may represent a hazard to health."*** http://medlibrary.org/medwiki/Codex_Alimentarius

As no other country in the world, the USA popularly and inconspicuously markets soy infant formulas, soy contaminated infant "milk" formulas and foods on grocery shelves without fair or law-abiding "Warning" labels. **Of no coincidence**, powerful multi-billion dollar soybean industries, Pharmaceuticals marketing soy infant formulas, and Monsanto GMO soy profiteers are also located in the USA.

I doubt if even **George Washington** understood the true depth of his statement, ***"Few men have virtue to withstand the highest bidder."***

INTERNATIONALLY

As previously stated, researchers Patisaul and NIEHS W. Jefferson conclude, *"Internationally the use of soy formula is viewed more cautiously than in the U.S."*

Unlike the USA, home to a powerful army of multi-billion dollar corporate soybean profiteers, Italy, France, Israel, New Zealand, Switzerland, Denmark, Germany, Canada, UK, India, Korea, (and how many more countries?), all prioritize their promised oath to responsibly first, and foremost protect baby-health, while refusing to market soy infant formula and foods on grocer shelves.
2002, UK Scientific Advisory Committee on Nutrition, (SACN) reports, ***"There is cause for concern about the use of soy-based infant formula. There is neither substantive need for soy-based infant formulae nor health benefit arising from their use."***

2006, **New Zealand, renowned soy researcher Dr. Michael Fitzpatrick** published several adverse health soy studies, and he wrote letters to the FDA and CFSAN requesting public disclosure of soy-phyto-toxicity. His requests are denied. **Dr. Fitzpatrick wrote,** "***...much research into the effects of isoflavones has shown quite conclusively their reproductive toxicity to a large range of animals. These included rats, mice, pigs, cheetah, quail and fish. It is well established that the soy-isoflavones can modify the menstrual cycle of human females at moderately low doses. I am involved with current research that shows that similarly low doses to adult male humans reduces testosterone levels.... I am particularly 'concerned' about the very high doses of isoflavones that infants fed soy-infant formula receive and understand this very issue is being closely followed by the EPA."***

National Institute of Toxicological Research in Seoul, Korea, researchers SJ Kwach et al, report: *"Risk Assessment of Soybean-Based Phytoestrogens. However, phytoestrogens are considered to be potential endocrine-disrupting chemicals (EDC), which interfere with the normal function of the hormonal and reproductive systems. Therefore, dietary exposure to soybean-based phytoestrogens is of 'concern' for Koreans.... These results suggest that dietary exposure to phytoestrogens, such as daidzein and genistein, poses a relatively higher health risk for humans than synthetic EDC."*
http://www.tandfonline.com/doi/abs/10.1080/15287390903212212

2005, **French Food Safety Agency, *"The consumption of phytoestrogens cannot a priori be considered safe, because they interfere with the hormonal system, and as such merit examination. For infant and young children taking soy-protein based formula, it is recommended that phytoestrogen intake be limited.... In the same way, in utero and neonatal exposure needs to be limited. …as has been shown in children, phytoestrogen consumption can increase thyroid hormone requirements in patients being treated for hypothyroidism."*** www.second-opinions.co.uk/soy-online-service/FFSA.pdf

2006 French (Pubmed) study reports***, "Phytoestrogens and soy foods in infants and children: caution is needed."*** **http://www.ncbi.nlm.nih.gov/pubmed/16862658**

German study reports, ***"Soy and infants--that is incompatible. Plant proteins are no substitute for normal milk products / adverse effects possible."*** Kinderkrankenschwester. 2008 Jul;27(7):286.

Additional Study Reported Soy Phyto-Poisonous Risks Caused to Exposed Children Without U.S. Health Disclosure:

As all parents' nightmare, throughout prior decades and to this day, there are nearly a thousand NIH Pubmed published studies that repeatedly and increasingly conclude fetal, infant, and/or child exposure to soybean phytoestrogenic endocrine disruptors plus additional developmental soy phyto-poisons have potential to cause multiple childhood diseases and disorders to include: **leukemia, pancreatic cancer, a variety of cancers, cancer metastasis, severe thyroid dysfunction or disease, immune deficiency diseases, diabetes, inferior growth and development, allergies, asthma, anaphylaxis, multiple reproductive diseases and disorders, (to include male or female infertility in adulthood), cardiovascular disease, obesity, gastrointestinal distress, gender chaos, hypospadias, homosexuality, (demasculinization/feminization of males, defeminization/masculinization of females), seizures, and multiple neurological and behavioral disorders that includes autism**. http://foodhealthroulette.blogspot.com

Another U.S. epidemic is **childhood obesity** that can be caused not only by poor dietary habits, and/or no exercise, but soy phytoestrogen-caused. According to the **Environmental Health Perspectives of the NIH NIEHS, *"Obesity is strongly linked with exposure to risk factors during fetal and infant development. Certain pharmaceuticals…have been linked to weight gain …as have a handful of dietary obesogens, including the soy phytoestrogen genistein…. Most known or suspected obesogens are endocrine disruptors."***

Again without public disclosure, soybean phyto-poisons are dietary obesogens, or the cause of obesity!

Worthy of, but sorely lacking representation from multiple U.S. Food and Health Laws that protect American children's health, innumerable soybean plant-poisons are NEVER proven as fetal, infant, or child physiologically, reproductive, or neurologically safe!

The math fits: Increase in popular U.S. marketing of omnipresent soy phyto-poisons contaminate fetus, infants, and children **+** Increase in U.S. diagnoses of severe and irreversible infant and child diseases and brain disorders to include Autism = **Not coincidence; but the soy phytoestrogenic endocrine disruptor plus additional soy phyto-poisonous CAUSE of multiple adverse developmental body and brain effects.**

FACT:

1. Boys:

* Estrogens are important for the development and maintenance of brain function. NIH Pubmed studies overwhelmingly conclude- **soybean phytoestrogenic endocrine disruptors plus additional soy phyto-poisons are able to permanently derail, disrupt, rearrange, and damage several developing brain neurotransmitter systems and brain circuitry in females, and cause even greater adverse neuronal damage in males. Soy phytoestrogenic hormone disruptors cause the dangerous imbalance between critical testosterone to estrogen hormone ratio levels. This fact coincides with the higher rate of autism diagnosed in boys.**

2. Multiple Children in One Family:

* Without law abiding public "Warning" labels, and while misled of developmental health and safety, families continue to unknowingly swallow soy phyto-poisonous products. **This fact coincides with the probability of more than one autistic child in a family.**

3. Autistic Children Commonly Suffer From Multiple Diseases/Disorders:

* Brain and body hormone systems are harmoniously connected. Most often autistic children suffer from multiple disorders or diseases. **NIH Pubmed studies repeatedly confirm soy phyto-poisons cause multiple developmental adverse physiological, reproductive, and/or neurological effects. Particularly diagnosed in autistic children are gastrointestinal disorders, epilepsy, and seizures. Published studies repeatedly confirm the soy phyto-poisonous cause of these precise adverse effects seen in autistic children!**

SOY Phyto-Poisons Are Proven To Force Medical Treatments That Force Medical Cost Hardships!

2015, **Renowned researchers Dr. Leonardo Trasande and his team report**, ***"Context: Rapidly increasing evidence has documented that endocrine-disrupting chemicals (EDCs) contribute substantially to disease and disability. Expert panels achieved consensus at least for probable (>20%) EDC causation for IQ loss and associated intellectual disability, autism, attention-deficit hyperactivity disorder, childhood obesity, adult obesity, adult diabetes, cryptorchidism, male infertility, and mortality associated with reduced testosterone. Conclusions: EDC exposures... are likely to contribute substantially to disease and dysfunction across the life course with costs in the hundreds of billions... per year."*** http://press.endocrine.org/doi/10.1210/jc.2014-4324

I asked Dr. Trasande, ***"Does your research on endocrine disrupting chemicals that contribute substantially to disease and dysfunction with your found resulting medical costs include exposure to soy phytoestrogenic endocrine disruptors?"***

Dr. Leonardo Trasande answered the affirmative, ***"Our analyses accounted for potential health effects of naturally occurring endocrine active chemicals, including the ones you described.... We estimated the cost of health effects... and whose exposure could be reduced through regulatory activity."***

NIH NIEHS Director Birnbaum confirms, ***"…environmentally linked diseases… can affect an individual's entire life, with potentially large impacts on both quality of life and health care costs."***

Although withheld from public disclosure, soybean phyto-poisons are overwhelmingly study established as environmental poisons that cause any host of diseases and disorders particularly in most vulnerable exposed fetus, infants, and children. Where is lawful public disclosure?

PLEASE do not use and abuse the sorely faulty NTP CERHR Panel "Opinion" as IACC SCAPEGOAT-

Why would unprofessionally, bogus, and brief 2006 and 2009 NTP CERHR soy infant formula meetings of which a small non-expert panel "Opinion" unfairly and unfaithfully trump multiple U.S. Health Official testimonies, and nearly a thousand in-depth and highly respected scientific soy phyto-poisonous developmental studies all concluding adverse developmental effects?

After the 2006, NTP CERHR Brief on Soy Infant Formula- Highly renowned soy researcher **Dr. Kenneth Setchell** wrote to CFSAN Director Michael Shelby, ***"So we are left pondering what all these animal experiments mean. To deny that soy isoflavones have biological effects would be absurd given a wealth of evidence from in vitro, cellular, and molecular studies."***

Responding to the 2006 NTP CERHR Brief on Soy Infant Formula, **Doctor Lindy Woodard wrote to NIH CERHR Director Shelby**, ***"I am deeply concerned about the expert panel's conclusion.... Over the years, expert independent scientists including leading toxicologists from the FDA's and NIEHS's own laboratories have expressed serious concerns about the effect of soy phytoestrogens on brain, thyroid, and reproductive development. We need to take their conclusions seriously. The U.S. should follow examples of the Israeli Health Ministry and British Dietetic Association who warn parents and pediatricians about the potential dangers of soy infant formula. I personally know of the dangers of soy infant formula because I have been practicing pediatrics for 30 years and observed for myself that babies are not healthy on soy formula. I hope that this letter will encourage the panel to reconsider its conclusions and to commit to precautionary principle of 'better safe than sorry."***

And **PLEASE do not use and abuse the scapegoat of the December 2009 NTP CERHR** review of soy infant formula. I was there, and it is my testimony that the vast majority of the 14 member panelists were NOT in the least soy experts, but most frightfully the majority being largely under the influence of direct and/or indirect soybean interest funding. From the start, a large number of panelists were obviously pro-soy biased and pleasing to multiple soy funded lobbyists in the room. 11 non-expert panel members voting their simple "OPINION" of "minimal concern" in spite of many times concluding ***"Clear Evidence of Adverse (soy) Effects."*** The higher soy-funded influence, Jatinder Bhatia, was the one panelist to vote the impossible, "negligible concern."

February, 2010, **Judith Palfrey the President of American Academy of Pediatrics states,** ***"Jatinder Bhatia,… recused himself from the review of this document and development of comments.... Concerns have been raised in relation to the safety of phytoestrogens and isoflavones, including their potential negative effects on sexual developmental and reproduction, neurobehavioral development, immune function, and thyroid function. AAP appreciates that the CERHR has revisited the potential developmental and reproductive toxicities of soy infant formula. Since the first panel convened in 2006, a number of new studies have been published related to human exposure, reproductive toxicity, and developmental toxicity for soy infant formula."***

"Concerns," there are massive numbers of professionally voiced legitimate ***"Concerns"*** over developmental soy phytoestrogenic endocrine disruptor plus additional soy phyto-poisons that

contaminate fetus, infants, and children as can also be common sense expected. Where is public disclosure?

Against NTP CERHR guidelines the 2009 panel refused to review multiple adverse developmental soy studies placed on their desks. Also, importantly, this NTP CERHR meeting was stated for exclusive review of soy phyto-poisonous-cause of adverse developmental reproductive health… of which was ridiculously reviewed on soy-exposed babies, instead of reproductive age. This NTP CERHR panel was also instructed to review evidence of soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisons exclusively on baby reproduction, and NOT for adverse physiological or neurological effects. Although the panel reports, "Clear Evidence of Adverse Effects" their 11 biased votes were the impossible "minimal concern."

Therefore, please do not use the bogus, non-expert NTP CERHR Brief, very brief soy infant formula meeting consisting of 11 non-expert "opinions" as your scapegoat.

CAA and CARE:

The 2006 Combating Autism Act (CAA)confirms, ***"Federal declaration of war on the epidemic of autism. An information and education program and its risk factors to be provided by the HHS to health professionals and the general public."***

As you know, CAA and CARE Acts read, ***"Recent studies supported by NIH have uncovered distinct differences in the brain development of infants who later are diagnosed with ASD, while studies supported by NIH, DoD and EPA have identified potential contributions to ASD risk from diverse environmental risk factors including nutrients, air pollutants, pesticides and paternal age."***

"Soy Infant Formula" phytoestrogenic endocrine disruptors are NIH NIEHS established environmental risk factors! Multiple U.S. Health Officials and Health Organizations all concur with the massive evidence confirming the soy phyto-poisonous cause of adverse developmental health. This acknowledgement deserves equal public knowledge that can result in the protection of developmental physiological, reproductive, and neurological health.

As your appointed duty, the IACC Committee is aware of established autism laws that require autism research; whether possible, probable, or absolute in the evidence that details a cause of autism, is to be unquestionably allowed as public information**.**

Therefore, this is an urgent request that you allow mass evidence that clearly documents the fetal, infant, and/or child developmental exposure to fluctuating levels of soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisons that are placed into soy infant formulas, soy added infant "milk" formulas and foods are physiological, reproductive, and neurological poisons that cause behavioral disorders to include autism, until proven as brain-safe.

As established, NIH NIEHS Director Birnbaum confirms, **"…it is apparent that endocrine disruption is an important emerging public health concern."**

As critically important right-to-know public information; fetal, infant, and/or child exposure to unknown fluctuating dosage levels of the several soybean phytoestrogenic endocrine disruptors, plus additional soybean phyto-poisons have never been proven as physiologically, reproductive, or neurologically safe, while overwhelming evidence concludes the cause of a host of severe and

irreversible adverse developmental body- and brain-effects that are wrongfully, negligently, and unlawfully withheld from trusting American public disclosure.

Executive Order 13045- ***"Protection of Children From Environmental Health Risks and Safety Risks"*** **lawfully requires:** ***"Section 1. Policy- 1-101- A growing body of scientific knowledge demonstrates that children may suffer disproportionately from environmental health risks and safety risks. These risks arise because: children's neurological, immunological, digestive, and other bodily systems are still developing.... Each Federal agency: (a) shall make it a high priority to identify and assess environmental health risks and safety risks that may disproportionately affect children; and (b) shall ensure that its policies, program, activities, and standards address disproportionate risks to children that result from environmental health risks or safety risks. 1-102. Each independent regulatory agency is encouraged to participate in the implementation of this order and comply with its provisions. 2-203- 'Environmental health risks and safety risks' mean risks to health or to safety that are attributable to products or substances that the child is likely to come in contact with or ingest (such as the air we breath, the food we eat, the water we drink or use for recreation, the soil we live on, and the products we use or are exposed to)."***

Catastrophic Bottom Line- Innumerable American parents are left ignorant to the potential of soy-poisoning of their own babies, while there remain NO lawful U.S. "Warning" labels as an equal opportunity for an innocent American public to protect their babies' health. All the while without lawful parental disclosure, a million or more American babies are repeatedly fed soy phyto-poisonous formulas, thus participating in an undisclosed and undocumented game of developmental adverse body- and brain-roulette. None of the HHS, NIH, or FDA studies have ever established developmental soy phyto-poisoning body- or brain-safety! http://foodhealthroulette.blogspot.com

In Conclusion:

EPA Office of Children's Health says, ***"American children have the right to a healthy and safe future…"***

In accordance with the above enclosed information*, "Soy Infant Formula" (soy food products)* are a highly toxic confirmed NIH NIEHS *"Environmental Agent,"* of which soy phytoestrogenic endocrine disruptor plus additional soy phyto-poisons are time and time again established as fetal, infant, and child neural-poisons, with brain-toxic probability to cause irreversible neurodevelopmental disorders, to include autism, of which requires life-long medical treatments and medical cost hardships.

As you well know, autism is a developmental health crisis reaching epidemic proportions. Autism is a life-long neurological disorder that may very well be prevented with law-abiding public knowledge of this mass evidence concluding soy phytoestrogenic endocrine disruptors plus additional soy phyto-poisons as a cause, while never proven as neurodevelopmentally safe. Autism steals the brain from American children who grow into the future of a large population of struggling American adults, of which even the slightest potential risk must be righteously and lawfully revealed as critical public health information. Here in your hands, you have the power to save the life-long neurological well-being of our most treasured population.
Frightfully unfair, the untold public health enigma remains: Will any particular fetus, infant, or child be able to normally body- and/or brain-survive developmental exposure to fluctuating levels of soy phytoestrogenic hormone disruptors plus several additional soy phyto-poisons?

Therefore, this is a truly valid request that you, the IACC Committee appointed to protect fetal, infant, and child brain-health will dutifully enforce law-abiding public disclosure “Warning” labels on soy infant formulas and foods, until the many soybean containing phyto-poisons can ever be proven as developmentally brain-safe.

I am most hopeful that while without evidence of fetal, infant, and child neurological survival, you will agree that IACC Committee acknowledgement of adverse fluctuating dosage levels of soy phytoestrogenic endocrine disruptors plus multiple additional soybean phyto-poisons, of which are repeatedly and increasingly concluded as developmental neurotoxicants, unquestionably warrants your urgent law-abiding public disclosure to protect a large American population from a lifetime of neurological disorders such as autism.

I very much appreciate your time, and will look forward to your reply.

Respectfully,
G.A. Elbek- Investigative researcher
Santa Barbara, CA
[PII redacted]

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

Simran Mangat-Garcia **January 5, 2016**

The new year has begun with another autism and wandering death. Jayliel was only 5 years old. 49% of individuals with autism wander from safe environments. Every life matters. Children with autism need protection. We need the IACC to act on behalf of families living with autism and keeping children safe. Please take the initiative to help families by pushing support of Avonte's Law and demanding action for the families you serve.

The IACC committee needs to be aware they have a lot of catch up to do. All these years and millions of dollars spent and the IACC has very little to show for their "effort". My son was diagnosed at [PII redacted] and by the last CDC numbers he was not included in the 1:68 stat as he was born in California (state not included) and born in[PII redacted] (only children born 2001 and prior). Autism has reached an epidemic level!! Families are in crisis and children will soon be adults. We need to address the severe lack of assistance and services.

Here is a summary of changes that can help families living with autism:

- Based on CDC autism estimates, declare autism an epidemic and public emergency. We need to treat autism with the urgency it warrants: 1 in 68 children are living with autism in the United States. With the new 1 in 45 parent survey we know this number is sadly outdated.
- Define and collect a true census of individuals affected by autism. It is important to indicate that four year old estimates based on survey samplings do not work. Real numbers and details such as age groups and severity are urgently needed to review and address their unique needs.
- Push for subtyping to determine appropriate treatments and therapies to meet the unique needs of each individual.
- Since 2006, over $2 billion has been spent on the IACC. Families are not experiencing any changes to services or help for these costs. No innovative treatments have been found. I would like to propose the following changes to the IACC:
    - Consider a more diverse board at the IACC to include some of the world's researchers in cause and innovative treatment such as: Dr. Martha Herbert, Dr. Jill James, Dr. Richard Frye, and Dr. Dan Rossignol. It is my opinion that the current IACC board lacks in ground-breaking research and medical treatments happening today
    - Push the U.S. Dept. of Human Health (HHS) and IACC to collaborate and recognize the needs for services and support for families. We cannot operate in a vacuum.
- Collaborate with families via support groups in identifying needs for those living with the autism today.
- Outside traditional therapies, medical treatments are helping individuals with autism live healthier. Based on new research, co-morbid medical issues exist with autism. Where are the initiatives addressing these concerns to define answers?
- Identify a task force to address the current and future needs of adults living with autism.
- Prioritize and evaluate all possible environmental causes of autism.
- Operate with a sense of urgency in your strategic plan and committees. We cannot waste another moment. We must drive for answers.

We need help for families and individuals living with autism. We can no longer afford the status quo. We now need to strive to drive positive change for families living with autism. They need you to step up and make a difference.

Sincerely,

Simran Mangat-Garcia mom to [PII redacted].
Not a doctor or a lawyer, just a mom trying to get her kiddo better.

Carol Fruscella **January 5, 2016**

We wish to alert the members of this panel of the recent passing of a 5 year old boy. His name was Jayliel. (We know you will redact his name as he was a minor child.) "He had no fear. He didn't understand the dangers." He is not the first to wander away and drown and sadly we fear he will not be the last.

Jayliel, had Autism.

This panel can talk about acceptance, education and better awareness to your hearts content... That will never save this poor lost child or the next child or adult. Nor has it saved the 30 others, from the middle of last summer till now, that were reported by the Media that wandered and died.

Jayliel is just one more victim. How many more children and adults will be needlessly lost?

Avonte Oquendo, was 14 when he disappeared. He had severe autism and was nonverbal. He left his school building. He also was found in a river.

Sidney Heidrick, was a 4-year-old autistic boy who drowned in the waters of Lake Erie after he went missing from his grandparents' home in Sheffield Lake, Ohio.

Jayden Morrison, who was also only a 4-year-old, who was also autistic, wandered into a pond on Christmas Eve 2014.

These are only a few names of children who died not because of neglect or lack of care. They died because of their 'lack of fear'. They passed because they had Autism.

How many more children will our nation lose? How many more children will wander while this panel meets? How many souls have been lost since this groups creation in 2006?

These types of events are growing at an alarming rate. It is every parent's worst fear who lives with nonverbal and lower functioning autism daily. When you are the parent or caregiver to an individual with Autism who engages in wandering, elopement, or bolting behaviors you are always on high alert. There are some days of little rest and little to no sleep. One Autism group used a statistic that up to 49 percent of all those with autism will wander at least one time. For too many... that one event... will be their last event.

As you sit and reflect on your meeting today... Will your actions save the next child or adult from danger and harm's way? The lower functioning autism community needs real help now... not next week... and not in the years to come.

Your work should reflect the urgency that our public first responders use to find those that have wandered!

Neurological diversity is not the issue at hand. You can research and blame genetics all you want to. One in 45 or better said over a million children now have some form of Autism. It is hard to track the real number of those that die due to Autism because their deaths are reported as drowning... seizure... encephalitis or accidental.

It is time you rise up as a group and explore all that you have refused in the past to explore. It is time that you hold a press conference and call for Autism to be at an Epidemic level. If One out of every 45 children disappeared from their beds tonight... there would be such an outcry, looking for all the missing children. But Wait... in some odd strange way... that is happening. For many of us, we place our children in bed... read them a story... turned the lights out and then we are awoken by screaming that we never heard before. Then our children were NEVER the same after that event... and we tell you this... and you fail to HEAR US... because, as parents, we could have 'no clue' what happened and when.

Trust Us and Hear Us Well... When it is your child that disappeared in front of your own eyes... whose body remained, but all language was gone, YOU KNOW! When your child makes eye contact one day... and never makes eye contact again till over a decade later... YOU KNOW!

For the record, the internet had not been invented, when I watched not one, but two children slip away into Autism.

We were able to save one child... and that was well before this panel ever convened ... because we stopped vaccinating that second child per the CDC schedule.

Do you really wish to be the change needed? Please start looking in your own back yard. William W. Thompson Ph.D., who is a Senior Scientist with the Centers for Disease Control and Prevention, and who has worked there since 1998... only confirmed what many of us figured out on our own years ago. Parents saw and knew the results without spending Billions to do so. Why... Because we lived it well before 2004!

With all interventions known, my oldest sons Autism remains. We wish, in any small way that he was typical. He cannot control his body. He cannot control his sleep pattern. He cannot shave himself. He cannot drive. He is not safe to work in his local community. He is not aware of danger. He cannot prepare his own food. He cannot shop independently. He cannot sit quietly during a church service or any community meeting. Not one thing that IACC has done has improved the quality of his life. Our son was [PII redacted] when this group formed. We teach him daily. We love him daily. He was the One in 2,500... well before the One in 45 started to literally drown in the waters of Autism every other week.

Respectfully Submitted

Carol Fruscella
Jim Olson
Parents/Guardians of a soul with Autism

Anne Jakus **January 5, 2016**

I sincerely hope you finally plan to address the CDC vaccine whistle-blower issue (Dr. William Thompson) at the upcoming IACC meeting. It's disgraceful that a full INDEPENDENT hearing is not already under way to get to the bottom of this most urgent matter (and no, the CDC doing an "internal investigation on themselves" is not at all satisfactory). It's been over a year now. What are you waiting for?

I also hope that this year you finally demand an independent study of the various health outcomes of fully vaccinated vs the never vaccinated children. Until this study is done your committee has zero credibility. This is a study that could and should have been done several decades ago. The fact that you obviously do not wish to investigate this (or anything else that might shed unwanted exposure on the possibility of vaccines being associated with the autism epidemic or chronic illness) is very telling.

Autism appears to be a man-made epidemic. As long as your heads remain in the sand on the environmental issues (including vaccines, pesticides, antibiotics, etc) more and more innocent lives will be ruined. You have the ability to bring this tragic epidemic to a halt. I certainly hope you finally show the courage to do so.

Just what level of damage to our nation's children will bring about meaningful action of the part of the IACC? I would really like to know.

I would think 1 in 48 children with autism is a national crisis already, is it not?!

Please do a much better job this year than you have in past years. I has such high hopes for your committee when it was first formed, but it's been nothing but a huge disappointment.
Autism numbers are skyrocketing on your watch. Please do something meaningful.

Sincerely,

K. J.

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

Brian Hooker **January 5, 2016**

Brian Hooker, Ph.D.
Science Advisor
Focus for Health

The Focus For Health Foundation respectfully entreats the Interagency Autism Coordinating Committee to maximize the amount of research dollars allocated for elucidating and understanding potential environmental causes and contributors to autism and the current autism epidemic. These funds should encompass environmental stressors including those found in food, water, the environment and medicines, including infant vaccines. Funds should be allocated to independent researchers devoid of financial and other conflicts of interest.

--
Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)
[PII redacted]
bhooker@simpsonu.edu

Again. Again the written comments will come into the IACC's hands asking for help. I hope that they will not fall on deaf ears, yet again. As you read this I ask that you try to imagine it all from a parent perspective. I assume many of you are parents, maybe even the parent of a child with autism. Please, read on with a parent's heart.

Many, many parents of children with autism have walked into your meetings, stood before you, and begged for you to do the work. They have pleaded with you to take on the challenge of REALLY looking into what is causing the continually rising autism numbers. We have written letters, poured our hearts out to you and given you our testimonials about what has happened to our children. Our babies are sick. They need medical help. They wander away and drown. They are self-injurious. They have bowel disease. They suffer from seizure disorders. Some cannot speak. Some cannot use the toilet. More and more children are joining the ranks with every passing year.

And we love them. We love them with every fiber of our beings and ounce of our souls and seek only to find answers. We want relief for them. We want to take away their suffering so they can blossom and grow and lead a happy life free from physical illness and pain.

We have asked you to help us. Parents every year ask you to help us find answers for our children and to try to prevent this from happening to other children. We have shared that some of our children went in for their well visits healthy and days later lost skills, sometimes even the ability to communicate. Parents have seen their children react to the well-baby schedule of vaccines or the overprescribed list of antibiotics and we have shared the stories of our children so that others may be helped. But you have not heard us.

I believed that perhaps there would be progress when the committee dedicated a meeting to discussing co-occurring conditions a few years ago. Bowel disease, seizures, OCD, and many other conditions were discussed. It was the first time I ever heard anyone from the committee utter the phrase, "parents know their children best." I was hopeful. But there has been no progress. No follow up. Nothing has been done.

Today, you need to open your eyes to the reality that there are two VERY different types of autism. Yes, there are high-functioning individuals who manage to do well in school, hold down jobs, and develop relationships with others. Often we hear from these individuals that people like myself want to 'cure' autism. To get rid of it. Take away part of who they are. This could not be further from the truth. Those of us who seek answers and treatments do so because our children have the other type of autism. The one that no one likes to discuss or acknowledge. The autism where a child screams in pain, scratches his skin down to the bone because he can't live with the eczema all over his body, or lies on the floor seizing multiple times a day. Are you still reading with a parent's heart? Answer this then: Would we be doing our job as parents if we didn't work all day, every day to figure out how to free our children from these physical burdens? WOULD WE BE HUMAN IF WE DIDN'T WANT TO STOP THIS FROM HAPPENING TO ANOTHER CHILD?

If we didn't love our children so fiercely, we would not be asking AGAIN…HELP US. You have a moral obligation to do so. You can't pretend we don't exist, that our children's injuries didn't happen, or that all autism is the same. You must address the autism that no one wants to talk about. You need to address the hundreds of wandering deaths that occur every year. You must talk about the health

outcomes of our children under our current medical system. This is the root of the problem. Heal the co-occurring conditions and you have taken a HUGE step forward. I only hope that you will hear us.

Respectfully,

Megan Davenhall
President of The Thinking Moms' Revolution

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

Michelle Del Rosario **January 5, 2016**

Subject: Autism and Wandering

I am writing to you with grave concern over the exponential increase in the prevalence of autism over the past ten years. When your committee began meeting in 2006, the rate of autism was 1:110. A recent parent survey in October 2015 concluded that autism now affects 1:45 children. My guess is that the number of individuals and families living with autism may possibly be even higher. After a decade of meeting, my hope would be that there would be a sense of urgency with the IACC to take immediate action towards positive change, but sadly I don't believe this has been the case.

My husband and I have a son with autism who will be [PII redacted] this April. Coincidentally, the same year you began meeting was the year he eloped (wandered) from the school playground, unbeknownst to the staff. I was shocked to find him in the parking lot, alone, where cars were coming and going during afternoon pick up. He was just [PII redacted] at the time, completely nonverbal and no form of communication. We had been begging our IEP team for help, intensive speech therapy, ABA therapy, a 1:1 aide and the answer was no. Even more upsetting was when we requested an incident report from the school principal we received a notice informing us that my son was being cited with an assertive disciplinary action for leaving campus without asking permission. A nonverbal child with autism, with language skills ranging between 6-12 months, and the blame was placed on him, not with the "highly qualified" special education staff that we trusted to be supervising him at school. So began our fight for help that my son desperately needed. Our medical insurance did not cover ABA therapy or speech therapy because our son had autism. The school system insisted their classrooms were qualified and trained to help. They weren't though and my son continued to regress. We were able to fund some therapies ourselves and eventually I was able to advocate with our county Regional Center for ABA services, but the financial and emotional toll has been great. Still we would do it all again. Today, we have successfully taught our son to type on an iPad we have funded because insurance does not recognize these as communication devices. Eventually, at [PII redacted], in the 7th grade, once my son was able to demonstrate the skills he had learned at home to our school team, the school finally agreed to provide my son an iPad and a voice at school. Lost, critical, early intervention years, without a voice because there was no expectation, presumption of competence, or value placed on my nonverbal son's need to communicate. We have also pay out of pocket for private swimming lessons so that my son can become water safe. While not fail proof, and my son still requires close, around the clock supervision, we know we are doing everything we possibly can to ensure his safety. We are fortunate that we can pay for some of these services or training to advocate for our son and that I can stay home to be his caregiver, but many families cannot. Wandering and drowning are a very real and scary statistic in the autism community. I still can't forget our own experience even with all the steps we have taken to protect our son. Since June 2015, 30 individuals with autism have died due to wandering. Those are just the cases reported. Most recently, this past week Jayiel Vega Batista wandered on New Years Eve and died. He was only 5.

How can you help? To start I would like to urge you to do what you can to ensure Avonte's law gets passed. Avonte's law is named for another child diagnosed with autism, wandered and drowned. Avonte's law is an important bill that needs to move forward. In brief summary, it is a proposed Federal bill that would allocate $10,000,000 to work towards education and prevention of autism and wandering. This would be a very important and positive action step in the right direction. Eventually, I'd

like to see you work towards declaring autism an epidemic, work with a sense of urgency, prevention and funding for families living with autism. For now though, I respectfully ask that you come up with a plan to get Avonte's Law passed and keep individuals with autism alive and safe. Let's make 2016 a year of action driving positive change.

Most sincerely,

Michelle Del Rosario

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

Joanna Ashline **January 5, 2016**

Subject: Autism and Wandering

In 2004 our son [PII redacted] was diagnosed with severe autism (by today's DSM-5 diagnostic standards, a level 3 in severity). Since then, the amount of sleep we have lost worrying about our son's safety cannot be quantified. There is no chart or graph or equation in existence that can statistically depict the fear we feel each day, the anxiety we live with, the constant reel of "what ifs" that consume our days and plague our nights.

Autism is real.
Wandering is real.
The threat of death is real. For families like ours, it looms in the foreground, infiltrating every decision we make, every thought we have. Where we go, how we get there, and what security measures are in place once we arrive are questions that lead every single conversation we have. Even our home is not 100% foolproof, despite locks on every single door (including the five different kinds on our front entry). The lock our son cannot open today, may be the lock he masters tomorrow. His triumph would be our tragedy.

His inability to understand the guaranteed danger he would find himself in should he ever escape our watchful eyes and protective measures compounds an already difficult and desperate situation.

The last eleven years of parenting our amazing, loving, exceptional son has taught us many valuable and wonderful lessons about life and love and purpose. But there is a dark shadow that penetrates these lessons, and it comes from knowing that just around every corner lurks the possibility for loss and heartbreak.

The burden is not on our children.
The burden cannot be on parents alone.
Moms and dads across the nation who are terrified of losing their child with autism to wandering need HELP. How many more sons and daughters have to die from wandering before we are heard? How many news stories will it take? How many graphs and charts and statistics do the experts need before they realize each number represents a human life lost?

I don't urge action.
I DEMAND it.

Training for first responders, support systems such as free GPS tracking for parents, prevention protocols in place in schools, educational programs and trainings for caregivers and respite providers, access to affordable swim lessons that accommodate various levels of ability (our children are extremely drawn to water), and passing legislation designed to protect our loved ones. It's a list of tangible helps that should continue to grow

What are we doing?
What are we doing to protect one of our most vulnerable populations?

I'll tell you what I'm doing.

I'm making sure the nearly dozen locks in and around my home are engaged.

I'm making sure everyone that works with my son is aware of his propensity to wander.

I'm making sure I understand as many of the reasons my son wanders as possible so that I and those who are a part of his life can accommodate him as best as we can (Is his environment too loud? Is he feeling anxious? Is he escaping from something aversive? Is he looking for something in particular? What is he trying to communicate?). I may not be able to fully grasp his motivation to wander every single time he tries to take off, but being aware of potential triggers can and does help.

I'm exercising discretion about where we take our son, what safety measures are in place, and how much influence we may have over the situation and the environment. This means as a family, we often have to say no, when what we really want to say is yes.

Did I mention those locks? I'm checking them, again (and again). It's the only time I've considered my OCD a blessing.

I'm lying in bed each night, losing sleep while trying not to lose my mind.

I - along with thousands of parents and caregivers across the country - are doing all of these things.

And still, it's not enough. It will never be enough.

My son deserves to be safe, and to keep him safe, it’s going to take a village, filled with villagers who are dedicated to providing more than lip service about an issue that is literally killing our kids.

With the current trajectory regarding autism rates, it is only a matter of time before you will know and care about someone diagnosed with ASD. And while not every individual diagnosed with this disorder wanders, many do, and their loved ones need to be heard.

And not just when they're screaming their children's names in desperation and anguish as they search and scour the earth while begging God for a miracle.

Because as we continue to see, over and over and over again, by then, it's almost always too late.

DO SOMETHING.

Sincerely,
Jo and Michael Ashline
Loving parents of [PII redacted]
Jo Ashline

Author: Joashline.com
Founder and Editor: Special Needs Orange County
Columnist: This Modified Life, for The Orange County Register

Melissa Schneider **January 5, 2016**

Last year, many dozens of children died from Autism related wandering. As parents, we had hoped that a strategic federal plan would have been passed, enacted and implemented by 2015 to combat these tragic deaths, a plan that involved combining the efforts of the IACC, our lawmakers, law enforcement, school system, local leaders and parents. Regrettably, no major plan has been enacted yet to help families that have been voicing their concerns and fears for years about their children who are at risk of eloping and succumbing to danger.

On January 2, 2016, parents learned that the very young child, Jayliel Vega Batista, from Allentown, Pennsylvania, who had eloped on New Year's Eve, was found deceased in a canal near his home. For his parents and family, this must have been horribly painful, like no other heartbreak or anguish a parent can experience. For Autism parents nationwide, it was a devastating and a terrible reminder of how our pleas, requests, demands, petitions, etc... have been ignored by our local, state and federal lawmakers, and also a reminder of how our hopes we placed in all of you, the members of the IACC, have not been fulfilled.

The purpose of my letter does not serve to assess blame or downplay the noble efforts of many of those members who have selflessly served on the committee. My sole purpose is to appeal to your sense of compassion, fairness, decency, integrity and ethics. According to the latest CDC information, Autism now affects 1 in 45 children. As the numbers continue to increase, there must be a plan of action to prevent more deaths and tragedies from occurring. It is imperative that the IACC represent our families, and express our concerns to congress and the president. You can do that. You serve as a liaison between the public, families, children and our govt. agencies. You do have that power. Please use it for creating positive change, for saving children's lives and families. If we don't implement a plan soon, the consequences will be devastating for so many more families in the future.

Also, please consider the medical underpinnings of Autism, such as G.I., autoimmune and metabolic issues that create susceptibility among many children who receive an Autism diagnosis. These children need medical assistance that often is not covered or offered because many doctors assume all behaviors are related to Autism and/or psychiatric issues.

With all due respect, Autism is not a mental illness, and if a child carrying a diagnosis behaves as though they are in pain, it should never be ignored or explained away as just behavioral. These children should have the benefit of every other typically developing child who goes into a doctor's office or an emergency room for a medical condition or pain.

Finally, as I stated earlier, CDC now states that Autism affects 1 in 45 children. I am sure it has occurred to many of you that we can no longer ignore the elephant in the room. We must find what is causing so many children to develop it. We know it can't be better diagnosing, not with numbers like this that are reflective of an epidemic. We all know that there is no such thing as a genetic epidemic, therefore, we have to broaden our minds and accept that some other environmental trigger is at play. That trigger has to be found and stopped before the numbers continue to increase even more drastically. Our children are the future of this country. If they are too disabled or dead from Autism related wandering or drowning, who will lead our country in the future? Without an abundance of healthy children, what will happen to our nation? Please consider the ramifications of continuing without a solution or prevention. It will be catastrophic to say the least.

Once again, thank you for your attention to my letter. I appreciate your commitment and am hopeful that solutions can be created to protect and save our children, and promote good health and a superior quality of life for all of them. We know that all lives matter, including the lives of children diagnosed with Autism.

Very Respectfully,

Melissa Schneider

Lori McIlwain **January 5, 2016**

Statement from the National Autism Association Interagency Autism Coordinating Committee Meeting *January 12, 2016*

Introduction
Since 2008, the National Autism Association (NAA) has dedicated the vast majority of its time and resources to autism-related wandering prevention and response. NAA sounded the alarm in 2010 before this Committee and we are grateful for your time and consideration. With your help over the last several years, our community has been able to secure many resources, including formal data on elopement, a medical diagnostic code, and a safety subcommittee under the IACC umbrella, albeit short-lived.

As an organization, we've recorded and analyzed close to 600 elopement cases, provided over 20,000 safety boxes to autism families across the country, trained law enforcement and child protection agencies in the U.S. and Canada, provided over 1000 safety toolkits to teachers, published a white paper on lethal outcomes, funded research on contributing factors, create the AWAARE Collaboration website, provided $100,000 in Project Lifesaver funding for law enforcement agencies, and the list goes on.

Our team has worked around the clock for many years with great compassion and urgency. Please understand our sadness in knowing that 2015 was our community's deadliest year on record.

2015 Data
Over the last year, the National Autism Association recorded 32 wandering fatalities in individuals with an Autism Spectrum Disorder (ASD), and over 200 missing person cases. The vast majority of fatalities were caused by drowning, followed by traffic and train-related fatalities, hyperthermia, and two cases of mistaken home invasions after the individuals walked away from their respective group home into nearby residences.

2011-2015 Data
Our data indicate that for children with autism age nine and younger, wandering cases ended in death 42% of the time. Based on our data, increased risk for wandering incidents continue to be during the spring and summer months, during holiday parties and outdoor gatherings, after a move to a new home/school, public outings, transitions, and visits to non-home settings. For families still unaware of this information, prevention may be more difficult.

In terms of safeguards, parents report that door alarms, stop signs, identification, swimming lessons, the "tag" approach, and tracking devices are the most useful short-term tools & strategies for wandering prevention. NAA continues to encourage families to use a multi-layered approach, as no one tool is 100% effective.

Education Is Crucial for Prevention
The National Autism Association closely reviews each fatality to determine what tool or strategy may have prevented the incident. Because many of these individuals go straight to water with little time for

successful search and rescue, prevention is key. Education is the first step, and must take place before any safeguard is considered. Yet, many families, law enforcement agencies, educators, and clinicians are still largely unaware of this issue.

Education Must Start At Diagnosis
The American Academy of Pediatrics (AAP) has developed wandering prevention literature for autism families, but we believe this information is being underutilized. Every autism family should have access to this information at diagnosis.

Federal Action Is Needed
Over the last two years, NAA has worked on federal legislation to combat wandering deaths. Avonte's Law echoes what's already in place for the Alzheimer's Community. It will also serve to help educate first responders, educators, and clinicians. In addition, the IACP Alzheimer's Initiative under the International Association of Chiefs of Police is an impeccable model that should be available for the ASD community.

Our Request to IACC
NAA believes we must approach the wandering issue with consistent urgency and remain proactive. We urge IACC members to re-engage the American Academy of Pediatrics on the topic of wandering prevention. With existing AAP literature, it's a matter of reaching families at diagnosis. All families deserve to be told that wandering can happen, when it's more likely to happen, and the steps they can take to prevent it from happening.

On the response side, federal action is needed. Those with autism deserve the same resources already available to those with Alzheimer's disease. We ask for IACC's participation and formal support of Avonte's Law and the IACP model.

If the Committee would like further information on the issue of autism-related wandering, NAA is available for consultation or a presentation at an upcoming meeting. We thank you for your ongoing work and consideration.

Sincerely,

The National Autism Association

Jackie Martin-Sebell **January 5, 2016**

I just heard of the 5pm deadline for public comment for the IACC committee. That is 5 minutes away. Unfortunately I am not able to spend much time on it due to crunch of time, and also because I am currently sitting at the doctor's office with my daughter.

However, I wanted to send a quick note. Please step up. There are so many incredibly important issues within autism that need to be addressed and can't wait any longer. Our children are sick. Our children are abused. Our children are not getting properly cared for. Our children are not being properly educated. Our children are wandering. Our children are dying.

Our children and adults with autism are important and need your help today. Not tomorrow or next month or next year.

We expect your committee to do as you promised to, for all children and adults living with autism and their families.

Jackie Martin-Sebell
Michigan

Deborah Haney **January 5, 2016**

I am a health care professional and mother of a child with autism. I want to know when the committee will provide a large-scale immunized vs non-immunized study of children and their health, and what your committee is doing to properly investigate CDC Whistleblower claims that data was destroyed and changed regarding African-American males and MMR risk.

Thank you,
Deborah Haney BSN, RN

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

Rosemarie Dubrowsky **January 5, 2016**

I am the parent of a 20 year old minimally-verbal young ma n with severe autism named [PII redacted].

I had been attempting to write a letter pleading for certain things for our loved ones with severe autism when I got a call from his school that he had had a seizure, bit his tongue, asked to go to the bathroom but did not make it before he peed himself and then threw up to relieve some distress he was having. The number of individuals with autism that develop seizures is much higher than the typical population. This is something that needs to be researched.

We, as parents are in the trenches every day and barely have enough time to get the things done that need to get done while trying to maintain a family life by going to work. There are some days that we are on one hand paralyzed because we attempt to deal with and process the things that are happening with our loved ones daily and on the other hand driven to find things that will help them to be the best that they can be.

I have read testimony that others have submitted in the past regarding the items that need to be looked into and I will reiterate what so many others have said in the past. LISTEN TO THE PARENTS! My son does not have the ability to tell us where he is hurting or how he is feeling. There are ways that he communicates that (some of which are not so pleasant such as aggressions) and we will continue to work with him to open up avenues of communication so that someday he may be able to tell us those things, but until then he has me, my husband and the others that love him so dearly to do that for him.

When [PII redacted] was young he attempted to wander many times and thankfully he was never successful at getting away from us for any long length of time. Almost 50% of children with autism wander, and even with Herculean efforts to keep them safe, some make it past all of the security put in place and die as a result. This is a serious issue and we need to make sure that Avonte's Law is passed so that parents can have access to tracking bracelets on top of what they may be doing to keep their child safe.

Additionally, we need to find out what environmental issues are causing/exacerbating our loved ones autism symptoms. There is no such thing as genetic epidemic. The numbers that are diagnosed keep rising and although some individual's autism may not affect them having a job and participating in life in a productive way, the number of individuals that fit into the category of my son have gone through the roof and need a kind of care that is so very different that others i n the past with developmental disabilities. I say this after speaking with many state and federal agencies that have served this community for many years. When I contacted our state's Department of Developmental Disabilities and spoke with people trying to get help for my son, the com mon theme was that they were dealing with a huge percentage of individual's like my son, whereas 10 or 15 years earlier they were a significantly lower percentage of their case load.

Another area that needs to be addressed is the comorbid medical issues that go hand in hand for many individuals with autism. The gastrointestinal issues, like seizures have been confirmed. We need to figure out what we can do to help our loved ones heal so that the level of care can be lowered.

As usual, I am rushing to complete this so l can meet the deadline for this to be submitted so I know I am missing many things, but I want to get these initial thoughts on the record and will submit additional testimony in the future.

I am a board member of the National Autism Association, however, this testimony is being submitted purely as a parent.

Sincerely,

Rosemarie Dubrowsky

[PII redacted]

Asha Kumar **January 5, 2016**

I am a parent of a child with autism writing in support of Avonte's law. It is a bill that is named after a child with Autism who wandered and lost his life to drowning. We worry about accidental wandering and an unfortunate accident with our child at all times. I'm hoping that this bill will educate everyone involved and prevent such tragedies as much as possible. A federal bill will make this issue a priority. With the growing rates of autism we need legislations like this to make the public and law enforcement aware of the dangers of wandering related to autism. Parents like me need the help and support of the community as a whole to keep our kids safe.

Thank you for providing me with a platform to voice my opinion!

Matt Carey **January 5, 2016**

As you are no doubt aware, public comments to the IACC include a large amount of discussion on vaccines. Over the past decade I have spent a great deal of time on this question, checking up on just about every claim that has been made. Time and again, I find that there is no basis to the arguments and studies that supposedly shows a connection.

Perhaps the main claim being made today is that there was a cover up at the CDC involving an MMR study. It involves a CDC researcher named William Thompson. Some have labeled this story "CDC Whistleblower".

I've taken this story seriously from the start. Which means I've checked the facts from the start. I've spent many hours researching claims made, to the point of requesting the documents that were handed over to Congressman Bill Posey.

Let me put this simply: there is no substance to the claims of fraud, malfeasance or other wrongdoing. There is no reason for a congressional hearing to be held, and certainly no reason for the IACC to support such an effort. Also, the finding discussed does not show that the MMR vaccine is associated with or causes autism.

If you wish to read more about this topic, here are a few of the articles I have written:

The William Thompson Documents. There's no whistle to blow.

The Hooker/Thompson conversations: were significant analyses omitted from Hooker's paper?

Discussions of the recent MMR/autism paper (and why the study isn't what the author wants you to believe it is)

Those are my words. Here are some of William Thompson's words:

The main claim of malfeasance is based on the idea that the CDC team deviated from their own protocol (analysis plan). William Thompson responded to this question in a phone conversation with Brian Hooker (transcripts of which were published):

> Dr. Hooker: And then you basically deviated from that particular plan in order to reduce the statistical significance that you saw in the African American Cohort.
>
> Dr. Thompson: Well, we, um, we didn't report findings that, um…All I will say is we didn't report those findings. I can tell you what the other coauthors will say.

William Thompson on whether the finding shows a true association between MMR and autism (from a statement given to Representative Posey's office):

> "The fact that we found a strong statistically significant finding among black males does not mean that there was a true association between the MMR vaccine and autism-like features in this subpopulation."

Please, stay focused on topics that can help autistics to a better life. The vaccine idea is not only a diversion, it is an idea that makes things worse in our community.

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

Ethel **January 6, 2016**

Pls. Pass Avonte's Law. We love and live for our children.

[PII redacted]'s mom,

Ethel

Be still and know that I'm with you. Psalm 46:10