

Written Public Comments

**IACC Full Committee
Meeting**

November 17, 2015

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

Jenny Allan

October 1, 2014

Subject: Matt Carey's internet Blog Left Brain/Right Brain

The following is copied from the IACC's home page:-

"The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum."

IACC public member Matt Carey (aka Internet persona 'Sullivan') is very pro-vaccine, as can be evinced by readers of his Internet Blog Left Brain/ Right Brain. Of course, Dr Carey is perfectly entitled to his views, and to promote them in reasoned arguments on his blog. He is also perfectly entitled to put his views forward at IACC meetings which should, according to the above statement promote **'a range of ideas and perspectives'**, including those persons who have legitimate concerns about the possibility of certain vaccines causing autism in children. Mostly, these concerns concentrate on mercury preservatives in vaccines and the MMR vaccine, (which does not contain mercury). Although mercury was phased out of most child vaccines around ten years ago, it is still present in Influenza vaccine injections administered to some children, and advised for pregnant mothers.

Mr. Carey's blogs are vehemently dismissive of both mercury containing and MMR vaccine concerns, Many of his blogs are devoted to the continuing vilification of Dr Andrew Wakefield, even although recent US research now supports the 1998 Lancet Wakefield et al reporting of a link between autism and bowel disease; recent estimates put this incidence of bowel disorders in autistic children at between 70% and 90%. This year, CDC whistleblower Dr William Thompson, claimed ten year old CDC research, which revealed links between MMR vaccine and autism, particularly amongst African/American children was fraudulently suppressed in order to deceive the public. There are other ongoing concerns about the long term efficacy of the MMR vaccine, also involving alleged fraudulent research by the manufacturers. This latter does not directly concern the IACC, but is certainly not irrelevant to any public vaccine safety or efficacy concerns. The IACC has a public duty to fully address these issues, by examining all perspectives, and being prepared to listen to those parents and other informed, qualified persons, who express their concerns and expect them to be properly and fully investigated.

Dr Carey's Left Brain/Right Brain blogs all have comment threads. As nominate owner of the LB/RB blog, Dr Carey has a duty to ensure these comments are properly moderated to exclude defamatory lies and vile, hateful or profane, 'ad hominem' insults. Investigative journalist [PII redacted] is a regular commenter. For the last twelve years [PII redacted] has devoted his entire career to the vilification and professional destruction of Dr Andrew Wakefield. These tirades extend to anyone else who dares to defend Dr Wakefield and his Royal Free Hospital colleagues, including the parents of the Lancet children, who were treated for their bowel problems at the Royal Free, under the leadership of distinguished pediatric gastroenterologist Professor John Walker-Smith, dragged in front of the GMC alongside Dr Wakefield.

[PII redacted]'s comments on a recent Carey article devoted yet again to Dr Wakefield, contained blatant untruths about the Lancet parents.

<http://leftbrainrightbrain.co.uk/2014/09/19/andrew-wakefield-loses-frivolous-defamation-lawsuit-to-pay-court-costs/#comments>

Firstly - UK High Court Judge, Lord Justice Mitting, during Professor Walker-Smith's successful appeal against the GMC's guilty verdict, examined the evidence and found the eleven UK children in the 1998 Wakefield et al Lancet article had been properly referred by their GPs to the Royal Free for treatment for their bowel disorders. They were all also appropriately clinically investigated and treated. Is [PII redacted] suggesting, not only the parents, but their GPs and the clinical team at the Royal Free, were all liars? Well that's EXACTLY what [PII redacted] was suggesting and is STILL stating along with some nasty snide asides about the Judge. Justice Mitting also found the GMC's three year examining of the evidence, most of which was provided by [PII redacted], the sole complainant, was 'superficial and inadequate' and in several cases just plain WRONG!!

As for the 1000 plus parents of profoundly damaged children, who attempted to obtain compensation for their childrens' suffering, the merits of the case never reached a court of law, because a conflicted UK Judge withdrew their legal aid money, after their group litigation cases were almost complete. 'Due process' has never been allowed to happen in any of the MMR related litigation cases. It would seem to be [PII redacted] who has been making wild 'fraudulent' allegations.

Since this letter will be made public, I won't quote the vile 'ad hominum' comments made by [PII redacted] about me, on the same comment thread, but these are exactly the kind of comments which Carey should be moderating. They bring both his blog, and indirectly the IACC into disrepute.

Yours faithfully

Jenny Allan

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

Clifford Zimmerman

October 2, 2014

Subject: My US Patent - My Gift To Children Suffering From The Affliction Of Autism

“Harmonic and Overtone Audio Therapy for Autism Spectrum Disorder and Regulated Emotional and Psychological Disorders”

Kindly take a few moments to read about my US Patented Sound Therapy Technology.

I have designed an encrypted chip headset, with proprietary frequency adaptation, specifically geared for the special needs community and US veterans suffering from PTSD.

Kindly contact me at your earliest convenience.

Warm Regards,

Cliff Zimmerman

United States Patent: 8343030

<http://patft.uspto.gov/netacgi/nph-Parser?Sect1=PTO1&Sect2=HITOFF&d=PALL&p=1&u=%2Fmetahtml%2FPTO%2Fsrchnum.htm&r=1&f=G&l=50&s1=8,343,030.PN.&OS=PN/8,343,030&RS=PN/8,343,030>

My name is Clifford Neil Zimmerman. I’m [PII redacted], born and raised in [PII redacted]. I now live in Atlanta, Georgia. My degrees are in both Music Education and Early Childhood Education. Here is why I am contacting you...

I have spent the last nine years developing a breakthrough technology in the treatment of Autism Spectrum Disorder. A Neuro-Vibrational Processor, the U.S. Patented Sound Therapy CD is the first – and only – technology to apply Deep Brain Stimulation via Prolonged Sympathetic Resonance Vibration.

Utilizing the center's own calibrated medical equipment, in 2008, I conducted an extremely successful clinical trial (non IRB approved), for Hypertension, at Emory Johns Creek Hospital. Every single test-subject’s blood pressure was lowered, some by as much as 49 points. The compelling factor was that, when the Systolic number needed adjusting – whether an increase or decrease – but the Diastolic number did not, that is exactly what happened, the same for the reverse. This is because of the direct cause-and-effect on the NTS (Nucleus Tractus Solitarius).

Data and details form this trial are available upon request.

Please be assured that this is not any type of “new age” nonsense. It is completely unique and totally science-based, the only technology that has ever utilized specific frequencies that are purposely all mathematically divisible by each other, resulting in the only technology ever to receive a U.S. Patent which employs “Prolonged Sympathetic Resonance Vibration.”

The US Patent is titled:

“Harmonic and Overtone Audio Therapy for Autism Spectrum Disorder (ASD) and Regulated Emotional and Psychological Disorders.”

The result is the most optimum form of Neuro-Plasticity, the brain’s ability to literally heal itself. This has never been tested on the human brain before. By employing “The Scientific Method,” (double-blind studies, placebo, control-group studies, etc.), and utilizing fMRIs, PET scans, blood and chemical analysis, etc., the goal is to prove its scientific and medical efficacy.

Some of these benefits will include – but are not in any way necessarily limited to – increases in Endorphin levels, such as Serotonin, Dopamine and Norepinephrine, as well as decreases in Cortisol and ACTH levels.

The ultimate goal, “The Holy Grail,” so to speak, is to stimulate and generate tremendous improvement in the Autistic brain’s Limbic System, enough to process the electrical currents between the brain’s Synapses properly, resulting in a dramatic improvement in alleviating symptomatic Autism Spectrum Disorder.

This is because of the effect that it has on the brain’s Neuro-Transmitters, on a sub-atomic level, because all matter is composed of quarks, strings, and ultimately, vibration, thus making this technology the vibrational equivalent of Higgs Boson, otherwise known as “The God Particle.”

Please understand, on so many technical levels, the magnitude and significance of this historic recording, the first and only one of its kind in existence.

Since 1857 (155 years), when Édouard-Léon Scott de Martinville invented the Phonograph - the first device that could record sound waves as they passed through the air - there has never been a recording as “technically pure” as The Sound Therapy CD.

First, the frequencies are accurate to within five decimal places. I have U.S. Trademarked two phrases:

(1) “The Perfect Recording of the Perfect Sound”

(2) "A De-Frag For Your Brain"

Second, the pure frequencies from absolutely pitch-perfect tuning forks are incorporated into a tuning known as “Justified” or “Justification” Tuning, which, for the very first time in audio and recording history, enables a pure Perfect 5th (P5), also known as an “Open 5th,” in the exact and precise ratio that Pythagoras formulated: [3 to 2] or [1.5 to 1].

This is uncommon and rare in Western Music and Western Civilization, which utilizes “Tempered” Tuning, in which the polar opposite is true, the frequencies are specifically not mathematically divisible.

Therefore, the concept and process which I have the U.S. Patent for, which utilizes Prolonged Sympathetic Resonance Vibration, is not technically, mathematically or scientifically possible.

Normally, when a tuning fork vibrates, the frequencies will continue to vibrate for 2-3 minutes. It has taken over eight years, and 15,000 hours, in order to technically, scientifically and mathematically, stretch those frequencies into an entire 60-minute (two 30-minute tracks), recording. In this process, the

“integrity” of the Harmonics and the Overtones – wherein lies the therapeutically medical value – has been maintained.

Again, this has never even been attempted before, let alone successfully accomplished, in the entire history of recording and audio-engineering. This is a monumental technical achievement.

These are the resulting scientific and technical reasons for the many therapeutic benefits consequently derived upon the human brain. This is the only recording which, through this patented process, achieves maximum Neuro-Plasticity, for the very first time. The resulting benefits for maximum Neuro Health are nothing short of astonishing for the Autistic brain.

I am the Owner and CEO of Sound Therapy International LLC. My web-site address is:
<http://www.SoundTherapyCD.com>

Although it reads “under construction, kindly scroll-down on that home page to see a picture of me with my daughter [PII redacted] and some of the babies that I have worked with.

On the upper left-hand corner, the following links are fully operational:

- (1) Clinical Data – my research. Also, please scroll-down to read my ‘Bio’.
- (2) Links & Literature – some newspaper Op-Ed articles that I have authored.
- (3) Contact Us – E.Mail

These 30-day "before-and-after" fMRI Neuro-Imaging brain scans that I am proposing will not involve typical high costs. For any individual/hospital/medical research facility wishing to be associated with this project, the benefits are extraordinary, because, together, we will be testing the most compelling, cutting-edge scientific technology available in the treatment against:

- (1) Autism Spectrum Disorder
- (2) Hypertension, the underlying cause of many diseases.
- (3) Clinical Depression
- (4) Parkinson’s Disease
- (5) Alzheimer’s Disease
- (6) Post Traumatic Stress Disorder (PTSD).

The financial benefits for any such facility will prove to be more than worth any initial expense.

Surely, this deserves serious consideration. Perhaps you know, and/or may very well have access to, research facilities that I do not.

I am represented by the law firm of Thomas, Kayden, Horstemeyer and Risley, here in Atlanta, Georgia. My attorney is Dr. Christopher Linder.

In addition, Sound Therapy International LLC's in-house counsel is Rob Hassett, of Casey Gilson PC.

I can be reached by E.Mail at: CliffZimmerman@SoundTherapyCD.com and by phone at: [PII redacted].

I look forward to hearing from you at your earliest convenience. Thank you for your time and your consideration.

– Clifford N. Zimmerman

From: [PII redacted]

Sent: Tuesday, November 23, 2010 01:56 PM

To: CliffZimmerman@SoundTherapyCD.com

Subject: RE: The Sound Therapy Technology For Autism Spectrum Disorder

Dear Mr. Zimmerman,

First of all, thank you very much for your help. I was in/out of the office because of a good reason. After 9 years living with only one child with Autism, we were blessed finally with twin boys by G"D. Both mom and the babies are doing fine. We not only tried The Sound Therapy CD for my daughter, but also my wife listened in order to reduce her blood pressure. She had a complex pregnancy, diabetic and blood pressure which forced her to be hospitalized for three weeks. She left last Friday the hospital and is now visiting them every day to feed them until they come home. They are over 4 lb. already and will stay for a couple of weeks in the hospital.

My daughter is listening to The Sound Therapy CD regularly, twice a day. One of the observations that I noticed with her was, she now answers a phone call. A few days ago, she had a phone conversation with her cousin who lives in NY. She has had very interesting conversations; she answered all of the questions about her, her Mom, and her twin brothers. Before, she was not interested, or did not understand a phone conversation. She used to speak while the other person spoke or did not respond at all to any questions. She picks-up the headphones and the CD when it is time to listen and asks me to listen with her. I will be in touch with you to update her progress.

Regards,

[PII redacted]

The technology developed, employed and utilized in the making of The Sound Therapy CD, specifically as it relates to my U.S. Patent:

HARMONIC AND OVERTONE AUDIO THERAPY FOR AUTISM SPECTRUM DISORDER (ASD) AND REGULATED EMOTIONAL AND PSYCHOLOGICAL DISORDERS is proprietary, specific, and unique in its creation.

It is the only existing audio technology, which, through Deep Brain Stimulation/Neuro Vibrational Processing - specifically and therapeutically combines:

(1) Sympathetic Resonance

The term “Gain” is defined as a measure of the reinforcement of any feedback system. It is the ratio of the intensity – or magnitude – of the output of any given system to its input, referring to a variety of units of measurements. In natural/acoustic reverberation, the “input” (i.e., the frequencies from a tuning fork), are significantly louder than the “output” (the echo). Thus, the system is inherently one of diminishing returns, and eventually fades into silence.

Conversely, with electronically generated frequencies, by definition, a feedback system with increasing gain, each subsequent output is increased over the previous, thus eventually becoming increasingly unstable. Therefore, when electronic frequencies are reproduced, the Harmonics and Overtones essentially become Fundamentals (see Terminology: Harmonic, above), which generate new Harmonics and Overtones, with characteristics that are inherent not of the original sound, but of the playback system itself.

In Conclusion:

Any kind of noise – including, but not necessarily limited to, electronic frequencies – in the brain is negative. If only people were conscious as to just how inadvertently counter-productive it is to the overall health of the brain.

It represents the complete antithesis of sustained healthy growth and Neuro-Plasticity, the brain’s ability to heal itself.

Kindly let me know if you have the time and the inclination to be a catalyst for this project.

The Recording Process:

This is the first time in the entire 155 year history of audio engineering that a recording of this accuracy, magnitude and significance has ever been achieved, in order to implement specific time alignments and measurements, including the Harmonic and Overtone projections of the audio waveforms.

Four dozen (48) digital oscillators were employed in order to morph and tune the band-pass filters, which are combined with the 12-band full-parametric High Q Equalizers, which are then fed into the digital diodes. This models the saturation of the tube phenomena, thus creating denser Harmonics and Overtones. The ideal net result, optimum Deep Brain Stimulation, via Sustained Sympathetic Resonance Vibration, is unlike anything ever previously heard by the human ear.

The Recording Equipment:

* Four Solid-State Microphones:

- (1) AKG C414 B-XL II
- (2) AKG C414 Limited Edition
- (3) AKG C1000 S
- (4) DBX RTA Measurement

* One Vacuum-Tube Microphone: Neumann U-87

* Reflexion Filters: SE Electronics

- * Sound Diffusion: Primacoustic
- * Microphone Preamp: Avalon Design Pure Class A AD202
- * Mastering Equalizers: Avalon Design AD2077 Dual Mono, Pure Class A
- * Stereo Summing Amplifier: Tube-Tech SSA 2B
- * Monitors: Genelec Digital Reference System 5.1
- * Pro Tools HD Platform: 64-Bit 96khz Resolution, Hot-Swap Fiber Optics SCSI 10k rpm System Driver.

HARMONIC AND OVERTONE AUDIO THERAPY FOR AUTISM SPECTRUM DISORDER (ASD) AND REGULATED EMOTIONAL AND PSYCHOLOGICAL DISORDERS is proprietary, specific, and unique in its creation. It is the only existing audio technology, which, through Deep Brain Stimulation, specifically and therapeutically combines:

(1) Sympathetic Resonance

(2) Prolonged Sympathetic Resonance

(3) Justified/Justification Tuning into a Complex Sound Bath Format, which, because of the limitations of any such existing technology, has previously been unknown

Researchers at the Boston Children's Hospital worked with magnetic resonance imaging (MRI), and found that early musical training enhances the areas of the brain responsible for executive functioning.

Also known as cognitive control or supervisory attention system, "executive functioning," refers to brain management, not unlike the corresponding corporate term.

This is the top of the hierarchy in terms of brain organization, for executive functioning enables information processing and retention, regulates behavior and is responsible for problem solving and planning, among other cognitive processes. Better said, it's a key player to success in life.

In the study, researchers considered a musically trained child to be one who had at least two years of private lessons under his/her belt. They selected 15 of them, ages 9 to 12, and the group statistics amounted to significantly more training than researchers had originally sought out, in that the children had played for 5.2 years and practiced 3.7 hours per week, beginning at the age of 5.9.

Researchers compared them with a control group of 12 children in the same age range with no musical training.

Next, two similarly structured groups of adults were formed, although the musical group consisted solely of active professional musicians.

Cognitive tests showed musicians in both age groups had the upper hand. MRIs showed children had an enhanced activity levels in the Pre-Frontal Cortex, indicating that they may be more apt at multi-tasking than their non-musical counterparts.

The numerous Neurological benefits of musical training are well-known and have been the centerpiece of many academic studies.

The Society for Neuroscience presented three studies at an annual conference, all of which conclude that musical training influences not only certain functions, but also the anatomy of the brain.

The Boston study, however, is one of few to explore executive functioning and adjust results for socioeconomic status, an important factor that past studies have not taken into proper consideration.

"Since executive functioning is a strong predictor of academic achievement, even more than IQ, we think our findings have strong educational implications," says study senior investigator Nadine Gaab, Ph.D, of The Laboratories of Cognitive Neuroscience at Boston Children's Hospital. "While many schools are cutting music programs and spending more and more time on test preparation, our findings suggest that musical training may actually help to set up children for a better academic future."

Gaab says future studies could determine whether children and adults who are struggling with executive functioning -- such as kids with ADHD or the elderly -- could benefit from music as a therapeutic intervention tool.

Researchers remarked that enhanced executive functioning is the very aspect of the brain motivating kids to stick to their music lessons, suggesting that training should begin early in life.

The study was published in PLOS ONE:

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0099868>

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

Eileen Nicole Simon

April 22, 2015

My autistic son is 52 years old. Like most parents, I began reading everything I could find on my son's developmental delays. That was 50 years ago. My starting point was head injury and oxygen insufficiency at birth.

For me the article by WF Windle in the October 1969 issue of the Scientific American remains most significant. Prominent injury in the brainstem auditory pathway and basal ganglia was documented. I believe this should have been recognized long ago as a possible cause of developmental language disorder and repetitive stereotyped movements.

The vaccine issue might never have arisen if the significance of the research of Windle, RE Myers, and others had been recognized in the 1960s and 70s. Subsequent research using the deoxyglucose method of Louis Sokoloff confirms the vulnerability of subcortical sites to injury by many different causes.

I will continue to try to bring these and other research findings to the attention of members of the IACC. The brain must be the focus of attention in trying to understand the increased prevalence of autism that began in the mid-1980s.

Eileen Nicole Simon, RN, PhD (Biochemistry)

[PII redacted]

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Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

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

Eileen Nicole Simon

April 28, 2015

My autistic son is 52 years old. I have been reading the research literature for more than 50 years now, and I returned to school and earned a PhD in biochemistry from the Boston University School of Medicine in 1975.

Autism has many causes. How all causes affect the brain and brain maturation should be the focus of discussions by members of the IACC. Subcortical centers of the auditory pathway and basal ganglia are susceptible to injury by all of autism's many causes, from prenatal exposures to substances like valproic acid, asphyxia at birth, as well as abnormal metabolites produced in genetic disorders.

Sincerely,
Eileen Simon

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

Eileen Nicole Simon

April 28, 2015

The requirement for self-advocates on the IACC is disturbing. I should have nominated my 52-year-old son, who is very high functioning, but still is not able to live independently as a self-supporting person. Self-advocates appointed to the IACC so far are within the upper 1% of high-functioning people. It should be important for the public to know what developmental problems they had, and how these problems were overcome.

The research evidence was available at least 50 years ago of brain systems with special vulnerability to toxic substances and asphyxia. I have been attending IACC meetings since 2003, and as a public commenter have been largely ignored.

Autism is too severe a condition to receive smiling comments that it is to be accepted. Autism is as serious a problem as polio in the past, especially its increased incidence over the past 20 to 25 years.

The vaccine issue should never have arisen. Complications at birth are the most frequently discussed problem in the records of children who develop autism. This needs serious attention and I will continue to speak out against the use of a clamp on the umbilical cord before respiration has begun.

Sincerely,
Eileen Simon

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

Eileen Nicole Simon

October 4, 2015

Autism is the disorder that has deranged the lives of everyone in our family, and clearly those of many other families.

My autistic son is now 53 years old, and I believe autism might have been understood 40 to 50 years ago, and the current increased prevalence prevented.

I just read with interest the article you wrote with Dr. Insel on new approaches to understanding psychotic disorders. I believe the focus should be on: (1) brain circuits and (2) neurodevelopment (brain maturation).

After a pediatrician told me I was not qualified to read the medical literature, I applied and was accepted into the Medical Sciences Program at the Boston University School of Medicine. I was hopeful, of course, that treatments like the dietary treatment of phenylketonuria might be found. But soon my focus became the brain, and how toxic products of aberrant enzymes might damage the brain.

Then the article by WF Windle on brain damage caused by asphyxia at birth (Scientific American, October 1969) came to my attention. Before doctors tried to tell us our first two sons' autism was genetic, we knew that both suffered head trauma and oxygen insufficiency at birth. Perusal of PubMed makes it clear that complications at birth, low Apgar scores, etc. have been reported more often than any other etiological factor.

When I entered graduate school in 1969, none of the professors were studying autism. So I decided to work with Dr. Allan F. Mirsky on schizophrenia. I thought his ideas about "hyperarousal" were interesting, and relevant to autism, especially hyperacusis and other auditory problems of autistic children, as well as failure of language development.

Windle, in his article on asphyxia at birth, reported selective damage of subcortical sites, with most severe injury in the inferior colliculus, in the midbrain auditory pathway.

Language develops with maturation of the language circuits of the cerebral cortex. Damage within the brainstem auditory pathway certainly should be considered to be disruptive to maturation of targets in the temporal lobes. Maturation failure of the auditory receptive area in turn should be considered likely to alter maturation of connections to Broca's area of the frontal lobes, and beyond.

Schizophrenia appears to be associated with birth injury and developmental problems in many cases. Autism should be considered to be the earliest form of schizophrenia, as it was in the past. Schizophrenia cuts short intellectual development, which appears far more tragic to many, than complete failure of development of autistic children.

Acceptance, early intervention, neurodiversity hinder the scientific investigation of autism. I hope meetings of the Interagency Autism Coordinating Committee (IACC) will resume soon. I hope more time will be devoted to discussing the concerns of parents. Vaccination had nothing to do with my sons' autism. And, the vaccine issue might never have arisen if the effects of asphyxia at birth had been looked into long ago as a cause of developmental disabilities.

I have submitted comments to the IACC public record since 2003. I will continue to request discussion of my comments. I hope you will not, like so many in the past, dismiss autism as less important than schizophrenia and other disorders that blunt development of people in adolescence and later.

Sincerely,
Eileen Nicole Simon, RN, PhD

cc: IACCPublicInquiries@mail.nih.gov, for inclusion in the Public Record
Eileen Nicole Simon
[PII redacted]

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

John Best

October 28, 2015

As usual, I'll start with a [offensive language redacted]. You [offensive language redacted] are harming more babies and you know it. We have known the truth for 16 years and you [derogatory language redacted] persist in denying that mercury in vaccines is the primary cause of autism.

[Offensive language redacted]

John Best,
Londonderry, NH

Matthew Carey

October 29, 2015

Dear members of the IACC,

When I started with the previous IACC I had many areas of research and policy I wanted to see the IACC focus upon. While all of those areas are still important, I also learned the lesson of concentrating much of one's efforts on one primary area and I will continue that effort now in the public comments.

The area I chose to focus upon primarily is one which is very important in my family: that of minimally verbal autistics. I flew out a day early for the first meeting of the previous IACC so I could meet with some researchers—especially Barry Gordon of Johns Hopkins. Dr. Gordon was a member of the very first IACC and researches and works clinically with minimally verbal autistics. While on the IACC I pushed for and got an IACC meeting devoted to minimally verbal autistics. I would encourage you to watch (even if you were there the first time) the video from that meeting. The thing is that while we devoted a day to this topic, we were not in a good position to put that information into action as we did not have the opportunity to revamp the Strategic Plan.

After our day devoted to minimally verbal autistics, this paper came out (written by some of the speakers who presented to the IACC): Minimally verbal school-aged children with autism spectrum disorder: the neglected end of the spectrum. (<http://www.ncbi.nlm.nih.gov/pubmed/24124067>).

I mentioned this paper in an IACC meeting and said I agreed very much with the sentiment in the title. I was informed that the funding spent on minimally verbal autism was actually higher than that called for in the Strategic Plan.

While it is great that more resources were devoted to this area than originally planned, it didn't change my observation that the amount is still too low. Which says that the Strategic Plan needs to have a greater emphasis on minimally verbal autism than it does now.

And you get to draft the new Strategic Plan.

Which is to say that I—and the whole community—are counting on you to act. We didn't spend a day on this topic just to raise awareness and make a segment of our community feel like they are getting attention. In holding that meeting we made an implicit promise that the IACC would provide support. And as anyone who has been in an IEP meeting will tell you, that means goals. We need goals written into the Strategic Plan that focus attention on minimally verbal autistics of all ages.

Usually when someone lobbies action like this, one will often discuss how large the group is that needs this help. In this case, that percentage of the autism population which is nonverbal, minimally verbal and/or non-conversational. You may wonder why I do not. Perhaps I am too idealistic, but I see this as being the right thing to do because of how important this topic is to our community. Communication difficulties, whether they be social or verbal, are the hallmark of autism. There are few ways to benefit the community as great as helping to ameliorate the challenge of communication. As such, there can be few more pressing goals for the IACC to include into the new Strategic Plan than those which focus on minimally verbal autism.

To bring this home in a very personal way, consider this exchange from a recent IEP meeting I had. I was asked for a long term goal for my son. I answered that I want him to be in a position to be able to say—and be believed—"this person is abusing me". Because if he can say that and be believed, the chances of him needing to say it drop dramatically.

So much focus in parent and researcher directed autism advocacy is on children, especially young children. We need to insure that focus is spent on older children and adults. When I spoke with Barry Gordon he told me about his work on teaching verbal communication to nonverbal youths. This isn't an issue where we abandon a population once they leave pre-school.

There is a requirement in the Autism CARES Act to draft a report on the transition from school to adulthood. That report must include a discussion of minimally verbal autistics. And in areas where the Strategic Plan calls for research on autistic adults, those areas must specifically include minimally verbal autistics.

Lastly, let me point out that we as a society typically equate "communication" with "verbal communication". All too often I read someone discuss a nonverbal individual as being "unable to communicate". We need to insure that people learn, acknowledge and respect nonverbal communication. Or to put it another way, we in the majority tend to try to put the burden of overcoming communication challenges on those in the minority—those for whom overcoming those challenges is the most difficult.

Respectfully submitted,

Matthew J. Carey, Ph.D.
Parent and former public member to the IACC

Caroline Fruscella

November 2, 2015

Will this be the IACC Panel that will prevent just one case of Lower Functioning Autism?

Will this be the panel that addresses co-morbid conditions associated with Autism?

Will this be the panel that addresses that not one hospital setting in the United States will treat all facets of Autism?

Will this be the panel that will fully address and acknowledge that William W. Thompson, Ph.D. is a CDC Whistleblower?

Will this be the panel to acknowledge that time is indeed running short as the tracked Autism Rate has never declined but only increased every year?

Will this be the panel that reads existing science and listens to parents after parents that report the same events occurring time and time again?

Will this be the panel to address 'mercury' found in hair samples of those newly DX with Autism?

I respectfully ask you... No, frankly, I will beg you to be that panel!

I am the Mother of a delightful young man who is now age 24. I am his legal guardian. You would only redact his name so I will not include it here.

But this is the issue, parents like myself are frankly use to the world ignoring our pleas.

We have called and written and faxed more Congressman and Congresswomen than this group collectively might be able to name.

We know our Senators. We have emailed The Whitehouse.

I personally begged a few years ago for 'one' family practitioner to even accept my then 21 year old son as a patient. The first nine family practitioners that I contacted, reported that they would not be comfortable treating a patient that cannot report symptoms or reply to Yes or No questions. They also reported that they knew little about Autism or how to care for a person with Autism.

As daily care providers and loving parents we have approached this group in the past, numerous times... Yet our plea goes unheard.

Why?

Are you afraid of finding what we know and have researched what we know in our hearts must be sadly true?

Honestly, it was your former IACC panels that leave me with no greater world view that the current US Vaccination Schedule MUST have something, in some way, to do with this current rate of Autism. If not,

YOU as a group would have held a double blind study by now showing the rate of Autism in the non-vaccinated community verses the vaccinated community.

Would that study be easy... probably not. Cheaper in the long run now that you have spent Billions of tax dollars to find nothing that stops the Lower Functioning Autism trend... YES.

The worst case scenario is that study also would lead to another dead end... and this group in the past has reached many of those.

If my son had a voice that could talk or write for himself, I would not be typing to you... but he and his friends do NOT have their own voices.

Autism is and can be fatal if you wonder without fear from your home... which has happened many times again this year to many young children. Seizures also, at any age, can be fatal if no one hears you in the middle of the night.

How will this population of Autism, once their family passes on... and have no doubt... we will pass on, be provided for?

I stopped looking for cures years ago. I love my son for who he is and he is happy for the most part. I am sure, and I know in the gut of my Mothers heart that early intervention does not save all. I still provide treatments daily of vitamins and minerals that insurance never did cover, because even as my sons recovery is slower than slow... My son, is now better than where he once was.

I also have another son with a much milder form of Autism. He graduated from college this past spring and he is now independent.

I have two sons. They are blood brothers. They have the same parents. They share the same genes. They had two different outcomes. Why is that? Maybe because in 1995 after my older child ran one too many post vaccination temperatures and then was sick for week after week of post vaccination... I wised up! That is not scientific, but it is a fact. I visited my local library. I did not own research. I was a worried mother that had watched one son silently disappear in 1994. He then disappeared more and more with each CDC recommended vaccination. I did vaccinate because I wanted my children to be healthy and have a great life until I realized 'maybe' just 'maybe' a 'one sized shot does not fit all' any more than all adults wear all the exact same sized clothing and shoes. Do all Adults take the same dosage of blood pressure medicine? Do all diabetics need the same insulin dosage? Do all forms of Cancer need the same amount of radiation? Should a 4 pound newborn have the same amount of vaccine as an 8 pound newborn?

For those MUCH less fortunate... For those adults still in adult diapers and depends and suffer from seizures daily... This IACC group is running out of time. Your time was up before you even sat down this morning because there is a population of MILLIONS depending on what this group chooses and chooses not to do.

Be happy and thankful that you have that free will choice daily... to react or to ignore this plea. My son has few real choices, daily.

After 21 plus years of daily intervention my oldest son, does not even know, nor care, that this groups exists... But his higher functioning brother now knows and he is watching your actions... as am I.

It is now your job not to lose another generation to Lower Functioning Autism.

Good Luck... God Speed... and our Nations Innocent Children and maybe your own Grandchildren are awaiting your reaction.

Respectfully Submitted,

Carol J. Fruscella
Mother/Care Provider/Legal Guardian

LANGUAGE AND AUTISM PREVALENCE

Language development should be promoted by the IACC as the highest priority for research. The increase in autism prevalence over the past 30 years should also be a priority for the IACC.

Language is the distinguishing feature of the human species.

Aphasia, loss of language in adulthood, is the most serious of all neurological disorders. Aphasia results from damage within the frontal or temporal lobes (Broca's or Wernicke's areas). Language development occurs during maturation of the frontal and temporal lobes. What injuries disrupt maturation of the language areas in autistic children?

One injury should have been investigated decades ago: The brainstem auditory pathway was prominently damaged in monkeys subjected to asphyxia at birth. At first no brain damage could be found in monkeys following asphyxia. But, lookup research on blood flow in the brain by Seymour Kety. Kety's 1962 paper is free online via PubMed.

Following advice from Dr. Kety, damage in the auditory pathway was looked for, and found! Auditory system damage has been reported in human infants. Trophic neurotransmitters produced in the brainstem are essential for postnatal development of the cerebral cortex, especially the late developing language areas.

Complications at birth have been documented more often than any other cause of autism. Why has this evidence been neglected?

Clamping the umbilical cord immediately after birth was adopted in the mid 1980s. Traditional textbooks taught that pulsations of the cord must cease before it is tied. If the cord is clamped before the first breath, some degree of asphyxia will occur. Please discuss umbilical cord clamping as a possible factor underlying the increased prevalence of autism.

DISCUSSION POINTS

Above is the oral presentation I would make, if I were able to attend the IACC meeting on November 17. I would appreciate discussion of (1) the importance of language development, and (2) that clamping the umbilical cord before the first breath may cause impairment within the brainstem auditory pathway. Even minimal compromise of the auditory system may impede language development.

Public participation in activities of the IACC in the past has been kept to a minimum. Since 2003 I have attended meetings in person, and submitted many written comments on language development and the outrageous error of umbilical cord clamping. If what I have to say is not important, I would like an explanation.

More than half an hour should be scheduled for discussion of public comments at IACC meetings. Reasons for NOT discussing particular comments should be stated.

I would like to know why the following topics are NOT to be discussed:

1. Language development.

2. Blood flow and aerobic metabolism in the brain.
3. Vulnerability of the auditory system of the brain.
4. Evidence of auditory system injury by 8 to 12 minutes of asphyxia at birth.
5. Clamping the umbilical cord at birth before the first breath can cause asphyxia.
6. The auditory system is essential for language development.
7. Maturation of the language areas of the cerebral cortex.
8. The increase in autism prevalence since the mid 1980s.

Below I will cite case reports of people who lost the ability to comprehend spoken language following injury of the inferior colliculus. Most prominent damage in monkeys subjected to asphyxia at birth was found in the inferior colliculus.

No one expects a monkey to learn to speak, but injury of this midbrain structure should be considered a very serious impediment to language development in human children. Shouldn't the IACC promote research on the importance of the inferior colliculus for language development? If NOT, why NOT.

CITATIONS TO THE MEDICAL LITERATURE

Following are citations to the medical literature in support of my statements on the language disorder in autism. If these citations are NOT relevant to understanding autism as a disabling disorder, please explain WHY.

1. The discoveries of Broca (1861) and Wernicke (1874) have now been confirmed in MRI scans.
 - Price CJ. The anatomy of language: contributions from functional neuroimaging. *J Anat.* 2000 Oct;197 Pt 3:335-59.
 - Yourganov G et al.. Predicting aphasia type from brain damage measured with structural MRI. *Cortex.* 2015 Sep 25;73:203-215.
2. Language development takes place during maturation of the temporal and frontal lobes of the cerebral cortex.
 - Suskind, D. *Thirty Million Words; Building a Child's Brain.* New York: Dutton, 2015.
3. Trophic neurotransmitters guide maturation of the cerebral cortex.
 - Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity-dependent and activity-independent processes. *Cell Tissue Res.* 1999 Aug;297(2):187-95.
4. The brainstem auditory pathway was prominently damaged in monkeys subjected to asphyxia at birth.
 - Windle WF. Brain damage by asphyxia at birth. *Sci Am.* 1969 Oct;221(4):76-84.
5. Blood flow and aerobic metabolism are higher in relay centers of the brainstem auditory pathway than in any other area of the brain.
 - Kety SS. Regional neurochemistry and its application to brain function. *Bull N Y Acad Med.* 1962 Dec;38:799-812.
 - Sokoloff L. Localization of functional activity in the central nervous system by measurement of glucose utilization with radioactive deoxyglucose. *J Cereb Blood Flow Metab.* 1981;1(1):7-36.
6. Highest blood flow is now evident in functional MRI scans of the human brain.
 - Budd TW, et al. Binaural specialisation in human auditory cortex: an fMRI investigation of interaural correlation sensitivity. *Neuroimage.* 2003 Nov;20(3):1783-94.
7. Complications at birth have been documented more often than any other cause of autism.
 - See citations listed below, and in a subsequent Public Comment to be submitted.
8. Injury of the auditory pathway has been reported in infant autopsies.
 - Natsume J et al. Clinical, neurophysiologic, and neuropathological features of an infant with brain damage of total asphyxia type (Myers). *Pediatr Neurol.* 1995 Jul;13(1):61-4.

- Roland EH et al. Selective brainstem injury in an asphyxiated newborn. *Ann Neurol.* 1988 Jan;23(1):89-92.
 - Leech RW, Alvord EC Jr. Anoxic-ischemic encephalopathy in the human neonatal period, the significance of brain stem involvement. *Arch Neurol.* 1977 Feb;34(2):109-13.
 - Schneider H et al, Anoxic encephalopathy with predominant involvement of basal ganglia, brain stem and spinal cord in the perinatal period. Report on seven newborns. *Acta Neuropathol.* 1975 Oct 1;32(4):287-98.
 - Smith JF, Rodeck C. Multiple cystic and focal encephalomalacia in infancy and childhood with brain stem damage. *J Neurol Sci.* 1975 Jul;25(3):377-88.
 - Grunnet ML et al.. Brain changes in newborns from an intensive care unit. *Dev Med Child Neurol.* 1974 Jun;16(3):320-8.
 - Griffiths AD, Laurence KM. The effect of hypoxia and hypoglycaemia on the brain of the newborn human infant. *Dev Med Child Neurol.* 1974 Jun;16(3):308-319.
 - Norman MG (1972) Antenatal neuronal loss and gliosis of the reticular formation, thalamus, and hypothalamus. A report of three cases. *Neurology.* 1972 Sep;22(9):910-6.
 - 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.
 - Gilles FH. Hypotensive brain stem necrosis. Selective symmetrical necrosis of tegmental neuronal aggregates following cardiac arrest. *Arch Pathol.* 1969 Jul;88(1):32-41.
9. Injury of the auditory pathway has been reported in brains from people who were autistic, and in an animal model of autism based on prenatal exposure to valproic acid.
- Kulesza RJ Jr, et al. Malformation of the human superior olive in autistic spectrum disorders. *Brain Res.* 2011 Jan 7;1367:360-71.
 - Lukose R, et al. Malformation of the superior olivary complex in an animal model of autism. *Brain Res.* 2011 Jun 29;1398:102-12.
 - Rodier PM, et al. Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. *J Comp Neurol.* 1996 Jun 24;370(2):247-61.
10. Clamping the umbilical cord disrupts natural transition from placental to pulmonary respiration.
- Morley GM. Cord closure: Can hasty clamping injure the newborn? *OBG Management*, July 1998: 29-36.
 - Mercer JS, Skovgaard RL. Neonatal transitional physiology: A new paradigm. *J Perinat Neonatal Nurs.* 2002 Mar;15(4):56-75.

VERBAL AUDITORY AGNOSIA

Isabelle Rapin suggested that inability to comprehend distinctive features of syllables and words might underly the language disorder in some cases of autism. She referred to this as "verbal auditory agnosia,"

Below are 14 case reports of verbal auditory agnosia. These are reports of people who lost the ability to understand spoken language following injury of the inferior colliculi. How much more serious this should be for an infant who has not yet begun to learn to speak.

1. Poliva O et al. *Cogn Behav Neurol.* 2015 Sep;28(3):160-80.
2. Kimiskidis VK et al. *Otol Neurotol.* 2004 Mar;25(2):178-82.
3. Pan CL et al. *Neurology.* 2004 Dec 28;63(12):2387-9.
4. Musiek FE et al. *J Am Acad Audiol* 2004 Feb; 15(2):133-151.
5. Hoistad DL, Hain TC. *Audiol Neurootol* 2003 Mar-Apr; 8(2):111-223.
6. Vitte E et al. *Neurology* 2002 Mar 26;58(6):970-3. -- 2 cases

7. Masuda S et al. *Ann Otol Rhinol Laryngol*. 2000 Dec;109(12 Pt 1):1107-12.
8. Johkura K et al. *J Neurol Sci*. 1998 Nov 26; 161(1):91-6.
9. Hu CJ et al. *Neurology* 1997 May;48 (5):1448–1451.
10. Meyer B et al. *J Neurol Neurosurg Psychiatry*. 1996 Oct;61(4): 423-4.
11. Nagao M et al. *Neuroradiology*. 1992;34(4):347.
12. Jani NN et al. *Neurosurgery*. 1991 Jul;29(1):106-8.
13. Howe JR, Miller CA. *Neurology*. 1975 Mar;25(3):286-9.

REPORTS OF COMPLICATIONS AT BIRTH

In the ebook I published online in 2012 (amazon.com), I listed 26 citations from years 1970 to 2010 (table 6-1) on perinatal complications associated with autism, with excerpts from each paper. I will submit this table as a separate Public Comment for discussion by members of the IACC.

Search terms "birth asphyxia autism" in PubMed on November 1, 2015 displayed 18 citations. Three are to articles and letters I wrote: Lessons of MMR (2004), Infantile autism and Wernicke's encephalopathy (1990), and Echolalic speech in childhood autism (1975).

Search terms "birth complications autism" displayed 89 more recent citations. Most relevant would appear to be:

- Duan G, et al. Perinatal and background risk factors for childhood autism in central China. *Psychiatry Res*. 2014 Dec 15;220(1-2):410-7.
- Mamidala MP, et al. Prenatal, perinatal and neonatal risk factors of Autism Spectrum Disorder: a comprehensive epidemiological assessment from India. *Res Dev Disabil*. 2013 Sep;34(9):3004-13.
- Polo-Kantola P, et al. Obstetric risk factors and autism spectrum disorders in Finland. *J Pediatr*. 2014 Feb;164(2):358-65.
- Gardener H, et al. Perinatal and neonatal risk factors for autism: a comprehensive meta-analysis. *Perinatal and neonatal risk factors for autism: a comprehensive meta-analysis*. *Pediatrics*. 2011 Aug;128(2):344-55.
- Burstyn I, et al. Autism spectrum disorders and fetal hypoxia in a population-based cohort: accounting for missing exposures via Estimation-Maximization algorithm. *BMC Med Res Methodol*. 2011 Jan 5;11:2.
- May-Benson TA, et al. Incidence of pre-, peri-, and post-natal birth and developmental problems of children with sensory processing disorder and children with autism spectrum disorder. *Front Integr Neurosci*. 2009 Nov 11;3:31.

ASPERGER SYNDROME AND HIGH FUNCTIONING AUTISM

Cederlund and Gillberg's 2004 and 2005 articles suggest that boys with Asperger syndrome were late learning to speak, suffered complications at birth, and had high levels of neonatal bilirubin.

Szatmari et al. discussed differences between Asperger syndrome and high-functioning autism (HFA). Are some cases of Asperger syndrome the result of brain damage?

My 53-year-old son suffered head injury and asphyxia at birth. He learned to speak just before age six. He is a savant, and co-authored two of the 6 ebooks I published on amazon.com. However, his current situation in a group home for schizophrenic men leaves a lot to be desired.

Autism was very rare when my son was a child, even on the inpatient unit he was admitted to at age five. Every possible reason for the current unacceptable prevalence of autism must be sought.

Our pediatrician told me I did not have the technical expertise to read the medical literature. What? I had just earned a master's degree in mathematics. I immediately enrolled in a graduate program in biochemistry, from which I earned a PhD five years later (Boston University School of Medicine, 1975). Still, as a parent, I am disdained as an ignoramus without qualification to be part of the conversation on autism.

I am angry! Would anyone have tried to tell parents to just be accepting of polio back in the 1940s and 50s? I remember the horror of polio, and how grateful we were for the vaccine that ended that epidemic.

Head injury in sports is now viewed as serious. Head injury is not just to be accepted. Shouldn't head injury and asphyxia at birth also be avoided? Everyone learns in CPR that respiration must be restored within four minutes. A low Apgar score 5 minutes after birth is recognized as ominous. Brain damage caused by complications at birth must be made a focus of autism research.

--

Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

**Rebecca Estep
Birgit Fisher
Lisa Radkte
Keri Maxwell
Sarah Man
Stephanie Smith
Becky Howell-Adams
Katie Christensen
Donna Delikat
Debby Lammam
Jeannie Fernandez
Betty Gusho
Vicky Carney**

November 5-10, 2015

IACC has been in recess for fourteen months. Within that time period, thousands of parents have expressed growing concern over the revelations of Dr. William Thompson also known as the "CDC Whistleblower." Will this new committee address the allegations of CDC misconduct made by Dr. Thompson? Parents are counting on an honest dialogue about this very troubling situation.

Sincerely,

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

Teresa Holman

November 5, 2015

My son, [PII redacted] will be 25 this month. He is profoundly and severely autistic. He began having seizures around one. He continued to develop normally until around two and a half. He had over 500 words, when he regressed into the black abyss of autism. He has seizures that are not controlled with medications. He has Crohn's disease, which is so painful; he sits on the toilet and screams sometimes for hours. He has to eat very special food, or his even more sick. He takes lots of medications, and I mean lots, and lots of natural supplements just to keep from getting worse.

He is a very brave young man. He even smiles a lot. But when he has painful weeks, the kind, gentle, sweet person becomes someone that makes us all afraid. He becomes very aggressive, and pinches, and bites. The truth is, he can be uncontrollable.

It's been many, many years of therapies, and medications. He has been to numerous neurologists, gastro intestinal doctors, autism doctors, natural doctors, the list is just so endless. We finally pretty much just stick to the one autism doctor, and the one primary care now, unless some unusual situation arises.

He goes a great deal of the time without sleep. He is tired; however he can't sleep most nights. We've tried lots of melatonin, lavender, even Ambien a time or two, and nothing really makes any difference. He has days that his anxiety and frustration are so high that he literally shakes. He has become so OCD that he can't stop touching other people's foreheads. He has periods of time that he washes his hands until they bleed. His last few years have been a horrific cough. He lays down at night and begins to cough and/or choke. It seems like he might be sick, and yet, all the doctors can find nothing.

No post nasal drip, no reflux, nothing. He suffers from autoimmune encephalitis, which causes lots of OCD issues. ALL OF THIS began with seizures, and autism.

Now he is 25, he has times that we can get ZERO help with him. NOW is one of those times. We have no caregivers, we can't find anyone. We even pay a lot, but no one knows how or what to do.

We try try try. So I work until 3:30, go pick him up, and then I stay with him until my husband comes home at 8. It's a sad, lonely life for all of us. I wish I could work until close, but that's not possible.

We need caregivers so we can work. We need respite caregivers a few times a year. Someone so we could go to a Christmas party. Someone so we could celebrate a birthday. We don't get to do any of those things. Haven't done them for 25 years. It's not a normal life, and it's a horrible way to live. There really is no one that seems capable of helping with him.

These are the things that families of the profoundly autistic pray for. So now, you know, HELP US.

Teresa Holman

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

Michelle Guppy

November 5, 2015

My name is Michelle Guppy, parent of a severely affected adult with "autism" - which we all know is not autism at all, but vaccine injury. Those responsible for causing it and those who do nothing about it in the medical industry - call it autism to avoid any awkward guilt of having been absolutely apathetic about causing it and too cowardly to admit it. "Pharma's profit and their political career protected at all cost!" is their secret motto!

My son is 22. He cannot read, write, or speak. He has autoimmune bowel disease, PANDAS, seizures, chronic yeast infections and a host of other illnesses that I guess I made up because no one in any medical center has ever been brave enough to acknowledge it. Only those physicians who either have their own vaccine-injured child or who were brave enough to believe parents and left traditional medicine to actually rediscover what medicine was supposed to be about all along -- healing. Healing, not prescribing. Listening, not doubting because "it just can't be".

I testified before this very committee in November 2013. You are welcome to view my blog where I shared about that experience. At the bottom of that blog is a video of what my testimony was that day. I encourage you to listen to it. I have the same things to say for this meeting, plus these new remarks.

[Video](#)

Not one thing has changed since I attended that meeting. Not one thing has changed for any of our children since the very first IACC meeting. Except that they are now adults with even fewer options. With even more exhausted parents. Who are even more in debt because insurance still won't cover treatments that actually work. Except that more are diagnosed with "autism" -- and more will have no doctor in their medical centers who know a thing about testing and treatment. More doctors in mainstream medicine will refuse to attend biomedical conferences by other doctors who have been brave enough to listen to parents and who are successfully helping their patients overcome pain, make progress, and gasp! work toward healing! More parents will have need for respite services that aren't there or that they cannot afford. More "children" will age out of public school and not have been properly educated or prepared for vocational anything and will have nowhere to go. Our children need "college" not institutions. Lifelong assistance on working toward skills.

I sat at my desk with a blank document for a week now. Simply paralyzed. There is so much I need to share in this letter of testimony to each of you on the IACC that I have simply not been able to sort it out to begin. But something happened last night that helped me. Yet another crisis. From yet another mom. I will share snippets of our conversations, and those from other warrior parents. I want all of you on this committee to read their words. Their cries for help. And never forget them. These words reflect what is happening to parents all across America. Warrior moms and dads and caregivers who have given their all for so long and who are simply exhausted. Their "HOPEISM" and their "NDCQ" (Not Dead Can't Quit) mentality that has held them up for so long - cracking to the point of wanting to just surrender. Wanting to just die.

Why is this happening? Why are parents at their breaking point? Because people like each of you on these committees will not listen to parents. You will not go where the truth leads nor where the need lies. For fear of what it might make you have to confront. So instead, you study the same things over and over, things that have been asked and answered but no action ever taken.

And all the while parents like me are helping pull back parents who I am speaking of from the edge of despair. I don't pity us parents and our trials. I pity those of you who are made aware of our trials, our needs, yet do nothing.

This is not just one parent -- I hear these same vents, these same cries for help from many! We parents who are overwhelmed with our own children and adults cannot physically help in these situations! We need help ourselves! We need crisis caregivers and a safe Prescription drug free place where they can get help and we can get sleep! Respite! Reprieve! We need doctors who understand that autism is medical, NOT psychological! We need healing, not prescription drugs! We need treatments and testing, not restraints and more prescription drugs! We need short term residential options that will honor and respect use of supplements, special diets, and individualized treatment plans. Where? Where is such a place that parents can afford and don't have to be on a waiting list? Behavioral meltdowns and crisis' do not wait until the child's name comes up on a waiting list.

This from a parent:

Well ya know he seems okay, til he's not! We all cried ourselves to sleep around 1. Talked about family suicide, that's just so not normal. We r just going through so much. I can't stop crying and I know I have to calm down but I'm not handling it all. Too many days without sleep! I'm scared, of so many things that I feel paralyzed. I've got to help him somehow! I know that it's his stomach as well because it's happening right after food! I'm teetering on the edge of despair! Either God will intervene or.... Life will be not worth living!

This from a parent:

It's sad that other people don't have any idea the life we live. The despair, the constant struggle.

This from a parent:

I don't know if I'm okay it's all just too much. It's so hard to have NO HELP so I can work. I'm gonna call and get his teeth done, even though stupid insurance won't pay. I don't know what to do. Maybe his teeth hurt. THEN, I'm going to go to the neurologist and see about these crazy incidents being seizures? What else is there? I surrender. Surely God cares, I just can't tell anymore

How many more similar messages must be shared with this committee for you to understand the emergency this epidemic of vaccine injury, excuse me, "autism" is?

The meeting I attended to give oral testimony was during a strategic planning. There were items listed for people on the committee to "discuss" that any parent like me could have drawn out a treatment and action plan for in one day. It took this committee a year to look into those things! Things we've been begging organizations and committees to take action on for years.

Part of the problem is that the scope of this committee is too large. There must be two separate committees to address the needs of both ends of this diverse spectrum. Those who are higher functioning and who can speak for themselves, and those like the majority of our children who are non-verbal and significantly affected. To have high functioning "Asperger" adults or professionals on a committee addressing the needs of those like my son is not appropriate. They have no clue what our lives are like. We need parents on this committee -- parents who know what is needed. What it's like. The entire first half of each of your meetings should be parent presenters or independent thinking professionals and physicians who actually help heal our children. Then the second half of your meetings is making what they share that is needed -- happen.

In closing -- though I have much more to say -- I will say this... If you want to truly know what the issues are for us, ask us. Set up an online survey and ask. Ask what are fears are, our needs are, what is working, what isn't. And if you want to actually be the committee who does something about it -- believe what we say. And act on it.

Back to my friends in crisis...

One of them has an adult son who is non-verbal. He has a myriad of iatrogenic and epigenetic disorders that cause him to have periods of behavior issues because he is in pain and cannot communicate that. He has aged out of public school, and his parents fear he will be dismissed from the private program because of medical based behavior manifestations that he cannot control. His parents have gone to infinity and beyond for him and still cannot find consistent medical care nor can they afford to pay for things that might help that insurance won't cover or that are deemed illegal to medically use. They both work just to care for him, and if he must leave this program, one of his parents will have to stay home with him until they can somehow find another place that will accept him. He needs 24-hour supervision. He needs highly trained staff. State-based institutions are not an option. Parents like me, like all I know, would rather die than send their child to such an abusive restrictive incompetent prison. As if there were even enough to hold all our children if we had to resort to that.

So tell me - what do I tell her? What do I tell all who message me long after each of you are sleeping soundly? Where do they turn? Who will help them?

I sure can't. While my friends are living their own brand of hell, I'm living mine with seizures in my son. I've been to every top Neurologist in my mega-medical center. No help. None. It is I who bring research to them, and they who look at me dazed and confused. One replying with, "Well, what's your end game for him?"

The truth is a lion. It is a powerful thing. It is a scary thing for those living a lie. When that truth roars in the jungle, many instinctively run away if they value their life. Their career. But few....only a few brave souls run toward that roar. Pursuing truth at all cost is greater than any harm or death that might happen in its pursuit. Dr. Wakefield was one such person. Recently, RFK, Jr. another such. Many parents and advocates and thinking organizations and physicians have run toward that roar. Recently the Nation of Islam has joined the ranks of those brave souls running toward the roar of truth.

What will this committee do?

Will you run toward the roar for our children and adults, or will you remain in the safety of the shadow of a lie?

The truth is a lion. It is a powerful thing. It is a scary thing for those living a lie. When that truth roars in the jungle, many instinctively run away if they value their life. Their career. But few....only a few brave souls run toward that roar. Pursuing truth at all cost is greater than any harm or death that might happen in its pursuit. Dr. Wakefield was one such person. Recently, RFK, Jr. another such. Many parents and advocates and thinking organizations and physicians have run toward that roar. Recently the Nation of Islam has joined the ranks of those brave souls running toward the roar of truth.

What will this committee do?

Will you run toward the roar in pursuit of truth for what has happened to an entire generation of our children who are fast becoming adults, or will you remain in the safety of the shadow of a lie?

Your position, your influence on this committee means that you agree to be a pacesetter in addressing the epidemic of "autism" and all that goes with it.

If you do nothing, if you do not run toward that roar and do all it takes to help our children, you will still be a pacesetter.

You will have simply decided that there will be no pace.

Michelle M Guppy
[PII redacted]

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

Deborah O'Leary

November 6, 2015

First, I wish returning and new members well in your role on this Committee. From my own personal experience serving on boards and commissions, I can tell you that you will learn more from the experience than you could ever imagine. Maintain a curious mind. Ask tough questions and think outside the box. And, always remember why the IACC was formed in the first place. There is an epidemic in this country. American's children are sustaining neurological damage (among other chronic illness) and you in your role on the IACC is to leave no stone unturned looking for answers as to WHY?

For over a year now, Congressman Bill Posey of Florida has been appealing to his House colleagues to investigate the CDC, and subpoena Dr. William Thompson, a CDC researcher who has sought and received Whistleblower protection. Dr. Thompson has indicated that a published study of the MMR vaccine omitted statistically significant data which indicated an increased risk of Autism particularly in African American boys vaccinated before 36 months of age. Dr. Thompson also indicated that the data which showed this was destroyed by the CDC. He maintained copies of those documents. I would like to see the IACC call for a Congressional Investigation and support Congressman Posey's quest for the truth. If the CDC was willing to lie and destroy research documents on this study, what else have they manipulated? As a parent, and a citizen, I respectfully ask you to encourage further investigation into the CDC Whistleblower issue.

Sincerely,

Deborah Z. O'Leary
[PII redacted]

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

Michelle Mood

November 6, 2015

I am writing as the mother of two autistic children aged ten and sixteen who are not well served by resources in our rural county in Ohio. Greater equality in service provision and education is needed to enable our children to become highly productive members of society. My oldest is in Calculus 3 class at Kenyon College even though he is only a junior in high school but his planning and organization ability has not been appropriately addressed in public school, so our society may miss out on my son's talents. At age fourteen, his ACT scores were 34. Yet Autistic adults are unemployed up to 80% of the time, and they rarely can hold a job past six months. Instead of a productive taxpayer using his gifts in STEM fields, society may be saddled with another disabled autistic adult. Coordinated and concerted effort is needed by your organization to advance education and requirements for services. In the long run, it will save money. Our district does the minimum and move the kids on through and society pays the cost. Autistics are at higher risk for mental illness, depression, and suicide. They are at risk for fatally misunderstanding encounters with authority figures. We turn to you for advocacy, coordination, resources and problem-solving. Don't let us down.

Michelle S. Mood, Ph.D.
[PII redacted]

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Patti Carroll

November 6, 2015

During the fourteen months that IACC has been in recess, thousands of parents have expressed grave concern over the revelations of Dr. William Thompson, the scientist from the CDC who admitted that CDC researchers deliberately altered studies and destroyed evidence to cover up an association between vaccines and autism.

When will IACC finally address the blatant CDC misconduct alleged by Dr. Thompson? It is time for IACC to actually DO something about this very troubling situation.

Thank you -

Patti Carroll
[PII redacted]

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

Joseph Jason

November 7, 2015

Subject: Testimony regarding the Criminalization of Asperger Syndrome and Mental Illness.

<https://www.youtube.com/watch?v=3KuZYUF9HvU>

Press release to Associated Press:

Iowa's Appeal Court approved a 45 year sentence last Wednesday on October 30, 2015. It's called the Criminalization of Asperger Syndrome and Mental Illness.

Iowa affirmed [PII redacted]'s convictions in the Appellate Court. The Court approved [PII redacted]'s 45 year sentence since he was a habitual offender. The Appellate Judges decided that wearing a shock belt despite being non-violent was irrelevant. There was no consideration that [PII redacted] was not even in the state. There was no consideration that [PII redacted] is not violent and has never been. There was no consideration of people with Asperger Syndrome being unable to show remorse. Despite the enormous debilitation caused by Asperger Syndrome, the court stated that [PII redacted] has mild autism.

Basically, the Court ruled that [PII redacted] is a smart guy, "with a photographic memory" to boot, whose ASD is of minor significance; and who tried to manipulate the judicial system after continuing to harass the victim because he didn't think it would get him in much trouble; and who received a fair sentence from a patient judge. They do believe that punishment will deter future crimes and Asperger Syndrome and Mental Illness is irrelevant. [PII redacted] a past Psychiatrist in Iowa's prison system noted for torturing the mentally ill once said "Mental illness is no bar to a person's doing time." Apparently Iowa is going back to the good old days while the rest of the country is seriously trying to cut down on the prison population.

I witnessed the trial. The legal system is stacked against the mentally ill and they have no chance of getting a fair trial. [PII redacted]'s forensic psychiatrist was the real expert and that opinion did not count.

The following is an excerpt from Joseph M. Jason, Chairman of the NAMI Criminal Justice Advocacy for the Mentally Ill and a past President of NAMI BA.

"The trial took place on February 25, 2014 and lasted three days. The actions of the prosecution in Iowa City are indicative of the criminalization of Asperger Syndrome. My son was tried at this date for extortion and stalking. My son sent various emails and made two phone calls. These charges are a travesty. My wife and I met with the prosecutor in December of 2012 and explained Asperger Syndrome and mental illness. We explained that our son's behavior is childlike rather than criminal. We told them he needs treatment and not incarceration. We gave them a forensic psychiatrist's report that demonstrates he is not violent. He is a nuisance. We told them that his behavior according to [PII redacted] is typical of one with Asperger Syndrome. We told them he has an organic brain disorder. His criminal behavior consists only of phone calls and emails. This meeting has made no difference. If the Iowa prosecutor's office was serious about avoiding an expensive trial, they would have offered a humane plea agreement. Instead they offered an agreement of ten years. During the trial [PII redacted] testified that [PII redacted] has no history of violence. In fact people with Asperger Syndrome are more likely to be bullied. [PII redacted] did not have intent and is not a stalker. His actions are part of having Asperger Syndrome and not a suitor stalker. His actions were flawed and ambivalent. He did not want to contact his ex-girlfriend so he chose a flawed

way. He had her phone number and did not call it. He was blowing off steam. [PII redacted] cannot connect the dots. There is a disconnect between how we feel and how he feels. [PII redacted] made reference to an embarrassing incident in the Johnson county auditor's office. This referred to an employee who defecated in their pants. He was given two counts of extortion for this by overzealous Johnson County prosecutors.

The typical offender sitting in Johnson County right now has been charged with robbery, theft, murder, sexual abuse, domestic abuse assault, drug offenses etc. My son is not a thug, but yet received the stiffest sentence out of all of them. It is the criminalization of Asperger Syndrome. A full one-third of the nation's states get a D or F grade for using mental health courts and crisis intervention teams (CIT) – diversion programs proven to reduce the criminalization of mental illness, the study found. Iowa received a well-deserved F. "People with untreated psychiatric disease should be getting the treatment they need before law enforcement shows up at their door because of behaviors caused by their illness," said Doris A. Fuller, executive director. That is punishment fit for a major drug dealer and/or murderer. This case, as it always has, cries out for treatment and not incarceration. I had found a place for my son to live. It is called Trinity in Illinois and it is an excellent place for people with issues similar to my son. That is where he belongs. [PII redacted] was living with us for the entire time and did not go to Iowa. This has not stopped the charges of stalking and extortion. This is not what our founding fathers envisioned that America should be. [PII redacted] has already been in jail and prisons for most of the time since 2007. [PII redacted] has stated that [PII redacted]'s so called criminal conduct is caused by his Asperger Syndrome. "[PII redacted] cannot legitimately be considered morally responsible for his misconduct." [PII redacted] also states that "The lack of significant history of violence is important." As stated in the article, Forensic aspects of Asperger's Syndrome by Justin B. Barry-Walsh and Paul E. Mullen in the Journal of Forensic Psychiatry & Psychology, "It behooves us to draw to the court's attention the obvious: that patients with Asperger's Syndrome suffer from mental disorder and that their offending and subsequent disposition must be placed in this context. The core features of Asperger's Syndrome and how they determine what the individual knows and understand of the world should form a basis for sophisticated assessment of the issues of disability." NAMI National, Senator Durbin, and Senator Harkin have been apprised of this situation.. The Autism Society of America believes this to be the most egregious case in the United States. Murderers have received less of a sentence than my son is facing. [PII redacted] has a brain disorder and needs mental health treatment not incarceration. National organizations such as NAMI and CURE are following this trial. This typifies everything that is wrong in the State of Iowa regarding the Criminalization of the Mentally Ill and Asperger Syndrome. This Criminalization of the mentally ill must be confronted and stopped. I have seen and heard the overzealous prosecutors. It took courageous people to say no to slavery in our history. We must say no to the incarceration of our non-violent mentally ill. This is my mission in life."

Joseph M. Jason, CPA, MST
Past President NAMI BA
Chairman NAMI Criminal Justice Advocacy for the Mentally Ill
[PII redacted]

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

Mike Hoover

November 7, 2015

In early 2001, my beautiful, typical, normal baby boy was injected with autism. I vowed that day that I would fight to get him out of being trapped in his own mind, or that I would die trying.

Over the past 13 years, I've met thousands upon thousands of parents with the same story, a completely typical, happy, healthy toddler, that "suddenly" disappeared into the depths of autism within few days or weeks of receiving their vaccinations. I've learned more than I ever wanted to know about the level of lying and corruption in our system, and it's time to put an end to it.

It starts today.

It starts with YOU. YOU are the ones who have to look yourselves in the mirror and sleep at night. YOU are the ones who have the power to right a terrible wrong and the poisoning of an entire generation, and doing nothing to help them afterward. All of you know a friend or have a family member that is affected by autism, and if the rates continue as they are, the ratio will be 1:1 in just 63 years. Then what will your children and grandchildren do? Who will run the Country? Who will defend the country? Who will be left to take care of those with autism, when 100% of the population has autism?

Over the past few years, we've started our own autism Charity called The Make It Fit Foundation. Our mission is to help make all of the so called pieces of the autism puzzle fit together. It's also our mission to help as many families as humanly possible to learn the TRUTH and to learn how to fight for themselves and for their children. We provide as many things as we can possibly financially provide, given the limit of the funds we raise through the efforts of thousands of everyday people. People who give of their time and hard earned money in order to help others because you have wasted BILLIONS of dollars since you formed and have done absolutely nothing to help fill the needs of families affected by autism and those with it. If you're not going to do anything, then at least please distribute those funds to organizations like ours that will actually do something to help those families and individuals. Since you refuse to do anything to help, at least allow those of us who do things to help, do them on a larger scale.

We're sick and tired of meetings, conferences, hearings, and summits, where nothing gets resolved and nothing changes.

"If Nothing Changes – Nothing Changes. "

I'm here to tell you that the army of autism parents in the United States is gaining strength every single day, and we won't be shut up, shut down, or bullied. Thousands upon thousands of Americans already know the truth, because we've lived it. You see, autism has given us all a gift – The gift of being fearless. Fearless of Government Agencies who tell us "No". Fearless of School Districts that tell us "No". Fearless of ridicule from the CDC, FDA, Big Pharma, and the Medical Community, for knowing our rights and knowing the truth. Fearless of anything to do with our kids, because we have been given no choice but to deal with it on our own, because YOU refuse to do what's right and help those who you are supposed to be helping. The entire system is failing MISERABLY, from the top of our Federal and State Governments, to the entire education system, to the medical system, and all the way down the entire chain.

It's terrible. Shameful. It's time for it to stop.

You're all well aware of the truth, and it's long past time for all of America to know what we know. It's time that all of the secrecy, fraudulent behaviors, and cover ups to come out.

You see, nothing is stronger or more powerful than the love of a parent, and I made a promise to my scared to death 2 year old baby boy, some 13 ½ years ago, and I will fight for him until either YOU admit the wrongs of the past and do something about it, or I take my final breath on this Earth.

Do something right.

Do something positive.

Do something that your children and grandchildren will be proud of you for.

Right a terrible wrong.

People are suffering, kids are dying, families are falling apart. Society has a whole generation of kids with moderate to severe autism entering adulthood soon, with nothing in place for them.

Remember that you work for us. This is still America.

We won't be silenced due to your greed, ignorance, your inability to tell the truth, and the inability to do your jobs.

A promise is a promise, and I WILL keep mine to that little boy, to the 1000's of kids like him, and to the 1000's of parents like me.

We're watching you.

Sincerely,
Mike Hoover
[PII redacted]
President of The Make It Fit Foundation
Westerville, Ohio
Dad of 2 boys on the autism spectrum

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

Donna Jo Kazee

November 7, 2015

As the parent of a 15-year-old boy with autism who was diagnosed fairly early (age 2), I request that the committee actually open themselves to all avenues of possibility for the current dramatic rise in autism in our society. Having worked with people with disabilities in the school system for over 10 years, I can say that there are an astounding number of individuals presenting with autism today. It will be an enormous societal responsibility to identify, remediate, educate, and serve these individuals over their lifespans. I stand with others who demand that the CDC whistleblower (Dr. William Thompson) be called before Congress to present information about his and others' research practices that may have resulted in valuable autism correlations being hidden for over a decade! There is no public health program that is so important as to not merit scrutiny and ongoing data collection and analysis. And the hundreds (thousands) of parents who provide anecdotal accounts of their child's quick regression into autism should give pause to any person studying the issue.

It is long past the time of "awareness." Nothing is being done to PREVENT future rates of autism by identifying and eliminating risk factors. There has to be a dual approach to this challenging issue: identification of risk/causal factors and mitigation and the provision of lifelong services to individuals who are diagnosed with autism but with respect for individual family differences and preferences and a deep respect for the neurodiversity and maximum inclusion of all affected individuals.

Donna Jo Kazee
[PII redacted]

Nydia Olvera

November 9, 2015

Quoting: For children with truly isolated autism the yield of finding a gene change to explain their features is quite low. In children who have autism with other clinical features (e.g., a heart defect or other structural differences) that we would refer to as “syndromic autism” then there is a higher yield on genetic testing. In general we would need to clinically evaluate a child with autism to determine the best diagnostic test to send which may include chromosome based tests (e.g. a microarray), metabolic testing, mitochondrial testing, single gene testing, gene panels or exome sequencing (which looks at all genes at once). Again the decision about what testing to do would be driven by the clinical features in the individual child. Not finding a genetic cause for isolated autism is more the norm, as we simply don’t understand the complete genetic contribution to isolated autism at this time, which is likely a “complex” trait with genetic and environmental contributors. - End of quote

The information above was provided by CHOP.edu. Please have the information included in the public comments.

Thank you,

Nydia Olvera
New York City

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

Michael Kazee

November 9, 2015

Subject: Concerns

As the father of a teenager with moderate autism (formerly severe, nonverbal autism with diagnosed expressive/receptive language delays), I am appalled at every stage of his life with the lack of and difficulty getting proper services. I am also astounded by the number of affected kids. Prior to our son's diagnosis, I only knew of a couple cases of autism. I was a middle school math and science teacher and never saw it in my classroom or schools. Now I see it everywhere. This is not better diagnostics or identification; these kids were simply not around 15-20 years ago.

I call on the committee to figure out what is causing this rise in a profoundly disabling condition, which will result in my child and others requiring high levels of care their entire lives. I ask that no stone be left unturned in this search, especially allegations that there was fraud committed regarding the connection between vaccines and autism at the CDC. I request the IACC to put pressure on Congress to subpoena Dr. William Thompson and any others who may come forward with data indicating a cover-up at CDC. How can any group pretending to tackle this issue ignore such allegations? There is a crisis right now, and the sheer numbers of kids filtering through the system and families attempting to access supports is staggering.

I also request that you work on access to long-term therapies and supports. If one manages to get a waiver in Ohio before adulthood, it is a miracle. There are waiting lists with thousands of kids on them, straining family resources to their very core. The prospects for many kids, who are not able to go to secondary education and pursue mainstream employment are very bleak. Families have found things that work well for them but often have to use other, sanctioned strategies which do not help their children. We need to be able to access the latest options in diet, supplements, medical drugs, and a variety of remediation therapies. ABA and psych meds are not the answer for all of our children. There is a sudden drop off in services after high school, and there is a lack of good transition planning for these kids.

We want true numbers in this area. No 10-year-old data on school-age children. We know that the county boards and various medical/psychological facilities have abilities to report on new cases diagnosed, access to services, and outcomes -- with no revelation of sensitive information. Data should be collected on this in a timely manner, so that the public truly understands the situation and its implications.

Michael Kazee
[PII redacted]

Courtney Reid

November 9, 2015

This is not my first time submitting written comments to this panel.

In the past year since my last written comments more has come out about the CDC whistle-blower. Many documents have been forwarded to Posey who has called for investigations twice now on the Senate floor. The CDC has chosen to not work with him. I believe someone should hold the CDC accountable for the corruption they've allowed to ensue.

I hope this new panel will do more to actually help those who have autism. Getting together to discuss things isn't enough. We're ready for action. We're ready to see preventions, cures; we're ready to see movement on ways to help those who cannot be cured. We have many children who will be aging out and something must be done to help the families who do not know what the next step is. We need more doctors who understand what autism really is, encephalopathy. We need this panel to finally recognize that yes, vaccines cause encephalopathy, and so vaccine induced autism is very real. We just need more. More than what has been done. Which, by my last count, was zero.

Thank you for your time.

Courtney Reid
Hockley, Tx

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

Jackie D. Igafo-Te'o

November 9, 2015

My son is 21 years old and has autism. I'll get right to the point. People see him coming and grab their children's hands and pull them back or cover their eyes/ears. It's disturbing, humiliating, degrading...inhumane. Yes, he's big. Yes, he's loud. Yes, he has autism. His name is [PII redacted]. Sadly, I have grown to expect that kind of reaction from the public but I do NOT expect it from educators and medical professionals.

There is so much money being poured into research for the cause(s) of autism but really nothing toward those who are living with it right now and have accepted the fact that it isn't going away. We, as parents, have to fight for everything like stray cats in the alley who all see the same speck of food at the same time. We are treated like second-class citizens or beggars. To get support from the education, physical health or mental health agencies, we pretty much have to give up our pride. Swallow it whole and accept whatever they throw at us to keep us back. Degrading. Humiliating. Unnecessary! When our kids go to the hospital for treatment, medical professionals cannot see past their "behaviors". They see is someone "misbehaving" and they are often quick to blame the child's upbringing.

Let me ask you this. We have every moment of our lives dissected. We get advice on parenting from people who don't even have kids - - much less kids with autism - - and we take it all in, in an effort to help our loved ones with autism. Why aren't we as a nation supporting those LIVING WITH AUTISM? Why are we forced to beg, litigate, complain, go bankrupt, lose our homes, lose our jobs...all because SOCIETY wants to sweep adults with autism under the rug?

My son is here to stay, as are thousands upon thousands of other children and adults with autism. They're not going anywhere. As a nation and as a committee, I urge you to spread your wings. Start focusing on care for those who obviously are not going to "heal" or "recover". I have attached a photo of my son and his fiancé, [PII redacted]. Their lives are no less valuable than anyone else's. Their medical treatment should be just as focused on causation, as those without autism, instead of their reaction. Systems and agencies should treat families and people with autism with RESPECT and not like beggars. We are not going anywhere. We have hopes and dreams. We love and we hate. We feel and we grieve. We are asking for your help.

Thank you.

Respectfully submitted by: Jackie D. Igafo-Te'o, mother of [PII redacted], Jackson, Michigan

[Photo redacted]

Eileen Nicole Simon

November 9, 2015

The agenda for the meeting on November 17 is to include issues related to autism research and services. I submitted a comment last week (November 4) requesting discussion of language development as the highest priority for research. I hope my comment was received. I hope language development will be discussed, and not be overshadowed by discussion of the neurodiversity movement.

On the CDC website, submitting "language" as a search item brings up:
PHINMS (Public Health Information Network Messaging System) security software.
ABA techniques for working on expressive language.
Plain language for health literacy.
Learning language, hearing loss.
CD Health literacy.
Spanish language print materials.
Tools for cross-cultural communication

...

Milestones: 3 years, 9 months, 18 months, 2 years. Learn the signs. Act early.

"Autism" as a search item brings up:
www.cdc.gov/ncbddd/autism/index.html
Autism and genetics.

...

seizures

Search item "brain" as keyword displays:
Traumatic brain injury (TBI)
Cysticercosis (a parasitic tissue infection)
Autism and the brain, PDF file

"Prevalence" brings up (among other things)
1 in 68 children diagnosed with autism spectrum disorder (ASD)

Language is clearly important for communication, health literacy, cross-cultural communication, for people with hearing loss, and an important developmental milestone. Please consider the possibility that autism is a form of auditory system degradation in the brain.

As a parent, my attempts to engage in discussion have largely been rebuffed. My extensive education in biochemistry and neuroscience is overlooked, and attempts to publish my viewpoint have been rejected as anecdotal lay observations, not based on "data driven" research. As a parent I see a lot of "data driven" research on language way off course.

"Pronoun reversal" results from use of phrase fragments (echolalia) by an autistic child. Ideas like non-pragmatic language or deictic-shifting are not helpful in efforts to promote the human ability to make syntactic transformations. Inability to hear syllable and word boundaries leads to adoption of unanalyzed phrase fragments.

If the views of neurodiversity advocates are to be discussed, can I please request that the comments I have submitted not be omitted from the conversation?

--

Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

In the years you have been in council with one another, not one policy, idea, strategy or new revelation has taken place on why we have an epidemic of autism in our nations children. Children are waiting for your help and answer. These meetings are seemingly pointless, fruitless and to be honest, a diversion tactic. Bring up the V word, and either a person is shot down, ridiculed, told they don't know the science, or worse, maligned or a simple you are out of time.

The CDC has withheld damning information for over a decade, of which you deny, that vaccines are in fact, causal. Who is right? The CDC or your scientific committee, enlighten me please? Significant revelations such as this should be the number one topic of discussion. To deny, dismiss and defer such is liable and outrageous. Meanwhile, all across our nation states are aggressively undermining health freedom by greatly restricting medical and religious vaccine exemptions. What parent in their right mind would either re-injures their child, or other children in their families after what they experienced with their child's severe vaccine reactions? Would you? In regards to that...there never was a measles outbreak. It only existed in the media. Measles is a common disease and smaller and bigger outbreaks happen all the time. So 100 people with measles is nothing special. The hype was carefully staged to create a basis for forced vaccination. And people all over the world fell for it. Willfull ignorance, cognitive dissonance...whatever is happening here, you are drinking the same koolaid and or, are bought with the same people. I want disclosure here. Transparency.

The truth is this...As long as we are looking for "the issue" we will never find it. "The issue" is that the entire vaccine schedule has never been studied for either safety or efficacy. There has never been a single study on the effects of vaccines as they are administered at ANY of the "well baby" or "well child" check-ups. There has never been a study of the synergistic effects of injecting even miniscule amounts of mercury along with aluminum, formaldehyde, polysorbate 80, 2-phenoxyethanol, Triton x-100, human and animal DNA, and multiple viruses and bacteria. It's all experimentation on human subjects (our children). Along with that, continued focus on "mercury is the issue" or "MMR is the issue" is playing directly into pharma's hands. They WANT us to keep focusing on those two things so we DON'T talk about aluminum. The entire vaccine is neurotoxic. How scientific do you want to become? Why don't vaccine manufacturers evaluate vaccines for carcinogenic or mutagenic potential, or for impairment of fertility? Is it because they know what they will find if they do?

Yes, there are leads up/set ups to autism. Autoimmunity mothers (most likely due to her vaccines and toxins). Toxins in our environment, synergized with vaccines. Birth Damage via cord clamping or drugs. GMO's. Retroviruses/SV40. Low Vit D3. High Nagalase and need for GcMAF therapy (which doctors are being murdered over by the way). Future immune therapies geared towards viruses in the brain and CNS are needed NOW!

What can we do as a nation to either quell the epidemic, not start it in the first place, or help the people in the abyss of autism? It's not going to happen if you think a child can get better with the current medical system. I truly need for my two vaccine injured children, real biomedical help. They need Hbot, they need GcmAF and immune therapies, that likely cancer children get before mine. They need help when their brains are malleable and able to be healed. They need help if they are also having symptoms of PITANDS or PANDAS, which involves high fallootin high cost immune therapies, aka, long term antibiotics, long term antivirals, long term anti-inflammatory medicines. Our children need neurologists who don't ask for vaccine status, but rather, what happened questions after their vaccines? They need a level of concern of a child dying of cancer....because autism is deadly, drownings, seizures, etc. SUDAP does occur

in our children. Drownings do happen to our wandering Alzheimer's like children. My son almost died in the ER via heart block, asystole. Autism can be deadly, treat it as such.

Please do something..and I mean SOMETHING of value.

Kathy Blanco

Katie Harris

November 9, 2015

Congratulations on your first meeting of 2015! I want to thank you all for working so diligently on behalf of our children. "The Committee shall meet at the call of the chairperson or upon the request of the Secretary. The Committee shall meet not fewer than 2 times each year." If you buckle down and work assiduously you might be able to fit a second (required) meeting in before the end of 2015. I understand, Dr. Insel resigned and it put everything in a whirlwind, but here's the thing - Autism has put our lives in a whirlwind - and my son isn't getting a 10 month break. You have to be able to understand how unbelievably frustrated we are as parents.

I would like to welcome all the new committee members, including a new chairman, which means new leadership, a new direction, new motivation, and new momentum. I have followed this committee for 4 years now, watched committee meetings while some previous members either didn't attend or left early. Please, please show up for our children. I am sorry but one full day, two – four times a year isn't too much to ask. And if it is too much to ask then please resign your committee nomination. My son's future and millions of other children's futures are dependent on the progress of this committee. How can the committee make progress when the members do not attend and participate?

The tasks before this committee are daunting, see we've expected progress for years now; expected assistance with interventions, expected appropriate medical care for our children, expected supportive services for transitioning adults, expected, expected, expected then turned into disappointed, disappointed, disappointed with billions of dollars gone. We desperately need more research into co-morbidity and autism, sleep disturbance, gastrointestinal function, anxiety, epilepsy, and alternative therapies and these are just to name a few.

At the July 2013 IACC meeting, I watched presentations by Dr. Richard Frye and Dr. Tim Buie. Dr. Buie specifically spoke of GI issues and autism and Dr. Frye presented on recovery; both areas that need additional research. Some children recover from autism. Why hasn't there been a study on the children that have recovered? Has the IACC recommended this route for research to Secretary Burwell? We aren't preventing children from being diagnosed with autism (regardless of how much money we have spent on genetic research), can we at least help them have a more independent and fulfilling life after diagnosis? We aren't prepared for all of these children to become adults with autism, there is no infrastructure in place to house and care for all of these soon to be adults with aging caregivers.

We need a plan and action before another generation of children are lost to autism. I beg you, be part of the solution; help us, help our children.

Sincerely,

Katie Harris

When my first son was formally diagnosed with autism, I had already known he had autism at least a year before it was confirmed. By the time my second son was diagnosed, I'd had at least two, if not three years of processing the facts and details before his autism was confirmed, medically speaking. When the neurologist gave me the news, his face had that look on it – the look people get when they are about to deliver devastating news. I was familiar with that look from working as a registered nurse for many years and watching doctors let loved ones know that death had come. I was very confused by the neurologist's somber tone when confirming the diagnosis. This was our third official diagnosis, and I didn't see anything wrong with autism.

That was more than 10 years ago, when the autism rate was still supposed to be 1 in 10,000. My confusion left me without words, so he began to speak again. When he said "you must have really bad luck," my confusion disappeared immediately as I replied in a cheerful tone "Oh, no. I know God wouldn't have given me something like this if He didn't know we could use it for good." The doctor seemed confused, but responded pleasantly. I had a perspective that he knew many did not share.

I had learned about autism not so much as a parent but as an individual with autism. A month after my first son was diagnosed by a physician friend, my friend pointed out that I, too, was autistic. He explained, "It is why you never saw anything wrong with your son." That made perfect sense. We spent the first couple of months re-evaluating my life, especially the medical aspects, confirming my medical diagnosis and revealing all the times I was mistreated medically because of the core deficits of autism: communication, socialization, and behaviors.

For years, lights continued to go on for me, revealing more facets of myself and removing confusion over many dark issues of my past. With the light came understanding, and the issues no longer hurt or had the power to influence my behavior. I was thankful, happy, and even proud to be autistic! I told people it was like finally having a pair of shoes that fit; now I could comfortably walk forward in life.

My enthusiasm often created problems with others, especially other parents. So I opted out of nationally known, long-standing autism groups and found the few hidden self-advocacy groups and joined them, even helped start some efforts, especially in the political arena. I lived in Virginia at the time, and our family was mostly located in the Midwest. I decided that I was ready to move back and accept help. Now that I knew what we were and what we needed, I thought it would be easy. To my surprise, I found it was more like moving back 50 years in time, and the darkness became too prominent to ignore.

Within the first year or two, the joy that I was filled with – the light that radiated out of me – did help create some positive sparks, but mostly created more confusion for me. For example, I was offered a chance to be featured in the first ever book about girls with autism, *Aspergers and Girls*. I had to accept that they made a political choice to call it "Aspergers" because "autism" was too negative – as was the reality of my "normal" life. Even though I hated how easily people can substitute words, I knew that was due to the autistic wiring in me and worked through it. I had already learned enough to realize that this "black or white" thinking of mine is an autistic trait that had created too many problems for me already to let this opportunity pass by over a single word. I worked through my discomfort with the word change faster than ever before.

For the most part, I have learned to switch out words or phrases such as anything with the word "death" when in a conversation with most people. As an RN, I never got that, even as a bereavement specialist.

The diagnosis of autism helped me see the problem *and* the solutions. The word “death” is too harsh for most people to hear, and I need to use “expired” or “passed.” Learning things like this confirmed and continued to feed my “joy” of knowing why I was the way I was.

With this faith and joy, I decided I had enough strength and courage to go meet some parents and share with them at the AutismOne conference in Chicago in 2006. I had no fear, but I also knew I would have one friend and fellow advocate at the conference to meet up with. Lack of fear, also a common trait in many autistics, has served me well most of my life, but realizing that I lack fear, and learning what it physically feels like, has also saved my life since.

As an autistic, being rejected by other autistics can be very painful. Before going to the AO conference I had already been rejected by a popular “self-advocacy” group leader who had asked me about the vaccine issues related to autism. I was clueless about the subject, but very curious to know more. The reasons were personal and scientifically sound. I gave him my honest answer, “I am curious to learn more about it.” My communication skills were not yet improved enough, or perhaps my processing just wasn't up to speed, for me to recognize that when he asked “What do you think about the vaccine conspiracy issue?” he was also giving me his opinion: conspiracy theory.

I probably would have changed my answer if I had known I was being interviewed, rather than just having a discussion with another self-advocate – what I often call a “sibling in the spectrum.” I have since come to realize that most people seem to be interviewing rather than discussing, and it is only after that rejection, or at least non-acceptance, that I understood my own communication problem. A similar situation occurred at the conference when I met a vendor who was willing to listen to me as a self-advocate. It took over six months for me to figure that one out, and now, nine years later, I consider this person an ally, perhaps a friend.

On occasion, when I go to these conferences, I still feel like I am the “enemy” that they are trying to rid the world of. I am autism and they need to cure, combat, and recover from it. My heart hurts often, and then I have to self-analyze: is this emotional pain or physical pain? It's kind of funny because I now realize that if I don't ask myself this, I won't get medical treatment when I need it. That's because of how bad health care as a business has become. I am so tired of it all that some days I want to quit everything autism, but it's kind of hard to quit it when you are it.

Fortunately, I have learned so much from these biomedical warriors that I realize the key word in my sentence is “tired.” When I am tired, I don't function as well. Whether it is from fibromyalgia, or some other, not-yet-understood diagnosis, or a busy day, I can't let it control me. I have a choice: go rest or go forward. And I'm not going to let the desire to quit be the thought I hang onto. Unlike other moms, I can't just call in help and take a break from autism, because it is how my brain and body is wired too. Like other moms, I know how few really “get it” when it comes to raising these amazing kinds of children.

It is difficult to accept things if we don't understand them. It is impossible to change things if we don't understand what the problem is. When I first tried to research autism it was in 2000, maybe 2001. I heard someone mention their son had autism but they could not tell me what autism was. To me, that was as crazy as saying “I have a newborn baby” and not being able to say if it was a boy or a girl. The Internet, books, and the professionals I knew had similar blank responses, accompanied by a very sad look. They reminded me of the movie *Rainman* but still did not answer the question, just gave the one example. I decided to meet other people with autism, and I understood them better than anyone else in my life. Still, I couldn't see anything “wrong” or what autism is because I am autistic. It took a medical professional

looking with me to help me recall the information our family tried so hard to bury. The truth did set me free!

The conflict is this: if autism is wrong and I am autistic, then according to logic I am “wrong” or “a disease.” But I see it as no different than being left-handed in a right handed dominant world: neurologically diverse.

Having four children, two with autism, has definitely helped me become less self-absorbed or off in my own world and has helped me want to be a part of this world we are all living in, but it hasn't magically or medically cured me of autism. When my health is at its best, I pass very easily as just another mom in the crowd, which has enabled me to observe and learn what the majority of other self-advocates don't seem to grasp. I think they, like neurotypicals (NTs) as well, believe that if you can't get something, then that something is not worth trying to obtain. They'll decide they don't really want or need what's on the “other side.” That kind of black-and-white thinking doesn't help any of us.

Being able to go to these biomedical conferences has helped in ways that so many on the spectrum may never appreciate if we don't learn to work together. Today, before I wrote, this I found myself at the hospital with my son. I was in tears, tears of joy and pain, emotions all over, thankful for the progress and the knowledge I had that gave me the strength to persevere. My youngest son, with autism, has always had gastrointestinal issues that the world wants to dismiss as “mental,” and I know there is a physical basis. I have met Dr. Andrew Wakefield, the gastroenterologist, and had many different discussions with him. He was the first one to mention a pill cam. We finally have a doctor in our community that knows what it is and uses it! My son's issues were finally medically confirmed today! A diagnosis is to follow, a name for his pain and problem . . . not for him.

Healing can only begin when you know what the issue really is. If you don't, then the enemy will convince you it's your choice to be this way. I choose to acknowledge that I have autism because it helped me understand me, which is helping my children and I in many ways. One of those ways is letting us get closer to obtaining appropriate medical care. Another is getting closer to other amazing parents, both on the spectrum and not.

Having children inspired and motivated me to become a better person in the areas of career, financial goals, normal stuff. But having autistic children has made me not only want to be a better person, but also help the world become a better place for all our children, now and in the future.

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

Susan Henderson

November 9, 2015

I am the mother of [PII redacted], who was born May 10, 1993. [PII redacted] has severe autism, moderate mental retardation, and epilepsy. He has many disruptive behaviors, is aggressive towards others, and has extensive self-injurious behaviors. Due to his disabilities, I have been his main caregiver his whole life, and this has affected my life, my husband's life, our daughter's life, and Joseph's life in many, many ways.

Our family has taken two vacations in the last twenty years. We have been unable, as a family, to attend plays, concerts, family events, movies, and many other activities that are normal parts of everyday American life. Although I have a college degree, I have not been able to work due to [PII redacted]'s needs. Due to the severity of [PII redacted]'s behaviors, it is extremely difficult to find caregivers to stay with him for more than a few hours at a time. Waiting lists for services are years long, and payment to providers is woefully inadequate. We need help, yet at this time services and provider payments are being cut, facilities are being closed, and the future is frightening.

Chanda Jackson

November 9, 2015

Hello, my name is Chanda Jackson. My son is now 7 years old and severely affected by "autism". Why are IACC meetings so scarce? As the rate of autism continues to increase, your meeting decrease. Why?

What have you done to investigate William Thompson's claims of intentionally hiding a link between the MMR and autism rates for black children?

How many more of our babies will be injured before you do something?

Vaccines cause autism. The research is there. It's no longer a scientific debate. It's political. And until parents are informed, autism will continue to wreak havoc on our children.

Thank you for your precious time.

Chanda Jackson

This is my third written comment to the IACC. I will reiterate briefly the points from my last letters, adding some thoughts along the way:

1. The increasing numbers of autism diagnoses among the lowest functioning are not related to better diagnosis or to wider understanding of the condition. Where were the multitudes of nonverbal adults just one generation ago? Where were the folks who couldn't provide the most basic self-care for themselves?
2. To bring about tolerance and understanding, we need more awareness of the dirty, often shunned type of autism. You have the power to make people see ALL types of autism, not just the high functioning.
3. Medicaid waivers need to have portability between states. Parents waiting for residential treatment for their children or placement in group homes for their children are locked into their state. Medicaid waiver wait lists are FAR, FAR, FAR too long. My eight year old son bites strangers, family, and even friends and teachers at school. I want him to have ABA for this and so much more. He's been waiting YEARS. YEARS.
4. There is too much infighting between the vaxers and anti-vaxers. The vaxers wave away any concern about vaccines because "Wakefield was discredited". What about the over ONE HUNDRED studies that DO show a link between vaccines and autism that are NOT discredited? Where is the study that will PROVE that vaccines do not cause autism---- if you as a panel are so certain of it (I count very few people on your panel who are not pro-vaccination)--- then PROVE it with a double blind study that pits the rate of autism in the non vaxed community versus the rate of autism in the vaxed community. While we're at it, why not pit the general health of the vaxed community against the non vaxed community? Where will we see more auto immune illnesses, more type 1 diabetes, more adhd? MMR has been studied somewhat. Thimerasol has been studied somewhat. What about aluminum? What about the HUGE increase in the NUMBER of vaccinations on the current CDC schedule? What about studying the effects of environmental factors on children who have MTHFR? Mitochondrial issues? What about studying the fact that mercury was found in hair samples of children recently diagnosed with autism? Do all diabetics need the same amount of insulin? Do all cancer patients need the same amount of radiation? Then why is it acceptable to give the SAME vaccination, and the same vaccination schedule to a 4 pound newborn and an 8 pound newborn? The last time I wrote I gave you a link showing a study that every time a new vaccine with human DNA was introduced, the autism rate went up starting with children born that year. We need more studies along those lines. EVEN IF WE WILL NOT LIKE THE RESULTS and the entire vaccination schedule needs to be completely revamped. Far too many parents of children with autism have stopped vaccinating. Vaccines are far too dangerous until we can PROVE that vaccines are NOT the cause of the horrendous infant mortality rate in America, along with autoimmune diseases, type 1 diabetes, adhd, and yes.... Perhaps AUTISM.
5. I would like to see parents of those severely affected with autism on the IACC.
6. We need access to hbot, GcMAF, immune therapies, and ABA. Why is insurance coverage so limited for the wealth of treatments we COULD be utilizing? Far too many parents are paying out of pocket for what WORKS to recover our children. Why can't insurance pay for a wealth of options when our children are young and their brains are most malleable? We need cannabis legal in every state, as a valid option for families dealing with autism.

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

8. The last percentage I saw showed that 84% of autism research was duplicative in nature. You don’t know what parents want to see you research? ASK US! How about an online survey--- one for parents. One for high functioning autistics. One for teachers of those with autism. ASK US what you should be doing. As far as we can see, you’re not doing much of anything. With all due respect, this is your ONE meeting in 2015? That is unacceptable, as the rate of autism grows at such an astounding pace.

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

Thank you for your consideration.

Heather Price

Cleveland, OH

Parent to eight year old twins on the spectrum



Our organization is Educate. Advocate. We educate ourselves as parents and caregivers so we can advocate for children with special needs including autism. We are a statewide organization primarily based in the Inland Empire (San Bernardino and Riverside Counties) of California. We are a member organization with the Lanterman Coalition.

The purpose of submitting public comments today is to alert you to a whistleblower at the CDC, Dr William Thompson. A few weeks ago a rally (we sponsored) was held in Atlanta at the CDC. Dr. William Thompson gave data to Congressman Posey who spoke on the floor of Congress testifying that scientists at the CDC were instructed to trash data that showed a link between the MMR and autism with African American baby boys under age 3 (36 months). Here is Congressman Posey <https://youtu.be/qxr-cv-Jul8>

We want the IACC to reach out to legislators to get them to subpoena Dr. William Thompson so we can get the truth in a hearing. We want IACC's assistance in making certain both the states and federal government cease the coordinated efforts in pursuing vaccine mandates when the truth about the safety of vaccines is being suppressed and vaccine manufacturers face zero financial liability when vaccines injure our children or kill them. Many of our families with children with autism were injured by vaccines. Families with children with autism deserve the truth. At long last. It is time.

Thank you for your attention to this issue.

On behalf of the families we serve,

Kristie Sepulveda-Burchit
Executive Director, Educate. Advocate.

VIAL PRESENTS *Rally Demanding*
TRUTH TRANSPARENCY & FREEDOM
 CDC | ATLANTA, GA | OCTOBER 23-25

Please join us as we generate a new paradigm of **TRUTH, TRANSPARENCY & FREEDOM** within our regulatory agencies starting with the **CDCcrimes!**

In addition to our rally-happenings, this day, *we will stand united* to call for the CDC to come forth with the truth.

#HEALTHFREEDOM | #CDCWHISTLEBLOWER | #2MANY2SOON | #HEARUS

DAY 1 | RALLY

FRIDAY, OCTOBER 23 2015 | 7AM - 2PM

CDC HEADQUARTERS | 1600 CLIFTON ROAD, ATLANTA, GA

DAY 2 | EVENTS

SATURDAY, OCTOBER 24 | NOON - 4PM

GRANT PARK | 840 CHEROKEE AVE. SE, ATLANTA, GA

LINEUP:

MINISTER TONY MUHAMMAD
 ERIC GLADEN
 STACEY FRANCIS
 LYN REDWOOD

BARBARA LOE FISHER
 DR. BRIAN HOOKER
 ALISON FOLMAR
 ALL STAR BLUES MESSENGER
 RON CUMMINS

ROBERT F. KENNEDY, JR.
 DR. TONI BARK
 MARCELLA PIPER-TERRY
 THE REFUSERS

DAY 3 | INTERFAITH PRAYER

SUNDAY, OCTOBER 25 2015 | 9AM - 10AM

MUHAMMAD MOSQUE #15 | 3642 CAMPBELLTON RD., ATLANTA, GA

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

Dwight Zahringer

November 10, 2015

I am the parent of a 4 year old boy named [PII redacted] with severe autism. His condition is not a gift, nor did God place a special child in the hands of special parents. We do not value his condition and wish it never would have happened. We are frustrated by the lack of compassion from governmental resources, big insurance and educational resources. Frequently I am told that *"everything happens for a reason."* That this was something that *had* to happen in order for him to grow. For my family to grow. That's the kind of [offensive language redacted] that destroys lives. And it is categorically untrue.

Autism affects the entire family.

[PII redacted] was diagnosed with severe autism one year ago November 15th 2014. We knew after his 1st birthday routine trip to the pediatrician that something was wrong shortly after him receiving his Pneuma Conj 4, Hep A1, MMR1, Varicella 1 and Influenza all on the same day. He cried, was fussy and miserable with a fever for days. Our pediatrician told us that his reaction was normal and a week later on an additional concerned visit, was given his 2nd Influenza vaccine.

We were reassured any delays were "normal" as boys grow and communicate at a much slower pace than girls do. All his other progress for growth was on track and had been. Our first child was a girl so the Dr said we were spoiled with her progress. So we listened, placed full trust in the Dr. as that is the way we were raised. With his reassurance we continued on his vaccine schedule and check-ups. As the year progressed [PII redacted] did not. In September of 2013 after another Influenza shot we watched our fussy child over the next two weeks slowly lose interest, eye contact and increasingly slur word like mom and dada that he once said pretty well. Again the Dr reassured us that it was normal, but yes, his speech did seem delayed so wrote us a script for speech therapy and was suggested to utilize public services, which we did. [PII redacted] was now tippy toe walking, moaning, and hand flapping with no verbal words. Our speech therapist from the Macomb Intermediate School District in Macomb County, MI suggested that he may be on the spectrum but these were also traits of young boys with communication delays.

That December my employment took me to Mexico and I brought my family but only after seeking and placing both my 5 year old daughter and 3 year old son in an IB international school near our home. The school provided a mixed curriculum of both English and Spanish 5 days a week. For the next 6 months they attended school in proper grades full time and my family worked with my son nightly to help him learn to say simple words. We tried to help him grasp motor skills like holding a fork or a sippy cup that he once could. We tried many things with little interest or results.

That June when returning to Michigan we visited the Dr. and got a script for an assessment for Autism. We then learned that in order to seek treatments through insurance or public assistance we needed a valid assessment from an accredited facility, approved by my insurance United Health Care HMO. We had two options through the DMC or Henry Ford. After calling both I was informed that I was on a 4-6 month waiting list for an assessment. At this time I enrolled my son in speech and OT all at the expense out of pocket reimbursing myself with the what was left in my HAS while waiting for his assessment. He attended speech and OT three times a week each during this time.

Late in September we received a call for a cancellation in October and took it. On November 15th 2014, 3-172 weeks after my son's assessment we were told he had moderate to severe autism. At 8 AM in the

morning we were the first appointment with the Psychologist at the DMC. By 8:20 we walked out the door with a poorly copied packet explaining what autism was in brief, treatments like ABA, speech and OT that he should receive to better his chances of correction and had a short list of providers we should call. We were reminded that the best opportunity for treatment was in the next two years of his brain developing and to have him start as soon as possible. To try and get as much service as we could for him and that it could exceed 40 + hours a week if insurance would cover it or we could find the means.

Upon returning home I called the numbers only to be placed on 12-24 month waiting lists. Calling the insurance company I only learned about our coverage after providing proof his is certified assessment. After meeting our \$4,000 family deductible and our \$8,000 out of pocket maximum we could receive ABA services not to exceed \$60,000 for the year. And each session came with a \$60 co-pay even after the premium was met. (for nearly \$1,100 per month premium with UHC for a family of 5.)

I was not able to get additional speech or OT from the state of Michigan because they tell me the 1 hour a week in a group of four children is the required therapy he is by law to receive. That gives him 15 minutes of both speech and OT per week provided for by the government. From my tax dollars that is all he gets.

Only by chance in conversation with a co-worker did I learn about an ABA service provider in Chicago, IL that I was put in touch with. Through some string-pulling I was aligned with a provider local to me and had my son start receiving in-home ABA in early December. I also had him continue on with speech and OT 2x per week. We already had him full time 5 days a week at our school special education program as well. By the first week of 2015 [PII redacted] was receiving as much as 32+ hours of ABA, 20 hours of school and 4 hours of both speech and OT 6 days a week. Whenever a therapist could do an extra session we accepted on Sundays as well.

This crippled our family for almost everything: family relationships, friend relationships, play-dates, birthdays, employment and time our other two daughters, 6 and 2 years old. And our son, he has been beat for nearly 11 months now mentally.

In May we had full genetics on him and the results were negative, no fragile x or other disparities. All normal and at a cost of almost \$5,000 out of pocket. UHC says it was not a needed test.

That same month I learned about a petition in Michigan to have autism covered under the Michigan Medical Marijuana laws as a treatable condition. Never being one to partake in illegal substances I paid an attorney to explain the petition and the in's and out's of the laws, treatments and introduce me to other parents in the same position. This is when I learned there is a very, very large underground movement for the use of medicinal cannabis for the treatment of autism, epilepsy and other neurological conditions. Parents that illegally grow and share cannabis oils to provide to their own and other children who see real results.

In June I traveled to Colorado for the Autism Alliance's annual conference to do more research on Autism and cannabis. There was no chatter at the conference but the city's dispensaries, caregivers and medical community spoke openly about utilizing cannabis to treat ASD with success.

When returning home I became a part of that movement and after placing my family and my son on the front page of the Sunday paper. Later that month we put him on national news and press at the hearing. Michigan's regulation arm, LARA toyed with the petition. They misplaced over 800 pages of scientific and peer research with testimony of top pediatric neurologists on the benefits of using cannabis to treat ASD.

After the LARA appointed committee was allowed to review the evidence they later voted 4-2 in favor of allowing medical cannabis to be a treatable condition for autism in the state of Michigan. The first in the country. A short month later in August the new director of LARA denied his own appointed members' suggestion. Any legal chance for me to try cannabis under the guidance of two medical physicians was taken from me.

Now in September and October we are navigating mis-billing code approvals. While his ABA continues along with school, speech and OT have met their limits. I've been navigating United Health Care's external service providers who are mis-informed that all related autism services do not fall under mental health services and should not have limits in the state of Michigan. This has been going on for nearly 60 days with delays in return calls, no urgency while my son lacks the services he deserves. And now we are back in waiting lines to even get the opportunity to get speech again as the waiting list is over 6 months at best.

In October after a 6 month wait I had an appointment with the chief of pediatric neurology at Children's Hospital in Detroit, MI to review my son's assessment, MRI and condition. I waited six months to be told in 8 minutes that we are doing all we can, we should try cannabis oil but don't get caught. I was told to find on elf the Pot Dr's that would grant my son's condition to fall under one of the approved conditions of the Michigan Medical Marihuana qualifications. That this should be easy to find and obtain. He also suggested to try some ADHD pharmaceuticals, because it's normal for autism and that we should also prepare for his entry into puberty the realization that a group home may be his destination as an adult. We should speak to a financial planner to also look at options to saving for this.

That was the outcome to speaking with one of the top Dr's in Southeastern Michigan. No empathy. Just a drug push to calm him his symptoms of autism.

So I attempted to fill the prescription however, learned that the ordered ADHD drug was not a brand name covered by my insurance. That I would need to call the Dr and have him write the script for another covered version of the medicine unless I wanted to pay the \$278 dollars for a 30 day supply. Once placing that call the following day to the Dr. I was informed that he prefers to only prescribe one of two brand names. Now I was caught in a pickle match between the Dr and the insurance company kick-back monetization.

During my continued education this past year on Autism coverage in the state of Michigan, I learned that most insurance providers (including United Health Care) are reimbursed for all paid autism services by a special state fund. All while I still pay the \$60 co-pay per session and my monthly coverage premium. Is this fair? My tax deduction for health care won't even put a dent in my out of pocket costs when I file for 2015.

Being that many of you are professionals in the field you have been exposed to all types of the spectrum. You have heard the stories, witnessed the pain of an adult or a child with sensory overload and seen the terror in their faces.

I'm here to inform you that Autism is a family disease. It is not easy since you cannot understand "what" it is that you are trying to correct or treat. When our loved one hurts, especially a small child it effects the entire family. As parents we are helpless other than to try and comfort and search for answers. As siblings, they reach to comprehend "why" their brother won't speak to them, or answer when they call. They are confused when he approaches them and pinches their arm or face out of his personal communication frustration.

As parents once the initial shock is over you are told to navigate a complex system of forms, auto attendants and hourly-wage monotone people who “add us to a list” that can span 12, 24 to as much as 36 months to seek treatments. As advocates for our family member with ASD we must understand billing codes and preauthorizations that do or do not fall under the autism umbrella (even when they are supposed to) or are mislabeled only to be treated with uncovered bills that were issued by people with no feeling to my situation when we call. And all this is to be done in our free time, in-between work conference calls, sales appointments and such trying to maintain the source of income and insurance that will allow our family to survive. To allow our family member a chance to possibly lead a normal life.

Has ABA helped? Yes to an extent. But we have not gotten to the root of the cause. We’ve changed his diet to remove Gluten and refined sugars. Helps his health but not his autism and stims. I suppose he is better off now than if we did nothing at all. But what am I trying to correct? What is broken, misaligned? No one can tell me for sure. Some days I feel that I may be better to list therapies on a wall and throw darts to determine what I should invest the little money we have left in.

When is the last time one of you had to break down and shed a tear to your boss, or a client explaining that you’ll bounce back and be better at your job in fear of them replacing your position or funding? At 40 years old I never thought I’d have to fear the financial stability of my family.

Autism has brought me to my knees, and I know I am not the only one living through this. My situation is probably much better than most families with autism. I sit and wonder what his future holds if he cannot get better. Who will take care of him when we pass? Do I need to place the burden on his siblings or assume my state will provide fully for him? I hear the horror stories from actual people with adult children on the spectrum who “grow-out”. These are a few of the things that keep parents like me up aside from our children’s night terrors or irregular sleep schedules.

We need answers. We need information on how we can better understand the condition and potentially treat ASD for each individual- at all ages. We need better insurance coverage from private and public outlets. We need clear-cut, easy to understand coverage with no loop holes or paybacks for premiums we already cannot afford. We need your full attention of this epidemic that is increasing every year. We need solutions now.

We need more funded studies on treatments involving natural CBD/THC from cannabis. We need you to solicit and hear the stories from parents with children on the spectrum who have successfully treated their family member’s conditions with cannabis. How did they do it? What was to dosage, who gave oversight and what were the results? Some I’ve met have even claimed a reversal of autism.

The medical community keeps saying that vaccines do not cause autism. Vaccines are good for kids. They also say that cannabis is not good for children but cannot tell me why. None can tell me why there is a vaccine court, why the vaccine manufactures and Dr’s have immunity to damages from their drugs and oversight.

I’m not here to fight the vaccine controversy, or the war on drugs. What is done is done, I need to get my son help. I’m here to hold you accountable.

You all have agreed to be on this committee and have a job to do. This involves obtaining, soliciting studies, managing them, the data they collect and how to best use that data and share with the public. I enlist each of you to seek answers with compassion. Having year-long lapses in meetings and the sharing

of information to families like mine is inexcusable. You need to be accountable for your agreement to be on this committee and not just use it as a segway to another job, seat on a board or a resume builder.

The prevalence of autism in U.S. Children increased by 199% from 2000 (1 in 150) to 2010 (1 in 68). (CDC 2014) Autism is now the fastest-growing developmental disability in the United States.

We, the parents and families and individuals with autism spectrum disorder need to know what you are doing about this epidemic?

—

Dwight Zahringer
Clinton Twp., MI
[PII redacted]

Thanks to C-Span, America is watching. Can you hear us scream at our TV screens as you pat each other on the backs for just showing up? When our son was diagnosed in 1995, the rate of Autism was 1 in 10,000, per the CDC. Today, the rate of Autism is 1 in 50. The statistics would say that the IACC is a failure.

Government waste is unfortunately no shock or surprise and Americans can expect no accountability. What angers Autism parents is that the IACC has effectively wasted precious time and a billion dollars on the backs of our children and unborn kids by running in place and doing nothing to stop or slow the rate of Autism growth.

The IACC has failed to determine the causes of the enormous increase of the prevalence of Autism. It failed to prevent a single case of Autism, and failed to produce any new biomedical treatment for Autism. The IACC failed to ensure even basic safety protocols for people affected by Autism who “wander”, unfortunately some to their deaths. Overall, the IACC failed the families facing Autism – most especially the approximately one-third of families with children most severely affected by Autism, who literally cannot speak for themselves, and whose severe disabilities portend one of the largest unfunded Federal fiscal liabilities of the 21st century.

From our view, the IACC members talked a lot about problems and the lack of services for those affected by Autism. That was not an “AHA moment” for parents because that is a daily reality we encounter. There are inconsistencies in standards for the delivery of Autism services (i.e., academic, social, medical, training and employment) from one state to another, from one school district to another, from one county to another. Some school districts extend their services after high school with an 18-22 year old program, while others allow their high school special needs students to “graduate” to the couch when the school’s academic responsibilities end. These inconsistencies make it difficult to impossible for parents to navigate as they try to relieve their child’s physical pain, push for modifications to academic curriculum and provide for social interaction and acceptance. Unfortunately, parents and families are left to dangle on our own.

When our son was in the depths of his Autism, we had him in a local elementary school class. The number of kids being diagnosed with Autism was increasing daily and the wave of children affected by Autism entering the school district increased at an alarming rate. Our family was forever changed by our son’s regression into Autism with his medical issues, bowel issues, behaviors, lack of sleep, and loss of language. At one meeting, a teacher said that “This is hard!” Our answer was “[Offensive language redacted]!” The same answer applies to the IACC. Your platitudes and back-slapping did nothing to serve the countless children affected by Autism and their families, your failure to develop public policy proposals and your waste of precious funding has exacerbated the Autism epidemic. You failed to call for studies of vaccinated vs. unvaccinated children and follow the leads that parents have been screaming for.

Please listen to the parents of all these children, or simply continue to pat each other on the back, which is what we’ve come to expect. The Autism epidemic will not be solved with silly platitudes. Bold action and leadership is needed now. The IACC’s inaction has exacerbated the Autism epidemic. For the sake of America’s children, the time has come for the IACC to become part of the solution.

Sincerely,

WILLIAM & KAREN FULLER

Yuba City, California

1 in 50 American children are affected by Autism, including our son.

Subject: Medical Error

MEDICAL ERROR

Clamping the umbilical cord may be the most horrific medical error of all time.

If clamped before the first breath, a brief period of asphyxia will occur. Evidence of auditory system damage from 8 to 12 minutes of asphyxia was published in the medical literature decades ago. Why has this evidence been overlooked for so long?

Auditory system damage caused by asphyxia was considered to be minimal. Monkeys subjected to asphyxia at birth were delayed in early motor milestones, but with time appeared to recover completely.

I have asked Dr. David Amaral to repeat the experiments on asphyxia at birth. MRI can now be used to look for brain damage, and follow brain development in monkeys subjected to asphyxia at birth. Also, the University of California in Los Angeles has movies made by WF Windle of motor development. These should be looked at.

In addition to asphyxia, clamping the cord will cause capillaries to burst at the fetal-maternal interface in the placenta. This leads to maternal antibody formation. This is what happens when an Rh-negative mother gives birth to an Rh-positive infant.

ABO incompatibility is now considered to be the cause of many problems, including allergies and development of homosexuality.

Traditional textbooks of obstetrics all taught that pulsations of the cord should cease before it is tied or clamped. Pulsations are evidence that the fetal heart valves have not yet closed (ductus arteriosus and foramen ovale).

Clamping the umbilical cord is unnatural and brutal. Medically trained members of the IACC should be able to understand this, and the dangers it poses, especially for brain damage.

--

Conrad Simon Memorial Research Initiative

To seek understanding of brain system impairments in autism.

<http://conradsimon.org/>

Jessica Dowler

November 10, 2015

I am the mother of three boys, all diagnosed with severe autism. My children are ages 19, 12, and 5. We live in Ohio.

My 19 year old son has a history of severe aggression, including injuring both his father and myself severely multiple times. My oldest son doesn't have the ability to initiate communication, including his most basic wants and needs. His behaviors are so severe that we cannot place any demands on him, and his school does not work with him. I wish I could say that my son's story is unique, but it isn't. Severe autism gets overlooked. Why? No one knows what to do for an individual with severe autism. No one wants to admit that there are individuals so severe that they injure family members. It is similar to domestic violence, where the outside world can see what's going on, but they choose to ignore it. Thousands of parents are taking care of their severely autistic child, and in some cases multiple severely affected children. They get no help, no respite, cannot work, have no friends, and cannot leave their home. They feel isolated and alone, and no one is listening to their cries for help. IACC needs to acknowledge that the needs of individuals with severe autism are extensive. These parents need help and support now.

With the new CMS changes, I am very concerned with the inclusion of all individuals with developmental disabilities. Inclusion can be a wonderful thing, but for a small percentage of the population, it will not work. I hope that the IACC can look into options that are best for individuals based on their unique needs. Severely affected individuals will not get the intensive care they need in an inclusive setting.

My oldest son was seven years old when I gave birth to my second son. I was very concerned that my second child was at risk for autism, and learned as much as I could about autism prevention. There was not very much information available on autism prevention in 2003, so I did the best I could. When my second child regressed into severe autism, I knew what to do to get him services. He got early intervention, and all the supports he needed. Now, at age 12, he is only mildly affected, and is very independent.

When I unexpectedly found out I was pregnant with my youngest son, the first thing I thought of was, "He will have autism too." That very day, I began to research autism prevention. There was more information available in 2009, so I was confident that I would be successful. From birth, my son received many preventative interventions including medical, play therapy, ABA, and sign language. He was advanced for his age, and completely neurotypical until 26 months, and then he regressed into severe autism. He was the most severe out of my three children. Immediately after he regressed, I got him into an EI program, into a psychologist for an autism evaluation, and into therapies. I acted immediately, and I know that is why he is doing so well today.

Within just a few short weeks of his regression into autism, my youngest son had interventions in place to help him, he was in the process of being evaluated for autism, and was admitted into a school for children with autism. He had a medical evaluation by a pediatrician specializing in autism. I provided my youngest son with intensive home interventions as well, so he had round the clock programming. It wasn't easy, it was very expensive, and I am not sure how I was able to find the time to and energy to provide him with that amount of programming. It was worth it completely, as within a year, my youngest son was only presenting with minor delays.

What if every parent knew what to do after their child regressed into autism, or when they felt concerned their child wasn't developing appropriately? What if pediatricians knew what to do to help families get started with the process of an autism evaluation? What if there was a national committee that had the influence and ability to create a universal system for pediatricians, physicians, schools, and therapists? What if everyone had the information they needed to get help for their child? What if insurance covered the therapy and interventions needed for autism, including early and intensive interventions? So many individuals with autism would have a better outcome if this happened.

As a parent who has lived with autism for over 19 years, the biggest obstacles I see in the community are a lack of intensive, early intervention programs, a lack of services for children and adults with severe autism, insurance coverage for autism interventions, and a lack of anyone talking about autism prevention.

As the rate of autism continues to increase, I beg the IACC to address these issues, and help the thousands of individuals and families affected by autism.

Sincerely,

Jessica Dowler

Marcy Mullins

November 10, 2015

First, let me thank you for FINALLY holding a meeting to discuss the FASTEST growing public health crisis that no one wants to talk about -- AUTISM.

I have lived it for the past 14 years with my beautiful and amazing son. He is the love of my life and I will never stop fighting for him - but the question is - why should EVERYTHING be a fight? From medical care, to therapy, to treatment, to school, to LIFE. Why should it all be a fight? There are millions of dollars allocated to your agency alone to help us, and yet, no meeting for FOUR years.

This is despicable treatment for our families that live with Autism everyday - and the numbers are growing.

I BEG YOU - please find out the answers and HELP families. Autism is NOT going away and one day, our administration is going to realize that an entire generation of children has been harmed and will NEVER be productive members of society, and the parents of those children? What will happen to them? They will also no longer be productive members of society because they will have to quit their jobs, to care for them. When the parents are gone, who will do this? NO ONE. This is a bleak future for our kids/adults with Autism, and no one will listen. NO ONE will help.

PLEASE - just listen to parents, ask what they need, and HELP. We don't have telethons, we don't have the NFL wearing a special color to support us. Our children - 1 in 68 at last count - are lost - and WE NEED HELP.....

Sincerely,

Marcy Mullins
Cincinnati, OH

Laura Cellini

November 10, 2015

Thank you for the opportunity to submit a written comment. We are the parents of a seventeen year old, who developed moderate to severe autism after regressing, losing more than a year of developmental milestones and the ability to communicate at age two. We are very fortunate that through appropriate diagnosis and treatment of co-morbid medical conditions, our son has made tremendous progress and his symptoms of autism are nearly nonexistent.

As the parent of one of the children who would recover from autism while he had a fever, I applaud the IACC on any studies designed to elucidate answers on the role of fever, immune activation and the central nervous system. However, we need more in this area. Especially, in the population of children that regressed. While some cases of maternal infection may impact the immune system of the fetus, there must be other factors to consider for the sub-cohort that regressed. We need studies on why some children develop seizure disorders when they hit puberty. We need more on biological marker changes in the first two years, such as changes in cytokine expression, microglia activation, cerebral folate deficiency, autoantibodies, and mitochondrial disease markers.

It is my hope that the IACC will begin to recognize the myriad of co-morbid conditions of children with ASD, promote the accurate diagnosis and treatment of these conditions and recommend a "standard of care" that reflects these issues. For far too long autism has not been well understood by the medical community and far too often underlying medical conditions are ignored. It is often stated that some of the more promising biomedical interventions are too controversial or not evidence-based, the consequence being that scientific inquiry lags and a generation of children suffer. Children with autism deserve to have proper assessment, diagnosis and treatment of underlying and co-morbid conditions. Health care providers need immediate training in recognition and treatment for pathologies and abnormalities that occur more often in children with autism than the general population. Recent meta-analyses and numerous peer reviewed publications confirm these findings.

It's no longer sufficient to simply define "autism" as a disorder affecting behavior, social and communication. It is a whole body disorder. Scientific inquiry has provided many answers to the mystery, it's time that we acknowledge them. My family and more importantly, my child, is a stakeholder in this epidemic. Please see the following information which contains a small fraction of the types of studies we would like the IACC to support and encourage.

Sincerely,

Laura Cellini

Springfield, Illinois

Attachment

Emerging Science Shows that Autism is a Medical Condition Affecting the Whole Body

Scientific investigations have now shown that co-occurring medical conditions can occur more commonly with persons diagnosed with autism, including;

- Autoimmune Conditions
- Gastrointestinal Disease
- Immune Dysregulation
- Metabolic Abnormalities
- Mitochondrial Dysfunction
- Neuroinflammation
- Seizure Disorders

Selected Scientific Studies:

Autism is clearly a multi-system disorder that impacts the brain, the immune system, the gastrointestinal tract, and other organ systems.

Consensus Paper: Pathological Role of the Cerebellum in Autism, S. Hossein Fatemi, et.al The Cerebellum September 2012, Volume 11, Issue 3, pp 777-807

“The scientific evidence is quite credible for our autoimmune hypothesis, leading to the identification of autoimmune autistic disorder (AAD) as a major subset of autism. AAD can be identified by immune tests to determine immune problems before administering immunotherapy.”

Phenotypic expression of autoimmune autistic disorder (AAD): a major subset of autism. Singh VK. Ann Clin Psychiatry. 2009 Jul-Sep;21(3):148-61.

“For patients with ASDs, a detailed history (including personal history of allergic disease, dietary history, and family history) and physical examination should be performed to accurately identify potential co-morbid allergic disease... The role of immune responses in the pathogenesis of gastrointestinal disorders with ASDs warrants additional investigation.”

Consensus Report on Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs, Buie, et.al.

www.Pediatrics.org

“ASD patients displayed an increased innate and adaptive immune response through the Th1 pathway, suggesting that localized brain inflammation and autoimmune disorder may be involved in the pathogenesis of ASD.”

Elevated immune response in the brain of autistic patients. Li X1, Chauhan A, Sheikh AM, Patil S, Chauhan V, Li XM, Ji L, Brown T, Malik M. J Neuroimmunol. 2009 Feb 15;207(1-2);

<http://www.ncbi.nlm.nih.gov/pubmed/19157572>

“Extensive alterations in immune function have now been described in both children and adults with ASD, including ongoing inflammation in brain specimens, elevated pro-inflammatory cytokine profiles in the CSF {Cerebral Spinal Fluid, sic} and blood, increased presence of brain-specific auto- antibodies and altered immune cell function. Furthermore, these dysfunctional immune responses are associated with increased impairments in behaviors characteristic of core features of ASD, in particular, deficits in social interactions

and communication. This accumulating evidence suggests that immune processes play a key role in the pathophysiology of ASD.”

The role of immune dysfunction in the pathophysiology of autism. Onore, Careaga, Ashwood Brain, Behavior, Immunology, Vol. 26, Issue 3 <http://www.ncbi.nlm.nih.gov/pubmed/21906670>

“While the etiology of ASD remains unknown, various clues suggest a possible association with altered immune responses and ASD. Inflammation in the brain and CNS has been reported by several groups with notable microglia activation and increased cytokine production in postmortem brain specimens of young and old individuals with ASD. Moreover several laboratories have isolated distinctive brain and CNS reactive antibodies from individuals with ASD. Large population based epidemiological studies have established a correlation between ASD and a family history of autoimmune diseases, associations with MHC complex haplotypes, and abnormal levels of various inflammatory cytokines and immunological markers in the blood.”

Immunological and autoimmune considerations of Autism Spectrum Disorders. Gesundheit B1, Rosenzweig JP, et.al; Autoimmun. 2013 Aug;44:1-7. doi: 10.1016/j.jaut. 2013.05.005. Epub 2013 Jul 15.

“This supports the possibility that some forms of autism could be a manifestation of a genetic predisposition to abnormal methionine/glutathione metabolism and oxidative stress. Further, the abnormal metabolic profile observed in a significant proportion of autistic children suggests the provocative possibility that some autistic behaviors could be a neurologic manifestation of a genetically-based systemic metabolic derangement.”

Metabolic endophenotype and related genotypes are associated with oxidative stress in children with autism, S. Jill James, et.al. Am J Med Genet B Neuropsychiatr Genet. 2006 December 5; 141B(8): 947–956.

“Autism spectrum disorder (ASD) has been associated with mitochondrial disease (MD). Interestingly, most individuals with ASD and MD do not have a specific genetic mutation to explain the MD, raising the possibility of that MD may be acquired, at least in a subgroup of children with ASD.”

Unique acyl-carnitine profiles are potential biomarkers for acquired mitochondrial disease in autism spectrum disorder; R E Frye, et.al. Translational Psychiatry. 2013 January; 3(1): e220

“In this exploratory study, children with autism were more likely to have mitochondrial dysfunction, mtDNA overreplication, and mtDNA deletions than typically developing children.”

Mitochondrial dysfunction in autism. Giulivi C1, Zhang YF, Omanska-Klusek A, Ross-Inta C, Wong S, Hertz-Picciotto I, Tassone F, Pessah IN. JAMA. 2010 Dec 1;304(21):2389-96. doi: 10.1001/jama.2010.1706. <http://www.ncbi.nlm.nih.gov/pubmed/21119085>

“A key concept that has emerged during the past 40 years is the strong association between intellectual disability and a higher prevalence of epilepsy in individuals with ASD. In addition, the two peaks of seizure onset, one in early childhood and one in adolescence and continuing through adulthood may be unique to individuals with ASD.

Autism and epilepsy: historical perspective. Tuchman R, Cuccaro M, Alessandri M. Brain Dev. 2010 Oct;32(9):709-18.

Autism Society Central Ohio (ASCO) offers this written statement for the Interagency Autism Coordinating Committee meeting on November 17, 2015. ASCO continues to have the following concerns about the diagnosis, treatment, education, employment and acceptance of individuals with autism in the United States.

- Delayed diagnosis, misdiagnosis and delayed treatment of autism, particularly for children of color and poverty.
- Lack of access to appropriate intervention and services in rural areas.
- Lack of appropriate special education services in our public schools, despite IDEA. Many schools continue to operate on outdated assumptions and models which are not appropriate for those with autism. Systems designed for those with intellectual disabilities often fail to provide appropriate education for students with autism, 48% of whom have average or better IQs. Many children with autism are able to function academically, but need intervention for social, organizational and communication deficits. Certain schools, however, deny that any intervention is needed if children are achieving passing academic grades. The long term effect of this failure is the inability of graduates to function independently in college and in the workplace.
- Lack of training and education by educators and law enforcement which leads to improper disciplinary action for those with ASD. Too often, schools regard disability-related behaviors as voluntary actions requiring suspension and detention (rather than intervention) and the involvement of law enforcement.
- Lack of appropriate employment opportunities. Due to the broad spectrum of autism, it is essential that customized employment services be developed and implemented in every community. The outdated model utilized by most states of placing those with disabilities in jobs as grocery baggers, cleaning staff and dishwashers, means that many qualified individuals with social and sensory deficits remain unemployed. Models promoting creative placements and self-employment must be developed and implemented. Moreover, it must be recognized that there are those for whom a segregated, sheltered employment environment is the least restrictive alternative due to behavioral and sensory issues and such must continue to be provided. A continuum of employment services must be developed and offered to every individual.
- Lack of appropriate medical, dental and optical care for adults with autism. Many adults with disabilities have no place to go once they are dismissed by their pediatrician. We need health care practitioners trained in the management and treatment of adults with autism. We also need more practitioners who will accept payment by Medicaid.
- Appropriate housing options for independent living with customized supports need to be developed. As the population of adults with autism increases, and their parents age, options will need to be in place for those who have continued to live in the family home due to lack of safe, affordable options in a least restrictive environment.

Very truly yours,

Kathi J. Machle

President

Kerry Lane

November 10, 2015

Subject: IACC Public Submission Autism Acetaminophen Documents

Please find enclosed peer-reviewed journal articles on the now irrefutable link between Acetaminophen acting as the trigger for regressive Autism by depletion and oxidation of Glutathione, the master antioxidant, needed for all biochemical reactions in bodily activities. The time for inaction has long passed and the IACC, FDA and all other stakeholders should urge **BLACK BOX WARNINGS** on all acetaminophen products.

Best Regards,
Kerry Scott Lane M.D.

www.PalmBeachAutismInstitute.org

Articles

[Acetaminophen \(paracetamol\) use, measles-mumps-rubella vaccination, and autistic disorder: the results of a parent survey.](#)

[Association Between Prenatal Acetaminophen Exposure and Future Risk of Attention Deficit/Hyperactivity Disorder in Children.](#)

[Acetaminophen in pregnancy and future risk of ADHD in offspring](#)

You can be the much needed change for the autism community.

In September 2015, Dr. Thomas Insel announced he will step down as a director of the National Institute of Mental Health (NIMH) and interagency Autism Coordinating Committee (IACC) (1.) This change is effective November 1, 2015.

On The TACANow blog we have written about the IACC and their efforts since inception back in 2006 . You can find those biogs here (2.).

For the new incoming NIMH, IACC Director and committee, I would like bring you up to speed on autism. It is the fastest growing disability affecting the most children in the United States (3.) A Massachusetts Institute of Technology (MIT) research scientist has made a dire prediction that autism could affect 1 in every 2 children in the U.S (4.) Autism is also expensive, recently soaring from \$168 billion to \$268 billion annually (5.)

After serving the autism community for 15 years and working with over 45,000 families, I see areas of needs that can and should be addressed. Here is a summary of changes that can help families living with autism:

- Based on CDC autism estimates, declare autism an epidemic and public emergency. We need to treat autism with the urgency it warrants: 1 in 68 children are living with autism in the United States.
- Define and collect a true census of individuals affected by autism. It is important to indicate that four year old estimates based on survey samplings do not work. Real numbers and details such as age groups and severity are urgently needed to review and address their unique needs.
- Push for subtyping to determine appropriate treatments and therapies to meet the unique needs of each individual (6.)
- Since 2006, over \$2 billion has been spent on the IACC. Families are not experiencing any changes to services or help for these costs. No innovative treatments have been found. I would like to propose the following changes to the IACC:
 - Consider a more diverse board at the IACC to include some of the world's researchers in cause and innovative treatment such as: Dr. Martha Herbert, Dr. Jill James, Dr. Richard Frye, and Dr. Dan Rossignol. It is my opinion that the current IACC board lacks in ground-breaking research and medical treatments happening today
 - Push the U.S. Dept. of Human Health (HHS) and IACC to collaborate and recognize the needs for services and support for families. We cannot operate in a vacuum.
- Collaborate with families via support groups in identifying needs for those living with the autism today.
- Outside traditional therapies, medical treatments are helping individuals with autism live healthier. Based on new research, co-morbid medical issues exist with autism. Where are the initiatives addressing these concerns to define answers? (7.)
- Identify a task force to address the current and future needs of adults living with autism.
- Prioritize and evaluate all possible environmental causes of autism.

- Operate with a sense of urgency in your strategic plan. We cannot waste another moment. We must drive for answers.

I would be happy to discuss these items in more detail with a future director of the NIMH and IACC. We need positive change. We need help for families and individuals living with autism. We can no longer afford the status quo.

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

Sincerely,
[PII redacted]
Lisa Ackerman

TACA

References:

1. Insel Departure announcement http://www.nih.gov/about/director/09152015_statement_insel.htm
2. IACC TACAnow biogs:
<http://tacanowblog.com/2015/08/07/why-would-a-government-panel-question-universal-autism-screening/>
<http://www.tacanow.org/blog/what-the-iacc-must-consider/>
<http://www.tacanow.org/blog/the-iacc-reconvenes/>
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<http://tacanowblog.com/2013/12/31/if-the-iaccs-strategic-plans-were-ieps-would-they-be-in-non-compliance/>
<http://tacanowblog.com/2013/09/09/iacc-july-2013-meeting-recap/>
3. Autism prevalence <http://www.tacanow.org/news/cdc-releases-autism-prevalence/>
4. MIT dire prediction <http://www.autismdailynewscast.com/warning-half-of-all-children-will-have-autism-by-2025/12873/laurel-joss/>
5. Annual autism costs soar <http://tacanowblog.com/2015/07/30/the-annual-cost-of-autism-continues-to-soar/>
6. Subtypes in autism <http://tacanowblog.com/2014/04/11/science-and-subtypes-in-autism/>
7. Children with autism have other health problems <http://tacanowblog.com/2012/10/15/many-children-with-autism-have-other-health-problems/>

Kerry Lane

November 10, 2015

Please find attached my Video lecture of 27 minutes on the Etiology of Autism by Acetaminophen.

Best Regards,

Kerry Scott Lane MD

<https://onedrive.live.com/?cid=1b7c87b05b2a6b51&id=1B7C87B05B2A6B51%21165&ref=button&Bsrc=Share&Bpub=SDX.SkyDrive&sff=1&authkey=!Au5KkHIHegEJqI4#authkey=%21Au5KkHIHegEJqI4&cid=1B7C87B05B2A6B51&group=0&id=1B7C87B05B2A6B51%21165&parId=root&o=OneUp>

Monica Kay

November 10, 2015

I'm hoping that with new leadership, the IACC will be able to make a meaningful contribution towards discovering the causes of autism as well as effective treatments. We cannot continue to allow the autism epidemic to rage on while public health officials do little more than shrug their shoulders. We have a nation of sick children who have been lost to autism. This is not a "behavioral" disorder, it's a medical illness. There's plenty of research available that points to the bowel and the immune system as key players in autism, yet none of this research is making its way down to the patient. There should be a protocol developed for physicians to follow when they have a patient with autism-testing for allergies, immune system work-up, bowel disease, etc. But children with autism do not routinely get a medical work up unless parents ask for it, and oftentimes, not even then, despite obvious symptoms. Children with autism are medically neglected in a way that would NEVER be tolerated in a neuro-typical child. That has to end. These children have suffered for too long. They can be recovered and this agency has to start to move in a new, positive direction to save these children. The old "lifelong condition, nothing can be done" attitude is a disgrace to the scientific community and a disservice to the autism community. Please make the IACC matter.

Sincerely,

Monica Kay

Gwen Wise

November 10, 2015

I am a parent of two children with ASD. My older son will transition in 4 years. I am very concerned because of the lack of transitional services and job opportunities. There has been a lot of emphasis on early intervention but little emphasis on the adult ASD population. There needs to be more services – health care providers that take Medicaid and understand ASD individuals, more job opportunities especially at the governmental level and more emphasis on care coordination. I believe the federal and state government should play a large role in providing employment opportunities to ASD individuals. This would provide the government with much needed information on how to support ASD individuals in the work force. There is an expectation that the private sector will hire these individuals and I do not see this happening. Also, after a child ages out of the children’s hospital system it is difficult to find healthcare providers that take straight Medicaid. This is a huge issue. And I would like to see more research on the needs of ASD adults. What type of data gather of healthcare information is taking place? What are their rates of depression, suicide, loneliness, etc.? Are they getting access to quality healthcare? Are they being integrated into the community? Are they working and what types of jobs?

Thanks you,

Gwen Wise

I am the mother of a son with severe autism. He is non to low verbal and has a host of medical issues:

- Autism (low functioning),
- Mental Retardation / Developmentally Disabled
- Hearing Loss at low tones,
- Apraxia of Speech,
- Severe Allergies and food sensitivities (gluten, casein, soy, corn, blueberries, cane sugar, grass, mold, trees),
- Failure to thrive (X5 times).
- digestive and bowel issues (gastric reflux, rumination, ulcers in small intestine especially at the terminal ileum, severe constipation alternating with severe diarrhea, low motility, inability to digest / fully break down most foods; inability for his bowel to keep *bifidus* strain alive)
- motor skill impairments (gross and fine),
- sensory integration issues (especially with food textures and clothes),
- MTHFR gene mutation (disorder of the methylation cycle and Krebs cycle)
- Mitochondrial dysfunction (need for Carnitine, B-2 and CoQ10),
- Difficulty sleeping (when reflux is an issue, when dad is not home, when bowel issues are at their worst).
- And most recently, seizures.

Because of his inability to express when he is in pain, he used to lash out at people. Now he lashes out at himself (Self Injurious Behavior). The pain component accounts for >95% of his behaviors.

He and many others like my son are not the feel good autism stories success stories portrayed on TV. My husband refers to these kids as the “ugly side” or orphaned side of autism. They are the ones requiring 24/7 care and the community needs to know that they exist. Autism for my child is not just a difference in being – it is a life threatening condition because he wanders, he lashes out after hurting himself, and he is attracted to water.

He is a classic case of regressive autism and a mirror to the Hannah Poling case. But we were not doctors, so we did not know what tests to ask for at the ER following his vaccine reactions. We did not know about VAERS. My son is 1 in over 400 children descended from my grandparents and my husband’s grandparents on down. There is no other child with autism among our relatives.

What I want to see from the IACC:

- 1) Publicly announce that Autism is truly on the increase - there are many studies out there that state that this is NOT just better diagnosing OR diagnostic substitution. It is high time that the IACC acknowledge this to the public. Without this, the public will not know what hit them when the tsunami fully hits adulthood, and the **funding** necessary will not be there to take care of these kids. Because if they think there is no increase, there is nothing to worry about – funding will come from where it always has come from. So there would be no corresponding urgency to find how this can be prevented, treated, and symptoms (especially medical) can be mitigated or cured.

- 2) Publicly acknowledge that vaccines can and do cause autism. This may be difficult for you because you are under DHS, but this should have been admitted long ago.
 - There are enough cases of concession including Hannah Poling, Bailey Banks, etc.
 - In 2000, the rate of SEVERE or CLASSIC autism in my suburb was 1:150 (diagnosed at age 3 or less – children born in 1997). Of these, 3 of the boys had birthdays near each other - same month and shots given about the same time and they went to the same clinic and received vaccines from the same “hot lots.” This is the year following the HepB at birth AND the acceleration of MMR and chicken pox to 12 months of age from 15 months.
 - Call for a full OUTSIDE investigation into the CDC whistleblower story. Because there is an HUGE conflict of interest with an agency self-policing this. There again we have conflicts – the CDC mandates vaccines, is responsible for their safety AND counts the children with a 4 to 6 year delay in reporting.
- 3) Do the study suggested by Bernadine Healy – actually look at those children that became very ill from their vaccinations and became sick (REGRESSIVE AUTISM). What are the commonalities in these children?
- 4) Actually fund studies of biomedical treatments. LOOK at study design before throwing money at things. The elusive autism gene or genes will not be found without integrating environmental factors including vaccines into the mix. Look at treatments for GI issues, Apraxia of speech, different communication teaching methods, etc. Look at conflicts of those that will be authors BEFORE allotting money for a study. Look at Mitochondrial dysfunction and how to test for it PRIOR to vaccination if that issue is correlated.
- 5) Create guidance for states to give all parents respite breaks. I do not care how your child is functioning. Everyone needs a break from the caretaking role from time to time.

I could go on, but I need to send this in time.

Most of all, please get things going, not endless debates on how to accomplish your task, but break it down into sub committees and get things moving (set GOALS) – as a spectrum disorder you need to deal with ALL the people on the spectrum, not just those that can speak eloquently and what they want. For those like my son, you need to address his needs too.

Anonymous

Minneapolis, MN

Melissa Schneider

November 10, 2015

Children are still dying from Autism related wandering and drowning deaths and this year, it was reported that two children wandered and were hit by trains because the children did not understand the dangers of wandering on to train tracks.

More children died this year in the United States from Autism related wandering than had measles, yet there has been no action to prevent it, and our government, both on the state and federal level keeps pushing for unnecessary and draconian vaccine mandates with the media's assistance because of the influence the pharmaceutical industry is wielding over the media and politicians.

What is most disturbing is that the media rarely reports on these wandering deaths, yet portrays Autism as a gift that parents should embrace.

Do you think it's a gift that parents have to bury their innocent children? Do you think it's a gift that parents are going broke losing their homes, everything they have because they have to pay for medical care for their children with co-morbid medical conditions that are not covered by insurance? Do you think it's a gift that more and more children are being pushed into homeschooling because the public school system is overwhelmed and cannot serve the needs of our children? Do you think its a gift that parents are so overwhelmed in extreme cases, by the stressors of raising children with severe autism, that they are committing extremely heinous and violent acts such as murdering their children and themselves because they don't have help, and see no hope or any other way of dealing with their situation?

As the rate of Autism climbs not only in the U.S., but globally, what are you on the IACC prepared to do to prevent more cases of Autism, to help treat the medical symptoms that exacerbate "Autism", to stop the discrimination against children and families dealing with Autism?

Finally, what are you going to do separate your committee from corporate special interests, and rid yourselves of committee members who do not serve our families in the manner we desire? We want parents of children affected on the IACC panel who do not have ties to the pharmaceutical industry or vaccine industry.

The IACC lost our trust because they did not listen to us as parents. They still do not listen to us, and they do not implement policies toward saving our children's lives or helping them make progress.

This is most regrettable, that a body that has the power to affect positive change appears to parents to have been set up to prevent just that.

I understand there is a new chair and new members, but I also understand that families have been waiting long enough. We want this committee to be solutions and results oriented, not a waste of taxpayers' dollars.

Please do right by our families this time. We are observing and we can discern fact from fiction.

Respectfully,
Melissa Schneider

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

Christy Zartler

November 10, 2015

I am Christy Zartler. I have a 16 year old daughter who has severe Autism and Cerebral Palsy. She is low functioning and requires 24 hour care. She displays Self Injurious Behavior to herself and anyone who tries to intervene to help. This aggression is very hard to handle throughout the day. We have spent the last 10 years using pharmaceutical medications with very little benefit and horrific side effects. Earlier this year our Pediatric Neurologist informed us we are out of medication options.

Because we are out of prescription options I have begun researching and reading about how families are using medicinal cannabis for aggressive Autistic children like my daughter. The data that I have collected shows that Cannabis is a very effective medicine for severe aggressive behavior. There are over 78 medical research articles written in the past 5-8 years that show that it can help the Autistic brain improve. This is very exciting to me because my daughter is progressing very slowly; she has no form of communication skills at this time. Her most recent tests scores show an IQ of 20. This is heart breaking.

Another important concern learned in my reading is that Autistic people need the full marijuana plant to help stabilize their moods. Not just the CBD portion of the plant. Therefore a combination of THC and CBD oils would be the ideal medication to help the aggressive harmful behaviors. There are many anecdotal testimonies and videos all over social media showing the benefits of using whole plant cannabis for Autism.

Right now there are 23 states where medical marijuana is legal. The state I live in (Texas) has just passed a bill for CBD oil for Epileptic patients only. While this bill will help some patients, it will not help the growing number of Autistic patients. I am working very hard at my state level to educate communities and change this. Could you please do everything in your power at the National level to help families like mine?

Our aggressive children harm themselves, and hospitalize caregivers. We cannot wait for more pharmaceutical medications to be developed and tested. And who wants to be the first to try a new medication anyway? Ask yourselves if you want your child to take antipsychotics? The side effects from a cannabis plant are FAR LESS harmful then what is listed as the side effects to Risperidone.

Thank you for your time,

Christy Zartler

[PII redacted]

As founders of the non-profit group MAMMA - Mothers Advocating Medical Marijuana for Autism, we are writing on behalf our membership and our 6000+ FB followers to ask you to endorse medical cannabis as a valid treatment option for autism.

Autism is devastating, we can all agree on that. Many autism families who have reached out to MAMMA are suffering in hopeless despair because they cannot find relief through traditional medicine, diet or therapy for their children. These families are from all over the United States and are seeking the safe, effective treatment that medical cannabis offers for both the underlying medical issues as well as the behavioral symptoms of autism. As you may or may not know, there is no access unless you are 1. In a legal state and 2. You have a co-morbid condition that that state recognizes as a qualifying condition. Of the 23 states where whole plant medical marijuana is legal, none of them include autism specifically as a qualifying condition. California and Oregon have written their medical cannabis laws in such a way that doctors can recommend cannabis to people with autism (this is where we get much of our anecdotal evidence from) but parents across the whole country deserve the freedom to use medical cannabis to treat their children legally, under a doctor's care.

Autism rates have risen 14,000% since 1970. We don't know why, we don't know how to stop it and we don't know how to get help to make it better. Many of us are out of options – and have experienced firsthand that it's the alternatives to cannabis that are the dangerous drugs that we should be protecting our children from. Pharmaceuticals that are off label for autism are routinely prescribed to our children. Psychotropic pharmaceuticals that are potentially addictive are routinely prescribed to our children. Pharmaceuticals with extreme and sometimes permanent side effects are routinely prescribed to our children. And yet, autism families are routinely denied access to a plant with an unparalleled safety record because of their zip code.

Although simplistic, it is indeed true that autism is medical and cannabis is medicine. And while no medicine works in every case, we know the following about medical cannabis:

- There exists little risk of dangerous side effects (no documented death following an overdose)
- There exists abundant science, research and anecdotal evidence that points to its efficacy in autism
- Cannabis is used with pediatric patients in legal medical states and can safely be used for children with autism
- Medicinal cannabis has the potential to be both palliative and curative for autism
- US Government Patent 6,630,507 for Cannabinoids as Antioxidants and Neuroprotectants goes on to state that cannabinoids are also anti-inflammatory, can regulate the immune system and protect against glutamate toxicity

Given the above points, MAMMA is asking the IACC to join us in advocating for:

- Medical cannabis to be legal throughout the United States with autism as a qualifying condition
- Medical cannabis to be a first line of defense before psychotropic drugs for behavioral issues
- Autism doctors to learn about the Endocannabinoid system and apply this knowledge to autism

Besides the pleas for help, MAMMA also hears more anecdotal stories every day from all over the country about how autism is being helped by cannabis. Clinical trials could be conducted today in the states that are what we consider to be autism friendly – California and Oregon.

Thank you for reading this letter and we hope that the IACC will consider endorsing medical cannabis as a safe and viable option for people on the autism spectrum.

Sincerely yours,

AmyLou Fawell and Thalia Michelle

Co-Founders of MAMMA – Mothers Advocating Medical Marijuana for Autism

AmyLou@TexasMAMMA.org

Thalia@TexasMAMMA.org

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

Gabriela Ahlheim

November 10, 2015

On Friday, October 23-25, thousands of Americans were rallying in Atlanta at the Center for Disease Control and Prevention headquarters calling for Truth and Transparency. I am contacting you to inform you that I along with thousands of individuals support Congressman Bill Posey's request to investigate the CDC. Here is Congressman Posey <https://youtu.be/qxr-cv-Jul8>

For more than a century pharmaceutical companies have created and enjoyed a lucrative monopoly on health care in America. As you may be aware the National Vaccine Injury Compensation program was established in 1986 and signed into law by Ronald Reagan. The NVICP removed all liability from pharmaceutical companies for injury or death related to vaccines. As a result families of vaccine injured children are denied their right to a fair public trial. This allows pharmaceutical companies to profit on any vaccine they produce and relieves them of paying any legal compensation to families for injury or death. With this being said California's recent passing of mandatory vaccination bills such as SB277 and SB792 will increase the likelihood of individuals from vaccine injury or death. Although many legislators will say these cases are rare the reality is that they do exist and they are far from rare. U.S. Supreme Court also states vaccines are "unavoidably unsafe."

So why should we force a medical product on adults and children that has no liability? Why should pharmaceutical companies be allowed to profit from their products and not be responsible for injuries or deaths? Also, why are we forcing individuals to be coerced into injecting themselves with a pharmaceutical product that has been officially stated to be "unavoidably unsafe?" If you are truly for protecting the public's health then we ask that you take this request into serious consideration.

Many families, including myself have vaccine injured children and their disabilities are something we have to manage for the rest of our lives. Other families have experienced death due to the harmful effects from vaccines. Vaccines are not a one size fits all solution; they never have been and never will be. We deserve to hear the truth, we will not be ignored. The CDC along with the Pharmaceutical companies must be held accountable for their fraudulent actions.

I am requesting that IACC reach out to legislators to get them to subpoena Dr. William Thompson and have him testify regarding the omitted CDC data showing a link between the MMR vaccine and autism. The truth needs to be heard in a hearing. I am requesting IACC's assistance in making certain both the states and federal government cease the coordinated efforts in pursuing vaccine mandates when the truth about the safety of vaccines is being suppressed and vaccine manufacturers face zero financial liability when vaccines injure our children or kill them.

I look forward to receiving some answers to my questions.

Thank you,
GABRIELA AHLHEIM
Email: [PII redacted]

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

Linda Varsou

November 10, 2015

It is for the 5th time that I am bringing to the IACC meetings the serious, widespread and devastating issue of **“chronic parental denial”** (*non-acceptance or non-resolution*) of their child’s autism and/or denial of the extent of its severity, causing family dramas having detrimental effects to the child (or adult child) with autism, who becomes the final and definite victim.

As the prevalence of autism is on the increase, the same applies to the issue of chronic parental denial, increasingly reported in blogs, press, autism awareness groups and societies, where parents bring up some hints to the light and all desperately seeking help on the issue of denial. As yet, there are no available research data on the extent of its prevalence in the U.S. Relevant scientific literature is sadly wanting. An extensive literature search for papers on: *“denial, resolution, acceptance, non-resolution, non-acceptance in autism”*, besides some dissertations, shows no data regarding the prevalence of denial in the US. Most articles and thesis deal with *“mother’s stress”*, family questionnaires filled out by *“mothers”*, etc. As a consequence, it is impossible to assess the issue of denial as there is a substantial bias which masks the extent of the problem. We have only an Original Paper from a solid study in Israel reporting the prevalence of chronic parental denial specifically in autism as high as 53% (*“Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics”*, *J Autism Dev Disord* (2010) 40:89–99). Professionals in the field of autism estimate the prevalence of Chronic Parental Denial, i.e. permanent resistance of acceptance or resolution, or the attitude of *“flight instead of fight”*, close to 45% in the US and 50% in Europe, but not official research data are available (not counting rare cases of filicide).

Denial is part of a normal mechanism within the “grievance” process that follows the diagnosis of autism, a process whereby the parent’s reaction can be one of shock, denial, anger, bargaining, sadness, shame, guilt, depression, fear, anxiety, a narcissistic trauma, eventually leading to adjustment, reparation, and acceptance.

Chronic denial from a substantial number of parents (usually from fathers, rarely from both) is the most devastating issue only second to the diagnosis of autism, with the child (or adult) with autism being the ultimate victim.

Coping strategies by which parents adapt to the stress associated with autism are mainly: a) the *problem-focused coping*, aiming to solve the problem, and b) the *emotion-focused coping*, aiming to manage or reduce the feeling of distress. Denial, i.e. permanent resistance of acceptance, or the attitude of *“flight instead of fight”*, is the negative side of the latter.

One of the most harmful things a parent can do when they suspect their child has autism or any other developmental disability is to ignore the problem. Studies and supporting evidence have consistently shown that early intervention is a critical factor in a child’s ability to mainstream themselves into schools and society later in life despite their autism.

Sadly, the issue of chronic denial of a child’s autism, at least from one of the parents is so frequent, that its seriousness becomes only second to the diagnosis of autism, due to the many deleterious side-effects “denial” has to the definite victim, the child or adult child with autism. Unfortunately, advocates, professionals, researchers and parents active in the field of autism, due to the fact that by definition they

are not in denial themselves, have the tendency to ignore or to underestimate the existence, the significance and the impact of the deleterious effects chronic denial has on the child with autism.

The reasons of the widespread high prevalence of chronic parental denial especially in autism in many countries worldwide could be explained (besides the disability's stigma, prejudice, lack of awareness, stereotyping, discrimination, etc.), also by the fact that autism is also characterized as an "*unseen*" disability compared to other disabilities, often parents belong to the Broad Autism Phenotype themselves and by the impact of raising a child with autism has on the family. As a result:

- Children miss out on the crucial early intervention therapies and decisive earliest positive professional help and advice.
- Collaboration among parents and professionals, educators, etc., which is of undeniable and utmost importance, fails.
- Any amount of effort, services and funding provided for children with autism cannot prevent a parent's denial and the child doesn't get their benefits.
- Denial has a detrimental effect on the entire family. The parent who recognizes all the implications of autism has the additional heavier burden of having to deal with the other parent's denial. The child with autism pays the ultimate price of the family's conflict. (Family dramas due to divorces, abandonment, lack of support, lack of collaboration between parents, blaming mothers as causing autism, etc.). Children with autism should not be made to pay the cost of a parent's ignorance or denial.

Unfortunately, advocates, professionals, researchers and parents active in the field of autism, due to the fact that "*by definition they are not in denial themselves*", have the tendency to ignore or to underestimate the existence, the significance and the impact of the deleterious effects **chronic denial** has on autism. Even the excellent and comprehensive study from Israel mentioned above, has the bias of the voluntary nature of parents' participation, i.e. those not in total denial, expecting the actual prevalence to be much higher. These results will be very useful and can be used for social awareness and for every service, agency, State and Government.

I would propose **low-cost fast** research protocols and a meta-analysis, to investigate the issue of denial, its extent and consequences, as well as measures to deal with the problem and prevent family dramas, as follows:

1. From now on, any type of research on autism must include and evaluate the factor of chronic parental denial in each individual case. There are already available protocols and questionnaires easy to apply.
2. For all ongoing research protocols, there is still time to incorporate the evaluation of the factor of chronic parental denial.
3. For past, older or longitudinal autism studies, if access to data is still available, it is possible to go back and add the factor of denial, leading to a new updated publication. It is possible that denial could be a confounding factor altering the past results.
4. A meta-analysis could give an accurate estimation of the prevalence and degree of chronic parents' denial in the US.
5. Based on solid scientific data, IACC and Autism Organizations could propose the much needed mandatory changes at all levels, including judiciary changes to Family Court legislation, considering "denial" as serious as "child abuse" and the act of abandoning a child with autism.

In conclusion, I would like to see IACC addressing this particularly devastating question of “denial”, so as to show its support and commitment to every family and person struggling with autism in the US.

From Dr. Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, Immunologist, Assistant Professor. Mother and legal guardian of [PII redacted], college student with autism; advocate for the Rights and Strengths of People with Autism, and a fervent supporter of the concept: ***“An Autism Friendly Society will benefit us all”***. Contact: [PII redacted]

SHORT BIO: Long-standing member of the Autism Society, the Adult Autism Resource Group, the Howard County Autism Society, the Autism National Committee, the Autism Self-Advocacy Network, the Autism NOW, the One World Centre for Autism, the Pathfinders for Autism, the Autism Research Institute, the Hussman Center for Adults with Autism at Towson University. Founding and board member of the Greek Society for the Protection of Autistic People and founding member of the Greek Scientific Autism Network. Former member of the World Autism Organization. Long-standing member of the European Organization “Autism-Europe” and elected member to its Council of Administration. MSc in Biochemistry and postgraduate studies from Paris University; Specialization in Immunology from Paris Institute Pasteur, France; MSc in Public Health with honours; Diplomate of the American Board of Clinical Chemistry; Two PhDs in Diagnostic Laboratory Medicine; Research Associate at the University of Maryland School of Medicine, Faculty member at Johns Hopkins University School of Medicine where I studied neurosciences and initiated the “fever study in autism”. Current position: Assistant Professor at the University of Athens School of Medicine in Greece, responsible for teaching 3rd year Medical students and graduate students in three MSc Programs at the Departments of Biology, Chemistry and Clinical Pharmacy -a position which allows me to spend more than half of the year in the US with my son.

As a parent and advocate within the autism community I've been reaching out not in various public forum opportunities in an attempt to assist in the area of safety for individuals with autism as well as other disabilities. My wife, Carolyn Gammicchia, and I co-founded an organization in 2002 in the attempt to do so. I'm providing some of our testimony from over the past five years because our concerns are still valid and have not been addressed. I feel it's important to do so with this new IACC committee and we have provided testimony on some of these issues as has our son.

- 1) Previous testimony – (Available in the appendix)
- 2) [If you are the victim of a crime](#)
- 3) [Autism information for law enforcement and other first responders](#)
- 4) [Autism information for advocates, attorneys, and judges](#)
- 5) [Autism information for child abuse counselors](#)
- 6) [Autism information for paramedics and emergency room staff](#)

Dave & Lesa Walsh

November 10, 2015

Our family is one of the truly blessed and fortunate ones. When our son was first diagnosed, he was on the more severe end of the Autism Spectrum. Through blood, sweat, tears and hard work, he has recovered so much that he now has the potential for a decent quality of life.

We have too many friends who have sacrificed as much as we have sacrificed and who have worked as hard as we have worked to no avail. Their family's lives and their children's lives have been crippled as a result of their vaccine injury-induced autism spectrum disorder. They suffer serious seizures, gastrointestinal disorders, immune system dysfunction, and a myriad of other conditions.

This committee must investigate why recovery is possible for some and not for others. This committee must support the appointment of an independent investigation of the #CDCWhistleblower incident and Dr. Thompson's statements regarding serious improprieties by CDC committee members in 2004.

This committee must present substantial and productive recommendations that will assist families are currently overwhelmed by caring for their loved one now and in the future.

It is unconscionable that this committee, to date, has done so little to help so many. You must put politics aside and start making meaningful progress to assist those currently love with autism and to determine the cause of the current epidemic.

Respectfully submitted,

Dave and Lesa Walsh
Jacksonville, Florida

Christina West

November 11, 2015

Please fund research that will give parents actionable information they can use to attempt to lower the risk of autism in their children. Please explore environmental links as posited by Stephanie Seneff as well as risks associated with individual vaccines, their timing, the overall childhood schedule, cumulative mercury and aluminum exposure, etc. Support reinvestigation of MMR timing and rates of autism in African American boys per CDC whistleblower William Thompson's admission that evidence of a statistically significant link was concealed and destroyed. Investigate the role of the microbiome in developing autism and if relevant give parents actionable suggestions to improve gut health. Consider study into the effects of skewed micronutrient levels along the lines of research and actionable protocols developed by William Walsh.

So importantly, please develop a medical standard of care for autistic children. No parent should be told by a pediatrician to accept a diagnosis and grieve. No ER should attribute symptoms such as pain to just being part of autism without searching for a physical cause. We need training standards so that doctors can better recognize behavioral symptoms of treatable, physical conditions in low-functioning and non-verbal populations.

Thank you.

Christina West

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

Haven Delay

November 12, 2015

I am writing to you on behalf of my son, who changed completely immediately following the administration of four vaccines on March 7, 2001. His story can be found in the Congressional Record, submitted to the Congressional Hearings on Autism. I find it extremely sad and misleading that this council merely focuses on only ONE set of symptoms of this disorder. Calling this autism is like trying to call cancer a "cold."

In the fifteen years since the inception of this council, my son and tens of thousands like him have received neither benefit nor care from any decisions made by this council. We have been on our own to deal with the fall out of what was done to him.

It certainly looked to me like a STROKE, and recently, I found this article, which makes me even more certain of it: http://www.neurology.org/cgi/content/meeting_abstract/78/1/MeetingAbstracts/P01.009

I believe the incidence is way under reported due to the fact that when a child has a vaccine reaction, the doctors are more interested in covering it up than in telling the truth or doing any proper testing that will show stroke or toxic encephalopathy in a timely manner. Parents are most often "blown off" when their child reacts adversely to vaccines.

My son was seriously damaged. Yes, it includes "autism," but very often this was the "least" of his problems. For the first 3-4 years following his reaction, he had daily absence seizures and daily episodes of tremors with nystagmus. The vaccine reactions also caused an immune disorder NOS, metabolic disorder NOS; severe, debilitating gut pain; chronic constipation causing mega colon, digestive difficulties, auditory processing problems, attention problems, anxiety, asthma, chronic and severe infections - both viral and bacterial, and a host of other MEDICAL issues, and it changed the course of his life forever, disrupting every aspect of his life and the life of our family.

He is about to turn sixteen and since this happened, he could no longer even fight the bacteria introduced from an insect bite. He will get radiating staph from each and every bite which rapidly turns into cellulitis, putting him at risk for MRSA, septicemia and death. Even at sixteen, he cannot go outside to play alone, for he is prone to the immune reactions and to anaphylaxis. He must be supervised with an EpiPen at the ready.

Oh yeah, and then there is the "autism." which seems to always be the focus of a iatrogenic disease that is more about neurological and medical damage than BEHAVIORS. Certainly, these behaviors can often be challenging. My sons were very challenging for the first nine years, but with much effort (I could not return to my job), and a lot of money and diligence, our son's "autism" improved. The re-acquisition of communication skills played an important role in this. How terrifying it must be to a child who can have average or high intelligence and not be able to communicate! I also believe that due to neurological damage, many of these children may even think they are speaking clearly, and then get highly frustrated when they realize people cannot understand them. It is like those who become conscious under anesthesia - they think they are speaking when they are not.

My son is one of the "lucky" ones in that with interventions (no thanks to mainstream medicine) he has improved in function over the years and his absence seizures, tremors and nystagmus have dissipated,

though we think he had two absence seizures in the last year. The truth is we will never know. This iatrogenic disease is so pervasive and precarious that it can change on a dime.

His medical, therapeutic, nutritional, and dietary needs have been astronomical and highly expensive in OOP and lost wages, as one of us must stay home with him to teach him and care for him. Our state does not pay mothers of special children for their care until they turn eighteen while many other states do pay mothers as caregivers of minor-aged special children.

Sitting around your council and talking about research into the causes is a waste of time. We all know what has caused the vast majority of these cases even though we know it will probably never be admitted. I urge you to talk about HELP for these children and their caregivers NOW.

Many families have children who cannot talk and who suffer grand mal seizures frequently. You must focus on what the needs are NOW for these children. Social skills classes are few and far between and very expensive. The cost for medical services by specialists is very expensive. Waiting lists for state services are at least ten years long. Caregivers need respite services in order not to burn out. The suicide rate among caregivers of these children is climbing. The suicide rate among teens to young adults with this disorder are twice the national average. Wandering and drowning are serious major issues regarding this disorder, and families need help NOW to prevent these.

These children are often very chemically sensitive and so their nutritional needs and requirements can be very expensive, as well.

I urge you to please stop placating parents by meeting every so often and still accomplishing nothing. Fifteen years is far too long. Please do not waste any more money looking for the elusive "autism gene." This will do NOTHING for the families who are in desperate need of services and respite NOW.

You should also begin to discuss who will care for these children as they become adults who need constant care when their caregivers can no longer do it. More and more of these children are coming of age, and their parents are aging.

My child received a diagnosis of "Heavy metal Intoxication" from UT Southwestern Medical Center in August of 2002. The Pediatric neurologist talked in a whisper as if someone might be listening. He admitted to us our son's issues and the mercury had to have come from the vaccines. Then he admonished us not to go around repeating this as he said, "That idea is just not well accepted here." If it is the TRUTH, and it is, then doctors need to start accepting it.

He further went on to say, "I'm so sorry, but by mass vaccinating, we are saving so many, but there are going to be LOSSES. Your child is one of them and you just need to go home and accept it."

We have never accepted that someone thought they had the right to set our child on fire in order to possibly keep someone else's child warm. Children are not commodities to be traded! Had we been INFORMED of this possibility, we certainly would have used our common sense to prevent the risk of neurological and biological damage upon our only child. It is unconscionable to wait until AFTER the child is sacrificed to inform parents of the possibility!

Our son will have lifelong medical issues and will always have some degree of autism. He is delayed emotionally, verbally, and socially. It is high time we as a nation begin to take responsibility for these

children and help them NOW. I believe it the duty of the council to effect plans which will make a positive difference in the lives of these children and their families TODAY.

This epidemic is stealing a child's life every twenty minutes. This epidemic is the only one Americans should be outraged about.

Respectfully,

Haven DeLay
Mom to [PII redacted]

John Best

November 13, 2015

Hello [derogatory language redacted]. Since our government has been 100% corrupt for a long time, let's speak truthfully. The IACC has deliberately placed a bunch of [derogatory language redacted] on this committee as long as it has existed.

We know beyond the slightest doubt that thimerosal is the leading, and maybe the sole cause of autism. We have known this for a long time. We know that chelation cures autism. Yet, the [derogatory language redacted] on this committee have prevented that knowledge from being shared with the nation. This is child abuse. This bunch of [derogatory language redacted] has deliberately misled parents from learning that their babies are being poisoned by Congress and the other associated mental cases who have allowed this crime to persist. Since I'm one of THE PEOPLE, and I stand over you criminals as the authority in this country, I'm giving you a direct order. Tell the whole truth right now, today. Do you understand?

John Best

Londonderry, NH

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

Rose Walker

November 13, 2015

I have a teaching background, and a very small science background. They came in handy when son was diagnosed at age 3 with PDDnos by pediatrician [PII redacted] and Severe Communication Disorder (NOT autism) by a Neurologist.

I realize for some reason there is a major push for research in regards to autism. But research was of no help to me, maybe because my son is so mildly afflicted, no comorbidities except possible ADHD and LD. In fact, he may just be misdiagnosed and be ADHD and Dyslexic anyhow, an OO kid by nature. What was helpful, was education...Speech Therapy and OT, and a Resource Classroom pullout when needed allowed him to stay in regular classroom. From what I read, there is some question whether being taught the way one learns would lead to far, far fewer diagnosis of Intellectual Disability in autism. My son's is dead average (100) with peaks of 126 in verbal and listening, and about 50 in rote math skills. These peaks and valleys are very common.

Why do we not look to the gifts of autism to teach? Sometimes we dummy down everything for the non-verbal kids, when it may be more a matter of execution than of personal understanding, ie, they are much smarter than they are able to get across because of a glitch in output.....a lot like the Dyslexics IO problems. Somebody needs to look up the work done on altteaching.org. A-mazing!

Making autism a behavioral condition, instead of an educational condition puts the onus on the child to change in totality. BUT...looking to the educational needs of the child would remedy a lot of behavior. Why doesn't somebody chew on that? And the output....what neurological manifestations in other conditions, affect output? Lupus can lead to echolalia in adult speech. Do other autoimmune conditions do the same?

IDK...Good luck. Hope to observe the meeting.

Rose Walker
Near Atlanta

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Janet Shouse

November 14, 2015

Subject: Action is needed

Your committee has not met in two years. In that time, the prevalence rate for autism has gone from 1 in 68 children to 1 in 45. At what point will this epidemic reach the levels of a national health emergency?

When my son was diagnosed in 1998, the rate was 1 in 500. He is now 20. He is basically nonverbal, and he will require care for the rest of his life.

How many more like my son will be aging out of the school systems across our nation and in need of supervision, supported employment, supported living, housing, intensive behavior services and medical care? Probably about half of those 1 in 45. How will our nation handle this? Shouldn't the IACC be finding the needed resources and planning for these individuals?

Health care is a huge issue for people on the spectrum. Few pediatric providers fully grasp the physical health implications of autism, and even fewer adult providers understand the health care needs. Shouldn't the IACC be finding the needed resources and planning for improved health care for these individuals?

<https://www.urmc.rochester.edu/news/story/4449/study-sheds-light-on-health-needs-of-adults-with-autism.aspx>

A study out this week finds that people with ASD face a higher risk of premature death:

<http://medicalxpress.com/news/2015-11-people-autism-higher-premature-death.html>

And I believe 26 or 27 children with autism have drowned since June of this year. These deaths are heart-breaking. Isn't that a national health emergency? And shouldn't the IACC be finding ways to help families prevent these needless deaths?

The Centers for Disease Control and Prevention and the American Academy of Pediatrics both stress the value of early diagnosis and early intervention, both of which I applaud, but the vast majority of families struggle and often fail to receive the appropriate levels of intensive early intervention. What good is an early diagnosis if the needed treatment is not accessible to your child? That is heart-breaking as well. Shouldn't the IACC be finding the needed resources to help these families and their children?

There is much work to be done. This is a national health emergency NOW!

Thank you.

Janet Shouse
[PII redacted]

Katherine Jakus

November 14, 2015

I am a licensed physical therapist and mother of three vaccine-injured children (the round containing the MMR was the worst offender).

My main concern is holding VACCINE WHISTLE BLOWER HEARINGS that involve calling Dr. William Thompson to testify regarding vaccine fraud at the CDC (MMR and thimerisol).

Congress has been just sitting on his whistleblower information for an entire YEAR now, refusing to call him to testify (DeStefano and Boyle, among a number of others, should also be called to testify under oath, for possible crimes against humanity). The CDC seems to be operating more like an organized drug cartel than a government agency that is supposedly concerned about our public health. Until hearings are held and we completely clean house at the CDC, I have little regard for anything that agency reports. I simply no longer trust or believe anything coming out of the CDC (which is sad, as they used to be my trusted, "go-to" source of information).

Why is it that when a foreign car company like Volkswagen is involved in fraud, our government is right there calling them out, but when our own CDC has become as obvious [derogatory language redacted] not a peep is heard from anyone but a very brave few like Rep. Posey?! This is such an outrage, I have nothing but utter disdain for those who refuse to do their jobs and investigate these most serious allegations.

This whistleblower issue should be your TOP PRIORITY topic of discussion at the next IACC meeting, but I have little faith you will do one thing about it (if the history of your agency is anything to go by).

Please surprise me! I would love to find that I am wrong about you, but from where I sit, you don't seem to give a [derogatory language redacted] about what happens to the children in this country. As long as the big pharmaceutical dollars keep flowing in the right direction, I doubt you will do a thing about this crisis. I suspect you will continue to look the other way, focus blindly on genetic research, and pat yourselves on the back for a "job well done," while the autism epidemic rages on, out of control.

I have been writing to you for years, begging for a proper vaccinated vs never vaccinated study, but my pleas fall on deaf ears. I have had to sit by and watch helplessly, as more and more innocent children have had their lives torn apart by autism. The IACC has been nothing but a disappointment to me in that regard.

It is absolutely disgraceful that you have not called for a proper study of fully-vaccinated vs never vaccinated children by now (we are DECADES into this epidemic and that should have been one of the FIRST studies done!!!). Almost everyone dealing with this issue knows that vaccines are indeed a factor (if not causal, at least significantly contributing). We can see it with our own eyes, all around us, every single day. Our country cannot go on like this.

My other issue I'd like to see addressed by your committee involves biomedical research and treatment.

I have found regular biomedical testing to be crucial to progress in treating my own children. These tests include (but are not limited to): Urine and hair metals and essential elements tests, urine amino acids tests, organic acid tests, genetic testing for methylation pathway mutations, among many others.

Very few of those tests are even partially covered by insurance, yet are vital in monitoring progress and knowing how to treat these complicated kids.

Why is it that most pediatricians still know next-to-nothing about these types of treatments when they have been available so long and are so much more successful than just “behavioral therapy” and drugs?

I am SO sick and tired of insurance companies only covering some behavioral treatments and pharmaceutical drugs (and most of these drugs are currently being used off-label and often do more harm than good). Until the IACC shifts from solely focusing on genetics (which has not been of any use to the average parent of autistic children in the past several DECADES now), and puts MUCH more effort into environmental factors INCLUDING VACCINES and epigenetics, children will continue to be injured and suffer horribly. Without the proper research, there will never be the coverage for the most beneficial autism treatments.

The IACC should be ashamed of the new autism numbers that just came out. I’m sick of this crisis being continually spun as “better diagnosis.” Anyone over 45 about years old knows very well kids used to be so much healthier before congress gave complete immunity protection to the makers of vaccines. They have absolutely ZERO liability, so is it any wonder that they are continuing to add more and more vaccines to an already bloated, dangerous schedule, and basically buying vaccine mandates around the country?! They are laughing all the way to the bank, while our children suffer. And there you all sit, twiddling your thumbs, saying you “just don’t know what causes autism”. Well, maybe you should start asking the parents of all these kids! We have some very definite ideas. I never thought I’d see this in the USA. My husband is a retired Navy pilot who served this country for over 20 years. He was defending our country’s freedom, not medical tyranny.

My God, what is wrong with you people, and where is your conscious?! What ever happened to “first, do no harm”?! The CDC needs to be completely overhauled. They are a corrupt, failed agency that has absolutely no business dictating anything to do with vaccine safety. They have completely let the public down and are responsible for immense amounts of human suffering.

The IACC also shares a significant portion of the blame for the continuing autism epidemic, as your committee has done absolutely NOTHING in all these years stop the carnage or improve the life of any children on the autism spectrum. The IACC has purposefully blocked research into the role of vaccines in autism, and has stuck their collective heads in the sand when it comes to environmental causes of autism.

Autism is clearly a MEDICAL ILLNESS, so why on earth do you continue to classify it as a “psychological condition” and offer parents only recommendations for behavioral interventions?!

This course of action is insane and it’s bankrupting not only families, but our nation. If you actually want to improve the lives of these poor children (and also stop the financial drain on society) you need to finally address things like: THE VACCINE SCHEDULE, epigenetics, heavy metals, the micro-biome, bacteria and viruses, methylation mutations, targeted supplements, gaba/glutamate balance, and a host of other areas.

If your agency wastes any more precious research dollars on another bogus, useless study, like “eye gazing” I think I’ll scream (how many of those have we had, and exactly how has that helped anyone, really?!).

These children (many are now entering adulthood) are SUFFERING! We need to TREAT THEM, and PREVENT future cases! I think everyone is sufficiently “aware of the signs” of autism by now. It’s long past time too finally address the most important issues, and put an end to this epidemic.

It's my sincere belief that this epidemic could have been stopped in its tracks many years ago. I know there are incredible, extremely talented researchers at the CDC who could tackle this head-on if they were only given the green light to go forward. Unfortunately, it seems those in positions of power to do so are either bought off, or too afraid to address the real underlying causes, and continue to block research in "uncomfortable areas". That's not science, that's corruption.

I write each and every year with a simple request for proper, meaningful research into the most promising environmental areas (including vaccines), and you ignore my pleas. The only reason I continue to provide "input" is that I hope someday, someone with a conscience will finally head your agency and do the right thing and end this unnecessary suffering.

I'll end here, as I really find it increasingly difficult to be remotely polite to your committee after all these years of disappointment.

Please surprise me this year.

Legitimate CDC vaccine whistle-blower hearings and proper environmental research into the cause of autism top my "wish-list" this (and every) year.

Thank you for your time,

Katherine Jakus

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

Sheryl Melling

November 14, 2015

Subject: Autism community concerns

My name is Sheryl Melling and I am the mother of a 12 year old boy, who also has an Autism Spectrum Disorder. The intention of this letter is to express my concerns regarding the needs within the autism community.

There are so many needs within this community that I am not sure as to where to begin. First and foremost, there is a vast lack of appropriate research. Many people with autism have common, biological ailments that point toward autism being more biological in root verses just neurological. For example, the majority of people with autism show deficits in nutrients such as zinc and the b vitamins. A poor-functioning gut and a lack of good flora have also been seen in many people with autism. Through treatment in replenishing such deficient nutrients and improving the health of the gut, many people's symptoms are improving. Some parents' children have even lost their diagnosis through such biomedical treatment. More research needs to focus on the biomedical conditions and treatments of individuals with autism and needs to be performed from independent researchers that have no financial ties to the findings of such studies.

In general, the mainstream media shares the opinion that the science is clear and that vaccinations do not cause autism. However, the research is not clear. There have been many studies that have shown a connection of an onset of autism shortly after vaccinations. In fact, our own CDC destroyed documents showing an increase in autism in African-American boys after receiving the MMR vaccine. A whistleblower within the CDC, Dr. William Thompson, has come out with proof revealing the original study documents, yet congress has not investigated the issue. Such shocking information has also been kept out of the mainstream media due to the huge power and control the pharmaceutical companies seem to have over our entire country. Please demand that this fraud be addressed immediately as well as legal action taken against all involved. Please also fund independent studies regarding the link between vaccinations and autism.

With autism being diagnosed in 1 out of 45 children, there is still a huge lack of knowledge as well as appropriate placements for such children within our school systems. Some districts do have specific autism programs, but they are usually intended for the severely functioning children. There seems to be a lack of appropriate placements for the high-functioning children who exhibit some behavioral issues. The common recommendation with cases such as these is to move these children to an Emotionally Impaired placement. We need the educational system to be able to better serve and help such children instead of shoving them off to different programs. Autism seems to have an impact on nearly everyone these days.

Again, with autism being 1 out of 45 and growing, what will these children do when they reach adulthood? Where are the programs and support once they are finished with school? What happens when these children lose their parents and caregivers? It is the dark cloud that haunts every parents' mind.

Thank you for allowing me to express my concerns regarding the great needs of those with autism spectrum disorders as well as their loved ones.

Sincerely,

Sheryl Melling

[PII redacted]

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

Sherrie Sponseller

November 16, 2015

I'm emailing concerns for my family. I'm a mother to a 17 year young man living with Aspergers and ADHD. We live in the State of Michigan.

It is my hopes that this committee meet more than once a year. Parents such as mine would like to have some accountability of what is happening to better the lives of our children. My son is a senior at [PII redacted]. We have so many needs to address for transition after high school. I think it's very important to have this committee take account of what transition services are offered. Young adults are not given the same amount of supports and services once they reach 18.

I feel that the past few years, the push has been on early intervention and diagnoses. I do find it equally important for those families that it's crucial to begin intervention for their child. I feel the emphasis on what should we aim for our young adults and adults living with autism. They deserve the attention and support to work on getting help to gain a job, live in the community and go to higher learning if desired.

I do believe that having representation from someone with autism could benefit this committee. I feel that parents do need to feel their concerns are respected and heard.

Sincerely,
Sherrie Sponseller
[PII redacted]

APPENDIX