Written Public Comments

IACC Full Committee Meeting

July 8, 2014

List of Written Public Comments

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

Joseph M. Jason

April 05, 2014

Subject: Criminalization of Asperger Syndrome

NAMI Barrington Area
National Alliance on Mental Illness

PO Box 474
Barrington, IL 60010

My son with Asperger Syndrome has undergone cruel and unusual punishment in the State of Iowa by the state and federal government since March of 2007. He has been incarcerated with the exception of four months in jails and prisons for non-violent crimes. Please read the following information from my petition that follows. I have done a radio interview and had articles written in the paper about the grave injustice happening to my son due to his Asperger Syndrome.

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

Joseph M. Jason, President NAMI BA [PII redacted]
Board Member of Criminal Justice Advocacy for People with Mental Illness
Board Member CURE Illinois

Maria Lujan Ferreira

April 06, 2014

Subject: Autism Awareness News and Upcoming Events

Thank you for the updating. However, I as a non-USA citizen, am very disappointed about how the newest confirmation of an important increase is being analyzed and worse, managed. In the next meeting of the IACC nothing of the very urgent problems around the world many families like mine face are even mentioned with the needed deepness and importance. The urgent needs of a growing population of children, teens and adults are being dismissed with the importance given to epidemiological analysis or neurodiversity advocates. As I may testify, Autism is much more than only the brain... it is a whole body condition.

This material is full of sense of urgency
http://www.autismtreatment.org.uk/wp-content/uploads/2013/07/Medical-Comorbidities-in-Autism-Spectrum-Disorders-2013.pdf

IACC meetings aren´t.

Sincerely
María Luján Ferreira
Argentina

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Martha Moyer

April 08, 2014

Subject: Autism Issues

My name is Martha Moyer. I have created what is called a microboard, a one person support system for my severely dual diagnosed adult son age 40 with autism, IDD, OCD, seizures, minimal communications, MH issues and paralyzed bowels due to institutional neglect. . My son lives in his own apartment through section 8 housing with the support of the Home and Community Based Services waiver program here in Texas. My son definitely qualifies for institutional care, having had one nearly kill him due to neglect and another agency subsequently was another nightmare. I have taken over his agency care at the age of 75 but Texas doesn't allow hardly any money to run this program. I don't know how much longer I can go with this. You wanted to know about housing and adults...I certainly can give you information as my son has lived in his own apartment with section 8 for over 15 years. I developed this program on my own.

I also remind you that I contacted you earlier about his severe bowel disorder and the pulsated irrigate evacuation system www.piemed.com that has saved his life. I cannot get this equipment that is lifesaving paid for at all. I have tried and tried and tried! I am getting nowhere. What will happen to my son when I can no longer keep saving his life? I am paying for his bowel supplies for his procedure from administrative funds because I am too poor to afford this on my own. I just got an angry email from the waiver authority cost report critical of the money I am spending from the program to keep my son together. They just don't understand that I am not wanting to warehouse him. Texas is the worst state for warehousing disabled.

About vaccines...my son was BORN with autism!

Martha Moyer
Mother/Guardian
Agency provider
Executive Director
Seth Moyer Support Microboard, Inc.

My phone is [PII redacted]
[PII redacted]

Marian Dar

April 08, 2014

Regarding the “co-morbidity” talk this afternoon. I ask that the Committee consider the following:

My son (like many with autism) is heterozygous for MTHFR (methylenetrahydrofolate), A1298C. Jill James, mentioned earlier, has been doing a lot of work on glutathione, methylation, etc. Recently, there was an interesting, small study, out of Stanford using NAC to address folate deficiency. ODS is looking at nutrition deficiencies. So there’s activity here.

Meanwhile, a doctor who has worked with a lot of patients with autism and based on his history and labs, prescribed NAC for my son. The family practitioner disagreed -- said “she looked it up and it is for cancer, not autism.”

The (12 week) prescription never happened.

Yes we need to rein in the wild alternative scene, but like many things there are pieces worth salvaging, checking out and maybe offering potential benefit. At what point, and under whose directive does this happen? Thank you,

Marian Dar

Dawn Loughborough

April 08, 2014

Subject: 1 in 68: No Pass by Dawn Loughborough

One in sixty-eight children born in 2002 have been diagnosed with Autism. That is a 30% increase from last year. Part of the increase in prevalence estimates stems from greater recognition. However, it is absurd to suggest that there were just as many, or even anywhere nearly so, severely affected individuals with autism in years prior.

One would have to believe that large numbers of nonverbal, sometimes combative and often self-injurious children, unable to pass basic developmental milestones towards independence, many enduring intense pain from GI disorders or seizures, were somehow just never noticed before? One would have to believe that individuals with autism wandered and died in comparable numbers just a decade or so ago but, again, they simply went unnoticed?

In fact, the numbers of such severely afflicted of our children has skyrocketed, and if there is consensus on anything, it is that there are still far more questions than answers as to why this is happening, and still no meaningful advances in prevention for regressive autism, treatment and/or cure for those affected by co-occurring conditions, nor adequate services for those living with autism.

We have a public health crisis that begs for urgent federal response. 1.2M individuals with Autism… We need a special patient population defined so that when they show up, non-verbal or combative, in a hospital emergency room, the staff will know how to investigate their pain and diagnose their health problems using evidence based medicine. We need coordinated services across the lifespan.

As medicine advances for Autism, we will find the underlying medical associations and sourcing triggers. I have included some examples from the CDC website. They basically state that Developmental disabilities can be mental AND/OR physical. That sometimes we discover new ways of thinking about dis-ease, as in current research at Hopkins focused on GI issues triggering Asthma. And last that the cause of developmental disabilities can have genetic, environmental, and social factors.

This IACC has not fulfilled on the intent of congress to investigate all potential causes of Autism, in particular environmental causes, and a recent GAO Report states a concern for potentially duplicative research. Last night I read the letter dated April 3 from Dr. Marcia Crosse, Director of Health Care at the US Government Accountability Office in response to Ms. Singer's letter March 6th. Dr. Crosse's letter quashed Singer's rebuttal of the GAO Report and continues to stand BY the GAO evaluation which raised concerns about the potential for duplicative research, as well as the use of data that is outdated, not tracked over time, and inconsistent or incomplete.

The letter also requested that both letters be posted on the IACC website which is unfortunate, demonstrating another potentially duplicative effort taking up Dr. Crosse's resources to re-iterate what was already stated in the GAO report. The public was pleased that not everyone on this IACC agreed to this unproductive posturing. I am starting to sound potentially duplicative here so with that I will end this public comment emphasizing a 30% increase is a NO PASS. Society wants answers and real help for this national public health crisis akin to an epidemic. It's a matter of national security and human rights.

Michael John Carley

April 09, 2014

Subject: Autism and Sports Part 2 + a great blog to forward

All:
The second part of my three-part series on Autism and Sports for Huffington Post is up. Please click here to view.

And a fab (and humorously-titled) blog entry I just found, one that is quite affirming, "It's not Autism's Fault Other People Suck," by Jo Ashline, can be viewed by clicking here .

Yours, y'all,
Mjc

http://www.michaeljohncarley.com

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Shawn Swaim

April 10, 2014

Subject: Proposed Content Partnership - Children's Health

Hello,

I found your website in a list of the top children's health. I think the blog at leftbrainrightbrain.co.uk is doing great things in discussing child health and I wanted to reach out to explore the opportunity about the discussion of children's probiotics and other supplements in the future, as there would definitely be a huge benefit to your reader base.

My client is ReNew Life, the leading provider of digestive health supplements in that market, including a unique product for children specifically.

I think a content partnership between your website, a leader in children's health, and my client, the leader in digestive health supplements, makes perfect sense.

You can see their information here:

http://www.renewlife.com/ultimate-flora-kids-probiotic.html

I look forward to expanding the conversation soon. If we can set up a time to discuss by phone, that would be great.

Thank You,

Shawn Swaim
[PII redacted]

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Nydia Olvera

April 14, 2014

Below please find the footnotes that form part of my son's immunization record issued by the New York City Department of Health Citywide Immunization Registry (CIR).

My son was born healthy, Apgar 9, reflexes normal, newborn screening panel normal, normal labor and delivery and released from the hospital a day and a half after being born. We went to all pediatric well-child visits and completed all the vaccines of the National Vaccine Immunization Program including the flu shots. My son was born in 2001. In 2003 he was diagnosed with autism.

CIR Vaccine Record
Footnotes:
"This immunization event occurred prior to the recommended interval for this dose"
"This immunization event was an extra dose since it occurred after this series was completed."

On September 18, 2008 I contacted the New York City Department of Health to inquiry about my son's immunization record footnotes and I was directed to leave a voicemail to:

[PII redacted]
New York City Department of Health and Mental Hygiene

When I finally could get in contact with [PII redacted]. I asked if the amount of extra vaccines and the time the vaccines were giving might have caused my son's autism. The doctor asked me if my son was up to date with his vaccines. I replied with a strong "yes". The doctor continued by saying that giving extra doses of vaccines was not a problem and that in some countries they give extra doses to children. It was clear that none of my concerns matter. The doctor did not follow up with my inquiry. The doctor was more concerned about telling me what was going in other countries rather than explain the vaccine practices in the USA the country where my son was born.

On April 4, 2014 I watched the IACC meeting for the first time and I saw a research engineer and father of a child with autism being dismissed only because he said that vaccines caused her son's autism. Dr. Insel and the IACC could not give this father a few minutes of their time to let this father and research engineer express his concerns. Is IACC planning to follow up on [PII redacted]'s presentation?

The IACC refuses to acknowledge parents' concerns about the safety of vaccines, we say our children changed after each vaccination: fever, flu symptoms, loss of appetite, loss of sleep, pacing back and forth, tip toeing, hand flapping, humming, agitation, rashes, diarrhea, etc. Why would any doctor say that these symptoms are "just part of the autism spectrum". Had my son not being diagnosed with autism his pediatrician would have run all the medical tests they run on "normal" children, tests to rule out allergies for example. Why did my pediatrician wait for my son to turn 6 years of age to evaluate my son underlying medical conditions? Why did the pediatrician give vaccines when my son had a runny nose and doctor heard my son lungs and mention the word "pneumonia" and proceeded to vaccinate my son again and again. My son is now 12 years old and his autism is considered to be severe, he has been diagnosed with allergies and constipation (year 2007), vision problems (2008), epilepsy (2010), GERD and milk intolerance (2012).

According to our geneticist, my son has had all the standard autism genetic testing and all the results indicate normal findings. We have run Fragile X, chromosome count, Genome microdeletion/microduplication array CGH (microarray). Autism is not genetic in the case of our son.

I believe vaccines are necessary as my son has received all the vaccines, but after I've experienced what has happened to my son. I know vaccines can cause fever, rashes, diarrhea and pain. These severe reactions not "side effects".

Thank you,

Nydia Olvera
Woodside, NY

[Photo redacted]

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Marian Dar

April 14, 2014

Subject: Yesterday's meeting, 2 (Should, how and when should docs/fam access these -- guidelines, protocols?)

Thank you for your email and references.

In my response following the meeting, I described my son's experience because I think that there are many families and clinicians that find themselves in this position — where it is unclear how to proceed at medical crossroads (see NYT, Lisa Sanders, MD, April 13 14, and the point that what you "observe" may be an "indirect" result of a problem)) and which path is in the patient's best interest, on a specific decision and also in a sustainable and wholesome way.

My son [PII redacted] is an adult with autism, whose medical care and diet/nutrition are largely managed by an outside agency. As mentioned, his local family practitioner declined to support an outside recommendation for "folinic acid," and this opinion prevailed. And this may well have been the correct decision, but the details and dynamics here expose other things that are not correct — how to look for answers and integrate possible solutions.

This second opinion was sought following a precipitous drop in my sons' behavior —beyond his usual autism.* I thought that before we started tweaking behavioral and pharmaceutical options, we should get a clinical baseline and outside opinion.

I brought [PII redacted] to a local clinical group (our neighbors just over the State line in Ma.,) that espoused a "whole body" (whole budget and unrecognized by third-party payers) medicine. But we were in "crisis" mode, the concept was right, the team of doctors and nutritionists had a reputation, results and experience/traffic with autism and "between-the-cracks" symptoms and disease.

Following intake and labs, the opinion offered by this referral practice found that my son was malnourished* — that his diet was very off — deficient in nutrients ; of note, in recent months there was a change in agency staff that had complete discretion and entirely decided and implemented his food.

Because of policy in the system and on this issue, I was ignored and overruled on sequence (work on diet, behavioral and mildest drugs first and build, etc.), timing and plan of intervention; my son went directly to antipsychotics, etc. and this remains the sole intervention. All providers following guidelines.

Marian Dar

* [PII redacted] bolted 8.5 miles to a local Ct candy shop where he stuffed his pockets with sweets until the Police picked him up; one week later there was a 5.5 mile bolt to a bakery where when another Police car apprehended him, he requested some "wet wipes," getting too familiar with the v. off pattern here —

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Dr. Kathleen Levinstein

April 17, 2014

Subject: Human and Civil Rights Violations in ABA

I am a PhD level Social Worker with Autism and have accepted a position at the University of Michigan /Flint where I will study my comrades with Autism exclusively. ("Nothing About us Without us"!) I am presently working on research re: Human and Civil rights violations in ABA as well as ABA related injury and death. I am also working on a strength based model of Autism for Social Work practice so that hopefully in my lifetime we will say "Congrats" when parents receive the diagnosis instead of "I am so sorry"..- I can be contacted at [PII redacted].

Thanks so much!

Dr. Kathleen Levinstein, PhD, LCSW

Anne Jakus

April 17, 2014

Subject: Where are the studies on vaccines and autism?!

I'm not saying that all the research done to date is useless, however, when the vast majority of parents believe that vaccines are, in some way, responsible for the dramatic rise in ASD, I find it absolutely infuriating that your committee STILL REFUSES TO PROPERLY STUDY VACCINES' ROLE IN THE DEVELOPMENT OF AUTISM!!! EVERYONE KNOWS VACCINES CAN AND DO CAUSE AUTISM!!! It's long past time to figure out how and why this happens to some children and not others. Do the FULLY VACCINATED vs NEVER VACCINATED research now!

I have been a licensed healthcare worker for almost 30 years, and have not one, but THREE children who suffered various degree of vaccine injury following their routine childhood immunizations. I know how to read a research paper, and I know very well what constitutes quality research. The IACC has completely failed to conduct the proper research that would not only bring about an end to this horrible epidemic, but improve the quality of the life for those affected by autism. To say that the IACC has been a disappointment to most parents would be a huge understatement. You need to do much better!

This list of "Advances in Autism Spectrum Disorder Research" is insulting, not encouraging. Is this truly the best you can do?! If so, let's get some people who have biomedical experience, and who are actually helping to cure autism on your committee. Some of your current committee members, including Tom Insel should be absolutely ashamed of themselves for ignoring vital public input!

Parents are fed up! Our country simply cannot go on like this. Autism is bankrupting families, school districts, and soon, entire states will be buckling under the burden of trying to care for all of these kids aging out of the system into adulthood. It's ruining generations of innocent children. Continually trying to float the idea of "better diagnosis" or that "it happens before birth" completely contradicts what we are actually seeing happen before our very eyes. Typically developing children are regressing. Figure out why that is happening, or step aside and give the job to someone who can!

Sincerely,
Katherine Jakus

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Caroline Rodgers

April 21, 2014

Subject: What is causing autism – do we need a crystal ball or can prenatal ultrasound trends provide important clues?

The latest CDC autism prevalence figures[1] are disturbing and confounding. Some trends showed little change, such as autism prevalence is still increasing and boys are almost five times more likely to be diagnosed with autism than girls. Yet while the latest overall autism increase was the largest ever recorded in a two-year period, there were significant prevalence variations within subgroups such as geographic area and race/ethnicity. While these differences seem baffling, they actually are helpful because whatever is causing autism must explain both 1) why autism prevalence is not only increasing but gaining momentum and 2) why it is not evenly distributed among subgroups.

So far, none of the studies from the fields of genetics or environmental epidemiology can satisfy both questions. However, one possible risk factor that is loosely classified as "environmental" – prenatal ultrasound – has increased in usage while showing wide exposure differences among subgroups.

A 2009 study by Siddique et al, Trends in Prenatal Ultrasound Use in the United States 1995 to 2006, covers the gestational years of children who were or will be eight years old – the age at which autism prevalence is surveyed – between 2004 and 2015. Overall, the estimated average number of ultrasound scans per pregnancy almost doubled, increasing from 1.5 in 1995/97 to 2.7 in 2005/06. [2] There is a wealth of data in this study, such as Figure 1, which provides five graphs showing the increase over time in estimated prenatal ultrasound scans by race, age, region, payer type and risk group. There are many disparities among subgroups that may shed light on recent autism developments, such as the surge in black children diagnosed with autism or why New Jersey's prevalence is the highest yet recorded among the monitored sites.

Can ultrasound time trends predict the future of autism prevalence?

If exposure to prenatal ultrasound is a key risk factor in autism outcomes, can we predict what is yet to come? Only half of the data in Siddique et al pertains to the cohorts that were the subjects of published CDC surveillance reports; results pertaining to the second half, which covers the cohort that turns eight this year and next, will not be analyzed for a few years. However, if there is a correlation between prenatal ultrasound exposure and autism, a quick glance at the graphs in Figure 1 shows steep increases in the number of estimated ultrasound scans among white and Hispanic women; those between the ages of 20 and 40; women living in the Northeast, West or Midwest; and high-risk pregnancies, which could portend these populations having a higher prevalence of children diagnosed with autism.

The CDC autism prevalence report notes that Canada, like the United States, has shown an increase in autism. Once again, prenatal ultrasound trends may explain why. A 2010 study by John J. You et al, "Proliferation of prenatal ultrasonography," found a 55% relative increase in scans per pregnancy for Ontario women between 1996/97 to 2006/07. [3] [PII redacted]

These two studies, spanning similar periods of time, each note that the increase in ultrasound scans per pregnancy is not evidence based yet adds greatly to the economic burden of maternity care. The direct cost of a single scan for each pregnant woman in America was estimated at $1 billion dollars annually. 2 If the indirect result of prenatal ultrasound is a child subsequently diagnosed with autism in 1 out of 68 pregnancies, the cost quickly skyrockets.

There are limitations to both studies that keep us from discovering true ultrasound exposure rates. For instance, the United States study did not count emergency room visits and the Canadian study did not include mothers of multiple gestations or older mothers. Neither study captured data regarding commercial "keepsake" ultrasound scans, which could present a major wildcard in trying to understand ultrasound's possible effects on the brain. Further, neither study addresses the use of a variety of Doppler ultrasound fetal heart monitors that are: 1) used to confirm pregnancy as early as five or six weeks; 2) commercially available for home use; and 3) commonly used in hospitals for prolonged periods of time to monitor the fetus during labor right up to delivery.

Finally, there are many other variables such as ultrasound frequency settings and dwell time over tissue, the exact point of fetal development at the time of exposure and fetal genetic predispositions that when combined, may make the difference in autism outcomes – and which could undermine the most rigorous of epidemiological or genetic studies.

A spectrum of intrusions

It is easy to see how a spectrum of neurological issues could arise from this wide variety of insistent energy intrusions on rapidly developing brains. The good news is that if unnecessary scans – and possibly Doppler ultrasound that is often employed very early and very late in pregnancy – come to a hard stop, even children with genetic susceptibilities may be spared because such genes will not be exposed to the environmental trigger that catapulted autism prevalence from rare to urgent care. Going forward, the most fruitful research path may lie in systematic review of maternal medical records and parent surveys that capture all of the prenatal ultrasound and Doppler fetal heart monitor history.

References:

1. Prevalence of Autism Spectrum Disorders – Autism and Development Disabilities Monitoring Network, United States, 2010. MMWR Surveill Summ. 2014 Mar 28;63 Suppl 2:1-21.
2. Siddique J, Lauderdale DS, et al. Trends in prenatal ultrasound use in the United States, 1995 to 2006. Med Care 2009. 47:1129-35.
3. You JJ, Alter DA, et al. Proliferation of prenatal ultrasonography. CMAJ. 2010. 182(2):143-51. Epub 2010 Jan. 4. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2817321

Caroline Rodgers is a writer/researcher who specializes in public health issues. Her peer-reviewed work has been published in the Journal of Midwifery and Women's Health and Medical Hypotheses. In 2006 her article, "Questions about prenatal ultrasound and the alarming increase in autism" was published in Midwifery Today and can be viewed at: www.midwiferytoday.com/articles/ultrasoundrodgers.asp.

[PII redacted]

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Nydia Olvera

May 19, 2014

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I believe vaccines are necessary as my son has received all the vaccines, but after I've experienced what has happened to my son. I know vaccines can cause fever, rashes, diarrhea and pain. These are severe reactions not mild “side effects".

Thank you,

Nydia Olvera
[PII redacted]
Woodside, NY 11377
[PII redacted]

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Eugenia Ramsey

May 20, 2014

Subject: The Combating Autism Act of 2006 as amended (42 USC Part R (IACC meetings)

IACC:

Please be sure that the survey of stakeholders has questions concerning Autistic Adults over 21 require programs for speech therapy, transportation to work centers, training for job placement, housing, exercise program and respite care funding.

I am a parent of a 40 year old Autistic Adult and see these above needs not being met with adequate funding.

Thank you,
Mrs. Eugenia Ramsey

Eugenia R. Ramsey
[PII redacted]
Chatham, NJ 07928
[PII redacted]

Eileen Nicole Simon

June 10, 2014

THERE IS NO HEALTH BENEFIT FROM CLAMPING THE UMBILICAL CORD.
Dr. Batra, thank you for opening a discussion on my comments about language and obstetric injury. Yes, it would be helpful to invite someone from the obstetric profession to discuss childbirth protocols, asphyxia, evidence of subcortical brain damage, causes of "congenital heart defects," and more...

ASPHYXIA
The greatest concern over childbirth is oxygen insufficiency. Evidence was published in a series of papers from 1959 to 1972 on patterns of brain damage in monkeys caused by asphyxia at birth. Nuclei in the auditory pathway are especially vulnerable to a brief period of total asphyxia [1, 5-8]. Gilles reported the same pattern in a human child, and suggested that this should be investigated as the cause of aphasia in children [4].

Landau et al. reported damage of the medial geniculate bodies in an aphasic child [2], and Kulesza et al. described malformation of the superior olives in autism [10]. Lukose et al. produced similar damage of the superior olives in laboratory rats exposed to valproic acid during gestation [11].

Kety discovered that blood flow in the brain is higher in nuclei of the auditory pathway than anywhere else in the brain [3]. Sokoloff et al. adapted Kety's method using a tracer to measure glucose uptake and reported the highest values in nuclei of the auditory pathway [9]. Sokoloff's method has been used extensively to investigate the effects of drugs and other stressors on the brain.

Complications at birth have been reported more than any other factor associated with autism, but is avoided in discussions of autism's causes. Clamping the umbilical cord is clearly a cause of asphyxia when the clamp is applied before the first breath.

HEART DEFECTS
The first description of a clamp for the umbilical cord appeared in the Lancet in 1899, with the instruction to wait for pulsations of the cord to cease before clamping [12]. In 1912 an article in the American Journal of Obstetrics described use of a clamp, again to be applied after pulsations of the cord had ceased [13].

Pulsations of the cord are evidence of ongoing blood flow to and from the placenta following birth. Pulsations of the cord cease after the ductus arteriosus and foramen oval have closed. Patent foramen ovale (PFO) affects about 30% of adults and is associated with migraine headaches and stroke. Read the account of football player Tedi Bruschi [20]. Patent ductus arteriosus (PDA) is associated with many problems including pulmonary hypertension.

Pulmonary hypertension (PH) reflects failure of blood flow to be re-directed into the pulmonary artery at birth. It is outrageous beyond belief that PH, PDA, and PFO defects remain mysterious conditions requiring "modern research."

Clamping the umbilical cord was controversial in the early 20th century [14-16]. Clamping the cord was adopted in the 1930s to obtain blood for transfusions [17]. By the 1950s clamping the cord became more common, when episiotomy was adopted, and the need to maintain a "sterile field" for its repair.

After his retirement in 1998, Dr. George Morley first spoke out about the dangers of umbilical cord clamping [18]. Four years later midwives Judith Mercer and Rebecca Skovgaard described how clamping the cord interferes with normal transition from placental to pulmonary respiration [19].

Please read the excellent article by Tonse Raju, who works for Dr. Guttmacher [21].

REFERENCES, in chronological order

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[1] Ranck JB, Windle WF. Brain damage in the monkey, Macaca mulatta, by asphyxia neonatorum. Exp Neurol. 1959 Jun;1(2):130-54.

[2] Landau WM, Goldstein R, Kleffner FR. Congenital aphasia: A clinicopathologic study. Neurology. 1960 Oct;10:915-21.

[3] Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. Note: this seminal paper is free online at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed

[4] Gilles FH. Selective symmetrical neuronal necrosis of certain brain stem tegmental nuclei in temporary cardiac standstill [Abstract of presentation at the American Association of Neuropathologists: 38th Annual Meeting. Atlantic City. New Jersey]. J Neuropathol Exp Neurol 1963 Apr; 22(2):318.

[5] Lucey JF, Hibbard E, Behrman RE, Esquival FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. Exp Neurol 1964 Jan; 9(1):43-58.

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

[7] Windle WF. Brain damage by asphyxia at birth. Sci Am. 1969 Oct;221(4):76-84.

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

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

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Eileen Nicole Simon

June 11, 2014

CO-OCCURRING CONDITIONS

Autism has many causes, and many co-occurring conditions may derive from particular causes. All causes of autism must affect systems in the brain that are required for normal language development. Most causes of autism also affect brain systems that control motor activity.

Maturation of motor and language circuits in the brain continues during the months and years of early childhood. Thus autism may result not only from prenatal problems, but difficult birth and/or a difficult neonatal course. Genetic conditions are responsible in some cases, but clearly not all.

Prenatal rubella infection, prenatal exposure to alcohol or valproic acid have led to development of autism. Asphyxia at birth is an unpopular idea, but cannot be dismissed as the cause of some cases of autism. Neonatal jaundice has also been noted as a predisposition for autism, as has lead poisoning in early childhood.

Diverse genetic disorders like tuberous sclerosis, neurofibromatosis, PKU, adenylosuccinase deficiency, and even some cases of Down's syndrome are associated with autism. How the brain is affected is what must be determined. Might something like the dietary treatment for PKU be put in place for children born with Down's syndrome? What a wonderful alternative to termination of pregnancy.

Cases of autism among children with prenatal exposure to alcohol, asphyxia at birth, and brain damage by bilirubin provide clues to the brain systems involved in autism due to other causes. Alcohol, asphyxia, and bilirubin are all associated with damage of subcortical systems for hearing and motor control. A rank order of brainstem nuclei are affected in a bilaterally symmetric pattern. This pattern of damage was first reported by Wernicke in 1881. See the paper by Thomson et al. cited below, and free online.

Brainstem sites affected by alcohol, asphyxia, bilirubin, and other toxic substances are the sites of highest blood flow and metabolism in the brain. See the seminal paper by Seymour Kety cited below, which is also free online.

PATTERNS OF BRAIN DAMAGE

Ronald Myers (1972) confirmed the distinctive pattern of brainstem damage caused by asphyxia in adult as well as newborn monkeys, but he claimed this pattern of injury is not characteristic of damage caused by oxygen insufficiency at birth. The experiments on birth asphyxia were intended to produce an animal model of cerebral palsy, but Myers determined that cerebral palsy was the result of prolonged hypoxia late in gestation. See citations below.

A prolonged period of hypoxia produced severe damage of the cerebral cortex. Brief total asphyxia damaged the brainstem centers of highest blood flow. Brainstem centers, including those that control functions vital for survival, are spared during periods of hypoxia, but cortical areas of lesser blood flow ("watershed" areas) are then damaged.

Myers replicated the findings of Kety's blood flow experiments in monkeys. Kety's student Louis Sokoloff later demonstrated that areas of high blood flow in the brain are also the areas of highest metabolism. Sokoloff's deoxyglucose method has since been widely employed in investigations of brain metabolism.

Sparing of brainstem nuclei during hypoxia suggests that protective mechanisms go into action. For example, hemoglobin provides oxygen in exchange for carbon dioxide. Brainstem sites of high metabolic rate produce more carbon dioxide, and thus have priority for receipt of oxygen during a period of hypoxia. Nuclei in the auditory pathway and basal ganglia, and also brainstem nuclei that control heart rate, breathing, peristalsis, and other centers of autonomic control, remain functional at the expense of higher brain centers during periods of hypoxia.

BOWEL DISORDERS

Bowel disease is a prominent concern of parents caring for autistic children. In cases of autism caused by brainstem damage, centers of autonomic functions like peristalsis may be affected.

Working as a nurse in the Massachusetts Department of Correction, I see many men who have wrecked their brains and bodies using drugs of abuse. For some, little bowel function is left despite getting stool softeners, fiber, and intestinal stimulants daily. Lactulose, milk of magnesia, and citrate of magnesia are often needed to push intestinal contents along and out. This is one of the ugliest outcomes of drug abuse.

Parents want to believe that bowel disease affects the brain, and that this might be reversible by special diets. But damaged autonomic centers in the brainstem should be considered as the cause of bowel dysfunction.

One of the worst treatments I have heard about is use of metronidazole (Flagyl). Toxicology research has shown this substance produces the same pattern of symmetric brainstem lesions caused by alcohol or asphyxia. In PubMed (or Google) lookup metronidazole encephalopathy.

AUTOIMMUNE DISORDERS

If brainstem centers are damaged by asphyxia at birth (for example), irritation will evoke an immune response. This will be a response to host tissue, hence an "autoimmune reaction."

Again, parents want to believe that an "autoimmune" disorder affects the brain, not that damage within the brain triggered the autoimmune response.

MITOCHONDRIAL DISORDERS

Mitochondria are bacteria-like. Mitochondria may be remnant from symbiotic infections of primeval multicellular organisms. Mitochondrial enzymes promote successive steps in aerobic energy metabolism.

Mitochondria may suffer damage from antibiotics. Mitochondria are unable to mutate the way modern wild bacteria do, so while bacteria are becoming more resistant to antibiotics, mitochondria remain vulnerable. See the papers by WA Silverman and AF Robertson (citations below).

Are antibiotics overused in Neonatal Intensive Care Units?

SEIZURE DISORDERS

Seizure disorders result from missed connections between sites of signal transmission and intended target areas of the brain.

In the experiments with monkeys on asphyxia at birth, prominent damage was found in brainstem nuclei. Maturation of the cerebral cortex did not progress normally in monkeys kept alive for many months and years. See the paper by Faro and Windle, 1969, cited below.

Brainstem damage was thought to represent a minimal brain injury, possibly underlying what 50 years ago was referred to as “minimal cerebral dysfunction” (MCD). In keeping with the ongoing trend to find euphemisms, MCD is now referred to as “pervasive developmental disorder” (PDD).

Brainstem damage clearly prevents normal development of circuits in the cerebral cortex. Rewiring, or “plasticity” may occur, but is likely often aberrant. “Under-connectivity” seen in fMRI scans, and recent abnormal “patches” in the cortex of brains from people who were autistic, should be compared with the abnormal maturation of the cortex observed in monkeys subjected to asphyxia at birth.

Maturation of language and motor circuits continues for at least 4 to 5 postnatal years. Damage by oxygen deficiency at birth and toxic exposures during infancy clearly can be as disruptive as maldevelopment during gestation.

ATTENTION DEFICIT SPECTRUM

Disturbed social attention is believed by many to underlie failure of language development in autism. This may be another euphemistic way to deny maldevelopment of the language areas in the cerebral cortex. Social obliviousness in autism is part of a more extensive lack of general awareness, or deficit in consciousness.

Autism should be considered the most extreme blunting of environmental awareness, caused by the most extreme extent of perinatal neurological impairment.

Language is the defining feature of the human species. It is not completely abolished in most cases of autism. Children with ADHD are afflicted with language and intellectual deficits, but to a less severe extent than in autism. Autism and ADHD should be viewed as part of a spectrum of developmental disorders.

SCHIZOPHRENIA SPECTRUM?

Schizophrenia appears in adolescence or early adulthood, following apparently normal development during childhood. However, uneven development, especially in school, is reported by mothers in many cases. I know this from my 23 years working at the state hospital for mentally ill prison inmates in Massachusetts (Bridgewater).

High functioning autistic people, like my son, may get a diagnosis of “schizo-affective” disorder when they are apprehended by police, and presented to court evaluators. My son now lives in a slum of a “community” group home, with alarms on all the doors. Six men live in this house, with three shifts of 2 to 3 staff on each shift. Many residents of this house fit Kraepelin’s descriptions of “dementia praecox,” replaced by the euphemism schizophrenia a little over 100 years ago.

My son does not suffer from dementia. He continues to make cognitive progress. He is capable of doing useful work, but he is not being helped to gain skills for employment and independent living. He is a misfit in this house. I take him out several times a week to go to the library or a coffee shop to write.

We have written two memoirs together, and are working on our third. Look for our series Autism and the Inferior Colliculus on amazon.com and bn.com.

Do not confuse autism with schizophrenia. Both disorders may be initiated by the same disrupted systems in the brain, especially the auditory system, but childhood development and lifespan needs are different.

DEPRESSION

Depression is the final common condition that afflicts many who had developmental problems. This is especially true for those, like my son, who overcame the most serious of his disabilities.

My son did not speak normally until he was almost six years old. By then he had been excluded from attending public kindergarten (in 1967). He was admitted to the children's unit, Ward 6, at the Massachusetts Mental Health Center at age 5. He blossomed with the gentle guidance of an inspired and dedicated special education teacher [PII redacted]. By age 7 we thought he had overcome all of his problems, but by age 17 it was clear he would in no way be able to go to college.

"Not everyone goes to college," someone chided us in a lofty tone of voice.

What? College, and saving for it from infancy is one of the great American expectations.

From age 22 to 29 my son was often among the missing. I followed every dead body report on many occasions. He was often located at a state hospital, Northampton, Metropolitan, Taunton, Bridgewater, Medfield, and finally Westborough. All but Bridgewater (run by the Department of Corrections) are closed now.

My son's best 10 years were spent at Westborough State Hospital, where he had care and treatment by well-educated professionals of long experience. He had a job for which he was paid, at the Agnes Clarke Memorial Workshop, mostly assembling and packaging products for local manufacturers. His favorite was assembling bird feeders for the Opus Garden Song Company. How exciting one December day to walk into Caldors department store, and see right at the door an arrangement of birth feeders my son had assembled. They were on sale as Christmas gifts.

"That's my work!" my son cried out in excitement.

For the first time he felt like a full participant in life.

At age 40 my son was discharged to his current group home in the "community." He has run away from this house twice, and now wears a GPS bracelet.

Weekends, beautiful summer weekends, at this house are the worst. One cigarette every hour, on the hour, on the back porch, is often the only outdoor time residents get.

Now we are being told that the Department of Mental Health in Massachusetts (DMH) cannot fund housing for all "consumers," and if my son can't follow the rules, he may be discharged. How many times have I been asked if my son couldn't live at home with my husband and me? My son is 51 and my husband and I, in our 70s, are preparing to move into a retirement community. How would that work???

DMH is only interested in helping people for whom “Recovery is Real.” My son may yet get purged to Harvard Square or the Boston Commons, and assigned to a PACT team (Program for Assertive Community Treatment). I too am sick with grief and anxiety.

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Carol Fruscella

June 25, 2014

My comments are intended for the July 8th Meeting of the Panel... 96 hours after July 4th.

My son, with 'his level' of Autism, has yet to gain any independence... My son cannot drive. My son cannot live an independent life. He is dependent on my constant support.

My son is almost 23 years old... But you would hardly know that other than his size and outward appearance. My son still receives interventions daily. We still try to reach and teach him daily. Since my first visit to the IACC, where I spoke and reported my son's wavier list 'waiting' number for housing........ I feel obligated to let you all know his most recent housing number. My son backed up on the list by 11 placements. My son's number is NOW higher than when I addressed you all last November. His wait, is now going to be even longer.

I have a dear friend whose Autistic Adult son fell and chipped a front tooth. Due to his level of Autism and Seizures he will need sedation for repair. His wait for that repair on the Medicaid list..... will be a minimum of a year. (ONE YEAR!) I must ask if each member of this panel had to wait a year for dental work, would that be acceptable to you?

The 'adults' I have referred to above are humans, just like you and I. They deserve some level of respect and independence. They are the 1 in 2500 DX with Autism, per their birth years...... Not the 1 in 68. .... and this is the WAIT time now.

I must respectfully ask, what are you all waiting for? I know as I have seen footage of the meetings, almost half of this panel has left early to make flight connections to their next designations. That must be nice, to be able to just walk out on Autism. Please study what that freedom of choice is... to be able to do what you want, when you want... would be like.

For 22 years I have waited for answers....... REAL answers. As I stated last November 2013, I still as of July 8th 2014 can report that "There is no medical model that exists anywhere in the United States that allows patients with autism to seek emergency medical treatment with a simultaneous medical delivery model to treat psychiatric, behavioral and co-morbid medical conditions that may be causing the behavioral symptoms. Patients can receive ONLY one or the other. If their behavior is out of control they can be sedated with medication but the underlying cause of the behavior - brain inflammation, gastrointestinal distress, other pain - remains untreated!!! Masking these patients' symptoms with sedation is not providing healthcare treatments that would allow them to return home more quickly to their families."

I have a final point to make, that I fear that I CANNOT make strong enough. There are many with the DX of Autism that have thrived. I have one son like that, who is very much on the Higher Functioning side of Autism. The 'word' cure frankly offends many. It is NOT meant to be offensive.

When a child or adult cannot 'travel' openly at their own free will...... To be able to meet the cab or the next departing flight, or just leave a meeting early....... When they cannot read simple instructions on how to open a prepared meal and place it in the microwave....... When the same person cannot shower independently, due to the risk of seizures while bathing and possible drowning....... Yes, we would 'love' a cure!....... But until then....... How about a little respect....... How about No 'eye rolling' as is plainly and clearly seen on the video tape... by the women directly behind Dr. Insel as my name was called last November. Do you really think that after providing care to a differently abled person for 22 years that 'eye rolling' is going to bug me?...... That is just one of the many reasons that people find this panel disrespectful. When there is disrespect all credibility is lost... regardless of the credentials alongside a person’s name. I may never be the head of any formal organization of this magnitude, but I do know, as do thousands upon thousands of others the daily ins and outs of living with Severe Autism.

Parents and care providers have more 'everyday knowledge' of the real needs to this disorder, than possibly any one person setting at this table. We have seen and lived in the Forest and watched and watered and cared for the Trees......... While you study it from a distance. Very few members on this Panel have ran to aid the screams in the middle of the night...... only be left to guess, if your loved ones had their appendix burst, if they have a tooth ache, if the person has gas, if the person has an earache....... High Functioning Autism can report these issues...... the Lowest Functioning person cannot report......... When the problem is obvious, to be asked to wait a FULL YEAR
Autism Rate of 1 in 68 have we all not waited long enough for real change?

If you will never 'study' all the causes of Autism... Can you at very least suggest the immediate changes for services that the children and adults with this disorder will need? Is that too much to ask? What if it was YOU who had Lower Functioning Autism?... Would you be happy to wait eight more years for services and answers as you are now the nonverbal person on the spectrum who just wished they could catch a flight home.

Sincerely, Carol J. Fruscella

James Blanco

June 25, 2014

As a parent of two adult children with autism, complexed with seizures and comorbid conditions such as heart block, liver dysfunction, mitochondrial dysfunction and seizures, what has been done to find the COMORBID conditions in children such as ours, and how are doctors being educated on these complex cases?

For the most part, in the thirty years of my living through this nightmare with my children, not much. I have often had to educate my doctors on varying health issues with my children. One child had to have an emergency heart pacemaker because he lost all autonomic function. While asking heart doctors about this connection to autism, they only had shrugged shoulders of why this may be connected. There is plenty of literature that says autonomic function in autism is off.

Where are your studies on comorbid conditions found in autism, and what is being done on research in this regard? To my knowledge, NOTHING. Shouldn't we do this, with a population of children now becoming adults?

Children are going to die in the next few decades because you failed to recognize the multi systemic issues in "so called autism".

What are you going to do about it? Nothing, as usual and typical?

Where are you going with the research now? Genetics only? That's not going to help our kids today.

I wish to become a part of your panel. I have researched autism for thirty years, and I have yet to find you have described the children I see day in and day out, who have horrid health conditions that are not being addressed. In fact, they are being belabored by doctors and insurance companies who are uneducated, unskilled, and unwilling to treat my children with due respect.

Kathy Blanco
Ione California

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Heather Price

June 25, 2014

Many with autism cannot speak and WE must be their voices. I am a mother of seven year old twins with autism in Cleveland, OH. I am lucky that my children with autism are verbal and are considered "high" functioning. Regardless, in many ways, autism rules my life. A few years ago I stepped down from a position with the top 2% of my direct sales company in order to help coordinate my twins' care. When they were babies, it was simple for me to work while they napped. As they grew older and their needs grew more intense, they entered two separate preschool programs that met at two separate times. As I met the special ed bus outside four times a day while coordinating the appointments with the center for autism, the psychiatrists, the psychologist, the wraparound center, the developmental pediatrician, the IEP meetings, and the constant visits to the pharmacy to fill their ever changing prescriptions, I realized that my top priority needed to be their care. I still work, but very part time hours and I remain self-employed. Primarily, they need me as their unpaid advocate and care coordinator. It is not as their advocate but as their mother that I write you this letter. As the mother of "high" functioning children, I am one of the lucky ones. My children are cognitively on target. They might get married someday. They might be able to live alone. They might be able to hold down a job, or even a career. I am one of the lucky ones.

After years of trying to figure out how to get ABA therapy (the school district won't pay for it and insurance won't cover it), I am finally lucky enough to receive a Medicaid waiver for one twin. I spent last Saturday night writing up an FBA parent interview form, a 13 page social skills checklist, a list of what we need ABA programs for all for one twin, behavior frequency charts for the week and antecedent, behavior, consequence charts for the week all done for both twins. An unusual way to spend a Saturday night, for certain, but this is my life and I accept my role. In every county in every state, families have holes in their drywall, furniture bolted to the walls, parents and caregivers in emergency rooms with broken bones. They wait on waitlists for waivers to help them pay for therapy and respite. I have not yet had any broken bones, and I just received a waiver for one twin. I am one of the lucky ones.

The list of places I physically cannot take the twins by myself includes the zoo, chuck e cheese, the library, ice cream, out for a walk..... but I was still trying to do target and walmart by myself. After last week's Target trip I'm done trying target or walmart without help. At one point there were 3 uniformed security officers surrounding my daughter who was on the floor screaming "don't arrest me! don't arrest me!" I literally wouldn't have made it to the car without a psychologist and a preschool teacher – random strangers who came by----who offered to help, and a friend I ran into in the parking lot who totally understands autism meltdowns. I left target with no groceries but with plenty of bite marks. We were kicked out, but I was told I'm welcome back anytime (the undertone was... "by yourself please). I cannot simply take my children out of my house without physical assistance. But because sometimes my children CAN handle the outside world and sometimes my husband IS available to help, I am one of the lucky ones.

At the mall last week passersby saw a 7 year old lying on the ground screaming and kicking and another 7 year old running off to bite people, and myself, a frazzled mother who left without purchasing anything. I enter the village of judgmental stares (with my husband's help) in order to teach my children how to function in society. The judgmental stares have stopped bothering me. I am one of the lucky ones.

I write to you on behalf of the children with high functioning autism but primarily on behalf of the children with lower functioning autism. I write to you on behalf of families who NEVER can consider themselves lucky. I write on behalf of mothers in their 50's who have their nonverbal, severely behaviorally challenging children who are larger and stronger than they are living with them because they have been on a waiver wait list for decades. I write on behalf of families who watch their children suffer from seizures daily and in some cases, hourly. I write to you on behalf of the families for whom autism is perhaps genetic, and on behalf of the families for whom autism is clearly caused by environmental factors. I write to you on behalf of families, who knew that their babies were autistic, and on behalf of the families who watched their two or three year old lose all their language and eye contact and regress into autism after months or even a year of words and sentences.

My first point is this: The increasing numbers of autism diagnoses among the lowest functioning are not related to better diagnosis or to wider understanding of the condition. I think perhaps that may be true for the [PII redacted] among us--- children who decades ago would have been considered quirky are now given an autism diagnosis. However, 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? How is lumping all types of autism together into one spectrum not insulting to parents of the lower functioning and frustrating to the parents of the higher functioning? You have the power to help America and the world recognize the epidemic that autism has become. Too many feel that "better diagnosis" is leading to the lower and lower ratio which now stands at 1 in 68. That ratio terrifies me.

My second point is this: To bring about tolerance and understanding, we need more awareness of the dirty, often shunned type of autism. We need videos online of half hour meltdowns. We need the lack of emergency services for families with autism to be highlighted. We need everyone to understand that there are families stuck at home with their children that if the general public knew, they'd say "I could NEVER handle that!" Autism parents are expected to handle it. EVERY single day. Because I now have full days with no severe behaviors, I am one of the lucky ones. You have the power to make people see ALL types of autism, not just the high functioning.

My third point: 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. Military families end up at the bottom of the list each time they move. Now that my daughter has an Ohio Medicaid waiver, I can never leave Ohio even if my husband finds better employment elsewhere. We're happy here so at this time it isn't an issue, but I know families who inherit property in other states but cannot move due to Medicaid waiver restrictions.

A new autism diagnosis is given every eight minutes. The IACC is the panel who is to Research Autism and help us find answers. The IACC has spent 1.6 BILLION dollars over the last 8 years of our hard earned tax money. What have you found? Are you willing to admit that autism is an epidemic? Are you willing to accept that the increasing numbers of diagnoses among the lowest functioning are NOT due to better awareness? Are you willing to help spotlight the horror stories of the forty children with autism who have drowned in recent years due to eloping? Or the terrible tragedy of [PII redacted] and other mothers who felt they had no choice other than homicide and/or suicide because they simply couldn't get the help they needed as school districts offered as little as possible and residential treatment centers cost thousands more than any parent could possibly afford without help?

Videos of verbal kids on the basketball team or students with autism in college go viral and create a warm, fuzzy awareness of the high functioning. But it doesn’t help to raise awareness of the severity of the monster that is autism. We are down to 1 in 68 children. When will we work HARDER to find a cause? At 1 in 40? 1 in 30? When will there be not enough neurotypicals to provide for the autistic population, financially or otherwise?
Thank you for your consideration.

Sincerely,

Heather Price
[PII redacted]

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

Eileen Nicole Simon

June 29, 2014

Matt Carey, a public member of the IACC posted a report about a shaman healer on the lbrb blog. I responded, and want my comment, which follows also included in the "Public Record" of the IACC:

This kind of mumbo jumbo has come about to fill the void of stalled scientific research. I will submit a comment on this for the upcoming IACC meeting, but am responding here because you are a member of the committee.

A "facilitated communicator" was invited by staff at my son [PII redacted]'s group home to try to make sense of his echolalic manner of speaking. She reported that he told her he had been physically and sexually abused by me, his mother. I was then ordered not to visit [PII redacted].

My husband suggested just staying away for a while, "They won't kill him." But they did.

Informed at best by a few community college courses, staff urged the psychiatrist to increase [PII redacted]'s dose of Thorazine, which she did, to 500mg three times per day. [PII redacted] was found dead in bed on the morning of January 17, 1995. Toxicology revealed a lethal level of Thorazine in [PII redacted]'s blood. Details are on my website, conradsimon.org.

A "self-advocate" on the IACC suggested a year or two ago that "facilitated communicators" could be made available for language-impaired autistic people. NO, professional members of the IACC should long ago have made developmental language disability a primary focus of discussion and research.

Evidence has been available since the 1960s that nuclei in the brainstem auditory pathway are prominently damaged by asphyxia at birth. Complications at birth are recognized as ominous. Why did Virginia Apgar develop her scoring system in the 1950s? Why did she write a book, "Is my baby all right?"

Brain maturation did not proceed normally in monkeys subjected to asphyxia at birth. Auditory system damage should have been recognized as an obstacle to maturation of language circuits in human children. I am grateful that at the IACC meeting in April, some discussion took place of the dangers of umbilical cord clamping. I have submitted comments on this subject for the July meeting. Yes, I could be totally wrong, but then provide the evidence that clamping the cord within seconds after birth is safe. And, explain what health benefit is gained by clamping the cord.

Eileen Nicole Simon

I submitted the following in response to a negative comment from two anonymous frequent contributors to lbrb:

If autism were recognized as a neurological disorder, there would be no market for shamanic interventions. The "facilitated communicator" who claimed to have interpreted my son's echolalic speech, was also a shaman. She abused him. She was the reason I was not allowed to visit him.

But I did visit [PII redacted] one more time. Staff at the house yelled at me to get off the property. [PII redacted] waved goodbye from the front porch, and the last words I heard from him were, “I love you mom.”

Two months later he died from an overdose of Thorazine prescribed by a misguided psychiatrist. [PII redacted] was abused by an impostor, staff at the group home, and a psychiatrist, who should have been tried for murder. Staff at the group home were devastated when [PII redacted] died. I am sorry for the grief these young people endured.

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

Eileen Nicole Simon

June 29, 2014

Form letters are the only response I have received from my senators, Elizabeth Warren and Edward Markey, and my representative, Katherine Clark, and likewise from President Obama. President Obama's form letter included the following hurtful statement:

"...I will continue to work with Congress, experts, and families to improve Federal and State ASD programs. We remain committed to leveling the playing field for all Americans with disabilities..."

Thus I was very pleased to see the comments of Representative William Posey on the Congress Blog of "The Hill." Many of us responded to his invitation for discussion. I was appalled to see several negative responses. Therefore I posted the following thank you note, which I want included in the "Public Record" of the IACC:

Representative Posey, I want to thank you again for your efforts to keep the Combating Autism Act focused on meaningful goals. Children who do not learn to speak have suffered neurological injury. The causes of injury to the brain must be the focus of research.

People who have difficulty with social interactions need help, but this should not detract from efforts to understand maturation of the language circuits in the cerebral cortex. Broca and Wernicke discovered the areas of the brain required for speech production and understanding in the 19th century.

Development of the language areas continues after birth. What injury disrupts this maturational process? This should also be a primary focus of President Obama's "Brain Initiative." In 1990 President George HW Bush signed a proclamation designating the 1990s as the "Decade of the Brain." But brain research in the 90s was preempted by excitement over genetics.

Something like the National Transportation Safety Board (NTSB) should be considered to investigate causes of brain damage that disrupt language development. Could legislation be put in place to require (or at least encourage) parents to purchase long-term care insurance for every child born? This would involve actuarial scientists in the search for causes of autism.

The medical establishment has not been responsive to questions of safety in obstetrics and infant care. Use of diethylstilbestrol (DES) had to be stopped. Cancer occurred in the daughters of women treated with DES to prevent miscarriage. Waiting for results of a "randomized control trial" of DES was not an option.

Randomized control trials are not needed to determine whether it is safe to clamp the umbilical cord immediately after birth. In 10th grade biology we learned that the anatomy of the heart changes to redirect blood from the placenta to the lungs. "Congenital" heart defects should be recognized as the result of clamping the cord too soon.

My senators, Warren and Markey, and my new representative Katherine Clark have, like President Obama, responded only with form letters to my correspondence. Autism is clearly not important to any of them. I am therefore especially grateful for your interest in autism.

Eileen Simon, RN, PhD

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

Pam Rockwell

June 30, 2014

This year 40% of pregnant women have received influenza vaccine during their pregnancies, and the Center for Disease Control (CDC) is now recommending that pregnant women also receive TDaP and MMR vaccines during their pregnancies. I would like the IACC to instruct the CDC to stop recommending that pregnant women receive vaccines until they have collected safety data to confirm that prenatal exposure to vaccines does not cause autism. I would like the IACC to instruct the National Institute of Allergy and Infectious Disease (NIAID) to extend their safety studies of influenza vaccines in pregnancy and find out the autism rates of the children born in these study periods. I would like the IACC to recommend that the CDC ask their Vaccine Safety Datalink (VSD) partners to review medical records of pregnant women and determine if prenatal vaccinations had an effect on the developmental health of their child. I would like the IACC to recommend to the Food and Drug Administration (FDA) that pregnancy be listed as a contraindication on all vaccines that have not had developmental health reviews on children exposed prenatally. I believe that vaccination is a medical procedure that should be private between a woman and her doctor, so I would like the IACC to recommend that the Federal Government stop using vaccination compliance of health care providers as a measure that is used to set merit based fees.

Currently, no safety testing is done to determine if prenatal vaccination causes developmental delays, mental disorders, or even childhood cancer, especially for viruses that are already linked to autism like influenza and rubella. These vaccines are deemed safe for the baby based on his or her health at birth (although there is not data to assess miscarriage rates in the first few weeks of pregnancy.) Some studies have done short term follow-ups (less than 9 months) to see if the baby is protected from infectious disease the same way the mother is. But there are no published studies that follow the baby after the first year; certainly none that are long enough to determine if the baby has autism – or even long enough to determine if prenatal vaccination interferes with the long term immunocompetence of the child.

Pediatricians do not realize that prenatal vaccines have not been tested. It is a circular problem. The CDC will not test prenatal vaccines for developmental delays because no physicians are reporting autism following a prenatal vaccination, because the physicians do not believe that autism could be caused by a vaccination, so they do not even think to ask about prenatal exposure to vaccines.

In 2011, I asked the CDC why they did not require longer term safety data before they recommended that influenza vaccine be given to pregnant women during every stage of their pregnancy, and [PII redacted] responded that there were NO reports of autism following prenatal influenza vaccination in the Vaccine Adverse Events Reporting System (VAERS), so the CDC did not feel any need to investigate further. If vaccination had no effect, then you would expect at least some reports of children who develop autism. Influenza infection in pregnancy is a risk factor for autism, so if no children born to mothers who are vaccinated during their pregnancies, then vaccination could prevent autism, so that would be a great reason to be vaccinated! But the reality is that children and pregnant women have different doctors, and the VAERS system is not capable of detecting side effects in children from prenatal exposures.

Some forms of autism could be autoimmune disorders. There is more and more evidence mounting every year about the link between autism and the immune system. Carlos Pardo (Johns Hopkins) and Paul Patterson (Cal Tech) have linked maternal immune activation – increased cytokines and inflammation – with autism in human studies and can induce it with prenatal exposure in animals. All vaccines cause immune activation, including fevers, inflammation, and increased cytokines. Could these vaccine effects cause the same developmental delays that Dr. Pardo and Dr. Patterson see with cytokine and inflammation in their animal models of autism?

Rubella and influenza infections during pregnancy are both associated with increased autism risk in the baby, and it is not understood how these viruses cause this increased risk. Is it possible that the killed or attenuated viruses that are the active ingredients in vaccine could actually have the same effect as the live virus? Judy Van de Water (UC Davis – MIND) and Betty Diamond (Feinstein Institute) have each identified antibodies found in the mothers of autistic children that can cause autism with a prenatal exposure in animal models. Could antibodies to these vaccines be the brain binding antibodies that Dr Van de Water and Dr. Diamond have correlated with increased autism following prenatal exposure? Dr. Diamond has found that one of the antibodies she has identified binds to N-methyl D-aspartate (NMDA) glutamate receptors in the brain. Interestingly, one medication used to treat influenza, amantadine, also binds to NMDA receptors. Could amantadine receptors on the flu virus used to make flu vaccine trigger the production of cross reacting antibodies that destroy NMDA receptors and cause autism? (This year all natural flu virus is actually amantadine resistant, but the vaccine still uses an amantadine sensitive prototype – so only the vaccine could trigger such a cross reaction.)

But isn't autism genetic and gender specific? I know that you will question how a generic exposure like prenatal vaccine could produce such a gender biased effect like autism, but the reality is that infections and vaccines are gender biased already. Given an equal exposure, males produce more cytokines, and females more antibodies – that is why vaccines are generally less effective in men, but females are more likely to develop autoimmune disorders. Dr. Diamond sees this effect in her animal model of prenatal exposure to anti-NMDA receptor: the female fetuses are all reabsorbed early in the pregnancy, so that only male pups are born. Studies that linked narcolepsy to GSK's pandemic flu vaccine showed that it only caused narcolepsy in individuals with a specific genetic marker – HLA type DQ0602.

Vaccines work best when people get vaccinated before they get sick, so regulators like the CDC Advisory Committee for Immunization Practices (ACIP) have extraordinary power to recommend vaccines that have not been approved or are contraindicated in specific populations, like pregnant women. But with this great power comes responsibility. There is no incentive for vaccine manufacturers to be sure that their vaccines do not cause side effects if they are not liable for those problems. It is not reasonable to assume that these vaccinologists who have worked for their entire careers to support disease prevention by developing the best vaccines will honestly consider that giving it to a pregnant woman could cause long term problems for her child. It is time for the US government to step in.

Our government is letting us down by not insisting that there be a longer follow-up to prenatal vaccination safety studies. NIAID has four studies of influenza vaccine in pregnancy listed in clinical trials.gov that they consider "complete":

NCT01173211- 2010-2011 Trivalent Influenza Vaccine (TIV) in Pregnant Women
Intervention: Biological: Trivalent Inactivated Influenza Vaccine
Sponsor: National Institute of Allergy and Infectious Diseases (NIAID)

NCT00963430 - H1N1 Vaccine in Pregnant Women

Intervention: Biological: Inactivated H1N1 Vaccine
Sponsor: National Institute of Allergy and Infectious Diseases (NIAID)

NCT00905125 - Influenza Vaccine in Pregnant Women
Intervention: Biological: Fluzone®; Biological: Fluarix®
Sponsor: National Institute of Allergy and Infectious Diseases (NIAID)

NCT00992719 - Novartis H1N1 Vaccine in Pregnant Women
Intervention: Biological: Inactivated H1N1 Vaccine
Sponsor: National Institute of Allergy and Infectious Diseases (NIAID)

These are old studies – these children are 3-4 years old now. You could ask NIAID for a more thorough follow-up to these studies: calling the mothers and asking whether children born during these studies have met their developmental milestones.

The CDC has also partnered with health care providers across the country in a program called the Vaccine Safety Datalink (VSD). This program funds medical records reviews of large HMOs to look for links between vaccination and long term medical issues. You could ask the CDC to have their VSD partners study the effect of prenatal vaccination on developmental delay diagnoses in the child. This data is already there and available – it is just a matter of asking the right questions.

The FDA also licenses these vaccines. You could ask the FDA to require that drug companies submit 3-5 year follow-ups on other vaccines that are now also being recommended for pregnant women.

My government could just do these studies – quickly and quietly, because testing these possible safety problems will be cheaper and more efficient in the long run than waiting for a possible public outcry, and having to investigate every VAERS report of autism after prenatal vaccination (which could still be thousands of cases, even if autism is totally unconnected to prenatal vaccination.)

Stop blaming parents of autistic children who question vaccine safety for infectious disease outbreaks. It is hard to publish data that shows vaccines are ineffective or cause harm, because regulatory and licensing organizations will have us believe that all infectious disease is caused by poor vaccination compliance, not poor vaccine quality, and they do not want to provide any possible support for vaccine avoidance. That means that the FDA committee that reviews influenza vaccine components chose to keep the same formula for influenza H1N1 antigens for 2014-2015 without even discussing research that links narcolepsy to a specific epitope on H1 antigens in all flu vaccines for the past 5 years. This means that the US Military does not publish the data presented to that committee that says that vaccinated active duty service members were more likely to have laboratory confirmed flu infections than unvaccinated service members. This means that you never hear about the Canadian studies that show that people who were vaccinated with 2008-2009 seasonal flu vaccine were more likely to end up hospitalized with pneumonia from pandemic H1N1 influenza than people who had never received a flu vaccine.

This year there are several outbreaks of measles around the country and a whooping cough epidemic in California. The American Medical Association and CDC try to blame these outbreaks on bad information about autism and individuals who choose not to vaccinate. But the reality is that most of the cases of measles are from one Amish community in Ohio. (The Amish have never advocated vaccinations and do not use public schools.) Several other measles cases are in fully vaccinated young adults for whom the vaccine has worn off, or who had less severe, but contagious cases, that they spread to their friends and family – often with multiple trips to physicians and emergency rooms that did not recognize that they had a contagious disease. This is a problem with measles vaccine quality, and proper healthcare recognition of rare infections, not poor herd immunity.

Similarly, pertussis is coming back because the acellular vaccine does not last as long as the fever inducing whole cell vaccine that was phased out in the 1990s, and vaccinated people can be contagious without realizing they are even sick. Pertussis can be treated with antibiotics which will not only make the victim feel better, but also prevent transmission, but the mild infections that are present in vaccinated individuals are often not recognized as a treatable infection until the bacteria have spread to unvaccinated individuals. For this reason, this newer vaccine is worse than no vaccine at all, but unfortunately the old vaccine is not available in the US because doctors claim that parents are so misinformed that they will not comply with a vaccine that causes a little more discomfort.

These problems are not being caused because a few parents who are worried about autism are refusing some vaccines. These are the result of an arrogant system that believes that lack of data about poor outcomes is the same as actual data that a drug is safe and effective. These are also a problem with medical reimbursement system that benefits wider markets and newer vaccines that wear off quickly and need yearly boosters. And they are a problem with a social system that requires compliance with vaccination schedules for public school attendance and many types of employment.

But bad press for one vaccine might affect others, so making a lot of noise about a possible link between autism and prenatal vaccinations would probably affect vaccine compliance for good vaccines in non-pregnant populations – like polio boosters that are saving lives in the Middle East and Brazil. Having every mother of an autistic child who also received a vaccine during pregnancy fill out a vaccine event report, or even asking pediatricians to do it, will create a lot of bad press before there is real data. The responsible thing is to quietly collect the data from the studies that have already started, and then, do the right thing with it – even if that means stopping the practice of vaccinating pregnant women.

Please, make it clear to US agencies that test (NIAID), license (FDA), and recommend (CDC) vaccines for pregnant women, that safety testing should be extended to include possible developmental delays in the baby and that vaccinations of pregnant women should be suspended until real safety data is evaluated.

Thank you,
Pam Rockwell
Concord Massachusetts

Portia Iversen

June 30, 2014

Greetings to all IACC Members and Support Staff,

Thank you for the work you are doing. I wish to once again bring your attention to the nonverbal and minimally verbal population within the autism spectrum. This group constitutes somewhere between 25 - 50% of the total ASD diagnosed population. Exact numbers are unknown because of lack of research.

This nonverbal and minimally verbal group has received little research attention due to absence of directed funding by NIMH, other NIH institutes and private research foundations. A lack of focus on nonverbal autism persists in spite of the fact that the majority of gold standard autism interventions and treatments have little or no impact on this group.

Nonverbal individuals are rarely included in research protocols and almost no research is directly focused on this large ASD subgroup.

Nonverbal children and adults are often referred to as "non-responders" by researchers, clinicians and educators when they fail to respond to gold standard protocols. I would like to make the point that it is our job to research and develop treatments that can impact this group, not theirs.

Little has changed for the nonverbal individual with autism since inceptions of CAN, NAAR and Autism Speaks. Little has been done to better understand and help this group since the IACC was formed.

These are among the most challenged individuals with autism, there are a lot of these people, effective treatment and even basic medical care are largely unavailable. Social support is minimal, resources are few and inadequate. Appropriate educational opportunities are almost nonexistent. The quality of life outlook for the nonverbal person and their family is very grim.

What it is going to take to start addressing the needs of this nonverbal and minimally verbal subgroup? How has this disparity in research been allowed to persist for so many years? I would like to ask the IACC to make nonverbal and minimally verbal autism a serious focus of research in the immediate future.

Thank you,

- Portia Iversen

Co-founder, Cure Autism Now (CAN), Autism Genetic Resource Exchange (AGRE)
Founder, International Meeting For Autism Research (IMFAR)
Past member NIMH National Advisory Mental Health Council (NAMHC)

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John Best

July 01, 2014

Hey [derogatory language redacted], you receive the respect you deserve. All of you know that you're lying about autism. All of you know that autism is caused by mercury in vaccines. This is obvious to any person who bothers to honestly seek the cause.

Here are all of the autistic behaviors that I can recall which were cured by using Alpha Lipoic Acid to remove the mercury from my son Sam's brain. Some were physical ailments. First, four years of painful constipation vanished after three rounds of chelation. The screaming in pain from this also vanished. At the same time, my son, who had always dragged one leg behind the other began walking normally. Soon after this, we had eye contact for the first time in eight years since mercury had turned him into a zombie at age ten months. Then he began to respond to his name. He began to understand language. He began to feel pain. His head banging stopped. He learned to ride a bike on his own. He stopped flapping his arms. He stopped trying to bolt into traffic. He stopped running into walls. He spoke a few words. He stopped biting himself into a bloody mess and screaming a horrible scream that would make your blood curdle. (No doctor ever even tried to help decipher why he was doing this and we were thrown out of Emergency Wards numerous times while doctors told us they would not treat autism. They just let him suffer.) He stopped smearing feces all over the house, something that had happened over a thousand times. He learned to write his name. He learned to read some words. He learned to use a computer. He learned to tie his shoes. He spoke a few more words but remains non-verbal today. He learned some sign language to communicate and to respond to teachers prompts by pointing and touching where before chelation, he never responded to anything at all. He ate normally. He slept normally. He learned to hit a golf ball. His eye contact kept increasing. He began to smile, all the time. He still suffers brain damage from all the brain cells that the mercury killed but now he can function. He continues to improve.

You [derogatory language redacted] maintain that chelation is dangerous. You are viciously harming children whose lives could be immeasurably better as my son's is by refusing to tell the truth about this treatment. It is the only way to cure +/or ameliorate autism and you [derogatory language redacted] know it. I challenge you [derogatory language redacted] to contact [PII redacted] and allow him the national stage to teach people how to cure this nightmare that our 100% corrupt Congress refuses to stop by removing all of the mercury from the vaccines. As a final word for your [derogatory language redacted] of autistic children, [profanity redacted] all of you!

John Best Jr
[PII redacted]
Londonderry, NH
[PII redacted]

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Chanda Jackson

July 01, 2014

My name is Chanda Jackson. I am the mother of [PII redacted]. He is 6 years old. He was diagnosed with autism (severe), global developmental delay and benign congenital hypotonia at the age of 18 months. I am also the mother of [PII redacted], age 14 (same father). She does not have autism or any other health issues. I did do something different during my first trimester with [PII redacted] that I had not done while pregnant with [PII redacted]. I received an influenza vaccine at the end of my 1st trimester. I don't know if the nurse shook the vile appropriately before every withdraw. There is no way of knowing how much thimerosal had settled to the bottom of that vile before it was my turn to be injected. Post pregnancy, I did something different with both of my children. I was slow to have [PII redacted] vaccinated. We did not stick to the suggested vaccination schedule. Far from it. Our local health dept. (at that time) was using "air shots". We watched 4 women, one at each of her limbs, simultaneously shoot those guns off. With [PII redacted] kicking and screaming, I saw the woman right next to me quickly wipe away a clear substance from her right leg. My husband saw the same occur with a separate employee from the health dept on the opposite side. We left the health department knowing.... she had not received all of the vaccines they had documented for her on that day. With [PII redacted], completely different story. He was vaccinated for everything and on time. After his diagnosis, I was very reluctant to even suspect vaccines. I wasn't interested in pointing a finger. I didn't need a ride on the band wagon. And who would I have to blame, if injecting my developing baby with toxins did play a role..... but myself?
So for the past 4 years, that's what I have done. Endless hours of research on vaccines.

I'm not sure how some of you can sit at that table in your cushioned chair sipping on your flavored water.... and continue to look away from the OBVIOUS?? How many more children will be vaccine injured and we will just call it "autism"? How much more money will you throw in the trash looking at EVERYTHING else under the sun EXCEPT vaccines? How can you ignore the empirical amount of scientific evidence linking vaccines to autism? While you sit there.... and figure that out....
Our children are sick.
Our children are having seizures.
Our children have diarrhea 7 to 10 times a day.
Our children scream all day long.
Our children wander.
Our children have auto immune deficiencies.
Our children smear and sometimes eat their own fecal matter.
Our children punch themselves in the face.
Our children ARE DROWNING.
Our children bite themselves and others.
Our children cannot tell us when they do not feel good.
Our children eat 3 foods.
Our children are bullied.
Our children are perfect targets for lurking abusers.
Our children chip their teeth during seizures.
Our children bang their beds.
Our children are wearing diapers at the age of 7 and will likely always wear them.
Our children are injured.

Our children need resources that are not accessible.
Our children need constant 1:1 care.
Our children will one day be adults.

Thank you,
Chanda Jackson, F.U.A.

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Lea George

July 01, 2014

Hi, I am a parent to a nonverbal still in diapers severely affected son with autism and many co morbid medical conditions.

I would like this skyrocketing autism rates be declared an epidemic.

I would like a real count of current children and adults living with autism.

I would like causes identified, start testing the environment causes.

Stop saying it's better diagnoses - the school districts can assure you it is not just better diagnosis, your own memory should help answer that when did you attend a school with 10 % of the children have autism.

Start funding me ducal treatments train doctors and keep training them. Most have had maybe 45 min lecture on autism in med school.

Start studies without bias and funding from big Pharma. Create an independent committee from those who profit from vaccines.

End the vaccine courts, families deserve to sue companies that make products that harm a certain population.

Start preventing autism. Start creating housing and places for families to turn to when they need help and you need to meet daily till a solution is carried out.

Regards,
Mrs. Lea Googe
[PII redacted]
Plano, Texas
[PII redacted]

Melissa Schneider

July 01, 2014

Children are dying from Autism related wandering and drowning. This issue was brought to the attention of the IACC in 2010 by the NAA. The IACC brought it to the attention to Kathleen Sebelius afterward. To date, no strategic plan has been put in place to combat wandering deaths among our children with ASD. Where is the urgency? Families are desperate. Since May of 2014, 13 children have died from wandering and drowning. This is unacceptable and furthermore, it proves that "Autism" kills children, which brings me to my next point.

What is being done to prevent "Autism" and find the cause? The IACC and CDC have not prevented one case, nor have they found the cause for the explosion in the rate among American children, which is roughly 1 in 29 between the ages of 2-21.

It is predicted that in ten years, the rate will be 1 in 2 children. Autism is a disease that is destroying children's lives, breaking families, creating poverty and eroding the American family.

Also, these children's underlying co-morbid conditions are being ignored and children are suffering needlessly because of ignorance and stubborn behavior against treating them humanely and addressing their medical needs. These children aren't mentally ill, but medically fragile and deserve the same standard of care of every neurotypical child that enters a hospital or doctor's office. This must change.

It is time for all of you to finally do the right thing and admit that this does not have a genetic basis, but is epigenetic in nature. Lives are at stake and you were entrusted with the task of protecting these children, not disregard their needs and behave as though they don't exist. The elephant in the room has to finally be dealt with and it is widely known that nothing is getting done. The time to act is now.

Thank you,
Melissa Schneider

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Carolyn Gammicchia

July 01, 2014

We are writing you purposefully on July 1st due to this being the day we as a family celebrate our son Nicholas and his twenty third birthday. Hopefully many of you will recall Nicholas from when he provided oral comment in July of last year. He on that day, prior to his oral comments, participated in some testing for a NIH study to address inflammation in the brains of adults who have autism. On that day sustained not only an oral interview to discuss his right to participate in the research study, but submitted to an EKG was well as submitting blood and urine samples. After three hours of navigating the NIH gauntlet to do so, he then provided testimony to the committee that seemed to not be listened to in regard to the safety of those whose lives have been lost to victimization or wandering as well as the lack of appropriate medical intervention. Since that time last year many more individuals have lost their lives and adults still do not have representation within the data being used to show research within this area.

Additionally, statements keep being made regarding the GAO report and its ramifications to the IACC and its designated function. When this was brought up within oral comments, Mr. Insel as well as Ms. Singer deflected any concerns broached. It's difficult to do so since you're the ones who are under that microscope, but minimally there should have been more acknowledgements from the members who did express concern. However that does seem to be what transpires within these meetings, especially when there are not options to ask questions of those providing public oral comment. Again Mr. Insel you indicated also, as you did on Nov. 15th, that the IACC is not funded under the CAA. Well it's funded somehow and to indicate that wasn't necessary in an attempt to discredit those that are mentioning why and how the IACC exists. Your charter defines that role and there is funding that provides for meetings to be held, members to attend, as well as staff to be responsible to ensure the IACC functions. As Mr. Insel also indicated in testifying before the Chair Issa and the Government Oversight Committee, he spends ten percent of his time focusing on IACC activities. Somewhere our tax dollars are being utilized to do so.

That also brings up another point we'd like to discuss regarding possible conflicts of interest and why perhaps the IACC continues to regard the lack of research being conducted, and actually the need for one study to address vaccinated vs unvaccinated children who have autism. We still have not had that one, single study conducted via federal funding even though it is the only scientific study that would provide a basis for such an environmental insult. Of concern is the fact that Mr. Insel presented at this event:

"On April 10, 2014, the Autism Science Foundation celebrated its 5th Anniversary with a Day of Learning and an Evening of Celebration. The Day of Learning including the autism community's fist TED-style talks conference, which featured eight experts in the field. Topics included why fewer females than males are diagnosed with autism, why autism interventions fail in schools, and the new CDC report that 1 in 68 children now has an autism diagnosis." As many of you know, Ms. Singer is the founder of the organization. You can watch Dr. Insel's presentation here where he indicates Ms. Singer as one of his heroes:

"From Four Kingdoms to One Community for Autism"
http://www.youtube.com/watch?v=2RZ0pzfWCL4

We feel that it is essential that you watch this presentation and how Dr. Insel represents autism and also the concerns that have been voiced by the "community". It is very, very important to realize that the ASF obviously does not want to make the connection to vaccines as an environmental insult. She too has also stipulated numerous times her beliefs that there is no connection between vaccines and autism. The above quote and below photo are from the A.S.F. website. In the back row of the photo you will also notice the honoree for that evening, the second individual from the left, Mr. Paul Offit.

[Photo Redacted]

"ASF's Evening of Celebration was hosted by Dr. Richard Besser, Chief Health and Medical Editor of ABC News. The evening honored Dr. Gerald D. Fischbach, Chief Scientist of the Simons Foundation, and Dr. Paul Offit, Chief of Infectious Diseases at the Children's Hospital of Philadelphia, ASF Board Member, and author of *Autism's False Profits."* (quote from the ASF website.)

Additionally Mr. [derogatory language redacted], as a vaccine developer who has profited greatly from the industry, has not only written a book admonishing the connections between vaccines and autism, but assisted as an advisor in the recently released film "Invisible Threat" a film that has been questioned on its integrity due to those families being interviewed not being told the intent of the film, which was obviously to discredit those who choose to not vaccinated their children. After hearing families testify at during the oral comments over the last year on this subject, and seeing this committee again ignore this possible connection, it appears to be this may be due to possible conflicts of interests by committee members perhaps. The same holds true for those research pieces being approved for the IACC summary reports.

Lastly in Dr. Insel's piece he discusses environmental insults and the importance of studying this, but still does not discuss the one thing that has stripped health from children born healthy to those who regress into autism after being vaccinated. Many have presented on this at the IACC, such as Dr. Frye, however we are not seeing the acknowledgement as needed nor the causation for these medical conditions. There is a need here that is being ignored. Our son's current medical well-being is being supported via Medicaid funding via choice. His biomedical treatments are being paid for by Medicaid. He was born healthy. He was vaccine damaged. He is an example of one of the "autisms" that Dr. Insel discusses. That is essential to know, to share, and to realize within not only choice options for health, but one's civil right to choose options for overall wellness that will be of most benefit. That does not involve "Four Kingdoms" but only one, one that our freedom to choose should be acknowledged and supported. Yes, a multitude of problems that can and do involve vaccine injury.

We need the one study if you are to address not only causation, but prevention. That study, vaccinated vs unvaccinated children who have autism has not taken place as of this date. Why? That is the only study that will show the science and if indeed there is a connection. We would think that everyone would want that study, even those who support vaccines, especially those who support vaccine use. We implore you are a committee to not only address this, but request the study be done.

Respectfully submitted,

Andrew Gammicchia
Carolyn Gammicchia
Nicholas Gammicchia
[PII redacted]