

Written Public Comments

**IACC Full Committee
Meeting**

April 11, 2011

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Marian Dar

January 19, 2011

Subject: IACC Meeting of Jan 18 11: REMARKS

In response to "Public Comments" and elsewhere two issues:

(1) Pre-existing conditions + (2) thinking deductively about **causality**/how environment may challenge and impact genetic vulnerabilities.

PRE-EXISTING is an **arbitrary** call based on a variety of unstable and not always determinable factors; further, it is to a degree situational, dated, economic and behaviorally-linked.

I (and my autistic son) may have osteopenia, but it and other system irregularities are likely the result of an earlier (+ UNDIAGNOSED) condition of celiac disease -- which may be the result of something earlier (+ UNDIAGNOSED) as the incidence of those with genetic markers for celiac disease is much, much higher than the prevalence of disease, ETC., ETC.

I, and likely many other Americans, may not appear Biafran -- but we have a real (granted more subtle) form of malabsorption, gastrointestinal (GI) disease and health impairment.

This may be true of many if not all disease -- there are precursor situations, cross-system conditions, etc.

How does a physician/scientist, business analyst, etc. ferret out and decide sequence, timing -- ?? Pre-existing is what is documented and known -- limited and should not carry such consequence.

Marian Dar

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

Mike Frandsen

January 19, 2011

Subject: Wandering

I heard the first half of the IACC meeting yesterday on videocast. Regarding the wandering issue for children with autism, I know you are familiar with the story of [PII redacted] and the Mason Alert (<http://www.examiner.com/dc-in-national/mason-alert-would-help-prevent-wandering-drowning-deaths-of-kids-with-autism>), but here is a second article that talks about the implementation of the Alert by a police department in Pensacola, Florida: <http://www.examiner.com/dc-in-national/mason-alert-to-be-combined-with-take-me-home-program-to-prevent-autism-wandering>.

Mike Frandsen, Master of Business Administration (MBA)
[PII redacted]

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

Rebecca Healy

January 28, 2011

Subject: Individualized Education Program (IEP) & 504 Plan

Hello I am a parent of a 6 year old with ASD. I have been reading through the 2010 strategic plan for Autism spectrum disorder basically to see what the future hold for my son as far as treatment and services. I wanted to point out that it is my belief that the term "services" is very loose. Kids with ASD do require extra assistance in school however there is a gap in services for the high inelegance functioning kids like my son. IEP's are being reduced to 504's because they can read and do math two or three grades above normal. This reduction from IEP to 504 only makes it harder in the classroom, harder for the teacher and more stressful for the ASD kids. The behavioral and social issues require the same amount of intervention and support and it is my fear that these kids will be viewed as needing less help because of the plan change. My son for example hates music class because of the noise level, can no longer ride the bus because of bullying and anxiety caused by bus chaos. There's more but I guess my point is that ASD kids need the security of the IEP to insure they get the extra aid in and out of the classroom, proper sensory break time, class alternatives like a lower volume music class. I think it's important that All kids with ASD be placed automatically on an IEP regardless of their intelligence, the 504 leaves too much leeway and inhibits their likelihood of receiving services through the community as well as health insurance coverage. Please make the IEP a necessary and a requirement for all kids with ADS. Thank You

Rebecca Healy

Rebecca Healy Licensed Massage Therapist, Certified Yoga Therapist (LMT,CYT)
[PII redacted] <http://studio521south.com/> (IACC Note: URL is not valid.)

Elizabeth Yohe

February 15, 2011

Subject: Autism and Wandering

You all should be ashamed of yourselves! Wandering is not an issue in the winter really! Even if this was true wouldn't you all want a wandering order in place by spring! What about people who live in areas where it is 70 degrees right now? Shame on you! You should all be fired and let people who actually care about children's lives do the work you are too lazy to do!

Elizabeth Yohe

Annmarie Andress

February 15, 2011

Subject: Regarding: IACC

I am writing emails to IACC that parents of the most severely impacted need to be represented on the IACC. Our children need to be heard through us who can fight and advocate for them. Our severely impacted nonverbal children need their civil liberties and rights protected too and protected from dangers they cannot protect themselves from or get help or even ask for help they need to survive day to day. Losing a child is a parents' worst fear and losing a helpless child who cannot respond or scream for help because the IACC refused to help address it, is unacceptable.

Please have our children represented in IACC meetings by bringing parents of these children to the table and removing people who stand in the way of autism protections and assistance.

Thank you, Annmarie Andress

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

Aimee Doyle

February 16, 2011

Subject: Sharon Lewis

I am emailing to complain. I am the mother of young man with autism who is significantly affected by the disorder. I understand that at the recent IACC meeting Sharon Lewis emphatically spoke against an anti-wandering initiative that was being discussed. This is appalling -- children with autism can DIE when they wander off.

I know in my own case my son has escaped twice -- once into the woods at Greenbelt Park and once during a family outing to an amusement park. Fortunately we found him after several hours of searching. I can't even begin to describe the fear our family felt as we searched. Another boy -- from our autism support group -- wandered off during a morning hike and was not found until late that evening. In each case police, family, friends, and caring neighbors helped search. But that is not a solution to the wandering problem.

I simply don't understand Ms. Lewis's lack of compassion and her narrow vision. I read that she is interested in self-determination, which is important, but I don't see why this needs to be an either/or situation. Maybe someday my son will be at the point where he can benefit from self-determination, but that day is a long way off. In the meantime, a federal office dedicated to helping families with children and adults with development disabilities should be willing to recognize that the needs of everyone on the spectrum are important.

I would appreciate it if you would discuss this with Ms. Lewis and get back to me. I would be happy to talk to her if she is interested in talking to a parent whose child who is on the lower end of the spectrum and who has wandered.

Sincerely,

Aimee Doyle
[PII redacted]

Christine Zukowski

February 18, 2011

Subject: Adults with ASD

Good Afternoon,

As the parent of an autistic adult, I find it very upsetting that there are not enough programs for these individuals. My son attends a day rehabilitation, but frankly, it is not what he needs. I live on Long Island and the amount of ASD here is very high and many of the children are aging out of their schools. What happens when there is nowhere for them to go? So much time is spent during those younger years to help them achieve goals, but it seems like the door is slammed on them when the graduate. I am scared to death about what will happen to him when I die.

My son is basically non-verbal, but he is wonderful when it comes to taking care of animals and the yard. He rides horses and helps take care of them too. I know many individuals that are the same way. Why doesn't the department of agriculture and the department of health team together to help make small farms/residential so people with ASD can learn to work and give back to society by growing vegetables which they could sell? It seems so simple and much better than having these ASD adults sitting in a room, basically wasting away when they have so much to give. When my son completes a task, I cannot explain the satisfaction that he gets.

Is there any way that this can be achieved? I would really love to see this type of program be available to those who could benefit from it. I know that there are a few out there, in Ohio, New Hampshire, and Pennsylvania, but there should really be more. Maybe the government should have a meeting with Temple Grandin, I am sure that she would agree with this idea.

It would also help to create jobs.

Any help that you could send me would be appreciated.

-Christine Zukowski Bayville, New York

Dahl Natural LLC

February 28, 2011

Subject: Regarding: IACC News Update: Mother's Testimony to the IACC Sparks Rapid Response to Investigate Autism Rates in Somali Families Living in Minnesota

Since there is evidence that mothers mercury loads are correlated to children born with developmental disabilities, I hope that investigators of United States (US) Somali children will test mothers' mercury levels. To identify the source of mercury, if levels are high in mothers, could help prevent the problem from occurring. A likely source is fish and possibly water so it should be determined if this population is eating a diet high in mercury contaminated fish or water.

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

Maggie Nygren

March 28, 2011

Subject: Proposal to add a code to the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9 CM) for the purpose of collecting data on wandering behavior in people with autism and other developmental disabilities

Regarding: Comments on a proposal to add a code to the ICD-9 CM for the purpose of collecting data on wandering behavior in people with autism and other developmental disabilities

Both the IC9-CM Coordination and Maintenance Committee and the IACC are to be commended for their interests in the health and safety of people with autism and other developmental disabilities. The American Association on Intellectual and Developmental Disabilities (AAIDD) has serious reservations about the proposal to create a code for wandering behavior in people with autism and other developmental disabilities and is concerned that the risk of harm to individuals with developmental disabilities may be far greater than any benefit that might be gained through this approach.

Diagnostic and Functional Considerations

We acknowledge that wandering is a *behavioral symptom* associated with the degenerative disease processes of dementia; however, such behavior is not understood to be symptomatic of a disease process in children and adults with autism and other developmental disabilities. Rather, if an individual with autism and other developmental disabilities sets out to where a care provider (parent, family, or professional) doesn't desire or expect him or her to go, we understand the behavior to be discernibly *intentional* (spurred by boredom, curiosity, rebellion, eagerness for stimulation, escape from undesired tasks, etc.) and *modifiable* through learning processes.

The notion of wandering also assumes an individual exists within a contained environment (an institution, hospital, or nursing home) away from which an adult might "wander" (or the even more stigmatizing term "elope"), rather than within a community, home, or job from which one might reasonably enter and exit with personal discretion. While we acknowledge that children are not expected to have fully developed safety skills, a child with a developmental disability who absconds from their caregivers no more has a medical condition than does a typically developing child who exhibits the same behavior.

Maintaining personal safety does require a set of adaptive skills, skills that may require supports to optimally develop in people with autism and other developmental disabilities; however, lack of a particular skill at some point in an individual's lifespan is not typically considered a condition, risk factor for a disease, nor the basis of epidemiological research—what would seem essential criteria for the creation of a new code in the ICD-9 CM.

Policy and Practice Considerations

Historically, we have seen labels intended to be descriptive or diagnostic turn into justifications for limiting rights and opportunities. For those children and adults labeled as immutable wanderers, rather than

individuals who have responded to certain environmental stimuli with a particular behavior, interventions are likely to be more restrictive than necessary. It is well within the realm of possibility that, should such a code be created for the IDC-9 CM, children so labeled would be vulnerable to increased restraint and seclusion in school, as schools would be remiss if they failed to address such an issue in an individual education plan. For adults who might be so labeled, interventions designed to restrict movement could easily become civil rights violations.

While the possibility of compelling insurance coverage for tracking devices through the creation of such a code is well-intentioned, other pathways to such coverage are available. Creating and promoting the use of an ICD-9 CM code is highly likely to move focus away from addressing the support needs of the individual and toward strategies for minimizing organizational risk and liability. The likely risk of harm to people with autism and other developmental disabilities through the creation of such a code is far greater than any benefit that might be obtained by this approach.

Respectfully submitted,

Margaret A. Nygren, Doctor of Education (EdD)
Executive Director & Chief Executive Officer (CEO)
American Association on Intellectual and Developmental Disabilities (AAIDD) www.aaidd.org
[PII redacted]

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

Alan Levine

April 4, 2011

Subject: Statement for IACC Meeting

Please accept the attached statement for inclusion in the record of the IACC Full Committee Meeting to be held on Monday, April 11, 2011 and for the Committee's consideration. It outlines what happened to our family when our daughter was the victim of child abuse at her school, and of the completely inappropriate response to that abuse from school officials, from the teacher in her classroom all the way up to the School Superintendent and School Board who have completely ignored us. We are sorry that we could not attend the meeting personally, but we will be watching on the webcast. We would welcome the opportunity to answer any questions that any of the members of the Committee might have, and we are available by phone or email for that purpose. Thank you very much.

Child Abuse in School: One Family's Story

On November 12, 2010, our daughter, [PII redacted] (who is nonverbal and has autism) was physically abused by [PII redacted], an aide at her high school, [PII redacted], in Boca Raton, Florida. According to two eyewitnesses, while [PII redacted] and [PII redacted] were sitting on a bench outside of the school waiting for my daughter [PII redacted] to be picked up to go home for the day, the aide [PII redacted] struck my daughter [PII redacted] hard on the back of her head. The blow was hard enough to make my daughter [PII redacted] double over in pain and cry. The abuse was bad enough, but it was the reaction of the school administrators, the School Police, the State Attorney and every other Florida agency we contacted which was so distressing and appalling. While we recognize that bad things are going to sometimes happen at school, as elsewhere, we expect that when they do, the people in authority will do the right thing. Instead, as discussed more fully below, the authorities here have denied the abuse (notwithstanding two credible eyewitnesses and two investigations confirming the abuse occurred), have lied to us, have broken several laws (not including the abuse), have allowed a video that captured the incident to be destroyed (even though a Public Records Request was pending at the time), immediately fired the person who reported the abuse the same week she made her report to the Department of Children and Families (DCF) and the "investigation" has been tainted, primarily because the School Police have a blatant conflict of interest and not only fail to acknowledge any conflicts, but have no procedure in place for dealing with them.

School officials have broken at least five laws not including the abuse. They violated both the general Florida Whistleblower's Act as well as the Act protecting employees who report child abuse to the DCF when they fired [PII redacted], the aide who witnessed and reported the abuse on our daughter because she made her report. Notwithstanding that the principal admitted the reason that he fired [PII redacted] when we met with him initially, no disciplinary action has been taken against him whatsoever.

The Principal [PII redacted] and the Assistant Principal [PII redacted] as well as other school employees violated the Florida Act making the Principal, Assistant Principal and other school employees mandatory reporters of Child Abuse. They had received written allegations of child abuse in my daughter's [PII redacted] classroom, and failed to report the suspected abuse to the DCF as required by law. They violated Section 119 of the Florida Open Records Act when they failed to honor the request for a copy of the video which captured the incident of abuse, and instead, allowed the video to be erased. They then lied about the date of destruction and the contents of the video in an effort to cover it up. So far, they have

succeeded in their cover-up efforts, as no Florida agency has agreed to take any action regarding destruction of the video. They also violated laws prohibiting obstruction of justice and destruction of evidence in child abuse cases when they intentionally allowed the video to be erased, and then tried to cover it up.

Instead of taking appropriate action when the abuse of [my daughter – PII redacted] was reported to them, the aide who reported the abuse to the DCF was fired within one week of her making the report. When the abuse was reported to the DCF, the first reaction of the Principal [PII redacted] was to deny the abuse and fire the reporter, [PII redacted], despite the fact that there were TWO eyewitnesses to the abuse. Both the DCF and School Police have verified the abuse, and issued their reports finding the accounts of the two eyewitnesses to be truthful and accurate. To this day, [the principal – PII redacted] continues to deny that the abuse occurred.

[The principal – PII redacted] refused to remove the alleged perpetrator from the classroom for over two weeks despite the two credible eyewitnesses, two pending investigations, a contemporaneous journal outlining other abuse in the same classrooms, and numerous requests from us to keep her away from disabled children until the investigations were completed. When we complained to [the principal's PII redacted] superiors about his failure to protect our daughter and her classmates during the investigation, [the principal – PII redacted] finally succumbed to the pressure and agreed to remove the perpetrator from the Special Education classroom, and decided to assign her to the classroom of the victim's mother, who also is a teacher at that same school. This contemptible act was akin to assigning a rapist to the classroom of the rape victim's mother. That act was about as despicable as one could imagine, yet no disciplinary action has been taken against [the principal – PII redacted] as a result. Indeed, no such action is even pending.

Rather than remove the perpetrator, our daughter, the victim, was effectively banned from school. She ended up being punished for being attacked by [PII redacted]. Because [the principal – PII redacted] refused to remove the perpetrator from the classroom for over two weeks, or to take appropriate action to assure [my daughter's – PII redacted] safety, [my daughter] had to be removed from school. Because she was abused, her life was disrupted. [My daughter – PII redacted] was effectively expelled from the classroom because she was a victim of abuse, while the perpetrator was allowed to stay, notwithstanding numerous requests made to [the principal – PII redacted] to remove her pending the outcome of the two investigations.

Further compounding this wrong foisted upon [my daughter – PII redacted], no help was given to [my daughter – PII redacted] to find her an alternate placement. Her school failed to provide any assistance in finding her a new placement. She was not even allowed to visit the Special Education classroom at the nearest school. As a result, [my daughter – PII redacted] was basically kicked out of Palm Beach County and was forced to take a placement in a neighboring county, Broward County, solely because she suffered abuse at the hands of [PII redacted] while in her care.

During this experience, we learned that an environment of non-reporting existed in the Special Education classrooms at [school name redacted]. The aides in the classroom (justifiably) fear retribution if they dare to report abuse. One [PII redacted] has already been fired for her reporting. Another [PII redacted] was threatened that he better shut up or he won't have a job next year. The Special Education Coordinator's job [PII redacted] has also been threatened. Others have said that they are afraid to come forward to report abuse they have witnessed. The Detective involved told us that he confirmed this atmosphere at the school, but concluded his investigation without taken any action to fix the atmosphere. Moreover, so far, he has refused to give us a copy of his report.

The aide who was fired [PII redacted] kept a contemporaneous journal of various incidents of abuse she witnessed. She gave a copy of the journal to [the principal – PII redacted] in October of 2010, approximately one month before [my daughter – PII redacted] was abused. The journal contained multiple incidents of abuse in the Special Education classroom against multiple students with multiple witnesses. [The principal – PII redacted], who told us that he read the contents of the journal given to him carefully, never made a report of what he read to the DCF. When we asked to review the contents of the journal he was given, [the principal – PII redacted] claimed that he didn't retain a copy. No investigator has yet asked him why, if he was given a journal detailing abuse, that he would not have kept a copy of it, let alone why he did not make a report of what he read to the DCF. While his failure to report was an obvious violation of the law, as well as an utter failure to do his job as principal, no disciplinary action was taken against him for such conduct.

At least three administrators were made aware of other incidents of abuse in the same Special Education classrooms, and failed to report the incidents to the DCF: [PII redacted]. This not only violated School Board Policy, it also violated the law which provides that these school personnel are Mandatory Reporters, and have no alternative: they must make a report of any suspected abuse reported to them to the DCF. See Chapter 39 of Florida Statutes, specifically 39.201 (School teachers or other school officials or personnel are Mandatory Reporters). No disciplinary action has been taken against any of these administrators for their blatant and intentional failure to report Child Abuse.

Surveillance video of the incident of abuse against [my daughter – PII redacted] was “allowed” to be erased, notwithstanding a pending Open Records Act Request. There are two surveillance videos taken in the area where this incident occurred. At least one is now known to have been in position to capture the incident. That video was erased. Although both an explanation and an investigation have been demanded, neither has been granted. The Board Attorneys as well as the School Police do not want to admit that school officials are responsible for erasing the video. They don't want to admit that in erasing the video, at least two laws were violated: the Florida Open Records Act, as well as the law governing obstruction of justice and destruction of evidence.

School Officials, including the School Police, have refused repeated requests to make an attempt at data recovery. They have not been forthcoming regarding the existence of the video, its contents, and the date of its erasure. We have made numerous requests to send the hard drives on which the videos were recorded to a specialist to make an attempt at data recovery. These requests didn't get the courtesy of even a denial; they were simply ignored.

The administration has not been truthful with respect to the surveillance video. From day one, every school official has falsely maintained that the incident could not have been captured on the surveillance video, including the principal and assistant principal [PIIs redacted]. This was particularly curious, because while they said the video didn't show anything (because the cameras were allegedly obstructed by an overhang over the benches where the incident occurred) they also said that they, together with School Police Officer [PII redacted] had “studied” the video for two hours. If the video didn't show anything, then why were they “studying” it for two hours? And why have the School Police refused to ask that question (or any others for that matter)? The principal and assistant principal [PIIs redacted] steadfastly maintained that the video was “confidential,” while at the same time maintaining that it “had nothing on it.”

They told other lies as well to keep us from seeing the video. After our request was made, and before the video was destroyed, we were told that we could not see it because it was part of the “investigation.” Because the two investigations were confidential, neither investigator would confirm or deny whether the video was part of their investigation. We learned once the investigations were concluded that the video was NEVER made a part of either investigation, notwithstanding the representations made to us to the contrary. By then, it was too late because the video had been destroyed.

No explanation has been offered to explain the destruction of the surveillance video, and only the barest of apologies was given. The identity of the school official who was responsible for the destruction of this important piece of evidence (indeed, it was THE most important evidence of the abuse suffered by my daughter [PII redacted] at the hands of the aide [PII redacted] was intentionally withheld, as was the date of destruction. Although the Board Attorney, [PII redacted], was informed of the destruction on December 20, 2010 he provided no notice of the destruction until January 3, 2011. He never explained the lack of a phone message, a letter, or an email message prior to leaving for vacation. He never treated the destruction of that video anywhere near as seriously as he should have.

School officials, including the board attorney [PII redacted], engaged in a disinformation campaign to hide the actual date that the surveillance video was destroyed. The board attorney [PII redacted] falsely stated that the video was “erased over” between 10 and 14 days after the video was recorded. That representation was blatantly false, and it was designed to mislead and to falsely show that the Open Records Act had not been violated and even if it had, it could never be proven. We now know that representation was false because a test of how much video the applicable machine can hold was conducted. The answer, as witnessed by five witnesses was 25 days of video, not the 10 to 14 days originally represented. If video was recorded over in 10 days, as the board attorney [PII redacted] wrongfully stated, then it was possible that the pending Open Records Act request was not made before the erasure, and there would be no violation of the law. That’s why that misrepresentation was so important. It appeared designed to cover up the violation of the Open Records Act that had occurred, which in turn, was likely an act of obstruction of justice as well. Importantly, the key people responsible for preserving the video were given multiple notices of the existence of the request, and not one of them made an effort to preserve the video.

Furthermore, there is an abundance of circumstantial evidence that the video was intentionally allowed to be erased. The principal [PII redacted] and vice principal [PII redacted] and, according to the two of them and Detective [PII redacted], Officer [PII redacted], all were on notice of the request on November 22. In addition, the principal received a written reminder on November 29. Further, [PII redacted], the County Records Officer, also received notice no later than November 29. He undoubtedly would have notified the principal [PII redacted] and/or Officer [PII redacted] again. Despite all of these notices, all four of them allowed the video to be erased. That was at best gross negligence, but it is far more likely that the erasure was intentional. They could not allow the truth to be revealed: video had indeed captured the incident in which [PII redacted] committed a battery on my daughter [PII redacted].

There is substantial, irrefutable proof that the surveillance video captured the aide’s [PII redacted] battery of my daughter [PII redacted], despite the denials of school officials [PII redacted]. On November 22, 2010 both the principal [PII redacted] and vice principal [PII redacted] represented that they had studied the video with Officer [PII redacted] for two hours. “Study” is their word. No one studies blank video for two hours. When the DCF asked to see the video, just three days after the incident, the DCF Investigator, [PII redacted], was told that there was nothing on it, and accordingly was persuaded not to view it.

Likewise, when Detective [PII redacted], the School Police Detective, asked to see the video, he was told that it had already been erased. However, at the time the detective [PII redacted] became involved in the investigation, the video had not yet been erased. This blatant misrepresentation threw the detective [PII redacted] off the track. He had no reason to know that the video had not in fact been erased. He also wasted investigative resources identifying other witnesses and trying to determine whether the video had captured the incident. Due to his being misled, he reached the incorrect conclusion regarding whether the incident had been captured by the camera.

There is no longer any doubt that all three benches were not obstructed as represented. Only one of the benches was fully obstructed, and it is not disputed that [the aide and my daughter – PII redacted] were not sitting on that bench. The detective [PII redacted] recently conceded that that was indeed the case, but tried to suggest to us that it didn't matter, because he found the abuse had occurred, so the video was not "needed." This demonstrates the lack of an appropriate level of concern regarding how the video was allowed to be erased, who was responsible, and why. There can be no doubt that the erasure of the video deprived all of us of the best evidence as to exactly how brutally my daughter [PII redacted] may have been battered by [PII redacted] on November 12, 2010 in front of [PII redacted].

Both Detective [PII redacted] and Officer [PII redacted] have demonstrated motive to deny any abuse in the Special Education department at their school. They have both vigorously argued that the two eyewitnesses conspired together to fabricate the allegations of abuse by [PII redacted]. These allegations were later verified by both the DCF and the School Police investigations, i.e. they were found to be truthful and accurate. Likewise, they also claim a conspiracy against them regarding other allegations of abuse in the same classroom, as if the existence of any abuse is a poor reflection on either of them.

According to Detective [PII redacted], Officer [PII redacted] has made two material misrepresentations to him: that the video had been erased when [the detective] asked to see it (that was false) and that the overhang blocked the view of all three benches, including the bench that [my daughter] was on (also false). These representations raise the question of whether Officer [PII redacted] was a willing participant in the effort to cover up the contents of the video and the date of erasure. Unfortunately, Detective [PII redacted] is not in a position to investigate, because Officer [PII redacted] is his colleague and his buddy, and there is a blatant conflict of interest. Accordingly, a proper investigation was never conducted.

An investigation by an independent body should have been ordered to determine who was responsible for the erasure of the video and whether the erasure constituted obstruction of justice, or merely destruction of evidence in a child abuse case. Either way, the case was not properly handled by the School Police due to their obvious conflict of interest.

We have sought help from every government official and agency we could think of, and could not get help from any of them. This is the list:

School Principal
School Assistant Principal

Department of Children and Families School Police
School Detective
Florida State Attorney for Palm Beach County Florida Dept of Law Enforcement
Florida Department of Children and Families
Chief of Police County Manager
Palm Beach County School Board
Palm Beach County School Superintendent Palm Beach County Area Superintendent Florida Dept of
Education
US Department of Justice
US Department of Health and Human Services Florida Attorney General
Four television Stations
Two Newspapers
Disability Rights Florida Advocacy Group
In house Attorneys for Palm Beach County School Board Palm Beach County Sheriff Department
Boca Raton Police Department Our local State Representative Our local State Senator

In summary, my daughter, [PII redacted] was the victim of abuse by [PII redacted]. Our daughter [PII redacted], and our entire family, have been re-victimized by the reaction of the school administrators and School Police as partially set forth above. The number of misrepresentations made to us is staggering, several laws have been broken, a video that captured the incident has been destroyed, the School Police cannot or will not investigate because they have a blatant conflict of interest, the person who reported the abuse was fired the same week she made her report to the DCF and the same administrators are continuing to try to cover up all of the abuse and wrongdoing.

We have since learned that this type of reaction to child abuse in school is not an isolated case. We have spoken with other parents who have run into the same obstacles that we have. Abuse and other wrongdoing is denied, officials are all loathe to take appropriate remedial action, evidence of abuse is covered up, witnesses and victims are discredited, and reporters are victims of retaliation. The families feel there is nowhere to turn, and they are right. Somehow, this needs to be stopped.

Respectfully submitted,

Diane and Alan Levine (on behalf of our daughter, [PII redacted]) [PII redacted]

John Erb

April 4, 2011

Subject: Regarding: IACC Meeting

My name is John Erb, and this is the fourth time I have appeared to speak before you. I represent the Global Autism Institute and Academy, a network of people touched by ASD and the researchers determined to assist them to improving their lives.

Our volunteers have over the years uncovered direct links between the amino acid glutamate in foods and vaccines, and the increase in cases of ASD.

In May of 2008 Food Scientist Carol Hornlein and I appeared before you and submitted the following information to spur Dr. Insel and the National Institute of Mental Health into action.

Here is that information again:

A study done in 2006 by Page, Daly et al. found that "People with Autism Spectrum Disorders had a significantly higher concentration of glutamate...in the amygdala hippocampal region..." and suggested in their conclusion that "Abnormalities in Glutamate/glutamine may partially underpin the pathophysiology of Autism Spectrum Disorders.

As far back as in 1990, Sahai. S. in his article Glutamate in the Mammalian CNS [Central Nervous System] found that "the neurotoxic nature of glutamate resulting in brain lesions (neuronal death) is thought to possibly underlie several neurological diseases..." And that "This neurodegenerative effect of glutamate also appears to regulate the formation, modulation, and degeneration of brain cytoarchitecture during normal synaptogenesis"....."its function as a neurotransmitter in several regions of the CNS, glutamate seems to be specifically implicated in the memory process., Long term potentiation and long term depression, two forms of synaptic plasticity associated with learning and memory, both involve glutamate receptors."

Monosodium glutamate (MSG) affecting the brain has been a long known fact. Another name for Glutamate is Glutamic Acid,

Please take note of the following Human studies done on Glutamic acid, and pay special notice of their dates:

The role of glutamic acid in cognitive behaviors; Vogel et. al. 1966.

Glutamic acid and human intelligence; Astin AW, Ross S. 1960

Effects of glutamic acid on behavior, intelligence and physiology. Pallister PD, Stevens RR. 1957

Experimental studies of the effect of glutamic acid-multivitamin combination on the mental efficiency of mentally normal adults. Lienert GA, Matthaei FK. 1956

Effects of prolonged glutamic acid administration on various aspects of personality. Mehl J. 1956

The effects of glutamic acid upon the intelligence, social maturity and adjustment of mentally retarded children. Lombard JP et al. 1955

Glutamic acid therapy in intelligence deficiency. Pabst E, Wurst F. 1952

Improving mental performance with glutamic acid. Kuhne, P. 1951

Glutamic Acid and Intelligence Quotient. Delay J. Pichot P. 1951

An investigation into the effects of glutamic acid on human intelligence. Milliken JR, Standen JL. 1951.

The influence of glutamic acid on test performance. Elson DG et al. 1950.

Effect of glutamic acid on mental function. Kerr W, Szurek S. 1950

Effect of glutamic acid on the intelligence of patients with mongolism. Zimmerman FT et al. 1949.

Considering the nature of these studies on humans ingesting glutamate with effects on human intelligence, intelligence quotient (IQ) scores, Personality and behavior, I ask that this committee take seriously the overwhelming possibility that MSG is playing a role in the triggering of Autism.

In the National Institute of Mental Health (NIMH) press release of February 18th, 2007 the Genome Project was reported to produce the following findings:

“Clues emerged adding to evidence that implicates components of the brain’s glutamate neurotransmitter system in autism. Glutamate increases neuronal activity and plays an important role in wiring up the brain during early development. Since autism likely stems from faulty wiring, a genetic blueprint gone awry in this pivotal neurotransmitter system is a prime suspect. Some key genes associated with the glutamate system are located in chromosome regions previously associated with autism, note the researchers. Previous studies have also linked abnormal glutamate functioning to disorders such as Fragile X syndrome and tuberous sclerosis, which share some symptoms with autism. It’s not unusual for individuals with either syndrome to be diagnosed with autism.”

What will it take to make the Autism community wake up and take notice?

Just recently, Carol Hornlien uncovered evidence that the patent for glutamate in vaccines occurred in 1982, when a large spike in Autism also occurred.

Where is the hero on your committee bold enough to make a motion that a special task force be created to closely examine the research that I have brought forward, and to take a serious look at the possibility that MSG in food and vaccines is triggering the massive epidemic of Autism.

MSG was introduced to the public in 1950, only after 1950 did we see the increases in this serious disorder.

Who on this committee is interested in finding the likely cause of Autism?

Who among the members of this fine committee is willing to make the motion to create the MSG task force?

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

Sue Leteure

April 4, 2011

Subject: Statement for Public Inquiries on 4-11-2011

My daughter [PII redacted] had a reaction to her first diphtheria, pertussis, and tetanus (DPT) shot at nine weeks of age. She was perfect until then. I knew immediately after the shot that something was wrong, but at the time I didn't know anything about the reactions possible with the vaccines. She screamed a feral cry, almost immediately. She had suffered encephalitis, swelling of the brain. She became very lethargic, and had a grand mal seizure exactly six hours after the immunization. The seizures progressed over the next few months. She has had many thousand seizures over the past twenty-nine years. Her vaccine injury manifested in autistic behavior and mental retardation.

Our family has been fortunate to have been able to overcome this situation, and are blessed to have such a wonderful daughter. My daughter might be considered a statistic in the war against infectious disease. However, if my daughter [PII redacted] were your child, grandchild, niece or a friend's child, you may feel differently about being a statistic.

When my daughter [PII redacted] was young, autism was rare. Autism is incredibly prevalent today. I am shocked to hear from so many people that they have or know of a child with autism. I have heard many of these parents report that their child with autism had a vaccine reaction. My daughter [PII redacted] received compensation from the government for her vaccine injury. My daughter [PII redacted] has behaviors consistent with the autism diagnosis. If a vaccine injury caused my daughter's [PII redacted] autistic behaviors why couldn't this have happened to the other children with autism. This committee needs to take these parental reports of vaccine reactions and autism very seriously. This committee needs to fund independent research to look at this extremely important issue. I am not a doctor, nor a scientist.

I am a Mom of a beautiful child that is impaired due to trying to protect her. My daughter [PII redacted] is totally dependent on others for her every day care. She has been hospitalized countless times for seizure related issues, has had more tests than most people can imagine, has no speech, wears Depends, and will always need twenty-four hour care. There is nothing I can do to change what has happened to our daughter. The damage has been done. But if I can urge you to do the important research to help save one child, one family from going through what we have endured with my daughter [PII redacted], it is worth every breath that I have taken, every penny spent, to get safer vaccines for our children. It is so worth all we have been through. Please, when making decisions for children, remember my daughter [PII redacted], and what she has been through, as well as all of the other children damaged, or killed by the vaccines.

Respectfully yours, Sue Leteure

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

Laura Bono

April 4, 2011

Subject: Regarding: Public Comment

My name is Laura Bono. Today I am here representing the under-represented...the invisible individuals with autism who do not have the ability to speak for themselves. The individuals with autism that are banging their heads and causing physical harm to themselves because they are in pain and suffering with numerous unrecognized medical conditions overlooked because they can't communicate their pain. They also are unable to travel to these meetings to speak for themselves, they are totally oblivious to the world, and certainly to this meeting. In short, I am representing the autism that seems to have been forgotten by this group.

I've been at this a long time. My son [PII redacted] just turned 22. I told Tom last year that I wasn't even going to bother anymore because I was so disgusted with the inability of this committee to attack autism like the national health emergency that it is. Hope sustains me so here I am again.

Today, with your help I will be reassured that you will do all you can to respond in an appropriate manner to the epidemic that we have before us. I don't have a degree in science. Rather I have worked in business for 30 years. Because of that, I can tell you that if you were trying to solve a big problem with this strategic plan at a fortune 500 company you would be fired.

The parents told you 15 years ago that the majority of cases driving the epidemic were environmental. Now you know it is true.

The parents told you 14 years ago that our children's gastrointestinal systems were dysfunctional. Now you know it is true.

The parents told you 12 years ago that our children's immune systems were dysfunctional. Now you know it is true.

The parents told you 11 years ago that there was such a thing as regressive autism. Now you know it is true.

The parents told you 8 years ago that children were recovering with biomedical treatments and therapies. Now you know that it is true.

The parents have been telling you for over 10 years that children were regressing after vaccines. If you would have just listened, so many children would have been saved. We, along with the Senators and Congressmen who asked for it, are still waiting for a study of completely vaccinated children vs. non-vaccinated children.

So many years wasted. So much money funneled into meaningless studies. So many opportunities cast aside. The parents and researchers have practically had to beg for the studies that have proven that

children regress, that children recover, that autism is, by-in-large, an environmental disorder that is treatable and preventable.

You said you heard us, yet you still flushed millions of dollars down the toilet looking for an autism gene that doesn't exist for 95% of the children. During that time, there were no treatments, no preventions, no cures. In fact, the hundreds of millions of dollars wasted didn't even produce a gene finding that can be replicated. At best, genes can explain 5 to 10% of children with autism. What the gene research has confirmed is that the epidemic is environmental.

The best studies in the strategic plan are the environmental risk studies: Childhood Autism Risks from Genetics and the Environment (CHARGE) and Early Autism Risk Longitudinal Investigation (EARLI) -- and yet they are moving at a snail's pace compared to what is required in the midst of an epidemic.

I'd like for you to imagine 1 million sick, autistic children and adults knocking on the doors of this Reagan building who are trying to speak to you – not with words but with their eyes, their behavior, their toxic profiles. If they could, I think they would implore you to start a Manhattan Project for autism to figure out their disease. Such a project would allow us to start thinking of autism as the epidemic that it is.

Unlike how regular investigator-driven science is done, this project could quickly determine the low hanging fruit and carry it out with urgency. Then, allow the research to follow where the evidence takes them, looking to the ailments of sick children for clues. Need to know studies will govern the day. Nice to know studies go to the back burner. To pay for it, we need to re-prioritize the lion's share of the research money from genetics to the environment.

This committee has within its power to create a Manhattan Project. This Special Emphasis Panel, called the Autism Task Force should be made up of autism clinicians and independent, forward thinking scientists well-versed in toxicology, epigenetics, immunology, gastroenterology, endocrinology, neurology, the neuro-immune system. The selection process for the Special Emphasis Panel would favor those with innovative, pioneering thought. Restrictions of the group should be eased so that these scientists are unhampered by the peer review process that, by its own necessary design, restricts novel science. Lastly, this Special Emphasis Panel needs to be made up of critical thinkers who aren't afraid to go where the research takes them even if it veers from conventional wisdom. Let's face it. If conventional wisdom and science done the same old way could work for autism, we would have already cured the disease long ago and moved on. It's time to shake off the dust that is dragging this committee down and think out of the box.

Remember the sick, non-verbal children and adults knocking at the door? Rather than shutting them out, let's open the doors. Let them into your discussions. Imagine that they are sitting here at the table with you. Treat their environmental injuries. Hear their pleas for help. Remember that some can recover if only you will try. I believe this committee has the power to help them all. A Special Emphasis Panel called the Autism Task Force would be a great first step.

I will leave you all with a comment by Alan Leshner from the 2007 Institute of Medicine (IOM) meeting called, Autism and the Environment, Challenges and Opportunities for Research. He said "This meeting has been a very important start, and if we don't do something, then shame on us." My question to the committee, have any of you even been required to read the proceedings from this Department of Health of Human Services (HHS) sponsored event? How about the wonderful synopsis of scientific opportunities determined to be the low hanging fruit from the meeting? If not, then as Dr. Leshner said, "shame on us."

We have an epidemic on our hands. Please form an Autism Task Force to take on the challenge. That is how you respond to a crisis. That is how you work the problem. If not now, then when?

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Sarah Bridges

April 5, 2011

Subject: Re: Would like to make a comment at the 4/11 meeting

On behalf of my son: [PII redacted]

Born: [PII redacted]; Injured February 25, 1994

It seems like you should have a feeling that problems are coming, the way animals can sense a storm. But, we didn't. My son, [PII redacted], was born healthy on [PII redacted]. He progressed steadily until his four-month "well baby" appointment at which he was given a spate of vaccines. Ten hours later, my son [PII redacted] woke us with a high-pitched scream, 106 degree fever and two-hour seizure. This night marked the beginning of an odyssey of hospitals, and ambulances, and legal proceedings. We are one of the lucky ones. My son [PII redacted] "won" his case in the vaccine court. Our neurologist said that he was an open-and-shut vaccine injury. We were assured that the vaccine court would provide swift justice. That was a relief—we were staggering along as my son [PII redacted] was hospitalized regularly and unresponsive to medication. It may be good fortune that we had no idea how difficult a vaccine court case would be. In the end the case took 7 years; broke up a marriage, and culminated with my son [PII redacted] needing round-the-clock care in a specialized home.

My son's [PII redacted] formal diagnosis is "brain injury," caused by the brain infection triggered by a vaccine. He is diagnosed with autism. Additionally, he is severely retarded, has intractable seizures, and hyperactive. I've listened to the Centers for Disease Control and Prevention (CDC) claim that there is no link between vaccines and autism. I find this baffling as the government acknowledged years ago that my autistic son was rendered this way by his inoculation. His lifetime needs, for he will always require 24-hour care, are paid for by the vaccine compensation program. This includes caregivers trained to manage his behavior problems. Multiple experts, his neurologist, pediatrician, and school psychologist included, have corroborated he is severely autistic. Yet, the government continues to propagate the idea that vaccines and autism never mix. Most members on this committee continue to deny or refuse to properly investigate autism and vaccine link. That is beyond unfortunate. Again, I want you to listen to me. My son has been compensated by the government for his vaccine injury. My son has a diagnosis of autism. Vaccines and autism do mix, the federal government recognized this in my son's case.

What many of you fail to recognize is that parents like me do not want the same outcome for other infants. The thought of other children suffering the same injury as my son [PII redacted] because the proper research has not been done on vaccine safety, because of concerns about the vaccine program, is inexcusable. Please be courageous, get the vaccine and autism research funded. Enlist independent scientists conduct this important work.

I don't want vaccines abolished. I want a safer vaccine schedule. I want you to research the children that reacted to their vaccines and see what their common genetic issues are so that infants with the same genetic background don't suffer the same fate. IACC can do this. IACC must do this future generations of children are depending on you.

Events:

My son's [PII redacted] Date of Birth: [PII redacted]

[Medical records redacted]

Prognosis: Round-the-clock care in a group home for the rest of his life. Work: Unlikely to work at all (even sheltered workshop)