

Oral Public Comments

**IACC Full Committee
Meeting**

July 9, 2013

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Casandra Oldham

July 9, 2013

Thank you for the opportunity to tell you about my family and our struggle with Autism.

Let's focus on some facts. All 3 of my boys were born healthy. At my middle sons second birthday medical records have him normal, healthy and developing on target. Right after that he got sick regressed over a number of months and developed autism.

During the time my son regressed he had physiological issues that I was told had nothing to do with him developing autism. I was told I had missed the signs.

A few months later over a period of three weeks my youngest lost all his words, clapping, pointing, and responding to his name, eye contact, waving and the ability to chew. I called the "experts" they tested him for things that they didn't test his brother for. He came up positive for mitochondrial disease. After we brought his brother in for testing and he was positive as well.

We did genetic testing. I don't have it. My children acquired mitochondrial disease from an attack on their immune system from environmental toxins and the mito disease manifests itself in autistic tendencies. * Now it is important to note that no one else in the house was sick from environmental toxins.* This is how it was explained to me, is that if you get hit in the head hard enough anyone can develop epilepsy. Two people can get hit with the same force and only one might have a seizure. We all have different thresholds. It's not something you can test for or screen, we just need to wear helmets when doing activities where our head might get hit. So for my children and children like them (and there are a lot) we need to scale down how much stress we put on the immune system. What we are doing right now, is too much for too many.

So I said ok lets test for what these toxins are. They said, "We can't". So I shipped my children's urine to France for testing.

My boys were so sick and their behavior was insane. No Doctor that accepted insurance knew how to help them. I learnt of some doctors but you had to pay out of pocket. With 2 home ABA programs costing more than twice a monthly mortgage, it took a long time for me to be able to afford access to these Doctors. I couldn't bear the thought of choosing one child and not the other. No parent who's paying insurance should have to make a decision about which child to treat!!! When we finally got them tested they had ulcers all up and down the GI track; in the stomach, large and small intestines. The youngest had some in his throat. When we treated that, they slept for the first time in years. When we tested and treated for other conditions, all the self-injurious behavior went away. Head banging gone, in a few hours from treating!! They stopped beating me up and my little guy wore shoes for the first time in two years. When I put my middle son [PII redacted] on antivirals he started to put words together. [PII redacted] had cognitive leaps. Anti yeast and bacteria help them not *stim*.

I have medical evidence that my children were harmed by vaccines. I did not have that in the three year window that I needed to file in court because I could not afford the medical test and could not find an attorney to help me with that process. It would be ridiculous to expect someone who had a burglary in their home or experience any other crime to do their own forensic science. Why do we expect parents to?

My children have lost one of the very basic human rights...they lost speech! My [PII redacted] can't talk, he could... imagine! And then imagine the people who can help change it doing so at such a leisurely pace!

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Eileen Nicole Simon

July 9, 2013

Lexington, MA
[PII redacted]

I have a “banner” that I brought last year with three important pictures:

First is the picture of blood flow in the brain, from the 1962 paper by Seymour Kety [1].

Second is a more recent fMRI picture showing also that blood flow is higher in the midbrain auditory center (the inferior colliculi) than anywhere else in the brain [2].

This midbrain center is most vulnerable to injury from oxygen insufficiency at birth, and from exposure to toxic substances. Evidence of this has been in the medical literature for more than 50 years. The evidence is from experiments with laboratory animals and following suffocation or toxic exposure in humans [3-6].

Brainstem injury in the past was suggested to be the cause of “minimal brain dysfunction” (or MCD) in human children. But the primary sites of injury are in the auditory pathway and basal ganglia.

Development of the human brain continues after birth. That this development is blunted in children who develop autism was reported in an important paper published last year [7]. Integrity of brainstem auditory centers is essential for maturation of the language circuits in the cerebral cortex [8, 9]. Rather than “minimal” the damage caused by asphyxia to auditory centers should have been recognized decades ago as relevant to disorders of language development [10].

In the written comments I submitted for this meeting, I provided links to three online videos describing the dangers of clamping the umbilical cord immediately at birth [11, 12, 13]. If clamped before the first breath, damage to the brain is likely to occur before the baby can be resuscitated.

This committee should consider clamping of the umbilical cord at birth as an important topic for discussion, and bring this issue to the attention of the obstetric profession.

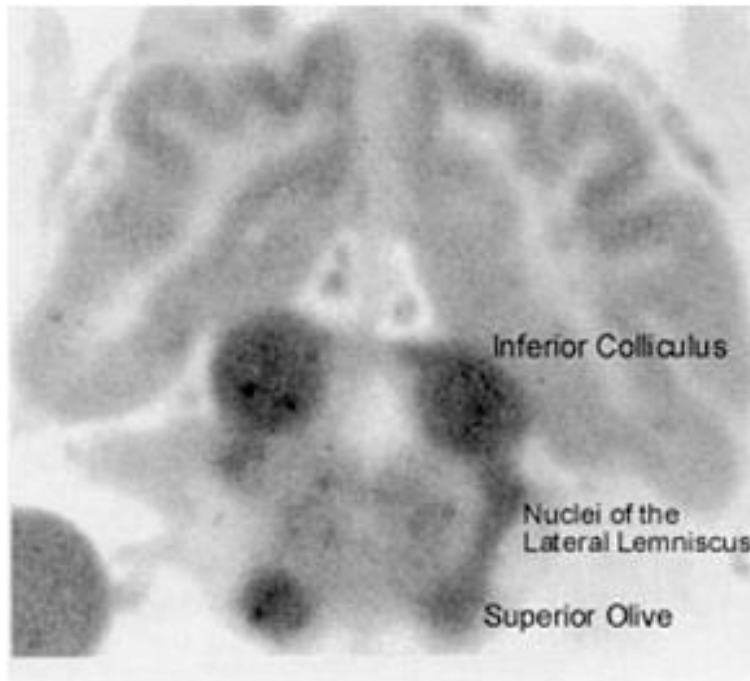
Clamping the cord immediately after birth became a standard protocol in the mid 1980s. Until that time textbooks taught that circulation to the placenta should cease before clamping. Use of the clamp sooner and sooner after birth should be considered as a possible reason for the increasing prevalence of autism.

The third picture in my banner shows that bilirubin (or any other undesirable substance in the circulation) concentrates in nuclei of the auditory pathway and basal ganglia.

Please discuss (1) the importance of the auditory system for language development, and (2) that repetitive “stimming” behaviors may be the result of injury to the basal ganglia.

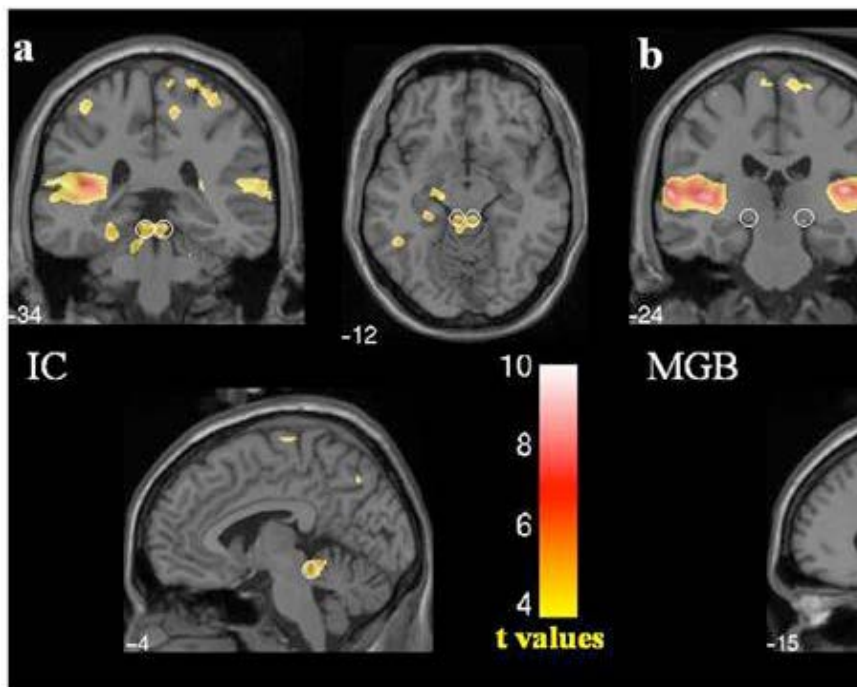
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- [10] Gilles FH. Selective symmetrical neuronal necrosis of certain brain stem tegmental nuclei in temporary cardiac standstill [Abstract of presentation at the American Association of Neuropathologists: 38th Annual Meeting. Atlantic City. New Jersey]. J Neuropathol Exp Neurol 1963 Apr; 22(2):318.
- [11] TICC TOCC, drgreene.com, Alan Greene (18 minutes)
<http://tedxtalks.ted.com/video/Alan-Greene-at-TEDxBrussels;Featured-Talks>
- [12] Contemplating the Cord. A seminar with Dr. Bruce Wainman (18 minutes)
<https://www.youtube.com/watch?v=t3EvxuQ3RiA>
- [13] Contemplating the Cord. A seminar with Dr. Eileen Hutton (29 minutes)
<https://www.youtube.com/watch?v=j09DkMnsOFo>



From: Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed>



From: Budd TW et al. Binaural specialisation in human auditory cortex: an fMRI investigation of interaural correlation sensitivity. Neuroimage. 2003 Nov;20(3):1783-94.

Note high blood flow in the inferior colliculi (IC) compared with lesser blood flow in the Medial geniculate bodies (MGB).

Vaccination after asphyxia may be double trouble.

Asphyxia disrupts the blood-brain-barrier, and allows bilirubin or any other substance into neurons.

Could autism be a variant of kernicterus?

← The inferior colliculi

From: Lucey JF, Hibbard E, Behrman RE, Esquivel FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. *Experimental Neurology* 1964 Jan; 9(1):43-58.

This was a slide included in a powerpoint presentation I made at the IACC meeting in November 2008:

http://iacc.hhs.gov/events/2008/slides_eileen_simon_112108.pdf

Vitamin K and hepatitis B shots given right after immediate clamping of the umbilical cord may not be a healthy thing to do.

[Photo redacted]

Cover of *Topics of Conversation*, book 4 of a series *Autism and the Inferior Colliculus* I have published as ebooks for Kindle and Nook readers, available at:

<http://www.amazon.com/kindle-store/dp/B00CKW4KV6>

<http://www.barnesandnoble.com/> search NOOK Books for inferior colliculus

The IACC must be urged to engage in back-and-forth conversations with stakeholders.

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Jill Rubolino

July 9, 2013

My name is Jill Rubolino. I am a mother of a ten year old son who is recovered from autism and also a co-founder of the parent support group AIM, Autism Is Medical in both Chicago and Houston. I appreciate the opportunity to speak to you today.

Autism is medical, but our children are denied access to appropriate medical care. Presenting symptoms of neurological change, loss of function, change in behavior, sudden onset of severe gastrointestinal illness, immunological symptoms and a myriad of other physiological illnesses are ignored and this patient population is referred to a paraprofessional for a developmental evaluation. All of these symptoms, in the absence of the "autism" label, would be and are routinely treated as emergent, as a standard of practice. This complete neglect of hundreds of thousands of children that are denied basic medical diagnostic evaluation under the cloak of a psychiatric label is called malpractice. Rarely does the practitioner, institution, clinic or pediatrician suffer the legal consequences from their total lack of adherence to the ethical guidelines and standards that govern their practice and organizational delivery of care. When an unfunded prisoner, on the way to jail after being arrested for cocaine use, claims he is having chest pain, he is diverted to the emergency department where he receives a complete medical work up including diagnostic cardiac evaluation. At the same time, a three year old child with loss of function, severe abdominal distension, incessant screaming, self-injurious behaviors and debilitating diarrhea gets an "autism" label and is sent home with the parents. Something is VERY WRONG WITH THIS SYSTEM.

Medical neglect and discrimination against this exponentially expanding acutely and chronically ill pediatric patient population will not go unchecked. Every person sitting on this committee needs to know this accountability begins here.

My son [PII redacted] is recovered from the label of autism because he was treated for the underlying causes of his illnesses. He was sick, and I've spent seven years travelling this country to get him treated. Not one "Autism" organization helped and not one local, state or governmental agency supported us. Every medical intervention he received, I made happen.

I've spend the last nineteen years as an acute care nurse at large university hospitals and I have never seen this degree of medical neglect in any setting with any other patient population. I plan to spend the rest of my days making sure every single child receives appropriate healthcare, and holding those who feel they are exempt from their oath, accountable. The continued denial of the symptoms of "autism" as anything other than neurological injury is medical neglect. The ever expanding body of research supporting the untoward effects of vaccines on both the neurological and immunological systems is staggering. The medical community and governmental agencies that continue to deny the connection between vaccines and autism, promote the practice of blocking our children from appropriate care while pediatricians refuse to see children whose parents choose not to further injure them by continuing to vaccinate. No other patients are denied basic medical care based on their vaccination status and this is truly discrimination in its purest form. The continued refusal to perform any diagnostic testing or appropriate treatment by pediatricians, and the American Academy of Pediatrics' continued lack of development of a **medical** standard of care for a pediatric patient population that outnumbers pediatric cancer is nothing short of criminal. By not testing and treating, no statistical information can be amassed from which to extract any

data useful in developing a comprehensive plan of care for these children. Conveniently, underlying pathophysiology of autism is also strategically avoided with the “if we don’t test for it, it didn’t happen” mentality. As a result, hundreds of thousands of children with serious medical problems go untreated and their parents are left to figure it out for themselves. Then, in doing so, they are labeled “alternative” or “biomedical” when the reality is they would love to just be able to take their child to the doctor like everyone else.

Our children deserve the same access to diagnostic testing, accurate diagnosis and complete plan of care as every other patient including that drug user on their way to jail. Medical neglect and discrimination can and will be prosecuted to the fullest extent of the law. We will not tolerate this one day longer.

Thank You.

Jill Rubolino, RN

[PII redacted]

AIM, Autism Is Medical, Chicago

AIM, Autism Is Medical, Houston

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Albert Enayati

July 9, 2013

U.S. Immunization Program and Autism

Testimony Presented By

Albert Enayati

Research Scientist in Medical Technology

Father of [PII redacted], who regressed into autism after a vaccination.

Board Member of SafeMinds

[PII redacted]

My name is Albert Enayati. I am a Board member of SafeMinds a volunteer organization aiming to eliminate the devastation of autism induced by mercury and other neurotoxins. As the past President of the New Jersey Cure Autism Now (Currently Autism Speaks), we have drafted and introduced the currently known Combating Autism act of 2006. At Rutgers University, we established the first nationwide Autism Gene Bank and recruited hundreds of twin siblings suffering from autism and we established the first Center of Excellence in the nation for Autism Research. I am a co-author of Autism: A Novel Form of Mercury Poisoning and worked closely with the United State Congress, FDA, NIH and CDC to remove thimerosal from childhood vaccines.

Sadly, despite 18 years worth of advocacy, we are still unaware of the cause of this devastation with no medication or prevention strategy in sight. For the past eighteen years, we have sought after the cause of autism, spending millions of dollars in many fields and have found nothing conclusive. It is now time to dedicate our resources into the right path; Vaccines role in the autism epidemic must be included in the IACC research portfolio.

Mr. Chairman many experts would have us believe that my son's regression was mere coincidence with his vaccination. However, as a trained scientist, my reading of vaccine literature indicates that many traits that define autism may be induced by vaccination. The timeline for increases in autism prevalence corresponds closely with the introduction of two new vaccines. In particular, the phased introduction of the Hib vaccine in 1985 – 1990 and the universal introduction of the HepB vaccine in 1991.

You may recall that after the Space Shuttle Columbia disaster an independent investigating board was created by Congress to investigate the accident, to get to the truth. Now, it is time to establish such an Investigating Board to explore the relationship between vaccines and autism. Ladies and Gentleman, U.S. Immunization Program must be regulated. Dangerous substances in vaccines still remain untested. The children are vaccinated without knowing the history of the mother's or the child's immune system or recognizing if the child immune systems can successfully respond to the injected vaccines. Multiple vaccines are injected in a single day without concern about side effects. Booster vaccines are injected without any testing to confirm if T and B lymphocytes have become protective.

Mr. Chairman, since 2009 the National Vaccine Advisory Committee (NVAC), recommended numerous times to this organization that research programs should be conducted within the field of Vaccines and Autism. As a devastated father I stand before you today saddened and frustrated as it seems that IACC does not care. It is essential that the IACC meets its obligation to thousands of concerned parents and immediately start issuing an RFA as per the recommendation of NVAC. In addition, the RFA needs to be issued to investigate the phased introduction of the Hib vaccine and the universal introduction of the HepB in relation to increases prevalence of autism and investigate the rate in vaccinated vs. unvaccinated children free of conflict of interest.

My son [PII redacted] and one out of one hundred children across America need answers to whether or not vaccines have caused this devastation and how we can return our loved ones home.

Sincerely and respectfully

Albert Enayati

Bernard S. et al [Med Hypotheses](#). 2001 Apr; 56(4):462-71

[Albert Enayati's presentation can be viewed here.](#) (PDF – 38 KB)

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Jeanna Reed

July 9, 2013

Good afternoon.

I came here today to ask questions, tell truths and beg all of you to truly look at the underlying medical conditions that make up the label of “autism”.

My name is Jeanna Reed and I am a mom to three beautiful boys. Today I would like to speak to you about my oldest son [PII redacted] who suffered severe adverse reactions to his recommended vaccine schedule. The picture you see in my hand is following his 12 and 15 month vaccinations. His body swelled, he became ataxic and suffered from relentless high fevers. Rashes became commonplace and episodes of petechiae/purpura appeared on his earlobes and body. His bowels went from tolerable, to acid- like and leaked from his diaper daily. His immune system suppressed to the point of 13 back to back ear infections following his 15mo vaccines. We watched in horror as our once typically developing, loving child declined medically right in front of our eyes.

After multiple reactions to his vaccinations, our pediatrician tried to put our son into a nice neat box, a “standard” if you will. We were all very concerned and our medical team clearly confused. Blood work was ordered, CT scans scheduled and specialist visits began. The photos I showed you a moment ago were now commonplace. He was miserable, febrile and declining. When some of the testing didn’t quite yield expected results, symptoms were explained away and even dismissed. I was told to “wait and see” more times than I care to tell you.

Eventually diagnosed as severely autistic, our son was lost in a system that truly had no clue how to help him. We were offered a school based program, along with typical therapy. Our medical diagnostic in Early Intervention added more useless labels “sensory processing disorder, mixed language disorder, disruptive behavior disorder” and then, they sent us home. The common theme here being that none of these labels did anything to diagnose or treat the true MEDICAL problems he faced. Not one.

Hindsight, we wasted precious time in turn allowing his vaccine injuries to damage him further. Refusing to allow those labels to determine his fate, we were forced to travel mostly outside of Illinois to find him the medical help he so desperately needed. That journey took us to Cleveland Clinic, University of Texas Houston, University of California Irvine, Austin Texas, Mass General-Lurie Center, Kennedy Krieger and Lurie Children’s Chicago to name a few. We eventually were able to form a team of specialists around our child and devised a plan to properly diagnose his medical conditions and treat each appropriately. That “team” consisted of a Neurologist, Gastroenterologist, Mitochondrial specialist, Geneticist, Immunologist, Pediatrician, Nutritionist, Family medicine physician and countless “therapists”. We worked together, coordinating care to ensure all were on the same page and treatment was appropriate and optimal for my son.

He was diagnosed with the following:

I’ll generalize to save time: Immune deficiency, mitochondrial disease, bowel disease, seizures, CNS “inflammatory” disorder, metabolic abnormalities and encephalopathy. There is more but that gives you an overview of how complex each child with an “autism” label can truly be ... if you look. You see, each one

of those diagnosis breaks down into more problems as we discovered, they all connect. His systems were either damaged, dysfunctional or trying desperately to repair.

Can you imagine if we listened to our pediatrician? "He's a boy, wait and see, it's most likely another viral syndrome". How about the immunologist? "He's a boy, not quite 2, bring him back if he declines further, vaccines all up to date, lymph nodes will go down". Early intervention, "sorry Mrs. and Mr. Reed we can't really test him, his sensory issues too much right now. Treat him as autistic and come back a year from now...Genetic testing all looked just fine."

Really?

That was 2006 and 2007.... What has changed since then? NOTHING!

What do YOU think would have happened to my child if we listened to this "advice"?

Please take a moment to look at the photos I have provided. The bowel disease photo shown to you in April at the previous IACC meeting was of my son's small intestines. With proper diagnosis and treatment he is now in remission. His seizures and abnormal EEG recently "clear" thanks in part to continued monthly IVIG treatments and a host of other interventions including dietary changes and specific supplements. The mitochondrial disease is a constant work in progress. While damage is still evident, we have been fortunate to find fantastic physicians who offer sound treatment based off biochemistry looking past the genetics. There is more, but I think you get the picture. It's called TREATMENT and even better, PREVENTION! We have worked hard, fearful of another environmental insult that will further damage his fragile system. However, we are grateful to have options to treat the underlying medical conditions. Simply, if you can identify the problem/condition, you can potentially treat it. And so I stand here asking you today, shouldn't this be offered to all children?

What did we learn from all of the above? My answer? Autism is Medical and that should be yours too. Did I mention my son no longer has that "autism" label?

He no- longer- has- an- autism- diagnosis. It's true. It happened. "Autistic disorder" removed. How can that be? Was it a mistake? No, he was diagnosed appropriately as severely autistic, we treated his underlying medical conditions, minimized continued insults and the severe autism peeled away. The extreme behaviors diminished. Autism, the label.... gone.

So I stand here asking each of you,

Why is no one asking me how that happened?

Why do we have to travel across the country yet again to come tell you what YOU should already know? Why are you not going to the AAP instead of waiting for them to come here? The headquarters were in my backyard and they offered nothing to help us help our child. Not even a basic standard of care. Why are we letting another day go by without one?

Why are you not talking to mainstream medicine and specialists that treat the many obvious medical problems our children face?

From the moment they present at that peds office with concerns, the first thought should not be "send them to Early Intervention" ...it should be a medical intervention right then and there while they wait for

services that many times never even come. Labs, MRI, specialists referrals forming a team around that child and family. The bulk of Mainstream medicine are failing these children miserably (please refer to the tragedy of [PII redacted] for a horrific example).

You have all had more than enough time and frankly resources, to do what we were forced to do on our own. We're exhausted emotionally, physically, financially so we're thinking now it's your turn. YOU travel around the country and find those physicians that are working overtime, risking everything to help OUR children.

YOU get them all in this room and start talking about Standards of CARE. All of them. YOU find a way to help the families afford basic medical care and insurance alongside the therapies for their children.

YOU are accountable. The hospitals, the AAP, the pharmaceutical companies, the government, the Dept. of Health and Human Services, the list goes on. But don't you dare blame this on autism.....no, see we know better than that. "Autism" is Medical.

I am begging you to Please God, start doing something! I can't listen to another one of these meetings where you all pat yourselves backs and act as if something monumental has been accomplished. Many of you are disconnected from the reality so many of us face. We are begging you to please listen. And when you finally do, may I suggest that you stay here until you get it done; day and night....24/7 because anything less than that, is completely unacceptable to every family ever sucked in to this tragedy. You are accountable to each of these children, the families too.

There is not one person or organization on this entire panel that helped us recover my son from his injuries. He was not born this way; he was harmed by a health care system that refused to consider him individually. That is a failure my husband and I will live with for the rest of our lives. However, the blame does not lie solely with us; we now realize that includes you too.

Research, Evidence based Studies, Standards of Care, Prevention, Treatments, Training, Education...the list is long. I get that but you've been given the resources, now it's up to you to actually utilize them. I am available to talk to if you care to know exactly what happened to my son and many others. You can also keep up to date with his medical file through the Vaccine Injury Compensation Program. A claim was filed on his behalf in 2008. We sit there today waiting for justice.....we're not holding our breath.

Respectfully submitted for public comment on behalf of our son,

Jeanna and Eric Reed

[Photos redacted]

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

Nicholas Gammicchia

July 9, 2013

Corrected Copy

Hello everyone,

I am here today to provide oral comment to the committee because I am very troubled. On June 9th a young man with autism who was only fourteen years old died. As a person living with autism, this was very hard to hear about because he was murdered. This young man also was denied the medical treatment that he should have been able to obtain. [PII redacted] was a young man that was misunderstood for what his behavior was trying to communicate. I at one time was like [PII redacted]. I would hurt my parents and I was not getting the help I needed. It was hard for me to communicate how I felt, tell people I did not feel well, or what could assist me. My parents were able to get me the medical treatment that I needed and not going into the hospital that was suggested.

I am asking you today to once again form a Safety Committee to look at issues like what happened to [PII redacted] and is happening to many other individuals with autism across the country. My uncle [PII redacted] died due to restraint used in 1999 in a hospital in Michigan. He had autism and epilepsy and was denied medical treatment that caused his death after being restrained. Things are not changing and many more people are dying. We cannot let my uncle [PII redacted]'s death be in vain. We cannot let all of those that have died, due to lack of medical care, have died in vain. We cannot let [PII redacted] death go unanswered.

We need to look at what is happening. People living with autism like me want choice in medical care. People living with autism also want to be safe. Please form a new Safety Committee ASAP to address this.

Thank you for listening to me today and I am grateful to have this opportunity to let you and others know my concerns.

Respectfully,

Nicholas Gammicchia

[PII redacted]

[Photos redacted]

Please go the Autism Tissue Program to learn more about [PII redacted] Donation and the program:

http://www.autismtissueprogram.org/site/c.nIKUL7MQIsG/b.5183791/k.9265/Memories_of_Hope.htm

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Carolyn Gammicchia

July 9, 2013

Oral Comment to the Interagency Autism Coordinating Council, July 9th, 2013 IACC Meeting by Carolyn Gammicchia

Dear Members of the Interagency Autism Coordinating Council,

I am here today for several reasons, but most importantly I am here today to support our son [PII redacted], as well as others living with autism. In my limited time I want to ensure that you are aware of what is transpiring across the country for many individuals like our son who have co-morbid medical conditions that often go undiagnosed, untreated, or inappropriately treated due to misdiagnosis. Our son's story is not unlike the stories shared in the publication "Medical Comorbidities in Autism Spectrum Disorders - A Primer for Health Care Professionals and Policy Makers", released in March, 2013, by the Treating Autism and the Autism Treatment Trust. Nor is his story different from his uncle [PII redacted], nor that of [PII redacted], and many others living with autism and medical conditions that go untreated and result in institutionalization, horrific suffering and even death.

We would like to also say that our son was born healthy and progressing ahead of developmental milestones prior to becoming ill in 1993. On a day when he received seven vaccines, (four including the MMR), he became ill within hours and had a fever and projectile vomiting. He was listless for the next two days, and despite repeated calls to his pediatrician on what to do other than the suggestion hydration and Tylenol, our doctor told us to not take our son for additional medical care. We did however and were sent home and told to hydrate our son which we had been doing. In those days our son stopped speaking, would no longer hold eye contact, and pulled away when we tried to embrace him for comfort. It took us almost a year to obtain a diagnosis of PDD-NOS for our son and for a specialist to tell us "Concentrate on your other son because you will have to institutionalize this one before age ten." We will never forget that day and the feelings we experienced when we went to our car in the parking lot and cried. We were given no direction and the word autism was only mention, almost in passing, when we were told that our son's behaviors were "autistic like". In that time we rarely slept due to our son not sleeping from 2am to 5am each night as well as his tendency to try to elope at every opportunity. Our house was a virtual fortress as we installed window, door, and cabinet locks, as well as a home alarm system. My husband and I at the time were police officers with the City of Detroit, when it was labeled the "Murder Capital of the United States", and when we were working opposite shifts we actually went to work to relax. That was how challenging it was living with a child that was physically self-injurious and assaultive to others, medically ill, and we were given little direction by every medical doctor we sought help from. Thank God we were able to find Dr. Bernard Rimland of the Autism Research Institute and his DAN protocol.

After reading about a variety of complementary alternative medical interventions, doing research, and looking at what conventional medicine and therapies that were offered, we chose the path we felt would assist our son. Within two days of taking our son off milk he started to speak again. We also began to address what he was eating as well as other options. Things began to look up. Unfortunately I then was almost killed in a car accident on my way to work. During my hospitalization for several injuries which included a closed head injury, a broken leg, and a fractural orbital, my husband was able to maintain however we were unable to obtain assistance for our son to help with his care. When I returned home, my

leg in a full cast and unable to even walk due to my TBI, my husband would have to lock us in a family room where I would stay for the next eight to nine hours with our two sons. One who needed to be constantly redirected and occupied to be kept safe and the other whom I needed to protect from his brother's biting, head butting, and jumping from the tops of couches and TV consoles. However during that time I began to see what was really happening to our son as I attempted to rehabilitate myself from my injuries. Our son too needed to be rehabilitated from his injury as well, and I knew then we needed to do what was necessary to obtain what interventions were appropriate. We spent the next fifteen years doing so and supporting others along the same journey. My injuries were easily recoverable compared to our son's because they were identifiable and able to be medically treated. My closed head injury took longer and I still do not have the fluidity within my thought process, nor literacy that I once had, and it had been a reminder to me along the way as we've supported our son to meet his daily challenges and be resilient. It is also important to note that at no time are we voicing dissatisfaction about raising a child that had our son's challenges. We love our son very much and those that know us know that we will do anything for him. We are sharing our story in the hope that you and others to know it is possible for our children to be medically sound and achieve overall wellness.

It has not been an easy journey however and along the way we've had our struggles. Our son regressed terribly when going through puberty and became physically challenging again at a time when he was doing very well in general education classes and with his overall health. However we had pulled back on his treatments and even his diet as needed and when those chemical changes occurred, we again fell into a mode of crisis prevention. The photos below are from that time and though we've not shared them widely, due to the stigma and misunderstanding attached, we felt the need to do so today and with you. Remember too that our son was only a twelve year old child, approximately 100 lbs and less than five feet tall, and he could literally cause both my husband and I significant injury. He had kicked my front teeth out, head butted us causing black eyes and swollen noses, and these bruises were from the biting he needed to do to allow him to subside after one of these episodes. These episodes were where his pupils would fully dilate and he was almost in a seizure state and would never verbally acknowledge us. My husband and I were both active police officers at the time and were able to keep our son from hurting others. We felt what transpired was not intentional, that he had no control over doing so, but knew my husband and I were "safe" in a sense to release his frustration on. We could see that was what he was experiencing, a heightened sense of not being able to self-regulate, and he could not tell us what was transpiring. Additionally we knew if we were to call for assistance from the police, they would take our son away due to our state's domestic violence laws. It is imperative that this council understands that and why we chose to do what we did and did not hospitalize our son as suggested by medical professionals

[Photos redacted]

What we chose to do was not institutionalize our son nor place him on the Haldol, Prozac, and other medication suggested. We went back to whole foods, supplements, a GFCF diet, increased exercise, decreased computer and TV access began therapeutic massage therapy as well as decrease some of the other stressors in his life. Within six weeks our son's physical challenges were gone. We had been implementing Relationship Development Intervention at the time and we also looked at vitamin deficiencies, increased levels of testosterone, as well as other things and treated those with supplements and appropriate interventions.

Today our son is doing well while living with autism. He is the healthiest individual in our family and most well rounded in his overall wellness. He exercises daily at a local gym and his membership is provided under his Medicaid. The same is true of his supplements, which are provided as alternatives to

medication(s) that would not assist him and are much less expensive. His story is one of success and one that needs to be heard especially due to the manner in which his Uncle {PII redacted}, a man living with epilepsy and undiagnosed Asperger Syndrome, died in a Michigan institutional setting due to the lack of medical intervention after being restrained in 1999. The same holds true for {PII redacted}, a 14 year old young man from Illinois, who suffered for months, was chemically and physically restrained, and not provided appropriate medical care.

We are here today to share our story, ask that you rethink autism by considering medical comorbidities that exist for some individuals living with autism, and work toward ensuring there are choices in medical care.

Respectfully,

Carolyn Gammicchia

Source: "Medical Comorbidities in Autism Spectrum Disorders - A Primer for Health Care Professionals and Policy Makers"

http://issuu.com/treatingautism/docs/medical_comorbidities_in_autism_spectrum_disorders

Autism Research Institute, Dr. Bernard Rimland, DAN Protocol, www.autism.com/

Andrew Gammicchia

July 9, 2013

Dear members of the Interagency Autism Coordinating Council,

I am providing this testimony to you that I provided to the then ADD (now AIDD) in December of 2010 because these needs still exist and have not been realized. I feel they need to be addressed here before you today for many reasons, those of which are stated in this testimony that is not over two and a half years old.

From our website: "The President of L.E.A.N. On Us, Andrew Gammicchia, provided a written proposal to be chosen as one of the forty individuals from across the Midwest to testify at the ADD "Envisioning the Future" Summit in Detroit, MI on Dec. 2nd, 2010. He was selected and allowed three minutes to provide testimony. This is the written transcript of that testimony along with some of the post scripts he provided. Each listening panel member was also provided a packet of information and resources for consideration. Please note that the ADD is providing an opportunity for written comment to be submitted via their website and we would urge others to do so. The ADD provides funding to support Protection and Advocacy agencies, Developmental Disability Councils, Centers for Independent Living, as well as parent training programs in most states. They also provide funds for other initiatives on a federal level and collaboration with many other national agencies."

Here is the link to access the public comment site:

http://www.envision2010.net/comment_submit.php

To view the transcripts from the Detroit Summit:

http://www.envision2010.net/transcripts/Detroit_Transcript.pdf

Commissioner Sharon Lewis
Administration on Developmental Disabilities
Envisioning the Future Summit
Detroit, Michigan

December 2nd, 2010

Good morning Commission Lewis and distinguished panel members,

I am Andrew Gammicchia, President of L.E.A.N. On Us, from Shelby Township, Michigan and the proud parent of two sons, one whom you've already heard testify today. As a parent of a young man living with autism, and currently an officer with 23 years experience in law enforcement, I have seen many individuals including our son not understood by those who are called upon to provide an appropriate response. What I would like to ask today is that the Administration on Developmental Disabilities creates a national committee to address safety concerns that often affect the quality of life for many individuals living with disabilities.

In the documents I've provided you will find several resources (1) our organization L.E.A.N. On Us currently uses. You will also find information on two trainings we have assisted in developing specifically to address

needs in this area. (2) However we still do not have a national training that provides for first responders to be educated on providing appropriate response to individuals with intellectual/developmental disabilities. Nor do we have a national training for individuals with intellectual/developmental disabilities, their care providers, and other natural circle of support members to be appropriately prepared for emergency situations or to prevent or report victimization and abuse.

Additionally we have seen much need for healthy maturation programs within the educational process to prevent victimization, recognize what abuse and neglect is, and provides individuals seeking a self determined life within their communities' safe options to do so. Due to lack of resources in this area, we have seen many individuals falling into harm's way across the country. We are also seeing individuals with developmental disabilities being accused of either crimes they often do not have the ability of intent to commit, or the knowledge that their actions may even have been criminal in nature. For those so accused, there is often no representation available to assist them since most Protection and Advocacy organizations do not assist those accused of crimes.

Lastly there is a need for data collection within police incident reports to show that a crime victim has a disability. There is currently no such demographic provided to law enforcement and we feel this is needed for both victim services and prevention programs. This also has an easy solution of just adding this demographic to the reports that over 17,000 police agencies complete daily (3). This would also allow us to track if through education, preparedness, and prevention programs are being effective and those currently most vulnerable are provided appropriate supports needed in these areas.

I would like to express appreciation for being allowed to speak to you today and please feel free to contact me if you have any questions on any of the information provided.

Respectfully,

Andrew Gammicchia
President, L.E.A.N. On Us
www.leanonus.org

Postscripts and References:

(1) Most of the resources provided are available on our website or Facebook page at:

<http://www.facebook.com/pages/Shelby-Township-MI/LEAN-On-Us/314400839740>

I will however provide them in a PDF form when submitting my written testimony on the website.

(2) The two trainings provided are the "Tools for Appropriate Response to Individuals with Mental Illness, Developmental Disabilities, and Special Needs" eight hour M.C.O.L.E.S. certified training that is currently being delivered in a two day "Train the Trainer" model that has mental health, law enforcement, and disability community representatives delivering the training. Often self-advocates are asked to attend as well as natural circle of support members to provide input which is often the most valuable parts of these trainings for all involved. This training is designed for law enforcement and corrections officers. The original funding for this initiative came from a Community Mental Health Block Grant in the amount of \$75,000 and was developed and implemented over a two year period. It also is currently being used in other states.

The second training is an eight hour curriculum developed via a Department of Justice grant through the Office of Victims of Crime. Our agency was approached by the OVC to submit a request for a Community Collaboration Grant which was done in collaboration with the Howard County ASA Chapter as the national partnering agency recognized as the Autism Society of America. The OVC grant, in the amount of \$50,000 was utilized to develop materials and the curriculum, deliver pilot site trainings, and present the materials at national conferences across the country. The curriculum has been approved by the OVC for national use and the six professional fact sheets and two informational brochures for community members are available on our website for no cost to download.

Those items can be located here:

www.leanonus.org

(3) Information regarding police incident reports can be obtained individually in each state by contacting the Uniformed Crime Report designee. Information about the U.C.R.s can be obtained via the F.B.I. website at:

<http://www.fbi.gov/about-us/cjis/ucr/ucr>

Also available there is a ten page FAQ document regarding UCR data:

http://www.fbi.gov/about-us/cjis/ucr/frequently-asked-questions/ucr_incspec_faqs08.pdf

The only area where disability has a demographic is in the area of Hate Crimes. We know however that these crimes are greatly under reported and generally not identified as Hate Crimes.

For that information you can go to:

<http://www2.fbi.gov/ucr/hc2009/victims.html>

Disability bias recorded for 2009

Of the 99 victims of a hate crime due to the offender's bias against a disability:

- § 74 were targets because of an anti-mental* disability bias. (*unknown what this category would include)
- § 25 were victims because of an anti-physical disability bias

Another reason these reports could be useful would be for mortality studies. Currently there has been discussion by the Interagency Autism Coordinating Committee on the issue of wandering and elopement and deaths resulting from such events. These reports could actually provide much of the information needed to show when, where, to whom, and how they occur.

Our agency has for the last six years been speaking to many federal level officials to try to get these demographics needed. They could also show events which take place at school, such as reported restraint or seclusion, and also incidents such as bullying. These reports also show arrest information as well as conviction follow-up information. This information and data could be very valuable in many areas for individuals living with a I/DD or other disability. This would also add a chance to train officers on proper ways to write reports when using the identifiers and would not require disclosure unless necessary. We see

this as a very inexpensive and viable solution to many needs across the board. The data could also be utilized to show what surveys do not, what is transpiring annually in these areas and reported by an unbiased third party.

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

Anne Bauer

July 9, 2013

My name is Ann Bauer; I am a doctoral student in epidemiology at the University of Massachusetts- Lowell. I am here today to ask the committee to direct funding to epidemiologic research to investigate an understudied, yet highly prevalent environmental exposure, for both pregnant women and their offspring. This exposure is acetaminophen. Close to 70% of US women take this medication during pregnancy and it is the most common drug administered to US children. Several lines of biologic and epidemiologic evidence suggest a plausible causal relationship between its use and the development of autism in a susceptible population. A recent ecologic study, importantly, identified a plausible explanation for the 4-5 times higher prevalence of autism among males. Males are differentially exposed and differentially susceptible to acetaminophen toxicity. Since the mid-1990's guidelines by the American Academy of Pediatrics and the World Health Organization have suggested 5-7 doses with the circumcision procedure. This study identified a 98% correlation between a countries' autism rate and circumcision rate. Several studies have identified a lower capacity to metabolize drugs during the initial days of life. These studies show a decreased capacity to metabolize acetaminophen specifically, through glucuronidation, one of the two major metabolic pathways. Additionally, it has been shown that autistic children have a decreased ability to metabolize through the second major route, sulphation. When these two primary pathways are saturated, the secondary pathways become involved and it can lead to glutathione depletion and reduced detoxification capacity. This has been shown to lead to oxidative stress, immune system activation, liver damage, kidney damage, asthma and possibly autism?

A consistent finding in autism is loss of the Purkinje cells in the cerebellum. A recent study by Dean et al. demonstrated that the use of acetaminophen (and other Cox-2 inhibitors) during early postnatal life altered cerebellar Purkinje cell development with atrophy in male rats only.

There is substantial evidence implicating oxidative stress and immune dysregulation in autism spectrum disorder. A recent investigation found transcriptomic changes in full-genome human miRNA expression indicating, for the first time, immune modulating effects and oxidative stress responses to acetaminophen even at low doses. Studies in animals have shown acetaminophen to induce apoptosis, necrosis and neurotoxicity. Several studies hypothesize increased apoptosis and necrosis in the autistic brain.

A little history....In 1980, after sufficient evidence emerged of an association between aspirin and Reyes syndrome, acetaminophen essentially replaced aspirin as the primary treatment of fever in children and pregnant women. Since that date, acetaminophen consumption throughout the world has increased dramatically. Although prevalence data for autism is of uncertain accuracy, many authors report strong increases in prevalence over this same time period. Admittedly, observing the correlation between two parallel time trends is of limited inferential utility; however the acetaminophen – ASD link is strengthened by an observation first made by Becker and Schultz. In 1982 and again in 1986, product tampering led to a few bottles of a leading brand of acetaminophen tablets being contaminated with cyanide. In each case, a rapid and brief decline in acetaminophen sales occurred, with the long term upward trend recovering within a year. In three populations for which good data are available, Becker and Schultz noted that brief

dips in the rising autism prevalence curves mirrored these sales anomalies. The prevalence curves continued their upward trend after 1988. It will be interesting to see what happens to the autism prevalence rates for children born since 2010, when, because of manufacturing issues, acetaminophen virtually disappeared again from store shelves.

In summary, I am asking those with the power to do so, make research into early life and prenatal analgesic exposure a top priority. Importantly, this is one of the very few hypotheses that can explain the male predominance of this disease. If found causal, this is a modifiable exposure, it can be removed. I have touched the surface of the biologic plausibility here but I suggest any skeptics do a little research. Acetaminophen toxicity causes the same alterations in epigenetic methylation pathways, miRNA, serotonin, mitochondria, gut microbiota and brain pathology, as is seen in autism. Please investigate this prevalent exposure for both children and pregnant women.

References available by request.

Anne Bauer

[PII redacted]

Brooke Potthast

July 9, 2013

I came last year to this committee meeting held at L'Enfant plaza. I left with a lot of thoughts, emotions and questions. A few of the questions I would like to pose to you today. First; has anyone on this committee experienced life with a child who regressed into autism? Have any of you watched either firsthand or Closely through a relative, a typically developing child who is bright, Engaged, talkative, happy and healthy descend into a state of pain, helplessness, Frustration, isolation, sensory overload and confusion? Can you imagine what it must Feel like to be a 18 or 22 month old who has experienced the wonders and joys of their Family, of their world, of communicating who one day or over the course of a few months Can no longer form the words that used to come so easily, who cannot make sense of the sights and sounds that used to be interesting and easy to assimilate. Who now feels frightened of regular noises and now hears sounds so intensely that He has to protectively plug his ears all the time? Who now either has no energy or too much energy that it drives him to run around in circles all day. Can You even begin to imagine how confusing and frightening that would be to a toddler whose brain and body worked well and was healthy until Something Triggers or tips him into a state of whole body dysfunction resulting in the Symptoms We call autism spectrum disorder? Honestly I don't think any of you Have witnessed this first hand or have lived with the results of it because If you had there would be a much greater sense of urgency in your meetings, your planning--Your priority above all things would be to find the root causes of this horrible, debilitating disease that is taking out a generation of child.

When I left the meeting last July I described it to people like this: It was like watching a town council whose town is being destroyed by a huge flood coming from a dam. The flood is devastating everything in its path and will eventually destroy everything surrounding it. But the council is so busy discussing what life preservers to use, What color and size is best for what victim that they are failing to focus on the most important thing—the cause of the flood. Where is the main crack in the dam? Or where are the small cracks in the dam and what can be done to repair them and stop the flood?

I find it incredible that we have the technology and science to Explore outer space, monitor, analyze millions of pieces information a day in the name of national security and even identify down to a specific leaf of lettuce in a specific field, on a specific farm and country when there is an ecoli outbreak but we cannot come up with a common consensus statement regarding the etiology of autism? The best we can do as stated by the Centers for Disease Control is a combination of environmental and genetic factors?

I know autism is very complicated. The name alone is a problem Because It is used so broadly to describe a whole range of symptoms exhibited in a wide of variety of people. But I still don't understand why and how the prevalence numbers for this illness can go from 1 in 10,000 20 years ago to 1 in 55 today and no one in public health is close to giving us an explanation.

My next question is would it be possible, or have you already considered mining the medical records of children who were typically developing and then regressed into autism? It seems to me that some answers to causation would be found if a wide, systematic evaluation was done on the records of these Children. You know most people agree that a mother's intuition is a Very real and potent phenomenon and I'd like to give you four examples of What my intuition tells me went wrong with my son and what his records Would back up. I think the information from his experience could easily Prevent Another child from regressing into autism.

Here are three main causes of my son's descent from a normal healthy toddler to A very ill and dysfunctional one.

1. I received IV antibiotics in labor and delivery. It was necessary as a precaution against Strep B infection. Those antibiotics killed all of my beneficial, healthy gut flora and did not allow my son to establish his own healthy gut flora which we know occurs in the first three days of life. This gut terrain or bio system is foundational for good immune health. Both my son and I should have been prescribed probiotics to replace what was eliminated.

2. Hepatitis B shot containing ethyl mercury when 5 days old then a Completion of that vaccine series all containing ethyl mercury. A study published in October 2008 in Toxicological and Environmental Chemistry demonstrated a nine times Higher risk of developmental disability in boys who were vaccinated with the full Series of hepatitis B vaccine as compared to boys who had not been vaccinated with the Hepatitis B vaccine at all. Another study in Neurotoxicology in October 2009 found that infant primates vaccinated with a Hepatitis B shot within 24 hours of birth demonstrated Abnormal neurodevelopmental responses as compared to unvaccinated controls.

My son did not need that Hepatitis B shot at in the first week of life or the first year of life. Postponing that series could prevent some autism.

3. Heavy metal toxicity. One can look for the heavy metal exposures in a lot of places, whatever the source. My son's urinary porphyrin tests and urinary Toxic metal tests show a great deal of aluminum, lead, mercury, cadmium, tungsten, etc. When he started showing signs of immune dysfunction, inflammation and developmental delay he should have been tested for heavy metal toxification and treated for it. I found this out on my own when he had already been sick for 5 years.

Treatment for heavy metals has improved his health and symptoms of autism significantly. I have more reasons on my list that you would learn about if you studied his Medical history. There are tens of thousands children just like him. Would it be that expensive to go back and look for patterns and trends in the medical records of these affected children. Don't you think it would be well worth it? I know my three Nieces who are currently all pregnant with little boys want to know how to prevent their sons from having a life like their cousin.

I thank you for the opportunity to speak to you today. I really cannot think of anything more horrible and tragic facing America today than the ever increasing rate of autism in children. I beg you to begin to find real reasons for it and real measures of prevention.

Clinton Potocki

July 9, 2013

My name is Clinton Potocki. I have a nephew with regressive Autism and am here to speak on behalf of my family and sister, Dawn Loughborough, who could not be here today. My sister has spent endless hours working on behalf of children's well being. She has supported families in autism in every way possible on a very personal dependable way hosting family farm days for autism, international medical supports, legal supports, education and fundraising for regressive autism projects. She worked on last November's Congressional hearing on Autism and has been a strategy and management consultant for large fortune 50 companies and she sees autism as a change vehicle for transforming healthcare. She asked me to relay the following lessons learned from her recent and direct work with the family of [PII redacted], who at age 14, was killed this past June, by his mother and godmother in a murder double suicide attempt.

Lessons Learned:

1. The systems are not in place to support the basic medical needs of children with regressive autism. If you Google this, there are 100s of families whose parents have killed their children with autism. Alison Singer talked on YouTube about her thoughts to end her child's life and is appointed to this agency. My sister has compassion for those who lose hope, and she is a person with endless possibilities to offer families, policy makers, and society. [PII redacted] uncle said at his vigil that his mother had loved her son very much. We will never grasp what had Alex' mother take these very final and desperate actions.
2. We do know that we need a standard of care for a special patient population and believe our consulting team and AIM to be the "go to" leaders in the trenches and in action on this endeavor. The hospital contacted AIM for help with [PII redacted], and a national program developed by AIM is being offered as a solution to hospitals going forward. It's time for real medical help. None of the Autism organizations that we reached out to for [PII redacted] had real solutions to offer the family. Many of these organizations expressed sympathy that many of the non verbal children with autism are sent home with psychotropic drugs, but no real solutions, pathways, or coordinated care for physiological autism illness were available. The services that the family turned down were not services that would fix Alex' medical health problems nor were they always feasible. The problems still are not fixed and we fear this will happen again.
3. What caused [PII redacted] to change at 18 months and regress into autism following his vaccines? Although anecdotal, no one can change the story of what happened. He regressed after his vaccines. His mother said, quote: "That was when the party began." Who is responsible for this? Is it the pediatricians administering the vaccines?
4. How much is this costing our nation? Loss of hope, loss of life, loss of potential, in and out of hospitals, cost of insurance, lack of insurance, loss of employment. We are the wealthiest developed nation and the least healthy nation. We take more medications and vaccines and we are low on the list. The health agencies proclaim medical success but we have 1 in 50 children with Autism. We have a flawed approach and it's time to transform how we manage infectious disease to the betterment of the greater good.
5. [PII redacted] was in tremendous pain. He was never to receive a pain assessment at any of the hospitals where his family took him seeking medical care. The mother agreed to psychotropic drugs for his care because she was afraid Child Protective Services would take him away from her if she refused. She also watched as the hospital struggled to get his medications correct and watched him have horrific reactions to

the drugs. This is nothing short of medical neglect and discrimination against non verbal disabled people to not assess them for pain or administer pain management.

6. [PII redacted] had bowel disease confirmed by [PII redacted], known as a leading world's expert on Autistic bowel disease and confirmed by pill cam procedure done through private community funding, travel and support. There were literally thousands of people across the world who knew of Alex' story and his terrible hospital mismanagement experience. The hospitals had scheduled multiple bowel investigations at the urging of pediatric in house specialists and other specialists like [PII redacted] who urged the head of GI to investigate [PII redacted] GI distress. While the hospital said they were looking into his bowel disease, and while AIM provided supporting research papers from Kennedy Krieger Institute and AAP's Pediatric GI Consensus Paper, the medical center cancelled the medical GI investigation and was also unsuccessful at transferring Alex to an appropriate Children's Hospital with an Autism Clinic upon the family's repeated request for GI investigation.

7. Basic medical work ups, blood tests, immune system, and bowel disease referrals were never made at the pediatrician's office visits. Alex' bowel pain and severity of his autism changed after his pediatricians said he could come off his special diet and eat foods he was intolerant of. Children can eat to soothe bowel pain and can become aggressive and combatant while in pain. [PII redacted] identified multiple diseases present in [PII redacted] GI tract, including a novel disease he had never seen before.

8. [PII redacted] had many problems with drugs he was prescribed. No assessments for drug allergies or drug interactions were conducted.

9. Alex was in four point restraint for over 22 days straight with improper pediatric compliance issues that were reported to proper regulatory agencies. The family at one point even submitted a request for investigation of the hospital restraint by CPS. The media coverage and interviews of the family created interest in [PII redacted] that exposed this internationally. Public concerns and reports were filed at the hospital and at compliance agencies. Thousands contacted the hospital. Immediately, the proper restraint procedures were implemented after over 20 days of consecutive restraint. The treatment of [PII redacted] was not humanitarian.

10. [PII redacted] was discharged from a hospital on May 31st after the family was told that their insurance would no longer permit them to stay and he was medically cleared after being on ER IV drugs just days before. Nine days later he was dead.

These are just ten high level issues. We plan to submit for public record a documentary of [PII redacted] hospital care during the months leading up to his death. We request that every member of this agency watch the 20 minute documentary and we will notify you as soon as it is released. [PII redacted] life was worthy of so much more. How much more time will pass before this gets handled so that families get the medical support they need for their struggling children? Autism is Medical.

Wendy Fournier

July 9, 2013

NATIONAL AUTISM ASSOCIATION

Public Comment submitted by Wendy Fournier on behalf of the National Autism Association

During the public comment period at your last committee meeting in April, NAA Executive Director Lori McIlwain discussed the serious co-occurring medical conditions affecting many individuals with autism. She also showed you a video of clips submitted to us by parents showing their children screaming, having grand mal seizures, self-injuring, throwing themselves to the floor and writhing in pain.

For many families, this is just a snapshot of their daily lives. There is nothing more heartbreaking than to see your child in pain and to be unable to help them. It was extremely difficult for these parents to pick up a video and camera and record these clips, but they did so because they are in desperate need of help. It is devastating to think of what the future may hold for these children and adults if they do not receive treatment.

There are several medical issues that frequently affect individuals with autism. But many physicians are unaware of what to look for. Sadly, it's not uncommon for us to hear from caregivers who see a physician or visit an ER with a child in serious distress and pain who are told that there's nothing physically wrong, "the child has autism, it's behavioral." Many times, no physical examination or testing is done at all to investigate what might be causing these "behaviors". Should a patient with painful gastrointestinal disease be denied testing and treatment for their illness just because they also have an ASD diagnosis? This amounts to medical neglect and is a serious human rights issue that we all need to work together to address.

These seriously-ill individuals need to be treated like any other patient in a medical setting. In some of our children, especially those who are non-verbal, pain can manifest as aggressive and sometimes even violent outbursts. They need thorough medical testing, proper diagnosis and treatment of co-occurring conditions to keep them free from pain, self-injury, insomnia and the secondary dangers that result, including elopement and physical and chemical restraint. Without proper medical treatment, these children may never have the opportunity to progress and live independently.

We need to develop resources and support for the medical community on what to look for, and how to effectively treat individuals with an ASD diagnosis. On behalf of the National Autism Association I am asking the IACC to work with our federal health agencies, community stakeholders and the AAP on coordinating a physician's training series including written protocols and guides, workshops, webinars and conferences. We have to provide support to our doctors, so they can support our children.

We must "Treat the Individual, Not the Autism".

**National Autism Association | 20 Alice Agnew Drive | Attleboro Falls, MA 02763
Toll Free: 877.622.2884 | www.NationalAutismAssociation.org | naa@nationalautism.org**