Oral Public Comments

IACC Full Committee Meeting

July 10, 2012

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Pam Rockwell

July 10, 2012

I'm Pam Rockwell. I'm here because I want the IACC to dedicate more research resources to maternal antibodies linked to autism.

I know you are aware of this research, and that the federal government does support this research as part of larger studies of environmental factors in autism.

- But no one is considering that these antibodies could be causing autism when they are transmitted through blood products that are routinely administered to pregnant women.
- No one is testing to see if vaccines that are routinely given to pregnant women could increase the titers of these antibodies.
- No one has considered that autism might be transmissible by contaminated transfusions just like an infectious disease like hepatitis.

This research has been conducted since the early 2000s in research labs at the MIND Institute at UC Davis and at the Kennedy Krieger Center at Johns Hopkins. Both labs identified antibodies in the sera of mothers of children with regressive autism that binds to human fetal brain cells. Both labs tested the human derived sera on pregnant animals and demonstrated autistic behaviors in the offspring exposed prenatally to sera from mothers of regressively autistic children. The Kennedy Krieger team used mice, and the MIND team used rhesus monkeys. At IMFAR this year the MIND team even presented imaging data that showed that the presence of these antibodies in mothers was also predictive of brain enlargement that's associated with autism – and this showed up in the naturally exposed humans and the blood exposed monkeys. In other words, this research showed that autism could be transmitted to animals by exposing them prenatally to the tainted blood of the mothers of regressively autistic children.

None of the research advances in this field last year were selected to be included the IACC 2011 Summary of Advances, and the possibility that the immune system could be linked to autism was only briefly mentioned in the 2011 Strategic Plan as an immature research field.

I know that scientific progress is slow and the complete nature of this connection may not be understood for many years.

But I want you to act on this research proactively because right now

- we give immunoglobulins, and vaccines to pregnant women as part of routine prenatal care,
- and we give transfusions to premature babies and to pregnant women during difficult deliveries.

The IACC should not be waiting on a few researchers to complete lengthy longitudinal studies or to nail down every little detail of how maternal antibodies can cause autism. You should be proactively recruiting experts to develop tools and test blood products to make sure that we are not inadvertently contributing to the rise in rates of autism because of medical interventions that could have been screened for autism producing antibodies.

Pregnant women who do not have the same blood type as the fathers of their child are routinely given immunoglobulin collected from human plasma donors (like RhoGAM) during their pregnancies to

prevent an immune reaction to their unborn child. Pregnant women who are potentially exposed to certain viral infections (like chicken pox) are also given immunoglobulin collected from immune plasma donors to prevent disease. Collected immunoglobulin products include all of the antibodies a donor makes, not just the target antibody.

There is no reason that we should be injecting pregnant women with antibodies that are even suspected of causing autism. The IACC should direct the Secretary of Health and Human Services to ask the FDA blood products safety labs to test immunoglobulin products that are used during pregnancy for maternal antibodies that are linked to autism. The companies that make these products have a protected donor population. If problems are found, then the company can test individual donors and stop using the ones who make the offending antibodies

Transfusions are also a common treatment during childbirth. A newborn could be exposed to autism causing antibodies in a transfusion that the mother is receiving before the baby's blood supply is separated from the mother's, or from breast milk after the mother has received a transfusion. The IACC 2011 Strategic Plan reports that, "preterm infants are at increased risk of developing autism." You cite an ASD rate of %8 of males born with <26 weeks gestation compared to %1 in the general population. This increase could be explained by administration of blood products containing antibodies that cause autism rather than merely the conditions that caused preterm birth.

Screenings for routine transfusions would require a faster test for these antibodies. So I would also like you to ask Secretary Sebelius for help from NIH and CDC laboratories that have experience developing fast antibody titer tests and better research tools. These antibodies were first noticed over a decade ago. The IACC should see to it that monoclonal versions of these antibodies are available for autism researchers within a year. And tests should be available for family planning purposes within two years.

I know that it is considered to be backward and uneducated to suggest that a vaccine might be implicated in any form of autism. But, the presence of antibodies that cause autism implies that some infectious agent might trigger the development of cross reacting antibodies. So we need to consider the possibility that some vaccines might also make unwanted antibodies.

This is particularly important because we routinely vaccinate pregnant women for influenza. We have a population of research subjects in the EARLI study at the MIND Institute who have had autistic children and make these autism associated antibodies. We should ask the ones who are not planning on having additional children if they would be willing to be test subjects for vaccines that might be used in pregnant women to see if being inoculated raises their titers for the offending antibodies. The committee should request that scientists at the CDC who develop influenza vaccines screen vaccines used in pregnant women to see if they stimulate an increase in autism associated antibodies.

The IACC was formed to make sure that there are no gaps in autism research. I want you to really think through all the possible consequences of antibodies that cause autism. Please, recruit the FDA blood safety labs to make sure that immunoglobulin products do not contain potentially dangerous antibodies. Reach out to experts in infectious diseases at NIH and CDC to develop faster antibody titer tests and monoclonal autism associated antibodies for research. And require that vaccines that are used in pregnant women be tested in women who are known to make antibodies associated with autism to make sure that vaccines do not inadvertently trigger damaging antibody production.

The US government has experts with experience at making antibody titer tests, developing monoclonal antibodies, and screening blood products, but these researchers usually deal with infectious diseases. They will not work on autism unless the IACC asks for their help. It's time to recruit these experts for our cause to make sure all blood products and vaccines used in pregnant women and premature babies are safe.

Thank you,

Eileen Nicole Simon

July 10, 2012

Following are five brief comment papers I would like members of the IACC to consider in planning research on autism:

LANGUAGE: The most serious handicap - p1

TOXIC INJURY: The auditory system is most vulnerable - p4

GENETICS: Involvement of the Brain - p6
OBSTETRICS: Dangerous protocols - p8
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LANGUAGE: The most serious handicap

Evidence has long been available on an impairment in the brain that can prevent a child's learning to speak.

Kety (1962) published a seminal paper on blood flow in the brain [1]. His research team at NIMH found that 60 seconds after injection of a radioactive tracer into the circulation of a cat, the highest accumulation was in nuclei of the auditory system of the brain. Budd et al. (2003) found on fMRI scans that blood flow is also highest in auditory nuclei of the human brain [2].

Windle (1969) subjected newborn monkeys to asphyxia at birth, and found severe ischemic damage in the brainstem auditory pathway [3]. Brain maturation did not proceed normally in the monkeys subjected to asphyxia at birth [4]. Friauf and Lohmann (1999) likewise reported disruption of brain maturation in laboratory rats with lesions placed in the auditory pathway [5].

Autism is not evident at birth. However, "under-connectivity" has been revealed in the brains of people diagnosed with autism in childhood [6]. Wolff et al. (2012) reported disruption of myelin formation, by 6 months of age, in the brains of infants who later developed autism [7].

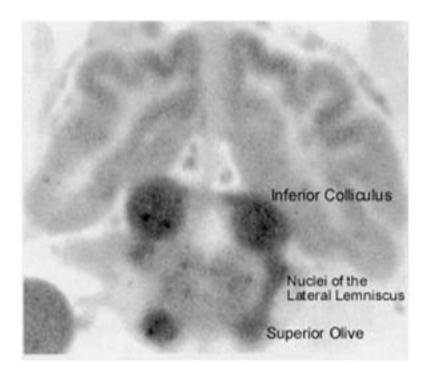
Subcortical injury should be investigated as the cause of this failure to establish normal connections during early childhood. Kulesza et al. (2011) reported "malformation" of the superior olivary complex in the brains of 9 autistic subjects [8]. Lukose et al. (2011) reported the same malformation in laboratory rats exposed to valproic acid during gestation [9].

Children normally learn to speak "by ear" without any need of formal instruction. However, evidence of auditory system impairment in autism has been reported often [10-23]. How injury of brainstem auditory nuclei may prevent normal language development should be made a priority for research on the language disorder of children with autism.

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The autoradiographic image above shows that 60 seconds after injection of a radioactive tracer into the circulation of a cat, the highest accumulation (dark areas) is in nuclei of the auditory system of the brain.

From Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;

38:799-812, online at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed

TOXIC INJURY: The auditory system is most vulnerable

In my comment on language (the most serious handicap), I cited a seminal paper by Seymour Kety, former Chief of the NIMH [1]. This paper provides an autoradiographic image from the brain of a cat 60 seconds following injection of a radioactive tracer. The highest density of radioactivity is in nuclei of the brainstem auditory pathway, especially the inferior colliculi, the superior olivary complex, and the lateral lemniscal tracts that connect these auditory way-stations in the pathway from the cochlear nuclei to the temporal lobes of the cerebral cortex.

Budd et al. (2003) published human fMRI scans showing the inferior colliculi (IC) as tiny bright dots. Dr. Budd contacted me after finding my website, conradsimon.org, searching on the internet for any explanation he could find for high blood flow in the inferior colliculi.

High blood flow exposes the nuclei of the auditory system to more of any toxic substance that gets into the circulation. Many papers have reported damage to nuclei of the auditory system from exposure to toxic substances [3-6].

Autism has been reported in some children with fetal alcohol syndrome (FAS) and children

exposed to valproic acid (Depakote) during gestation [7-10]. The association with fetal alcohol suggests that autism may also involve the well-known pattern of bilaterally symmetric damage of brainstem nuclei associated with alcoholism, Wernicke's encephalopathy [11-13]. Sokoloff et al. (1977) extended the method used to measure blood flow, using radioactive deoxyglucose, which enters the brain in the same way that glucose does but is not further metabolized [14]. The deoxyglucose method has been used extensively to investigate aerobic metabolism in the brain. Nuclei in the auditory system were found to have the highest rate of aerobic metabolism, and this metabolism is severely affected by alcohol, prenatal exposure to alcohol, and toxic substances [15-17].

Any non-natural substance should be considered to be possibly toxic to the brain, and especially the auditory pathway. Intact functioning of way-station nuclei in the auditory pathway is important for learning to speak in early childhood. Children exhibit a special ability to recognize stressed syllables [18]. This ability is lost by the teenage years, when a new language can no longer be learned without accent. Loss of hearing acuity is not readily evident because it is gradual, but as adults we have to admit difficulty hearing individual words in rapidly spoken foreign languages.

Gradual loss of auditory acuity with age may be due to all the toxic stuff we are exposed to in the environment. Extra care should be taken that children be protected from exposure to toxic substances from prenatal life, and at least through the years of early language development.

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GENETICS: Involvement of the Brain

Autistic traits are evident in many genetic disorders. Genetic disorders frequently (via faulty transcription) result in abnormal dysfunctional enzyme structures [1, 2]. Dysfunctional enzymes will (in many cases) introduce abnormal metabolites into the circulation. These abnormal metabolites can then get into the brain, and have a toxic effect.

Brain systems should be the first focus of genetic research, rather than how neurotransmitter functions are altered throughout the brain. Genetic disorders produce toxic metabolites that may affect some systems of the brain more than others.

Blood flow is higher in nuclei of the auditory pathway than in any other area of the brain [3]. The auditory system is thus more susceptible to toxic insult than other regions of the brain, and this has been pointed out in several investigations of the effects of toxic substances [4-8]. The auditory system is important for language development in childhood, and should be a focus of research in autism [9].

Phenylketonuria (PKU) was the first genetic disorder to be understood, two decades before the structure of DNA was discovered [10]. Phenylpyruvic acid and other abnormal metabolites are produced by a defective enzyme in PKU [11].

PKU is not evident in an affected infant at birth, because during gestation the abnormal metabolites cross the placenta and are excreted by the mother. Limiting phenylalanine in the diet of an affected infant lessens production of metabolites that can damage the brain. It appeared that children who later became non-compliant with the low-phenylalanine diet suffered no ill effects, but this is not true [12,13].

A low-phenylalanine diet must be reinstated in women with PKU during pregnancy. PKU is caused by a recessive gene, but an unaffected infant of a mother with PKU suffers teratogenic disruption of fetal growth and development, including the brain, from high maternal levels of phenylalanine and abnormal metabolites, which are able to cross the placenta [14]. Autistic behaviors were associated with untreated cases of PKU in the past, and in the non-PKU infants of mothers without dietary restriction during pregnancy [15-18].

Adenylosuccinate lyase defect is a very rare genetic disorder, often associated with autism, but fewer than 60 cases have been reported [19]. Downs syndrome is another genetic disorder associated with autism in some cases [20-21]. Maturation of the brain does not follow a normal course in PKU, adenylosuccinate lyase defect, or Downs syndrome [22-24].

The neuroanatomical systems affected during gestation and the neonatal period should be the focus of research on genetic conditions associated with autism, and the course of brain maturation should also be followed. Conditions associated with cranio-facial and other organ dysmorphisms also are likely to include abnormal development of the brain during fetal development.

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OBSTETRICS: Dangerous protocols

Mistakes in perinatal medicine and obstetrics have had to be corrected in the past [1-3].

Administration of vitamin K to prevent "hemorrhagic disease" was begun in the 1940s. A synthetic form was extensively used from 1945 to 1961, but reports of kernicterus (bilirubin staining of subcortical nuclei) associated with the synthetic form led to its use being discontinued [1, 4].

Diethylstilbestrol (DES) was given to prevent threatened miscarriages, but when it was found to cause vaginal cancers in the daughters born from the salvaged pregnancies, its use had to be discontinued [5, 6].

Another error is increasingly being recognized, use of a surgical clamp on the umbilical cord as soon as possible after birth [7]. Mercer and Skovgaard (2002) described how clamping the umbilical cord prevents normal transition from placental to pulmonary respiration [8]. It is truly beyond belief that the whole profession of obstetrics has so little understanding of fetal circulation and changes in the anatomy of the heart that must take place before a newborn baby can begin breathing on its own.

Use of a clamp on the umbilical cord began about 100 years ago, and this practice has been condemned over the decades by many obstetricians and pediatricians [9-13]. I strongly recommend that members of the IACC look at George M. Morley's websites http://www.autism-end-it-now.org/ and http://www.cordclamp.org/

The IACC should be in a position to mandate that clamping the umbilical cord be stopped.

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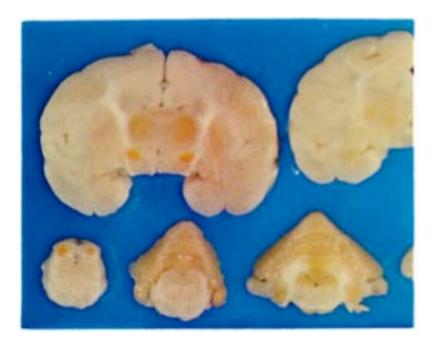
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VACCINES: Effects on the brain

Following is a research strategy that I submitted for consideration by members of the IACC at the meeting held on February 4, 2009.

- (1) A working hypothesis and plan for vaccine research is needed. I propose: Working hypothesis -- vaccine injury may be similar to that caused by bilirubin. Plan -- (a) Review existing evidence on brain injury from toxic substances [1-14].
 - (b) Design experiments with mice, rats, and monkeys
- (2) Bilirubin staining is not uniform throughout the brain.

 Vaccine components are likely also more toxic to subcortical areas of high metabolic rate.



From: Lucey JF et al. Kernicterus in asphyxiated newborn monkeys. Exp Neurol 1964 Jan; 9(1):43-58, showing that bilirubin staining occurred only in subcortical nuclei of high blood flow and metabolism - like the inferior colliculi of the midbrain auditory pathway (lower left).

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- (3) Not all children are injured by vaccinations, because injury likely results from two factors: Note, not all children are injured by high bilirubin levels [15-17].

 Bilirubin enters neurons following disruption of the blood-brain barrier [18-21].
- (4) The blood-brain barrier is disrupted by ischemic anoxia [22, 23].

 A baby slow to breathe at birth may suffer anoxic disruption of the blood-brain barrier.

 The blood-brain barrier can also be disrupted by synthetic vitamin K, or antibiotics [24-27].

A baby treated with antibiotics may suffer toxic disruption of the blood-brain barrier.

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Catherine C. Swanwick

July 10, 2012

Subject: Autism Reading Room: A New Science Outreach Portal



OVERVIEW

Our core mission at MindSpec is to advance research on neurodevelopmental conditions. Founded in 2006, MindSpec is an independent, non-profit research organization established to facilitate the discovery of a cure for autism. Although we initially focused on autism, we hope to expand our research to other types of neuropsychiatric illness.

We develop bioinformatics strategies using current information technology platforms to build diseasespecific databases. At MindSpec we place a strong emphasis on "translational" research

– that is, closing the gap between basic science discoveries and practical treatments with the potential of benefitting people who have autism.

Goals:

- Build an integrated, up-to-date, relevant, searchable resource on autism *AutDB:* http://www.mindspec.org/autdb.html
- Build a community of scientists, practitioners, educators, policymakers and people affected by autism to share and disseminate knowledge of autism

Autism Reading Room: http://readingroom.mindspec.org

- Identify gaps in autism research around the world
- Identify priority areas in autism research based on real-world needs
- Build an autism dictionary and digital information library
- Address cultural differences in treatments for autism, a social disease
- Build knowledge about autism for immediate use

Catherine Swanwick's presentation can be viewed here. (PDF – 332 KB)

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

Mark Blaxill

July 10, 2012

Subject: When Science and Health Policy Trumps Inconvenient Evidence

My name is Mark Blaxill. I am the author of the book, *The Age of Autism* and recently helped to launch a movement called The Canary Party, which was created to stand up for the victims of medical injury, environmental toxins and industrial foods. Unfortunately, we need to stand up for these victims, the proverbial "canaries in the coal mine," because so many of them cannot speak for themselves. I am also the father of a 16 year old daughter diagnosed with autism. Thanks to biomedical interventions and therapy, [PII redacted] is more verbal, social and flexible than most affected children, but sadly, she will not live independently. She most certainly does not have a capacity for self-advocacy, so (like most affected individuals) her parents must speak for her.

Unfortunately, the climate for parent advocates, never favorable in autism, has grown progressively more hostile. We have gone from being bad parents whose contempt for their infant children caused them to withdraw into autism, to raving lunatics who are a danger to the public health and whose opinions must be suppressed.

Why? Because the autism parent community refuses to stand down in offering inconvenient evidence to the makers of science and health policy. This evidence is simple. Before 1930, the rate of autism was effectively zero. Before 1990, autism in the United States was exceedingly rare, as low as 1 in 10,000. Three months ago, we learned that 1 in 88 children born in the year 2000 were autistic, 1 in 54 boys. The conclusion is inescapable: autism is manmade.

The health policy implications of this evidence are obvious. The only rational policy for autism would

- Declare a public health emergency as our country did with poliomyelitis (a much smaller epidemic) and AIDS.
- Urgently gather good numbers on the nature and extent of the epidemic
- Objectively and without financial conflict, consider the short list of candidates for such an unusual and massive scourge
- Collaborate closely with affected families to develop answers: prevention, treatments and resources throughout the lifespan.

Sadly, the policy response of the health agencies of our government has been precisely the opposite.

- The NIH has funded research to concoct arguments that the crisis is an artifact of better diagnosing. Instead of mobilizing for the epidemic, science policy has promoted denial.
- The CDC has organized surveillance to measure autism rates that are at least a decade old and trend evidence that starts just a few short years *after* the epidemic started. Instead of urgently gaining insight, health policy has promoted ignorance and delay.
- The agencies of HHS act in unison to promote vaccination, a candidate exposure of great concern
 to parents, while agency leaders rotate out of their government positions to take lucrative jobs
 at pharmaceutical companies. Instead of objectivity, the investigation of cause has become
 fraught with conflicts.

• The IACC, newly reconstituted after the explosive 1 in 88 report, appears to have been recruited to rubber stamp this policy of epidemic denial. Instead of collaboration with parent leaders, public servants have turned their backs on us.

Autism parents spend a lot of time debating how the science and health policies surrounding autism have gotten to this place. Is it because autism is merely fodder to help recover and extend the massive research investment in the human genome? Is it because psychiatry grabbed hold of autism with [PII redacted] and refuses to release its grip? Is it because pediatricians are afraid to confront the idea that they may be harming more children than they are helping? Is it because the massive resources of the pharmaceutical industry have so tilted science and medicine in the direction of their financial goals that policy is now driven by money rather than reason? Is it because government officials are too busy worrying about their retirement, too afraid to rock the boat and confront inconvenient truths? Is it because the idea that there are human costs to some aspects of technical progress is too difficult for intelligent people to accept?

Or, more hopefully, is it because some people have simply made bad decisions that we have the freedom to unmake?

I don't propose to answer all of these questions today. Instead I want to offer you all a challenge. Unmake your bad decisions. Treat autism as an emergency and not as something to celebrate. Approach the problem of prevention with the intellectual and moral urgency that an epidemic requires. Treat the canaries in the coalmine as signals of a crisis of public health not as a public relations problem. Offer respect and standing to those who speak for the injured, don't handpick more convenient representative to speak against us.

Most of all, I challenge you to do the right thing. Until you do, we will keep making you feel uncomfortable.

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

Jake Crosby

July 10, 2012

My name is Jake Crosby. I am an MPH student at The George Washington University School of Public Health and Health Services and contributing editor to Age of Autism: Daily Web Newspaper of the Autism Epidemic.

I am also a person with autism who favors preventing and curing autism. None of the three IACC members with autism share my point-of-view. Not only that – they are all highly unqualified. Scott Michael Robertson basically [offensive language redacted] everything said by Ari Ne'eman, who opposed the wandering code when he was on IACC and he also said an economist's analysis of what autism will cost society is nothing more than eugenics. Noah Britton heads up a [offensive language redacted]. Is the autism epidemic is nothing more than one big joke to our government. Finally, there is John Robison, who [derogatory language redacted].

But perhaps even worse than all three of those appointments is a [offensive language redacted] blogger whose real name is Matt Carey and who contributes to a blog neither owned by a US citizen nor registered under a US domain name. He spins every incriminating fact about our sham vaccine program in such a way as to favor his preconceived view of autism as natural diversity. Carey has gone so far as to defend [derogatory language redacted] journalist [PII redacted] even after he commented under a blog post of Carey's blaming parents for their Childs' autism. Carey was silent when [PII redacted] wrote on Carey's blog, "[offensive language redacted] all signal pathology to me... and they wonder why their children have problems with their brains." Carey has defended Tom Insel's [derogatory language redacted] leadership of IACC even after the head of the National Institute of Neurological Disorder and Stroke was caught speculating if Lyn Redwood's attempts to raise awareness for gastrointestinal disorders of children with autism was nothing more than a ploy to blame vaccines. Finally, Carey has defended HHS Secretary Kathleen Sebelius' strategy of taking the government cover-up of vaccine injury to the media through a campaign of censorship, proving Carey's appointment is nothing more than a political favor by corrupt politicians and bureaucrats. Carey's exact words were: "I agree with Kathleen Sebelius. Don't give equal weight."

Speaking of corrupt politicians, where is Barack Obama – the self-described "autism president" - in all this? Shortly before the last presidential election, Obama said he opposes vaccination choice. That statement was no mere slip of the tongue. It was his deputy assistant – an autism parent named [PII redacted] – who told him to make that statement, according to the vaccine industry's primary journalist at the time, [PII redacted] is in fact a long-time lawyer with the pharmaceutical industry lobbying firm Sidley Austin, where President and Mrs. Obama reportedly first met. [PII redacted] is Obama's close friend of 20 years. That's 20 years' worth of influence he has had over Obama that we don't have. We can see in today's IACC appointees what that influence has given us – appointees by-and-large complicit in the government cover-up of vaccine injury. Such appointees include [PII redacted], a former Merck scientist with the Simons Foundation – run by billionaire hedge fund manager [PII redacted]. The co-CEO of Simons' hedge fund is married to the FDA commissioner Margaret Hamburg, who previously worked for a major manufacturer of mercury-based dental amalgam. David Mandell is another such appointee; he sits on the so-called scientific advisory board of Alison Singer's vaccine industry front group posing as

an autism charity.

Enter Jose Cordero, who during his tenure at CDC wrote to the journal Pediatrics coercing them to fast-track a now-infamous report using fudged autism statistics to exonerate the highly neurotoxic vaccine preserative thimerosal, which is almost half mercury by weight. Today, the principal investigator on the project, Dr. Poul Thorsen, has been indicted on fraud charges. In a private email correspondence which [PII redacted] was party to, the researchers privately admitted the incidence and prevalence of autism was actually decreasing after thimerosal was removed from childhood vaccinations. If we are to expect anything from our elected officials, it should be that they would fire [derogatory language redacted] civil servants like Cordero, not appoint them to federal committees.

While the Obama Administration has taken a firm stance in cleaning up mercury emitted from coal-burning power plants, it continues endorse the injection of mercury into pregnant women and newborns. The H1N1 vaccine aggressively promoted by the Obama Administration was preserved in thimerosal, and despite being confronted about thimerosal's ill effects on CBS, Secretary Sebelius lied to viewers that thimerosal is safe when it has never been tested for safety. Rather than working to solve the problem of the cover-up, the Obama Administration has chosen to be an active part of the problem.

This problem heavily lies with NIH – the agency responsible for overseeing the functions of this committee. The former director of strategic planning for vaccine research at NIH made that clear when he told a Princeton University audience in May 2001 that:

"Four current studies are taking place to rule out the proposed link between autism and thimerosal," and, "In order to undo the harmful effects of research claiming to link the [measles] vaccine to an elevated risk of autism, we need to conduct and publicize additional studies to assure parents of safety."

Such fraudulent research would later form the basis of a report produced by the Institute of Medicine in 2004 rejecting a causal link between vaccines and autism, the chairwoman of this panel privately stated that IOM would never conclude autism was a true side-effect of vaccination before looking at any data. This white-wash would be reaffirmed in a later IOM report released last year – one openly endorsed by the chief scientific adviser of Autism Speaks, who also sits on this committee.

While the IACC may have been created by a law passed by some well-intentioned but misguided senators, the fact of the matter is that it just allows corrupt civil servants to further consolidate government control over autism research. We need to elect politicians who will get rid of these civil servants, not side with them as the Obama Administration has done. We need to vote out Barack Obama and his administration, as well as any politician who takes the same approach and fails to address this problem at its source. Thank you.

-Jacob Crosby

Dawn Loughborough

July 10, 2012

Subject: Autism, A Medical Definition: Getting to Causation

Thank you for letting me take a minute or two to speak. My name is Dawn Loughborough and I am the mother of three children, two who have chronic illness, one with Autism. I am an Autism parent mentor in the community and have advocated for many years for Autism. I am not here representing an organization but rather speak in the interest of health. I am here today to make a request of IACC. My professional background is in professional management consulting.

First, I want to create a listening in the room for something to emerge that may sound a little different. You see, I feel that the work that has been done to date has addressed many concerns of Autism (diagnosis, services, prevalence, bullying, adult transitions) and I want to acknowledge what has happened to date. Jon Robison, I have stocked my son's school with your book to help educate parents and family. And what the IAN Project has done to deter bullying in society in this past year. I for one don't want my son who has already done more than Olympian training in speech and physical therapies to be teased. So thank you.

And, if you look at the prevalence numbers as they continue to rise there is an area that is missing from the portfolio management that if we add it in to the picture will make a difference. I feel the piece that is missing is environmental causation. It's what is important to people and we must empower and enable, take action to get this next piece in place.

I know it is complex and requires observational science, and I believe that we are smart enough to figure out what is triggering the health concerns of our children. I do not think the research portfolio accurately reflects the concerns of parents and physicians who desire to understand the underlying causes of Autism. It needs to take shape and be coordinated from the top.

The premise of what I have to say embraces that there are different kinds of autism. And the kind I want to redirect the focus on is the type of autism that comes as a result of some regression which when addressed as a physical medical condition with multi system concerns has the result of reversing the autism condition. That is to say, a premise that says address underlying medical conditions to heal the child and get results that lessen or possibly even disappear Autism behaviors.

Additionally, the identification of underlying physical conditions will lead us to causes. Tracking of these symptoms will lead to trending reports that allow for further investigation into causation. So if a lot of children are slipping into Autism and many have gut issues and these gut issues are caused by an overgrowth of yeast in the gut, then we can treat the gut and also see improvements in eye contact and stimming behaviors, then we have a case to proceed with identifying what is causing the gut issues. So on and so forth...

Symptoms which should raise a red flag include: sudden milestone regression, gut dysbiosis, chronic illness, allergy symptoms, sleep disruptions or sudden aggression or melt downs. So as a standard of care I would like to request the standard psychological behavioral testing be followed up by a physical screening. I think we can find our causation triggers using this model. It needs to be developed with

integrative physicians who understand multi-system diseases - of which I could tell you many exist. These are MDs - some of our brightest in the community who are dedicated to managing chronic disease. Many who have arrived as a result of their own children being ill. I think a task force should be created and report to Sebelius.

Second, I'd request that we influence a shift with the CDC to track more details that may lead to trends shining light on causation. I want SEED to get funded so that it can track observational science: exposure to pesticides, what viruses/bacterial infections has this child experienced, did your child regress and at what age? Did you parents have any autoimmune diseases. I'd also like the CDC or IOM to do some work with the Vaccine Adverse Event Reporting System (VAERS) to contact and follow up with families to record how their children are health wise, asking about diagnoses and health history.

I'm here to request the **creation of a task force** to identify the following:

- **Mission**: Formation of a subcommittee task force whose sole task is environmental causation and prevention of Autism with the charge to deter the rise in prevalence and lower the Autism numbers for the future.
- **Create Integrity and Objectivity**: Individuals on this committee should be independent and objective. They should not have conflicts of interest no stock in industries/ pharmaceutical companies, no pressure for a certain outcome, and they will not be set up to prove or disprove an outcome, but rather to set up the structure that will identify tracking for trending and discovery. The objective is to look with fresh eyes for environmental causes.
- **Create Stucture**: Determine the charter, coordination, and funding in the portfolio management, government structure, teams necessary to figure out what is causing environmental triggers in autism, order of priorities, etc.
- **Identify Risks:** Initially this task force would identify environmental causations which might curtail the rise in Autism prevalence. I recognize we are living into something that does not yet exist, but that is the goal, just like figuring out a way to put a man on the moon we have the intelligence to do this work to figure out what is triggering autism.
- **Develop Strategy for Tracking**: This task force would be responsible for creating a basis from which children who have Autism behaviors will be tracked medically to include contributive underlying health concerns. Identification of what needs to be tracked for children with regressive autism throughout their lives/childhood as a medical condition to include, for example, bacteria, viruses, fevers, medications, hospitalizations, chemical screening, family health and health history (SEED could be fleshed out to perform the tracking).
- **Gather Information**: Include medical input from parents/guardians, medical integrative physicians who treat children with chronic illnesses and immune diseases, and researchers. Develop clinical medical checklists and databases.
- -**Perform Analysis**: Out of this gathered information, the subcommittee can perform an analysis and be able to identify the types of medical/multi system autisms such as children with bacterial overgrowth, children with yeast overgrowth, children with viral concerns, children with low immune systems, allergies, mitochondiral disease, metals. From that we can back track to causation much like cancer and

not from a genetics perspective, but rather environmental concerns.

- **Develop Diagnostic Procedure**: The basis will be considered a standard of care the Autism diagnostic mechanism. Part 1 is psychological diagnostic mechanism; Part 2 is medical screening to include blood work screening for top environmental items being tracked. This screening could lead into a triage approach to restore the child's health.
- **Move Quickly**: Have a deadline for recommendations for analysis and teams due in 6 months. If the tracking gets identified in a sampling to help identify trends at a high level that can be researched further. This could be considered through observational science, interviews, surveys, etc.
- **Develop Standard of Care**: Beyond 6 months the task force can identify a multi-system protocol to include medical treatment and research. And they can coordinate a solution, determine and prioritize the actions necessary to get this handled.

My desire is not out of touch with reality. Many people have expressed an interest in doing this work. I feel a task force approach will accelerate the process of innovation required to get to causation and make a difference for deterring future occurrences. I would love to be a part of this solution and hope that my comments today were clear and in keeping with the desire for healthy outcomes for all children in the future. We have an obligation to crack on with getting this sorted out. There was a time when people did not understand diabetes. I think we can be on that path with Autism by viewing it as, say, an autoimmune disease rather than a behavioral disorder.

Thank you.

Dawn Loughborough

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

Katie Weisman

July 10, 2012

Subject: Coalition for SafeMinds

My name is Katie Weisman and I am here today on behalf of SafeMinds.

I am the mother of 14 year-old identical triplet boys, two diagnosed with PDD-NOS and one with autism. I have been a full-time advocate for 11 ½ years now. I have run a parent support group for a decade, have fundraised, have started a safety campaign, have done autism awareness training for typical kids, have lobbied for insurance, and have worked on the bill that reauthorized this committee. More importantly, I have helped three of the best, hardest working young men on the planet learn how to talk and write and read and live in their world happily. But I am here to tell you that this is all taking too long. My boys and all the people like them and all the children who are being diagnosed now, today, while we are sitting here, need answers and help now, today.

I am here to tell you why the mercury/autism connection is stronger than it has ever been. It is time to set politics aside and look at the science. Anyone who truly cares about individuals with autism simply cannot ignore mercury. For those who say that the link has been disproven, I say go and actually read the literature – it currently supports a connection by a 2 to 1 margin. The positive studies rarely make the press. Included with my comments are e-mails, obtained through the Freedom of Information Act, showing that the CDC omitted data showing that autism rates in Denmark actually dropped in 2001 after they removed thimerosal from their vaccine program. I have also included [PII redacted] graphic analysis of the early Verstraeten VSD data, also obtained through the Freedom of Information Act, showing 7.6 times the relative risk of autism in children who received high thimerosal by one month of age compared to children who received zero thimerosal. This is important because, later, unvaccinated children were excluded from the study eliminating the zero exposure control group.

I have read most of the autism abstracts in Pubmed for over 4 years now, along with hundreds of studies and have followed the research for over a decade. I can tell you unequivocally that the number one, best supported, most logical suspect for autism causation is mercury and it is only being ignored because it implicates vaccines. It will not be the only cause, but it is logical to tackle mercury because exposures are often easy to avoid. With about 45,000 children a year being diagnosed with autism spectrum disorders in the US alone, based on the most current prevalence ratio, I do not believe that anything can be off the table for research.

However, thimerosal is not the only mercury exposure of concern in autism. Mercury comes from many other sources including fish, other food, dental amalgam, skin-lightening creams, fluorescent bulbs, Santeria rituals, air pollution and even tattoos. Despite recent emissions controls in developed countries, global mercury pollution is on the rise due to massive growth of industry in countries like India and China. The EPA estimates that 83% of the mercury deposited in the US is from international sources. Any candidate for causation must fit trends of exposure, and cause symptoms that make sense. There are obvious studies like those linking autism rates to mercury in the air or the number of fillings a

mother had, but there have been no studies yet of total mercury exposure relative to autism. Those studies need to be done.

What we do know is that the EPA estimates 1 in 6 women of child-bearing age in the US already has mercury blood levels that put her children at risk because mercury preferentially concentrates in the cord blood at a ratio between 1.8 and 3 times that of the maternal blood. It is not just methyl mercury that is the problem. NHANES data shows that inorganic mercury is rising in the blood of women of childbearing age and increases significantly with age. A Chinese study last year found that cord blood mercury level was negatively correlated with adaptation, language, social and average DQ while the relationship between cord mercury level and motor DQ was not statistically significant (Li et al. 2011). The single biggest roadblock in autism research is that researchers stay in their silos and do not pay attention to what is happening in other fields. The geneticists are not talking to the clinicians. The behaviorists are not talking to the neurologists. And almost everybody is avoiding the 800 pound gorilla in the room – mercury. There is currently enough research to write a paper titled, "How the known genetics of autism support mercury causation." I read about methylation defects due to MeCP3 in Rett's and know that Dick Deth has shown that thimerosal completely inhibits methionine synthase – thereby shutting down a primary driver of the methyl cycle. I read that calcium channel signaling and glutamate receptors are disrupted in autism and CACNA1C is a strong candidate gene and see the extensive literature showing that mercury is a potent disruptor of calcium signaling.

I would like to quote from two studies that have been published in the past week and see if you can make the connections to the autism. From Ye and colleagues – "A significant change in cell viability was observed after exposure to 0.001% thimerosal for 30 minutes. DNA single and double strand breaks were significantly increased in a dose-dependent manner with thimerosal exposure." The concentration of thimerosal in a typical vaccine is 0.01%, or ten times the amount in this study.

From Sharpe and colleagues, "We find that ethylmercury (in astrocytes) not only inhibits mitochondrial respiration leading to a drop in the steady state membrane potential, but also, concurrent with these phenomena, increases the formation of superoxide, hydrogen peroxide and Fenton/Haber-Weiss generated hydroxyl radical....Additionally, we find a five-fold increase in the levels of oxidant damaged mitochondrial DNA bases and increases in the levels of mtDNA nicks and blunt-ended breaks."

Gadhia and colleagues published this in May, "Exposure to metals alters gene expression, changes transcription rates or interferes with DNA repair mechanisms. We tested a hypothesis to determine whether in vitro acute metal exposure, with or without recovery, alters epigenetic pathways in mouse embryonic stem (mES) cells." They found that mercury and arsenic, in particular, not only alter gene expression, but impair the cells ability to repair DNA damage.

We need to stop looking at finding these risk genes as an end unto themselves. They are simply markers for the biochemical pathways of concern. It is not helpful to generate an endless list of candidate genes. We need to look at the toxins likely to both cause DNA mutations and trigger epigenetic effects on those pathways. He and colleagues published a study last week of four members of a Chinese family. They found 89 de novo copy number variations in the siblings with autism in that single family. Do we really need to be spending millions of dollars making a phone book of genetic variations that may or may not be relevant or do we need to look at potential causes of those variations? There is not a single identified gene that always leads to autism. For Fragile X full mutations, 67% of males are affected along with only 23% of females. For tuberous sclerosis 43-86% of cases meet criteria for a PDD. Those lead the pack by a wide margin. Untreated PKU results in only 5.71% of cases meeting autism criteria. We also need to

bear in mind that developing pharmaceuticals to correct genetically caused dysregulation is going to take decades and any individual drug is likely to help only a small fraction of those affected. Getting back to mercury, we have the Shandley/Austin study from last year showing that the grandchildren of survivors of acrodynia have 7 times the rate of ASD of the general population in Australia – 1 in 22. Acrodynia is a form of mercury poisoning in a genetically susceptible population - which should sound familiar.

The support for mercury causation goes well beyond genetics, though. We have studies showing that severity of autism is related to inability to excrete mercury in hair (poor detoxification). We know that porphyrinuria related to heavy metals shows up in children with autism.

Some less obvious connections are as follows:

Mercury accumulates as you age. (Autism risk increases in older moms and dads.)

Neonatal jaundice is a risk factor for autism. (Mercury is detoxed through the biliary system.)

Low birth weight/prematurity are risk factors for autism. (Mercury toxicity is relative to body weight.)

Mercury causes impaired speech and hearing. (Both are well-documented in autism.)

Mercury causes reduction in visual color discrimination. (This is also documented in autism.)

This is just a sampling of the strength and consistency of the mercury-autism research. For a good overview at the cellular level, see Garrecht and Austin, 2011. If we truly mean to improve the lives of those with autism and stop autism's most devastating effects, we need to stop ignoring the obvious.

Therefore, these are the challenges I have for you:

- I challenge all of you to actually follow all the autism research so you can see the imbalance, the
 holes and the connections. Also, look at the mercury literature and actually read the studies.
 Then decide if you are here to make a difference. If you aren't let someone else have your seat.
 The status quo is not acceptable.
- 2) I challenge you to hold a conference on autism with a sampling of leading autism researchers and a group of mercury toxicologists to discuss the connections and plan the research that still needs to be done.
- 3) Create a mechanism to determine the effectiveness of the work you are doing. Can you show that any of the studies you've funded have actually made a difference in the lives of people with autism? Have new treatments been proven effective? Have you established best practices for service programs? Are people with autism protected from abuse in schools?
- 4) Rebalance the autism portfolio. The Simons Foundation has the genetics covered and the imaging studies are not helping. There is a glaring vacuum of comparative best practice research past age 5 for all issues related to education, social skills, employment, service provision, staff training and, most importantly, treatment of medical issues. Commit 30% of the IACC research dollars towards environmental causation studies, particularly mercury, and 30% towards actual comparative studies of the best methods for teaching and providing services for people with

autism. The remaining 40% should go towards studies to treat the comorbid seizures, gastrointestinal disease, sleeplessness, allergies, anxiety, depression and sensory problems that so dramatically affect individuals with autism. Let's improve the quality of some lives today and let's try to prevent the severe impacts of autism on individuals in the future.

 I challenge all of you to visit a school or classroom that educates people with severe autism if you have never done so. You are here to serve and you must understand who you are serving.
 Thank you,

Katie Weisman
Director of Communications and Public Policy
Coalition for SafeMinds

SafeMinds is a non-profit 501c-3 organization whose mission is to restore health and protect future generations by eradicating the devastation of autism and associated health disorders induced by mercury and other toxicants resulting from human activities.

In addition to this public comment the commenter provided the following supporting documents:

- Verstraeten Generation Zero for IACC 7 10 2012
- Autism-Mercury Long Version Combined April 2007
- FOIA Evidence Exposes CDC Lies

Attachments

Bernard S, Enayati A, Binstock T, Roger H, Redwood L, McGinnis W. Autism: A unique type of mercury poisoning. *Safe Minds*. 2000 April 21.

Generation Zero

FOIA Evidence Exposes CDC Lies – Mercury in Vaccines IS Associated with Autism (Open new tab in web browser, copy and paste link)

http://library.constantcontact.com/download/get/file/1101201531086-606/FOIA+Evidence+Exposes+CDC+Lies+-+Final.pdf

Caroline Rodgers

July 10, 2012

Caroline Rodgers's presentation can be viewed here. (PDF – 436 KB)

Tara McMillan

July 10, 2012

Good afternoon. I am addressing my comments to the public as well as the members of the Interagency Autism coordinating Committee. My name is Tara McMillan. My son was born in 2006. He was a perfectly healthy baby with an apgar score of 8 and 9. On the second day of his life, he was given a Hep B shot, as well as at 2 months, and 4 months. At 6 months of age - he lost his ability to suck, and could no longer nurse. This can be compared to the primate study that was published in the journal of Neurotoxicology in 2009. The primate study showed a significant decrease in the survival reflexes of the male rhesus macaque monkeys after the hepatitis B vaccination.

My son also had two series of shots in one visit- to "catch up" his vaccines- which is routinely done all over the country. He should not have had ten doses of vaccines at once. I was not an informed parent. My son's brain swelled and he was thought to have hydrocephalus. It wasn't until a year later that I discovered on my own that it was vaccine related.

My son suffered vaccine reactions. Sadly this is the occurrence in many of the homes of the family member that will be affected by Autism. If you just hear the testimony of parents who lose their child after vaccination, you know we have a problem with the vaccines. It's not the children's fault, it's not the parents fault, it's the vaccines fault. Case studies need to be done on each family that has an ASD child. Case studies that include what triggered the illness, what history the mom might have had due to exposure to heavy metals, repeat antibiotics, and or other medical interventions while she was pregnant.

All it takes is for accurate data to be contributed to the Interagency Autism Coordinating Committee. This information must be verified by an independent source, and not one that contributes directly to the Interagency Autism Committee. As a parent of a child with Autism, I am doing everything that I can to recover my son from Vaccine induced Autism. If other kids can recover, and they do- my son should not have less of a chance.

The Interagency Autism Coordinating Committee needs to listen to the parents of Vaccine injured children, and they need to take direct action in finding out why Vaccines hurt our children. It doesn't matter if the CDC will think there is a panic and the safety of vaccines are questioned, it matters that our children are suffering and no one is doing anything about it.

I challenge the Interagency Autism Coordinating Committee to do the right thing, head the words of parents, and not be persuaded by those that have other interests. The truth will come out, one way or another. You can be the ones to bring it to press, or you can be a part of a group that keeps denying the link between Vaccine injury and Autism. More children will have Autism in the future because parents believe the lies that vaccines are safe. If I would have known that Vaccines would have caused my son to have autism, I would have never ever let him have the shots when he was a baby.

My son has Autism. I know why. I do not have a degree in medical science or in anything related. If I could find out on my own what caused my son to have Autism, don't you think that you could do more? Parents are relying on you all to find out why, and to do real studies, not those that are funded by vaccine manufacturers, who in return are just looking out for their business.

The Autism numbers are 1 in 88 now. Guess what? My son is not even counted in that number. He is only 6, and all children under the age of twelve are not counted in the new numbers that came out this past April. The numbers will be more, perhaps 3 in 25? Perhaps 2 in 10? Our children do not need to suffer this American Holocaust any longer. Listen to the parents. Thank you for giving me this time.