

Written Public Comments

IACC Strategic Plan Update Workshop

November 15, 2013

List of Written Public Comments

Linda M. Amity	4
Eileen Nicole Simon	7
Eileen Nicole Simon	9
Marian Dar	10
Donna Knepple.....	11
Benedetta Stilwell	13
Martha Moyer.....	14
Benedetta Stilwell	15
Eileen Nicole Simon	16
Eileen Nicole Simon	17
Eileen Nicole Simon	18
Yadira Calderon.....	19
Jill White.....	20
Amanda Hammond.....	22
Eileen Nicole Simon	24
Eileen Nicole Simon	25
Wendy Fournier	26
Jill Escher	27
Kerry Lane	29
Carmen Allen.....	30
Stewart D. Simonson.....	34
Rosanna Armendariz.....	35
Autumn Stevens.....	36
Eileen Nicole Simon	37
Ann Z Bauer.....	38
Caroline Rodgers.....	39
Eileen Nicole Simon	40
Eileen Nicole Simon	41
Laurie Sparks-Dennison	46
Laura Adams.....	48

Laura Adams.....	49
Linda Varsou.....	50
DT Welsh	52
Gina Pepchinski.....	53
Teresa Holman	54
Belinda	55
Maria Lujan Ferreira.....	56
Eileen Nicole Simon	58
Jill Rubolino	59

Linda M. Amity

July 3, 2013

Subject: Requests for Public Comment

To Whom it May Concern:

Hello. Thank you for the opportunity to share our children's chronic health needs and experiences with you, in effort and in hope for creating a mainstream medical system of appropriate medical evaluations and safe treatments for them.

I am the Mother to my now 15 y.o. son and 12 y.o. daughter, both of whom are on the spectrum of "autism". Today, I share with you copies of some of their test results that we have completed over the past decade, which span many professionals in different states across the country, as we looked for those medical professional specialists who were trained within the specialty of "autism", to try to help our children with the chronic health issues they have suffered with all of their young lives.

This search was exceptionally difficult, for as you may know, there are far too few medical professionals who have any "autism specific" medical expertise, to serve the hundreds of thousands of our children who are suffering in physical pain unnecessarily.

Starting with our family practitioner from our children's birth, with chronic ear infections, developmental delays but then developing G.I. health problems consisting of such acidic stools passed that if the stool was on their skin for even the shortest length of time, resulted in painful and sore burning, but most concerning, malnutrition due to malabsorption of food, failure to thrive and grow properly. One biomedical doctor wrote a book appropriately named, "Children with Starving Brains", which speaks to the medical needs of our children. Not having this knowledge, our family doctor explained that "diarrhea was a part of "autism" and sent us on our way home.

Like many parents of children with "autism", we learned from other "like" parents who were ahead of us on this journey to find medical professionals who could help us. Our first trip was to see a Pediatric G.I. who specialized in treating children with "autism" in New York, [PII redacted]. We drove to see him in July, 2003, for scopings with biopsies, which returned the confirmation of ileal lymphoid nodular hyperplasia, also termed enterocolitis.

In efforts to spare other "like" children precious time, I later became a parent mentor as well, to share vital information I had learned the long and hard way. I know many families who took their child to our own Children's Hospital of Pittsburgh, who had their child undergo the same scoping procedure for the same symptoms only to leave with a false negative report of findings, no help or appropriate diagnosis or treatment because even though they saw a Pediatric specialist in G.I. health, mainstream medical professionals are not researching nor are they trained in "autism" and the chronic health needs of our children. In other words, traditionally trained Ped. G.I.'s do not scope into the ileum where often our children's G.I. damage is.

Part of the initial consultation with [PII redacted] involved his asking us if our children "postured" their bodies, contorting them in efforts to relieve the pain. Laying their bellies across the arms of couches or the hard wooden seats of a dining room chair, screaming in pain, self-injuring, biting, hitting themselves

in the head, or striking out at their family because “autism” stole their words to express themselves that they were hurting . The magnitude of misunderstanding on behalf of our children is far reaching to the parents who rest in the doctor who tells them “diarrhea is a part of “autism”, to the traditionally minded teacher or paraprofessionals in the school system who do not understand that our children are chronically ill and in great physical pain, who treat their “behaviors” in terms of ignoring at best or at worst, punishing them, physically restraining them, even to the point of death.

Attached you will also see copies of my children’s food allergy test results. We started initially at the Children’s Hospital of Pittsburgh, Allergy Department, for traditional IGE food allergy testing, which often for our children return negative. More precious time wasted, we learned that it is the community of biomedical specialists, who have been trained by The Autism Research Institute (ARI) who developed the D.A.N.!(Defeat Autism Now!) treatment protocol, who understand our children, where families like mine can turn to for appropriate laboratory specialty testing, to learn that our children often have multiple, delayed (IGG) food allergies, which require a medically necessary special diet devoid of common allergens of wheat, gluten, dairy (casein), soy, corn, eggs, etc., etc. All of these tests, specialty foods, appointments with appropriately trained professionals are private pay because insurance will not reimburse for a mainstream medical system that does not understand how to evaluate or treat, or acknowledge that our children are chronically ill.

You will also see a copy of our children’s KUB (abdominal xray) to show that they still struggle with chronic constipation due to being FOS (full of stool), because of the tremendous amount of G.I. health damage they have. So much so, that in 2007, at the age of 10 years, my son had to have hernia repair surgery, because of the chronic constipation that went undetected for too long, as we searched to find appropriately trained professionals to help us help our children.

Ten years later and nearly a hundred thousand dollars later, near bankruptcy, financially, emotionally and physically from the level of care our children require, our story is sadly not novel but is repeated hundreds of thousands of times in our country alone and globally as well.

But you can help; you are in a position to do so. We know that in the past several years the American Academy of Pediatrics (2010) has published the work of Pediatric G.I., Dr. Tim Buie of Harvard University. Dr. Buie replicated Dr. Andrew Wakefield’s initial research, as did Dr. Arthur Krigsman , as did, Dr. Elizabeth Mumper and a few others in our country as well as in other countries, whose research resulted in the same findings, of enterocolitis in our children. Sadly, the treatment and understanding still falls behind that of the 30 years plus of research and appropriate treatments from within the biomedical community.

We also are aware that the AAP has also attended the D.A.N. (Defeat Autism Now!) biomedical conferences in the past several years. We pray and hope and work hard to support advocates like Safe Minds and Autism Action Network, as well as former Rep. Dan Burton, Grandfather to a Grandson who suffers terribly with the same health needs, and voice to our children and the families who love and care for them, to reach you, to urge you, to move Godspeed, to collaborate with the biomedical community, to save our children more precious time by not reinventing the wheel. Please, come together, unite the medical communities, mainstream and biomedical, train the mainstream medical professionals, teach them to listen to the parents who care for the children with “autism” who are in unnecessary physical pain and in a living hell on earth, so that children and families may have access to appropriately trained, insurance covered, medical professionals who can administer appropriate and safe evaluations, testing, and treatment.

Far too many decades, far too many precious and innocent children and adults hurt and they don't need to. The truth is here, the time is now, the need is greater than ever and deeper than you can imagine. There are not words strong enough to convey the depth and the immense and critical need for this help for our precious children. So many have stood in the gap to speak for them, for the truth of their pain, won't you help to ease it?

In gratitude for your time, and in prayer for your action, Godspeed,

Mrs. Linda M. Amity
Pittsburgh, PA

[Attachments (personal medical records) withheld due to PII]

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

Eileen Nicole Simon

July 7, 2013

Subject: My Son's Writing Notebooks

Attached is a file with pages copied from one of my son's journaling notebooks. The first page is a picture of [PII redacted] writing in one of these notebooks. This is too late to get into the committee folders for the meeting on Tuesday, but I would like this file (and this email) to go into the "Public Record" for the next meeting.

I read Portia Iversen's book about her work with the autistic Indian boy Tito, and that some experts questioned that he was the actual writer of his poems. My son is verbal, but behaviorally just as severely autistic and difficult to deal with in public. And, his writings are his own, and he continues to improve, and I think this is another way to deal with his disruptive behaviors. Note that his handwriting is "macro graphic" because of poor manual dexterity, a motor sign of neurological impairment.

I will send copies of his notebook pages on Julia Child shortly. I think I will plan to put these all in another Kindle ebook. Thanks again for all your help.

Sincerely,
Eileen Nicole Simon
[PII Redacted], Lexington, MA
[PII Redacted]

Excerpts from the journaling notebooks of [PII redacted]

[Photo redacted]

[PII redacted], *writer, coffee-shop retreat at Nantasket Beach, Hull Massachusetts, January 2012*

4/23/12

Omi would've been 100 in February of this year. OMI: Doris I. Baker BORN: Germany, February 22, 1912 to May 26, 2005.

----- FRIDAY APRIL 27, 2012:

I am at the Thomas Crane Library in Quincy. The weather today is fair. One of my housemates [PII redacted] is celebrating his 57th birthday. We will have a little party at the house for [PII redacted] this evening at about 8pm.

I have a bit of an addiction to the game of Scrabble, a popular word game invented by 2 men named [PII redacted] and [PII redacted]. It was created in 1948. Today I kept at it at Atlantic House between 12:30pm and 2 this afternoon. The following words in Scrabble will give you the most points: popquiz, quizwiz, quizzical, jazz, apple orchard, peach orchard, and a few others.

The most points anyone can get in a game of Scrabble is between 700 and 775 or 776. Depending on the words and the triple letter scores and triple word scores. The letters J, X, Q, and Z have the most points: either 8 or 10.

Selchow and Righter created this unique game in the summer of 1947. A year later it became an official game trademark product by September 1948.

At Atlantic House, I'm the only client there interested in Scrabble. The other clients either just listen to music or read the daily newspaper, or arts & crafts whenever it's available. Every Thursday at Atlantic House we have an AA group meeting lead by a lady named [PII redacted], who lives over in Randolph. The meeting is from 1pm to 2:30 and there's usually about 6 of us attending. Sometimes 7 or 8.

[Photos redacted]

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

Eileen Nicole Simon

July 7, 2013

Subject: My Son's Notebook Pages on Julia Child's Career

Attached is a file with copies of the pages my son wrote last summer about Julia Child's career beginning at age 50. Please add this file (and this email) to the Public Record. Thanks.

Sincerely,
Eileen Nicole Simon
[PII Redacted], Lexington, MA 02420
[PII Redacted]

[Photos redacted]

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

Marian Dar

July 11, 2013

Subject: Re: Upcoming IACC Full Committee Meeting - July 9, 2013 9:00 AM - 5:30 PM ET

Good morning and some comments and feedback on this week's meeting:

: IACC, AS are working towards getting state ABA coverage.

The GI testing that was proposed -- how will that be funded and in terms of quality control (highly variable), access and cost -- where and how should it be sought? How, when and by whom are policy plans and program information to be disseminated?

: Wandering.

49% of those with an autism diagnosis have wandered and 25% of those with autism are non-verbal. Who are the others?

My (verbal) son is the champ -- in terms of distance covered and variety of terrain. I have met police around the globe (we lived overseas) and amazingly he (and we) are still in one piece.

But the point here is that for him [PII redacted] there was always a destination: the bakery or the candy shop however distant, steep or, unfortunately, trafficked. In addition to law enforcement staff, we need to hold community (shop owners, etc.) workshops for those in public areas (e.g. library) and local neighborhoods.

In [PII redacted] 's most recent escapade, the police and I picked him up at the local gas station 8 miles yonder and across the street from the candy and ice cream shop, nat -. When the police arrived, [PII redacted] requested a wet wipe for his sticky fingers.

Thank you,

Marian Dar

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

Donna Knepple

July 15, 2013

Subject: IACC and AAP Submission

My name is Donna Knepple and I have two sons, ages 23 and 20, and a daughter age 15.

My daughter [PII redacted], born in 1998, has received all of her routine vaccinations as set forth by the American Academy of Pediatrics for Infants and Toddlers. Since November of 2000 to date, she is diagnosed with POD.NOS/Autistic Spectrum Disorder, Anxiety Disorder, ADD, ODD and OCD along with Medical Comorbidities based on lab investigations; she has immune dysregulation, mitochondrial dysfunction, unspecified metabolic disorder, autonomic nervous system dysfunction, polymorphism of MTHFR enzyme leading to detoxification problems, heavy metal toxicity, moderate to severe food and environmental allergies. In addition to the INFAMOUS BOWEL DISEASE, also known as Autistic Enterocolitis, in which she was diagnosed with in February of 2002, at the early age of 3 1/2 and continues to suffer from to date. You know the BOWEL DISEASE no one believes in which is completely DISREGARDED!!!

The very same inflammatory bowel disease as described in the 1998 Lancet paper, Ileal Lymphoid-Nodular Hyperplasia Non-Specific Colitis and Pervasive Developmental Disorder in Children. I am sure you have heard the news about one of the authors, Dr. Andrew Wakefield. You know, Dr. Andrew Wakefield from England who was declared in 2009: "WORST PERSON IN THE WORLD" as reported by the media. The Dr. Andrew Wakefield, who in the year 2010, made every media channel and headlines around the world; for him being a FRAUD, losing his medical license and the retraction of his 1998 Lancet paper, Ileal Lymphoid-Nodular Hyperplasia Non-Specific Colitis and Pervasive Developmental Disorder in Children, as ruled by the GMC in England. The Andrew Wakefield who challenged the medical system on behalf of our injured children back in 1995 and wrote to tell about it in his book Callous Disregard Autism and Vaccines - THE TRUTH BEHIND A TRAGEDY. - **UNBELIEVABLE TRAVESTY OF JUSTICE!!!**

Due to my daughter's vaccine injury, I filed for compensation under the National Vaccine Injury Compensation Program dated May 21, 2003, Federal Register Volume 68, Number 98, Page 27834, #506, Court of Federal Claims #02-I 890V. My petition was set forth in a list of an additional 666 petitions received by HRSA on October 1, 2002 through December 31, 2002. At the end of April of 2012, I received my dismissal papers after waiting 9 1/2 years; however, the attorneys representing us were paid in excess of \$3,900.00. Not only did the NVICP pay attorneys for dismissing thousands of cases they have paid out millions of dollars to a number of children just like my daughter and her fellow petitioners who they grouped under the Autism Omnibus ... only they did not mention AUTISM. Now let's add up all the money NVICP paid out on dismissing claims, money paid out to petitioners and the 7 million dollars it cost to try the Autism Omnibus test cases. - **UNBELIEVABLE TRAVESTY OF JUSTICE!!!**

I have been advocating for my daughter since she entered Early Intervention at the age of 2. I have been trying to get an appropriate education with related services for my daughter since the very beginning. Our school district recently preferred to throw away approximately one-half of a million dollars in tax payer money arguing over my daughter's educational needs. In all actuality the Board of

Education has no ACCOUNTABILITY for any of their wrong doing! The State, County and Town= NO HELP AT ALL. After all of the wasted years I finally have my daughter in an appropriate placement, however, it is only for a very limited time and I need to start the process all over again for the same placement next year!!! - **UNBELIEVABLE TRAVESTY OF JUSTICE!!!**

Helping my daughter overcome her vaccine injury has caused me and my family to lose everything. Needless to say, everything my daughter has had to endure on a daily basis. I can't even find the words to describe this nightmare that we are unable to wake up from and have to live with each day. For the past 7 years I have been a single parent taking care of my daughter, struggling from paycheck to paycheck, living in small apartment on top of a store front, on a main avenue in my hometown. My saving grace has been the wonderful people in the Autism Community that I have connected with from around the world since 2001. Unfortunately, my story is not all that unique and neither is my daughter's VACCINE INJURY AND INFLAMMATORY BOWEL DISEASE!!!

So here we are again at another Interagency Autism Coordinating Committee Meeting and each year since 2006 we MEET ... TALK ... WASTE TIME ... WASTE MONEY ... DO BOGUS STUDIES ... and raise AUTISM AWARENESS. Game over ... you cannot continue to stall nor hide from the TRUTH ... each year you have wasted since the 1990's the more and more children who have become affected and their families ... now 1 in 88 which can be as low as 1 in 50! **THIS IS NOT A GENETIC EPIDEMIC; THIS IS AN UNBELIEVABLE TRAVESTY THAT HAS BEEN BESTOWED UPON OUR CHILDREN AND THEIR FAMILIES!!!** ONE CAN ONLY HOPE AND PRAY THAT THE OCTOBER 29th MEETING WILL BE WHAT THIS COMMITTEE WAS SET FORTH TO DO AND THAT IS TO COMBAT AUTISM!!!

In loving memory of [PII redacted] and all of the other children whose lives were lost to Autism.

Respectfully Submitted on July 15, 2013 by,

/Donna M. Knepple/
Donna M. Knepple

Benedetta Stilwell

July 19, 2013

Just wanted you to know how last week went in our house hold.

My husband who had numerous tick shots and tetanus shots in his teen year and collapsed at age 28 after receiving a tetanus shot being pushed at work -- had pneumonia last week. His immune system does not fight off infections very well but it is doing a dandy of a job attacking the pigment of his skin and his muscle are slowly wasting away from a mitochondrial disease that the vaccine started. He is 6 feet tall and even in high school (top basketball player) he weighed 230 pounds - all of it muscle - so he has had a lot to lose. He is now 170 pounds.

He had a shot in his hip and a Z pack of antibiotics -but it was not enough. Three days later still running 103 temp we went to the emergency room for an additional prescription of antibiotics. He has been in bed ever since. He is in bed as we speak.

Also last week -- Such a LOVELY WEEK! My daughter a nurse - who reacted to the DPT several times as I slowly caught on -- with [PII redacted], and passing out with 105 temperature; some 30 years ago. My daughter also -and a few years back reacted to the Hep B shot that she was forced to take for nursing school with high Sed rates-- extreme stiffness. Once she became a nurse they were constantly on to her to get those flu shots and she reacted to a flu shot by psychosis-- that is how we found out that she had bipolar. Nothing like finding your daughter on a mother's day up in her room cutting imaginary bot worms out of her arms. It left some back scars, but her main complaint was extreme leg aches.

I am pretty sure I am going to lose my daughter, and there is nothing I can do, for she also succumbed to pressure this fall to have a DTaP. What can I say-- she has no longer the ability in her brain to resist authority?

But I found her last week-- on such a lovely last week - as I said, putting cinnamon in the washing machine as she talked rapidly and none stop nonsense. She was in one heck of a mania. She does have bipolar and probably always had since the [PII redacted], but the additional shots- starting with the flu shot and the DTaP have really brought it out.

The only one in the family that seems to be doing okay is my son. Who reacted three times to his DPT shot as a baby. The last DPT shot he had encephalopathy and had to relearn to walk, and it did damage his speech. Yes, he has a diagnosis by the school system of PDD- NOS -- (Schools--the real organization that really pinpoints problems -- not peds). He has had no more vaccines since he was a baby and last week was doing pretty good. Still as a young man he should not have to take medicine for epilepsy every day - Twice a day -----and we are on a low carb diet - and he takes handful of vitamins- to remain healthy. He is my rock and my help; but I grieve that he is 27 and still lives upstairs, no social life, and his joy and love is to play video games. He is a man, and even though he does a lot of things that men do - like run tractors, work on the farm machinery --he is not exactly doing all a man does.

Thank You for allowing me to tell you about my past week.

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

Martha Moyer

July 9, 2013

Subject: Another input on bowel disorders

Dear IACC:

I have a son [PII redacted] with autism, OCD, IDD, and severe bowel issues. He is 40 years old. I am age 75 and a widow. What has solved his problem is a little known device that pulls the feces out of his body because he cannot push it out due to paralyzed bowel muscles. The machine is called the pulsated irrigated evacuation system put out by PIE Medical in Duluth, Ga. www.piemed.com Enemas do not work for [PII redacted]. His bowel muscles are paralyzed and that is why ENEMAS DO NOT WORK! Dr. Buie is right on track with his information! You heard what he said.

[PII redacted] has had 3 big gut impactions that sent him into the hospital. (He goes on his own with urinary.) Until he was age 16 he had these gut busting huge bowel movement. I know it had to be painful. I spent most of my younger life sitting by the potty and trying to get him to toilet himself. We even had a potty trainer try to solve the issue. It has been a life-long issue! His behaviors got so bad that at age 16 the school district finally admitted he was out of control and put him in a private institution. In the state of Texas we have data on how many people are still in state institutions but I bet all the private institutions used throughout the state are forgotten in that count. This may be the case all over the country so we really don't know the true number of those people in other places.

Anyway, I accidently came across the answer to helping my son because I found an advertisement years ago in Exceptional Parent Magazine about the PIE device, similar to an enema but different because it cleans out in a pulsating way both the upper and lower bowel. It is the upper bowel which is often overlooked. In the case of my son, even enemas don't work because due to the impactions the bowel muscles no longer work. He had what was called a Megacolon with a bloated colon that made his stomach like a pregnant woman and he WAS SICK! No amount of electrical prodding or enemas would solve this problem and I see no way that electronic devices could help anyone with constipation and further issues.

We are back in the dark ages when it comes to addressing the bowel. I think a lot of health nuts have caused this because of the spa like colonic industry that causes people to come together, drink health laxatives and juices and who knows what else so they can go to these health spas and have their feces removed in a pampered environment but these people CAN TOILET THEMSELVES OK! They do not have paralyzed bowels like my son.

We do not ban people with urinary problems from dialysis....so why do we ban people like my son from having a life-saving treatment? Insurance, Medicaid or Medicare don't want to pay except in certain states where the battle won! Such is the case in California where Medical now pays for this machine and the disposables that go with it. The battle towards colon health continues for people like my son. By the way: PIE MEDical is the only company in the USA doing this.

Benedetta Stilwell

July 19, 2013

Subject: P.S. On last week's report on my family's health.

I sent an earlier message about how my family's week was last week.

I forgot to tell you that my daughter can no longer eat onions and wakes up every morning with diarrhea, and when going to sleep has trouble with acid reflux. Recently she was crying to me about a bloated stomach.

She also gained 100 pounds in six months and has a hump on her back. She also has trouble with her monthly too.

My son; if he gets one bit nervous goes for the nearest bathroom. We know where they all are - in all the towns around the area that we shop. He too suffers from cramps.

There is a host of health problems that only a damaged hypothalamus can account for.

Just thought you should know what we are dealing here with.

Benedetta Stilwell

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

Eileen Nicole Simon

July 25, 2013

Subject: Fwd: What every pregnant woman needs to know about cord clamping

Begin forwarded message:

From: [PII redacted]

Date: July 24, 2013, 8:18:40 PM EDT

To: [PII redacted]

Subject: What every pregnant woman needs to know about cord clamping

Reply-To: [PII redacted]

You've put months of study and tireless effort in to creating the optimal pregnancy for your baby, along with sleepless nights wondering if you're taking all the steps you can, to ensure optimal development for your child.

What would you say if I told you that after all of that, at the moment of birth, your care giver may be (unwittingly) destroying your efforts to ensure a healthy future for your child?

Read that again.

The first 90 seconds in any child's life are potentially the most impactful moment of their entire lives.

The push for efficiency in modern medical practices have created a situation where umbilical cords are being clamped immediately at birth, while nature is still trying to provide your baby with what it needs.

At DrGreene.com, we're starting a movement to fix this.

In [this week's video](#) I discuss what you can do to ensure your baby is beginning its life with the irreplaceable cellular material available at birth. If you know someone who is pregnant, please share this message with them. It will make a world of difference in the life of their young ones. If you do, [leave us a comment to tell us about it!](#)

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

Eileen Nicole Simon

July 29, 2013

Subject: Re: Request for oral and written comments

Thanks so much for sending me the oral and written comments for the July 9 meeting of the IACC. I have perused these, and definitely agree that all concerns raised should be discussed. Immune disorders, nutritional supplements, and more might require doing quite a bit of additional reading to begin an intelligent conversation.

The desire to find a cure is a common theme, thus the idea of brain impairment is something many parents don't want to consider. Sadly, language development requires an intact neurological system. Autism can be prevented by diet in the case of PKU, but diagnosis at birth must be made before toxic metabolites have begun to affect the brain. Maybe similar treatment in cases of Down syndrome may soon be possible also.

Language and the brain must be the focus of research, and why this has become such a widespread problem. My sons' problems resulted from trauma and anoxia at birth. Many reports of obstetric difficulties are in the medical literature, but with twisted conclusions based on the idea that no specific problem can be pin-pointed. This is absurd. Breech and other mal-presentations, or need for resuscitation for any reason, all provide evidence of oxygen deficiency to the brain.

Evidence of auditory system damage caused by asphyxia at birth has been in the medical literature for decades, and it is irresponsible that this should have been overlooked for so long. Perhaps the issue of "vaccine injury" might never have arisen if the ridiculous idea of clamping the umbilical cord immediately at birth had not been adopted as a standard obstetric procedure. Where is the evidence of any health benefit from clamping off placental circulation immediately at birth? What education in physiology are medical students now getting?

Please submit the above paragraphs for consideration by the committee. I hope that discussion of public comments will begin to take place before the October meeting.

Sincerely,
Eileen Nicole Simon
conradsimon.org
[PII Redacted], Lexington MA
[PII Redacted]

Eileen Nicole Simon

July 29, 2013

Subject: Re: What every pregnant woman needs to know about cord clamping

Thank you for submitting the email message from Dr. Alan Greene to members of the IACC. Dr. Greene shows a lot of courage in speaking out against the practice of umbilical cord clamping. Most intelligent people are also able to understand why clamping the cord is dangerous and wrong. An effort by the IACC should be made to stop use of a clamp on the umbilical cord at birth. This is as important as the current effort to prevent wandering.

Sincerely,

Eileen Nicole Simon

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

Yadira Calderon

August 6, 2013

Subject: Re: Autism is Medical - Treat it Now!

Greetings!

Feel free to share this information with the Spanish speaking parents who have children with autism.

I am Yadira, mother of [PII redacted] - 5yrs old - now HFA (ATEC 25); two years ago moderate to severe autism (ATEC 150).

A lot of work, a lot of love, a lot of patience. Learning a lot from parents like you.
I live in Tampa Bay FL... and no support group exists - and the numbers for autism diagnosis in the state of FL has increased by 80% in 2 years... no press coverage of course, too much emphasis on diagnosis by the school system, inadequate placements.

To top it all off, the Spanish speaking families have no group, place to go to...
For this and many reasons I've created a website in Spanish (Aplasta al Autismo = Crush Autism) with a variety of resources and sharing our experience crushing Autism, emphasis on early intervention, the understanding that each child is different, etc. -
<http://racayadi.wix.com/aplastaalautismo> (IACC Note: URL is not valid.)

Looking forward to great exchanges and learning more...

Thanks,
Yadira

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

Jill White

August 7, 2013

Subject: ASD testimony

Aloha,

Coming to D.C. wasn't an option for us. Not only is it a quarter way around the planet but my seven year old son is so severely damaged by vaccine & antibiotics he can only sit still for a moment. Commercial airlines would kick him off the plane. But wait, it is five hours over the ocean just to CA. You see our dilemma? We are limited to the help he can receive on the island where he was born. We have spent over \$330,000 trying to heal him in the last four and a half years.

I honestly believe because of the antibiotics and HEP vax [PII redacted] was given at birth he was injured. He suffered jaundice and thrush. He was only able to stay sleep five minutes before he would wake crying in pain & looking for his casein (milk) fix. This continued for months. Then we got to ten minutes at a stretch. For months. When we got him the "two month old round of vax" when he was eight months old we lost his speech and have not gotten it back. No more Dada. Mama. No babbling. No pulling up or supporting himself after that. His immune system was out of whack. He never was "sick" a day in his life until he was 17 months old. Then a bronchial infection with two rounds of antibiotics and we lost eye contact. He was diagnosed sever ASD by the State Early Intervention when he was 18 months old.

By the time a biomedical doctor opened up a practice here in 2008 when he was twenty months old the longest he ever had stayed asleep at one time was 90 minutes. It wasn't until we found a naturopath to use homeopathy when he was three and a half that he ever had a formed bowel movement. We did everything conventional science could offer. He saw a neurologist from the time he was two months old. CT. MRI. No one was running blood test for toxin levels. Only through "alternative" medicine and paying thousands of dollars for private lab tests were we able to get to the root of the toxins poisoning him. Off the chart: Mercury, Lead, & Aluminum. How did the get there? Food? Juice? Vax? Environment? Umbilical transfer? I'll always wonder was it my pension for processed food and soda before I got pregnant? Cleaning & personal care products? "Silver" fillings I had removed fourteen months before I got pregnant? Something as simple as plastic or pesticides? GMO? As a government YOU need to know. The epidemic is upon us.

We were told autism is behavioral. He would not be able to live independently for the rest of his life. We did everything possible to enrich his chances: Gymboree, Swim class, Music class, Gymnastics, & Play groups since he was five months old. We went to State of Hawaii Early Intervention when he was fifteen months old because he was still non-verbal. He never got an actual speech therapist session until he was thirty months old. I was told "Our district just didn't have one." He aged out of eligibility for that program just a few months later.

[PII redacted] was trapped. The only way he could communicate was to cry, scream, or flee. I had been using American Sign Language with him since birth since I got Signing Time DVDs as a shower gift. I knew

he was understanding a lot of ASL and suspected he was reading at a very early age. But he had no expressive language. He did not point at anything until he was 27 months old.

We told Dept of Education about the ASL knowledge but after years of getting no support we had to file a due process hearing. We have to fight constantly to get services from public school! Finally, we left DOE to attend a private Applied Behavioral Analysis school at a cost of \$16,000 PER MONTH. But it was worth every penny. For the first time at four years old [PII redacted] was able to “mand” or ask for his needs/wants to be met via American Sign Language. He could finally toilet train. He could share his interests. He could choose. He still doesn’t have his voice. But he can read and sign. Written words are starting to come and we pray we will soon finally understand how he feels. He is six and a half.

You have no idea the stress this disability puts on a family. It’s not just the sleep deprivation. Not just the more the \$330,000 we have spent out of pocket on top of what insurance and State of Hawaii have spent. It is putting the whole family in jeopardy today. Barely surviving the next time he bolts in a parking lot or steps off a curb in to traffic. The worry of providing the right diet, supplements, prescriptions, speech therapy, occupational therapy, & ABA. Not just today. Forever. Wondering about the burden we are leaving to his sister who is two years younger.

We have no conventional supports! No family on the island. No trust fund. We were a successful contractor and a Realtor couple before parenthood. Now we are sapped to the core. We are all paying the price of autism. But [PII redacted] who truly suffers. Speechless. Smart. Trapped by a system who doesn’t even know how or why this happened to him & doesn’t offer the services research truly shows will help him. It is only through parent organizations like Talk About Curing Autism (TACAnow.org) that we have been able to reach in to his world and try to pull him in to ours.

While much research is needed, I beg that you please stop wasting the vast majority of efforts on the genetic cause. That is certainly one of the bricks that build up to an Autism wall. We can determine susceptible kids if we just screen with questionnaire & labs before vax. I know from my own pregnancy that gastro issues (burping) began right away. Chronic yeast & acne soon followed. I didn’t know to heal my body with probiotics. Please seriously look in to GMO, apraxia, methylation failure, metabolic dysfunction, adrenal fatigue, food allergies/sensitivities, bowel disease, mitochondrial disease, sight issues (rubella), skin disorders, nagalese and cerebral folate deficiency just to name a few. It’s not just about autism. It is ADHD, asthma & allergies too.

Please take this national & global tragedy for the epidemic of a generation it is. Society will not be able to bear the burden of the harmed we already have. We cannot continue to create a toxic overload that is causing this. I beg you to call for a swift and immediate change in to the recommended vaccination schedule. Test each ingredient in vax. There is much work that needs to be done to accommodate the adult population of ASD. Safe housing. Enriching jobs. Protection for our silent population that has no voice to say “No” or “Help.”

Mahalo,
Jill White ASD parent
[PII Redacted] Wahiawa, Hawaii 96786
[PII Redacted]

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

Amanda Hammond

August 10, 2013

Subject: public comment submission

My son [PII redacted] has been made sicker by mainstream one-size-fits-all medical practices. He has had signs of immune-dysfunction since he was about one month old. Now we know he has autism as a symptom of a much larger problem—immune system damage facilitated by the medical community. In response to his chronic ear and respiratory infections in the first year of his life, he was bombarded with antibiotics. Many times the antibiotics weren't effective and we'd have to switch to a different type for another ten days. He's had over 20 courses of antibiotics from age 2 months to 2 years. When I told a nurse at my son's pediatric office that I was nervous to bring him in for a rash because I didn't want him sent home with antibiotics being that he'd had so many already, I was scoffed at and told that the doctors don't prescribe unnecessary medications. I call [Profanity redacted] on that. If you need proof, I invite you to look at my son's medical records.

I had to learn ON MY OWN what to do for my son because the doctors we took him to were useless, relying on faulty tests and faulty treatment. On my own, I found out that chiropractic care was a good preventative to ear infections. On my own, I learned that the ear tubes we had surgically implanted in his ears were most likely not necessary had we just been told to stop dairy and get his neck adjusted regularly. On my own, I grew very very angry with mainstream medicine and the lack of awareness about children's health issues by the professionals who specialize in their care. Antibiotics have caused chronic inflammation, yeast overgrowth and a great home in his gut for any pathogens coming in. His immune system is even worse off than it was to begin with. He is finally getting over the extreme PTSD from vaccinations at 3.5 years old and I am able to take him to our family doctor who will never vaccinate him, thereby keeping his trust.

We were manipulated into vaccinating our son after expressing concern about the rise in autism... told not to worry, etc. Told we would be bad parents if we chose not to vaccinate. That we should instead fear pertussis and influenza. So we did. And my son is the one who is paying for that choice. Don't worry... I am mad at myself for vaccinating too, but not as mad as I am at the pediatrician who told me not to listen to my instincts. They were indeed correct. He was not offered a blood test to check for the MTHFR-677t genetic anomaly he has which makes it hard for his body to process the toxins found in vaccines.

In addition to these obvious failures, there have been more subtle ones in the form of medical advice:

- I was told to supplement breastfeeding with formula.
- I was told it was safe to breastfeed him while I was on heavy doses of antifungal and antibiotics for a blood infection I contracted post C-section.
- I was told to use a formula that's main ingredient was corn syrup solids to help his colic. While it was easier for his tummy... it was not a nourishing food and it should not be on shelves filled with GMOS and synthetic vitamins.

All of this was damaging to my son who already had the genetic frame work to end up ill from chemical exposure. We have GOT to do better than this for our kids and people who do try alternatives to this crock of [Profanity redacted] called modern medicine should be celebrated and learned from rather than ridiculed. We are getting stronger in numbers and it will only be a matter of time before you have no choice but to listen.

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

Eileen Nicole Simon

August 30, 2013

Subject: Comment for discussion of "When should I be concerned?"

Please forward this email to members of the Planning Group for Question 1. I hope they will read my comment that follows (420 words). I hope my concerns can be discussed, without rolling of eyeballs or comments like "The apple didn't fall far from the tree." Above all, please understand that autism is a life-long tragedy. Thanks.

Eileen Simon

Concerns about delayed development begin within the first month after birth. Pediatricians do not want to discuss these concerns with parents, but should be mandated to do so. Developmental delay is the beginning of a tragic life-long affliction, and this must be faced up to. Delayed development is as serious as any of the childhood illness for which immunizations are mandated.

"Acceptance" is not acceptable, and is dishonest in the extreme. No one ever "accepted" polio, infections that result in encephalitis, or death by diphtheria or pertussis. These conditions became the focus of intense scientific investigation, which has paid off.

Autism is a neurological disorder, and merits the same level of investigation. That autism is a "mysterious" psychological (or psychiatric) condition is an outrageous and dumb way to try to cover-up the lack of focused research.

Evidence has been available in the medical literature about how the brain is affected by oxygen insufficiency at birth, and that traumatic anoxic birth is often part of the history preceding a diagnosis of autism. This needs to be investigated as thoroughly as infectious causes of childhood illnesses were, and should have been a focus of research long ago.

Obstetric injury happens. Obstetric interventions, especially use of a clamp on the umbilical cord, should have been more carefully thought through before being made standard protocol.

Errors have had to be acknowledged. Use of Thalidomide and Diethylstilbestrol had to be stopped. Resuscitation of the newborn can and should be done with the umbilical cord intact, which can at this point in time be verified by a google search.

The article by William Windle in the October 1969 issue of the Scientific American should be consulted before any fancy new research studies are designed. Evidence of auditory system and basal ganglia damage is reported, with an excellent discussion (yes back in 1969) of why a clamp should never be applied to the umbilical cord:

"... in any delivery it is important to keep the umbilical cord intact until the placenta has been delivered. To clamp the cord immediately is equivalent to subjecting the infant to a massive hemorrhage, because almost a fourth of the fetal blood is in the placental- circuit at birth." [p78]

The increasing prevalence of autism must not be dismissed as something simply unnoticed in the past. My "high-functioning" son is almost 51 years old, but he was cheated out of any semblance of a normal life, and it is my eternal regret that I did not obtain better obstetric care.

Eileen Nicole Simon

[PII Redacted], Lexington MA

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

Eileen Nicole Simon

August 30, 2013

Subject: Article by William F. Windle on Asphyxia at Birth

Attached is the article by William F. Windle from the October 1969 issue of the Scientific American, which I cited in my previous email with my comment for the committee. Please forward this to members of the committee who will discuss "When should I be concerned?" in the conference call scheduled for next week. I hope they can take time to at least look at the pictures of brain damage that resulted from asphyxia. Thanks.

Eileen Simon
[PII Redacted]
[PII Redacted]

<http://www.scientificamerican.com/author/william-f-windle/>

Wendy Fournier

October 2, 2013

Subject: IACC Written Comment

Dear members of the committee;

The National Autism Association commends you on addressing the issue of Comorbid Medical Conditions in People with Autism at your July 9th meeting.

For many years, fine physicians like Dr. Buie and Dr. Frye have been forging the path toward recognizing, diagnosing and effectively treating underlying medical conditions that commonly affect individuals with autism. As advocates, and as parents of children with autism, we know that with proper treatment of conditions including GI disease, seizures, sleep disorders and nutritional deficiencies, the severity of symptoms and quality of life of those with autism can be greatly improved. Unfortunately, the mainstream medical community is not aware, or equipped to treat our loved ones and many are left to needlessly suffer in pain. This is a travesty bordering on medical neglect and discrimination.

We urge the committee to devote all available resources toward expediting critical research leading to effective treatment and educating physicians on appropriate medical evaluation and treatment for individuals with Autism.

Sincerely,

[PII redacted]

Wendy Fournier
President

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

Jill Escher

Escher Fund for Autism

[PII redacted]

October 25, 2013

Subject: FW: IACC Strategic Plan for Autism: Gene-Environment Research memo

Re: Proposed Additions to Strategic Plan for Autism Research, July 9, 2013 IACC meeting

Dear IACC members:

Based on emerging science demonstrating plausible connections between past exposures, epigenetic germline and somatic alterations, and abnormal neurodevelopment that may include autism as a manifestation, the Escher Fund for Autism respectfully submits for your consideration the following proposed additions to the Strategic Plan for Autism Research.

Additional research opportunities

- Survey of multiplex ASD families, including families with children with related disorders including ADHD, learning disabilities, and mental illness, seeking to ascertain potentially relevant ancestral exposures, including pharmaceutical drugs, smoking, and endocrine disrupting environmental chemicals, that may have impaired pre- or post- conception germline epigenetics. Special attention should be paid to “windows of susceptibility” such as the sensitive period of fetal germline development.
- Epidemiological studies of grandchildren of women given acute doses of various pharmaceutical drugs in first half of pregnancy, or who smoked. Epidemiological studies of children and grandchildren of people exposed to Agent Orange (dioxin) and other military-related pharmaceutical and chemical exposures.
- Animal model studies of multigenerational effects of prenatal exposures to various compounds of interest, including exposures common in the past (synthetic hormone drugs, smoking, EDCs) and the present (antidepressant drugs, anti-nausea drugs, hormone drugs, others).
- Epigenetic and genetic assays of individuals with ASD, where ancestral exposures are known or reasonably suspected.

Additional short-term objectives

- Ensure the FDA, NIEHS and EPA collaborate to take appropriate steps to determine adverse epigenetic effects, on germline and fetal neurodevelopment, of synthetic chemical and pharmaceutical exposures, particularly during key windows of susceptibility.

- Ensure policies that entitle all Americans full access to records about their prenatal and early life pharmaceutical exposures.

**Proposed amendments to existing language in the Plan
(Proposed amendments are in bold.)**

Genetic and epigenetic variations in ASD and the symptom profiles associated with these variations, and where possible, ascertain past exposures that may be associated with the variations.

Studies in simplex and multiplex families that inform and define de novo genetic differences and focus on what role the environment might play in inducing these differences.

Better understanding environmental and biological risk factors during germline, prenatal and early postnatal development in "at risk" samples.

Cross-disciplinary collaborative efforts to identify and analyze biological mechanisms that underlie the interplay of genetic, epigenetic, and environmental factors relevant to the risk and development of ASD, including co-occurring conditions.

Initiate studies on at least 10 environmental factors, including factors that may affect germline synthesis, identified in the recommendations from the 2007 IOM report "Autism and the Environment: Challenges and Opportunities for Research" as potential causes of ASD by 2012. IACC Recommended Budget: \$56,000,000 over 2 years.

Emphasis on environmental factors that influence germline, prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations. IACC Recommended Budget: \$12,000,000 over 5 years.

Support at least three ten studies that focus on the role of epigenetics in the etiology of ASD, including studies that include assays to measure DNA methylations and histone modifications and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012. IACC Recommended Budget: \$20,000,000 over 5 years.

Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and epigenetic and genetic susceptibilities for ASD by 2012. IACC Recommended Budget: \$1,535,000 over 3 years.

These suggestions appear to be complementary to current research directions, and a logical extension of current efforts to assess the role of gene-environment interaction in the etiology of some forms of autism. Your consideration is greatly appreciated.

Kerry Lane

October 29, 2013

Subject: Evidence Acetaminophen Triggers Autism-

You may recall I have corresponded with you in the past, since 2009 - with respect to my concerns Acetaminophen, aka Tylenol, is the trigger for Autism. Attached is an article by Dr William Shaw of the Great Plains Lab which validates and further elucidates on my concerns. As IACC is meeting today and tomorrow I suggest you submit this to the respective meetings concerning Diagnosis and Treatments.

It seems IACC and FDA are missing the boat with respect to this critical piece of information...

Regards,

Kerry Scott Lane MD

[Evidence that Increased Acetaminophen use in Genetically Vulnerable Children Appears to be a Major Cause of the Epidemics of Autism, Attention Deficit with Hyperactivity, and Asthma](#)

Carmen Allen

October 29, 2013

Re: IACC Strategic Plan for Autism Spectrum Disorder Research *Public Comment Combating Autism Reauthorization Act of 2011*

Who is directly benefiting from the \$ 1.6 Billion+ of our hard earned tax dollars being allotted to Autism Research? How much of this money is directly benefiting the children and adults on the spectrum? Where is the choice of therapies?

Where's the harm data in the nonmedical studies using behavior modification practices like Applied Behavior Analysis (ABA)?

Esteemed IACC panel members,

One of the characteristics that make our nation the great country that it is, is the fact that it is comprised of millions of people from different influences, backgrounds and cultures, each individual is unique in their own way.

However, along with the many benefits and possible utilizations of all those incredible talents and human assets also comes the potential for negative biases and discrimination by some in those communities, directed at individuals whom they perceive to be different than themselves. It is well documented that throughout history, many of the individuals that have made the greatest and most meaningful contributions to the world, and monumental advancements in the fields of science, medicine, education, mathematics, religion, biology, physics, psychology, astrology, etc. were thought to be different and often subjected to great resistance and unfavorable public treatment, sometimes to the extreme of being ostracized from mainstream society, simply because their ideas and opinions were different than what was currently known and understood at that time, or accepted as the status quo. Sadly, many significant advancements and achievements in these areas were ultimately squashed, or postponed from being explored further, sometimes for decades or longer, by individuals supposedly possessing inferior knowledge and intellect, who lacked the capacity for greater discernment to realize the incredible potential that those inspiring men and women had to offer or were advocating for.

Unfortunately, we still see some of those same biases and prejudices being exerted on many individuals in our country today, especially when it comes to children and adults on the autism spectrum.

In 2006, President Bush signed the Combating Autism Act authorizing nearly \$1billion to be spent over the next 5 years, starting in 2007 for screening, education, and early intervention, prompt referrals for treatment and services, and research.

In September of 2011, President Obama signed the Combating Autism Reauthorization Act of 2011 (CARA, P.L. 112-32), ensuring the continuation of research, early identification and professional training under the Combating Autism Act of 2006 (CAA, P.L. 109-416), and authorizing \$693 million over the 2012-2014 period for autism spectrum disorder and developmental disabilities research, screening, treatment and education.

Some said that passing this landmark legislation recognized the daily plight of the thousands of families struggling every day with autism, yet how much of \$1.6 Billion+ allotted to autism spectrum disorders has gone to directly help those children and individuals on the spectrum and their families in their communities?

After attending the last few IACC conference calls this year, I have found those who benefit the most are the researchers and their families, not the average child/adult or their family who deal daily with issues related to autism. Why?

First, when I contacted the IACC administrative staff and asked to give oral public comment via conference call because of my illness and autism, I was denied and told I could instead provide oral public comment in person by traveling to D.C. or the only other option was to provide written public comment. I tried to explain that many individuals on the spectrum don't do well in crowds and also have issues with written expression. I was still denied my request for ADA accommodations and told the only option was to provide written comment.

If, after close to 8 years later and \$1.6 Billion of our hard earned tax dollars allotted to autism spectrum education and research, etc, the very same administrative staff tasked with dealing with the public does not understand the most basic needs of autistics and others with developmental disabilities and their need for ADA accommodations, then with all due respect, we need to STOP. Do not pass go, and don't collect any more of our hard earned tax dollars, because they have been largely wasted. The first individuals who need to be educated on the needs of individuals with autism and other developmental disabilities and the public they serve are the staff members of the IACC.

I am still working on a detailed analysis of the research presented during the IACC meetings I've attended, but as I explained to the staff, it will take me longer than it takes others. I will be submitting a detailed letter on the need to have the same ethical scientific standards afforded to children and adults on the spectrum that is afforded to everyone else. I will also be addressing the March 25, 2013 letter from the IACC members to the Honorable Kathleen Sebelius, which according to Autism Speaks' website was unanimously agreed to by the entire IACC. It cited sources of research and made recommendations on the need for specific amounts of hours for behavioral interventions, including but not limited to, ABA based behavior modification practices.

Source:

http://www.autismspeaks.org/sites/default/files/docs/letter_to_secretary_on_health_coverage_march_25_2013.pdf

Source: http://iacc.hhs.gov/news/press_releases/2013/pr_2013_coverage.pdf

My colleagues and I are especially concerned about the lack of reporting of harm coming to children and adults on the spectrum used in nonmedical studies of Applied Behavior Analysis (ABA) and other behavioral interventions. As stated in the Comparative Effectiveness Review (CER) by the Agency of Health Care and Research Quality (AHRQ), published in April 2011: "Harms data are also typically not reported in nonmedical studies, although potential harms of behavioral and other interventions should not be discounted".

Source: Page 11, Agency for Healthcare and Research Quality, April 2011

http://www.effectivehealthcare.ahrq.gov/ehc/products/106/651/Autism_Disorder_exec-summ.pdf

Where's the harm data? Why would we not insist on the collection and reporting of harm data on every study using human subjects, especially those vulnerable children or adults who cannot speak for themselves? Are our vulnerable children and adults on the spectrum not worthy of the same basic scientific and ethical standards that protect and benefit everyone else?

The last review by the AHRQ in their Surveillance Report, 1st Assessment: January, 2012
Surveillance Report, 2nd Assessment: October, 2012 does not address the harm coming to children in behavioral interventions either. Why?

Are IACC members aware of how ABA based behavior modification can use a Functional Analysis (FA) on children, and how a functional analysis is performed? How FA's can, and have harmed the emotional development of children? I will explain that in detail in my follow-up letter to this comment.

It is important that studies using human subjects use rigorous scientific standards before recommendations are made, because as stated by the American Academy of Pediatrics (AAP) "there is still a need for additional research, including large controlled studies with randomization and assessment of treatment fidelity. Empirical scientific support for developmental models and other interventions is more limited, and well-controlled systematic studies of efficacy are needed." (Myers and Johnson, 2007; reaffirmed September 2010).

The first IACC conference call I attended was better, in that IACC members spoke freely amongst themselves about how they felt about meeting the question #2 objectives of the strategic plan. Several other conference calls on the strategic plan have consisted of "external experts" or "researchers" basically telling the IACC panel members of the advances and aspirations of those in the field, instead of allowing IACC panel members to discuss amongst themselves which of the questions and objectives have been met or not met in the IACC Strategic Plan and their aspirations. Obviously, expert researchers will certainly feel they are making progress and want to continue more funding for their research.

One of the concerns brought up by a member of the IACC was that on one of the objectives in Question #1 Objective 4 had been allotted \$6million but no studies had been done: Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. IACC Recommended Budget: \$6,000,000 over 5 years.

Currently, there are no choices of interventions given to parents of children with autism or individuals with autism except for ABA based behavior modification therapies. Professional judgment and discretion is overriding parental or individual choice or even an older student's choice of intervention used on them, even though ABA has failed to produce progress in a child's development, and even if there has been harm. We need choice. No professional should override the choice of therapy by a parent or student. No one should be forced into any one intervention or another, especially when there is potential for harm. This is central to basic human rights.

Many in the general population, parents and advocates have lost confidence in many of the agencies, research universities and organizations involved in the Developmental Disability Network partners who try to promote participation in research, training, education, and parental and public participation. Many adults on the spectrum have been denied the right to share their personal views and ideas when in an advisory role while attending meetings in an advisory role.

Recommendation: There needs to be an increase in the number of individuals on the spectrum participating in all committees, panels, and boards dealing with the research, treatment of individuals

on the spectrum. Otherwise, we are nothing more than guinea pigs to be subjected to those wanting to use us in their research.

I look forward to continuing the interaction with the IACC members, so we can work together and proactively address the needs of the autism community.

Thank you for your time and consideration.

Respectfully,

Carmen Allen
Autistic Self Advocate
Georgia

Stewart D. Simonson

November 1, 2013

Since I help pay your salary I am forwarding this to you. I am an industrial chemical engineer in Atlanta. For the past 10 months on my own time I have been plotting fish kills, algae blooms, manatee/dolphin deaths, waterspouts and sinkholes in Google Earth and it appears to me their locations are strongly correlated near Dual Pol Doppler Radar Stations (0.25-1.25 MW energy output ea.) In other words I believe the high powered stations may be having a NEGATIVE effect on surrounding biology. If you might forward this email to any researchers looking at environmental triggers for autism, etc. that would be appreciated. I am not a researcher looking for funding.

Sincerely,

Stewart D. Simonson

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

Rosanna Armendariz

November 2, 2013

I live in El Paso, Texas with my husband and our five year old son who has autism. We are lower income and our son receives SSI/Medicaid. Although various pediatric specialists have recommended ABA therapy for our son, Texas Medicaid will not pay for it. They require ABA providers to be "state certified" which is a lengthy and difficult process that prevents kids in many parts of Texas from getting necessary therapy. This needs to be dealt with on the federal level, as part of the Affordable Health Care Act.

Thank you,

Rosanna Armendariz
[PII redacted]

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

Autumn Stevens

November 2, 2013

I'm a mother of a child with Aspergers and we are in a crisis due to our state not having the proper resources or educated state employees on Aspergers. If there are any persons with the ability to contact me to address my families concerns with what is wrong and how the issues we are facing need to be changed I would appreciate it.

We are desperate for help but also want to try to prevent other families from going through this.

[PII redacted]

Thank you ,

Autumn

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

Eileen Nicole Simon

November 4, 2013

Workshop participants, please consider my comments that follow on: (1) Language, (2) Auditory processing, (3) Asphyxia at Birth, and (4) Clamping the Umbilical Cord:

Language development is the most serious problem for children with autism, and this has not been adequately addressed in past strategic plan versions. Why? This is probably due to the idea that the language problem is secondary to “social disorder.” However, social disorder in autism may result from impaired environmental awareness. Orientation to auditory events is especially impaired in autism, but it is through the auditory sense that children normally learn language.

Oxygen insufficiency at birth should be a focus of research. I will continue to point out the article by William F. Windle in the October 1969 issue of the Scientific American. Evidence of severe damage to auditory nuclei was reported in this article. Auditory nuclei in the midbrain (the inferior colliculi) were most prominently injured in monkeys subjected to asphyxia at birth. Difficult birth has been documented in many articles investigating predispositions for autism. Authors of these papers tend to place blame on some condition of the mother or the child, but without providing specific evidence of such conditions.

Clamping the umbilical cord at birth clearly increases the risk of asphyxia at birth. This was the means Windle used, in addition to preventing the first breath. Clamping the cord at birth is a clear medical error. I have been trying to point this out since the IACC meeting 10 years ago.

Thalidomide use in pregnancy was stopped after recognition that it caused serious birth defects.

Diethylstilbestrol (DES) use in pregnancy was stopped after recognition that it caused vaginal cancer in female children. Cancer and infertility in males are now recognized to have been caused by DES treatment.

Clamping the umbilical cord was adopted more and more during the 20th century. When first introduced, the clamp was not to be applied until pulsations of the cord ceased. Why? Pulsations are from the infant’s heart sending blood back to the placenta. Transition from placental to pulmonary respiration is not instantaneous. Some infants respond quickly to suffocation caused by clamping the cord. Blood may be drained from the brain and other organs to supply the capillaries that supply the alveoli. The lungs take first priority after placental respiration is cut off.

Clamping the cord at birth is a medical error, as much as Thalidomide and DES use. Clamping the cord should be stopped. Clamping the cord as soon as possible was wrongly adopted as a protocol during the mid 1980s. This should be considered as a possible reason for the autism epidemic. Increasing numbers of children with autism was first recognized 20 to 25 years ago.

Eileen Nicole Simon, PhD, RN
[PII redacted] Lexington MA
[PII redacted]

Ann Z Bauer

November 6, 2013

A very well done prospective cohort study found that children exposed to **acetaminophen/paracetamol** for more than 28 days during pregnancy had **substantial adverse developmental outcomes** at 3 years of age. This included an almost 70% increased risk of problems in gross motor skills and behavior, as well as, double the risk of communication problems. Please support more epidemiologic research to see if these findings can be replicated, specifically for an autism diagnosis outcome. This research should investigate both prenatal and childhood exposure to acetaminophen and other analgesics.

This new study used data from the Norwegian Mother and Child Cohort Study to investigate the effect of acetaminophen/paracetamol during pregnancy on psychomotor development, behaviour and temperament at 3 years of age. Almost 3000 sibling pairs were included in the study.

The study was a collaboration between the University of Oslo, the Norwegian Institute of Public Health and the Hospital for Sick Children in Toronto, Canada, and was published in the *International Journal of Epidemiology* 25th October 2013.

Results

By comparing children who were exposed to acetaminophen during pregnancy with unexposed siblings of the same sex, researchers could control for a variety of genetic and environmental factors, in addition to other important factors such as infections, fever, use of other medications, alcohol intake and smoking.

The study shows that children who had been exposed to acetaminophen for more than 28 days of pregnancy had poorer gross motor skills, poor communication skills and more behavioral problems compared with unexposed siblings.

The same trend was seen with acetaminophen taken for less than 28 days, but this was weaker.

To investigate whether the underlying illness could be the cause of the effect on the children, and not acetaminophen itself, the researchers examined a different type of analgesic with another type of mechanism of action (ibuprofen). The researchers did not find any similar long-term effects after use of ibuprofen.

Caroline Rodgers

November 6, 2013

Just a little reminder: autism is caused by an increase in maternal body temperature during critical times in fetal development. This could be caused by a fever, even a low-grade fever, given enough time, or it could be caused by a chemical agent, such as some treatments for epilepsy or it could be caused by ultrasound. Now that you know this, you have choices...

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

Eileen Nicole Simon

November 6, 2013

Workshop participants, please understand that autism is for families a tragic catastrophe. My son is now 51 years old. He is high functioning and has co-authored two memoirs with me. Still, communication remains difficult. He attended a lecture a few weeks ago at the Boston Museum of Science on cars that drive themselves. He went early to get a seat right up front, but after 10 minutes he got up and walked out.

“That guy was talking a mile a minute,” he said, “I couldn’t understand him.”

The lecture was interactive, and many young children were eagerly participating.

My son clearly has an auditory processing disorder. This prevented his learning to speak until he was nearly six years old. He learned to speak after first learning to read, a task he set for himself beginning at age two.

In my previous comment I pointed out the article on asphyxia at birth by William Windle in the October 1969 issue of the Scientific American. The surprise finding was severe injury of nuclei in the brainstem auditory pathway. I have for more than 10 years tried to point this out to members of the IACC. Why has it not been discussed?

I will continue to point out the vulnerability of brainstem auditory nuclei. Can this be reasonably refuted? Why am I only allowed three minutes to speak at IACC meetings, with no discussion? Why are members of the IACC so hostile in opposing public opinion? What does the IACC have to show for shutting out the concerns of parents?

“Progress is painfully slow,” Dr. Guttmacher told the congressional committee last year.

Why should progress be so slow? I had an urgent need to look for why my son was so delayed in learning to speak. I found something I believe is important to discuss. Why isn’t language development a primary focus of the “strategic plan” so far? This should be an embarrassment to the IACC. Why is language development the primary concern for parents of an autistic child?

Please try to create a meaningful strategic plan. Please do not omit strategies for understanding language development, and the neurological systems involved.

I will continue to speak out until my views are recognized and discussed.

Eileen Nicole Simon, PhD, RN
[PII redacted] Lexington MA
[PII redacted]

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

Eileen Nicole Simon

November 7, 2013

Comments for oral presentation at the IACC workshop, November 15, 2013

Eileen Nicole Simon, RN, PhD

[PII redacted]

I have three pictures I want to present and briefly discuss:

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 written comments I submitted for the meeting last July, 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 below 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.

Blood flow in the brain

[1] Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed

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

Damage by asphyxia

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

[4] Leech RW, Alvord EC Jr. Anoxic-ischemic encephalopathy in the human neonatal period, the significance of brain stem involvement. Arch Neurol. 1977 Feb;34(2): 109-13.

Damage by toxic substances

[5] Cavanagh JB. Methyl bromide intoxication and acute energy deprivation syndromes. Neuropathol Appl Neurobiol. 1992 Dec;18(6):575-8.

[6] Morgan DL et al. Neurotoxicity of carbonyl sulfide in F344 rats following inhalation exposure for up to 12 weeks. Toxicol Appl Pharmacol. 2004 Oct 15;200(2):131-45.

Brain maturation in autism

[7] Wolff JJ et al. Differences in white matter fiber tract development present from 6 to 24 months in infants with autism. Am J Psychiatry. 2012 Jun;169(6):589-600.

Maturation of the auditory system

[8] Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity- dependent and activity-independent processes. Cell Tissue Res. 1999 Aug;297(2): 187-95.

Defective brain maturation after asphyxia

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

Childhood aphasia?

[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.

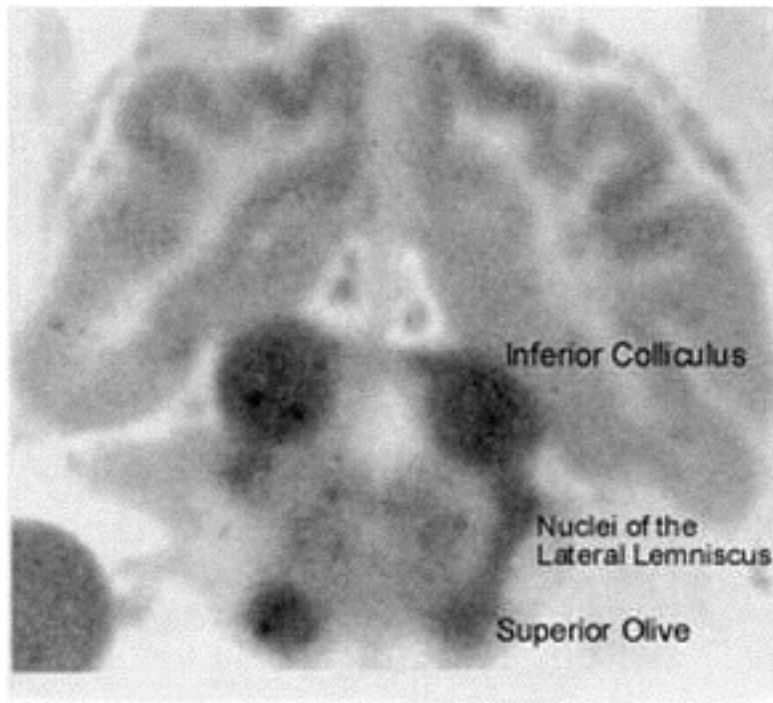
Videos on umbilical cord clamping

[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>

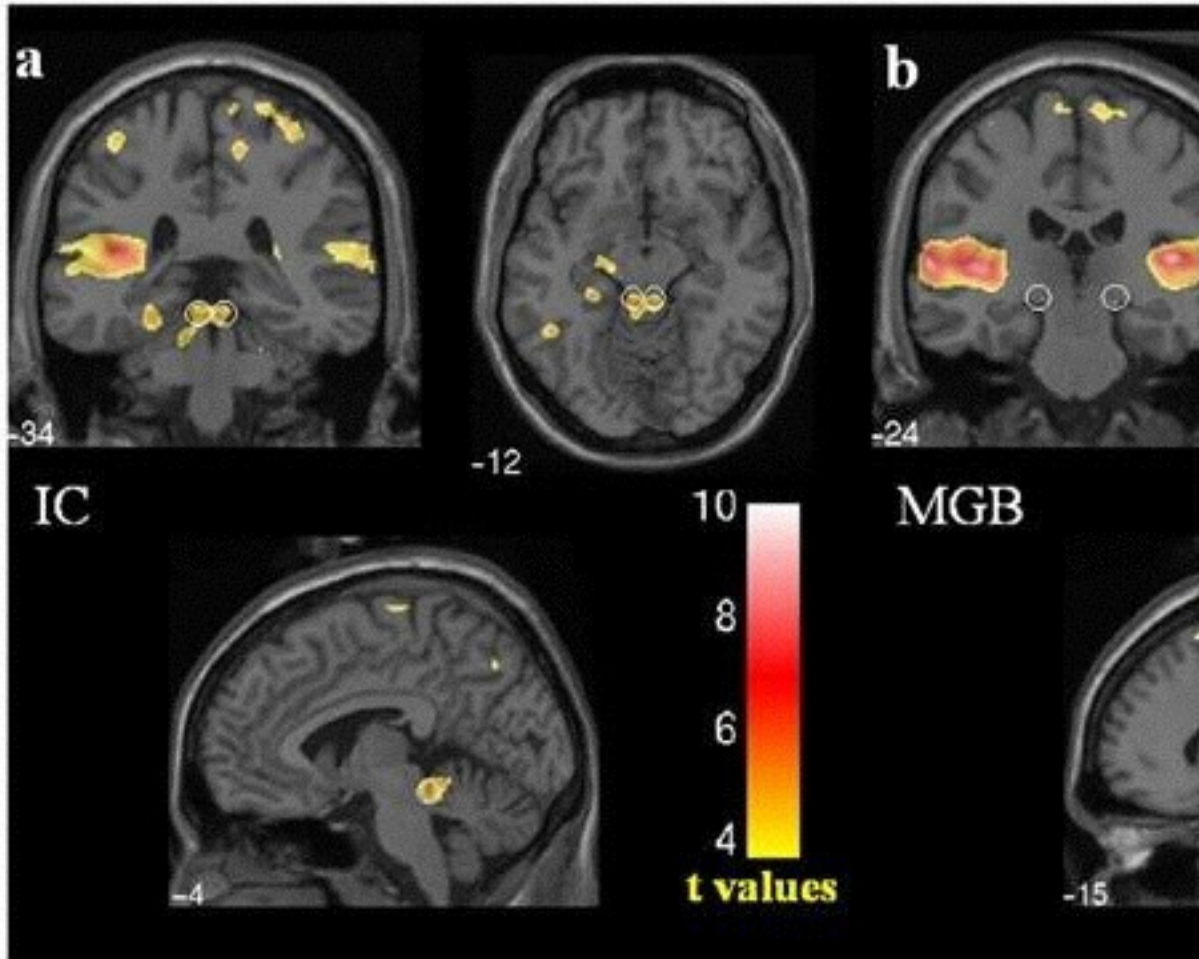
[13] Contemplating the Cord. A seminar with Dr. Eileen Hutton (29 minutes)

<https://www.youtube.com/watch?v=j09DkMns0Fo>

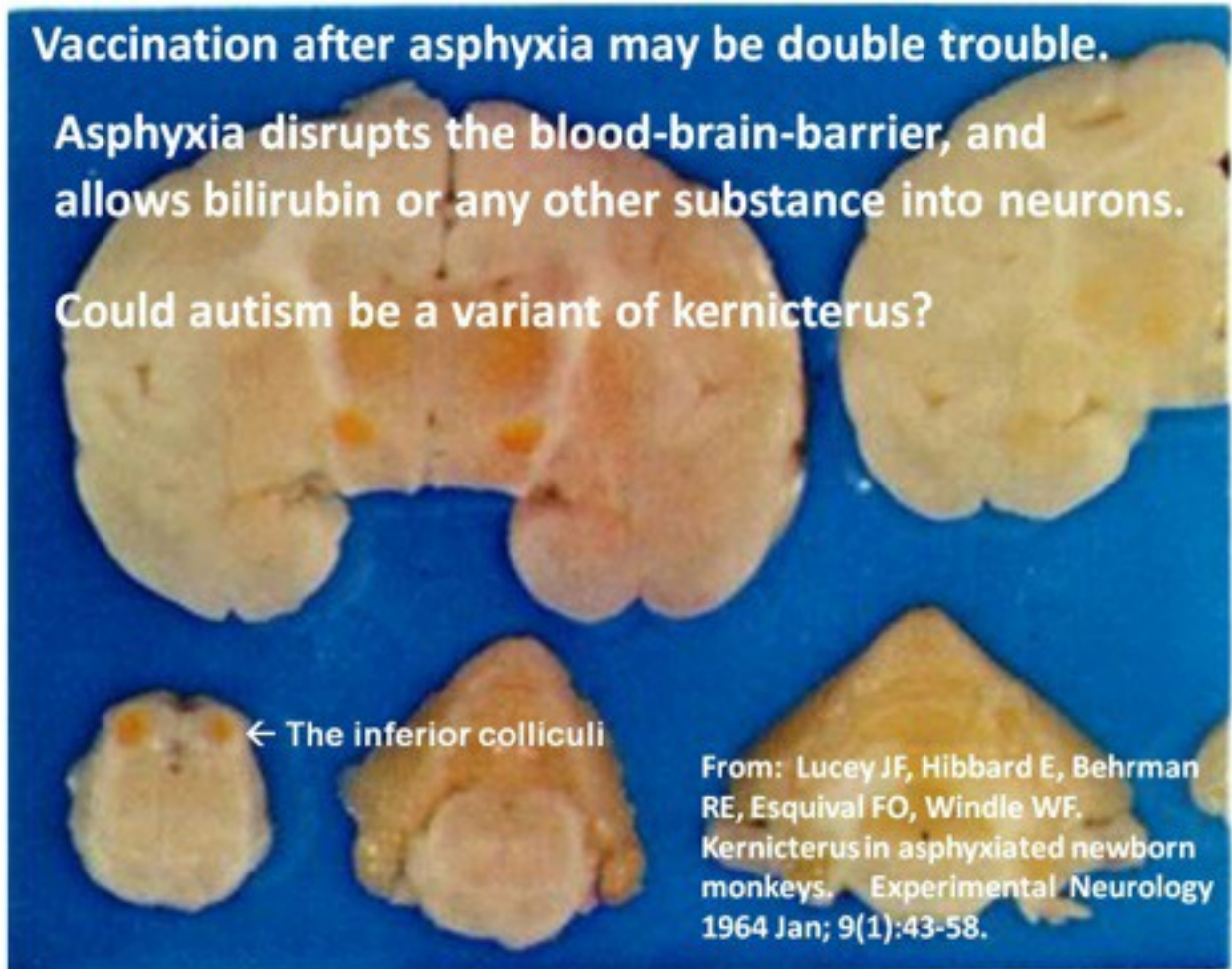


From: Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812.

<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).



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.

Laurie Sparks-Dennison

November 8, 2013

My comments are in regards to the needs of children and families with autism in the state of Ohio. There are a few things happening here that, at first glance, would seem to be progressive and aggressive measures to support the needs of this population. Ohio offers what is called the Ohio Autism Scholarship which allows a family up to \$20,000 per year to cover the cost of education for students with an ASD diagnosis. Ohio also has a strong affiliation to the Autism Treatment Network, which appears to be funded through Autism Speaks and has tied themselves directly to the autism programs at both Nationwide Children's hospital and a children's hospital in Cincinnati.

While it is great that Ohio seems to offer choices, the reality is vastly different. Case in point:

While there are a great number of Ohio Autism Scholarship providers listed for Franklin County, Ohio, the majority of those providers charge unmanageable amounts over the \$20,000 scholarship for children to attend. This means that the scholarship is only truly available to families who can either afford to pay the thousands per year of overage, or hire legal counsel to fight their school districts to cover the costs. It is not acceptable that a scholarship intended to help fund education expenses for children with autism is not accessible to the families and children who need these services the most, but cannot pay afford to pay the overage expected of them.

Additionally, there is virtually NO oversight as to the quality of these programs. While the public schools are facing rigorous standards, and necessarily so, these programs are more than often overseen by a credentialed person and ran by someone with little education, experience, or expertise to address the convoluted needs of many of these children.

Lastly, there is often no chance for inclusion for children who do attend an Autism Scholarship "school". Many of these centers provide zero peer interaction and have no plans in place to do so. This is the opposite of a LEAST RESTRICTIVE ENVIRONMENT in most cases.

OHIO NEEDS ATTAINABLE AND ACCESSIBLE INCLUSIVE EDUCATION FOR ALL FAMILIES AFFECTED BY AUTISM.

Secondly, many families are struggling to pay for basic human needs and are juggling multiple appointments at all hours of the day and in many different locations in an effort to meet their children's needs. Parents are having to leave jobs in order to either educate their children or simply to get them to all of the recommended therapy appointments. Parents really need some sort of liaison who understands the needs of families with a child diagnosed with ASD and is able to help them with scheduling, advocating, documentation, linking to appropriate services, and how to find FUNDING to pay for these things. County DD service coordinators are swamped and many go over and above, but this needs to be a specific role created solely to support parents of children with autism.

OHIO FAMILIES AFFECTED BY AUTISM NEED SUPPORTIVE CASE MANAGEMENT.

Thank you for taking the time to hear my voice. Although I only represent my own family, there are other needs that many families face in our state. We have to start the conversation somewhere and keep it going.

Sincerely,

Laurie Sparks-Dennison

Laura Adams

November 8, 2013

As it stands now someone in my situation being a single mom with our only income being SSI the autism scholarship is our only option for ABA and to get that you cannot be enrolled in school. It should not be either or, every therapy or school program available should be an option for all artistic for special needs children.

Laura Adams

November 8, 2013

My marriage only lasted 4 months because my husband couldn't deal with how hard things get with my son. So I'm back to being a single mom where everything falls on me. We are actually going this week back to a child psychiatric hospital for inpatient help because of how aggressive my son is with me. But yet Medicaid doesn't pay for in home nursing because he technically doesn't need medical help. So who is going to help me not get beat up every day for the rest of his life or until we get the aggression under control. There needs to be more help for people with autism and the people who care for them.

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

Linda Varsou

November 8, 2013

Baltimore, November 8, 2013

At the 4/9/2013 IACC Full Committee Meeting, I presented an oral comment raising the serious issue of parental “Denial” of their child’s autism. (See my “Statement Summary” on page 3) Since then, I continued researching the literature, by adding to the keyword “Denial”, the words “Resolution, Non-Resolution, Non-Acceptance”. I found some dissertations and a very interesting Original Paper from Israel, reporting the prevalence of a parent to be in chronic denial of his child’s autism as high as **53%**! I know how meticulous and reliable research work is done in Israel and this article is self-speaking. (See attached 11-page PDF file: Article resolution of autism diagnosis).¹

ORIGINAL PAPER on “Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics”, by Shahaf Milshtein, Nurit Yirmiya, David Oppenheim, Nina Koren-Karie and Shlomit Levi, published in the *J Autism Dev Disord* (2010) 40:89–99. On 7/9/13, at the IACC Full Committee Meeting, I expressed my wish and intention to do a presentation at the 10/9/13 Meeting, and I left my name and phone with the secretariat. Due to government’s shutdown cancellation of that meeting and the one of 10/29/13, I am requesting to present an oral comment at the 11/15/2013 Workshop at the NIH.

Sadly, the issue of chronic denial of a child’s autism, at least from one of the parents is so frequent, that its seriousness becomes only second to the diagnosis of autism, due to the many deleterious side-effects “denial” has to the definite victim, the child or adult child with autism. Unfortunately, advocates, professionals, researchers and parents active in the field of autism, due to the fact that by definition they are not in denial themselves, have the tendency to ignore or to underestimate the existence, the significance and the impact of the deleterious effects **chronic denial** has on the child with autism. Before any social problem becomes officially recognized by the scientific community as a serious issue, the press, the blogs and the parents bring up some hints to the light. Here below are some excerpts from “**Autism Key**”. (See page 2)

I am looking forward to see you on 11/15/13 and have the chance to raise again the serious issue of parental denial in autism, as IACC cannot be “in denial of denial” anymore.

Sincerely yours,

Dr. Linda (Angeliki) Papadimitriou-Varsou, PhD, MPH, DABCC, Ass. Professor,
Mother of a 28-year-old college student son with autism, advocate for the Rights and Strengths of People with Autism, and a fervent supporter of the concept: “An Autism Friendly Society will benefit us all”.

[PII redacted]

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

[Autism and Denial, from www.autismkey.com]

“Consequences of Autism Denial Can Be Far Reaching”

Posted on January 15, 2011 by Gary G. Porter <http://www.autismkey.com/autism-denial-can-be-far-reaching/>

1. Any thoughts?

DT Welsh

November 8, 2013

Subject: Requests for Public Comment

In Ohio, we need uniform diagnostic tools and assessments for kids suspected of having autism, and we need these services to be covered by insurance providers, as with any other medical condition!

We also need more therapy and education programs for children who are diagnosed at a young age. What we have gotten in the past is: "your kid has autism. Apply for Medicaid and then call Nationwide Children's Hospital to train you to administer an ABA therapy program. Then go out and hire trained ABA therapists to administer this program to your child. Medicaid will cover it." (This was an actual recommendation for my youngest son).

Part-time preschool (usually 2-1/2 hours a day) plus one hour of speech and one hour of OT a week is not enough to provide meaningful, measurable improvement to kids on the spectrum, especially kids on the moderate to severe end. Services need to catch up to diagnostic tools, and parents don't have the resources to do all of this themselves, and pay for it all themselves. The effect on the so-called middle class is devastating.

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

Gina Pepchinski

November 8, 2013

Subject: Public comments from the mother of a 23 year old son with autism

Thank you for this opportunity to submit written comments to the 2013 IACC Strategic Plan Update Workshop. My name is Gina Pepchinski and I live in Houston, Texas. I have a 23 year old son who has diagnoses of autism and apraxia. He is nonverbal, unable to use the toilet independently or live alone without having the care of another adult. He was diagnosed at the age of 3. There are 2 issues I would like to bring to your attention: the need for support to families raising young children with autism in the community and the need for future planning for adults with autism like my son. Both of these needs can be addressed by universal access to the state Medicaid waiver programs.

I will use my own family's story to illustrate these needs. My son is an only child and we live in Houston Texas due to my husband's work. All of our extended family live on the East Coast. When my son was first diagnosed, I had no help whatsoever dealing with his day to day care which included a number of challenging behaviors. I endured a very stressful existence during those years. I did not learn that I could apply for a Medicaid waiver program to provide supported home living services until my son was 6 years old. Due to the waiting list situation in Texas, we did not actually start receiving services until he was 12 years old. Our life as a family dramatically improved once we started receiving supported home living services and respite. All families who receive a diagnosis of autism for their child should be made aware at the same time of the Medicaid waiver programs available in their state and every state should have to provide those services. There should be one system in the United States and the situation with the states that have waiting lists should not be tolerated. A child diagnosed with autism in Idaho receives services after a brief filling out of paperwork. The same child in Texas can wait more than 10 years to receive any help.

Now that my son is an adult, my husband and I are quite concerned about what his life will be like once we are no longer able to be part of his care. We are fortunate here in Houston to have an organization called The Center that provides him with day habilitation and is the provider for his Medicaid waiver program. Our plan for him is to transition from our taking care of him to a foster care companion taking over his care. This arrangement is allowed by his Medicaid waiver program. But I personally know over 5 other families with adult children who only recently learned of the Medicaid waiver programs and will spend years on the waiting list. These parents may become unable to take care of their children while still waiting.

The supports and services provided by the Medicaid waiver programs are crucial to families with children with autism. They need to be made available to every family from initial diagnosis. There should be no tolerance for states that make families wait. This is the most important support that the federal government can provide to families with children with autism.

Thank you for your time in reading my comments.

Respectfully submitted,

Gina Pepchinski

[PII redacted]

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

Teresa Holman

November 8, 2013

Subject: Autism needs

I am a mother of a 23 year old man with Autism. The most important thing I need is help to pay for his school which is a Applied Behavior Analysis School.

It would be a miracle. I also need respite. I can't imagine a night with my husband. A date, where we could see each other before we are both so exhausted we can't do anything but fall into bed. My husband and I have to do continuing education over a weekend, and we can't EVER even go together.

We are ALWAYS A PART. Of course the money for respite is the biggest issue. Anyone who is really good will not work for 10-12 dollars per hour. Taking care of someone with Autism is just too challenging. So if you do find someone who will care for them, they won't stay.

It is an isolating diagnosis. Most kids rarely see outside their homes, besides school, and doctor visits. Because they don't usually know how to act in public they don't get to go anywhere, so neither do their families. There are huge issues, with finding a doctor who will even begin to consider helping a child/man who cannot speak.

So those are the big ones for me right now.

Thought it might help you to know.

Teresa Holman

[PII redacted]

[PII redacted]

Belinda

November 8, 2013

Subject: Requests for Public Comment

Increase in funding as far as food, clothing, child care ect! I hear all the time that things are normal expenses. My child does not eat what we eat, sensory issues cause destruction of clothing, and day care centers and after school programs are not equipped to care for my son. He is eligible for home health but I have to be home! This defeats the purpose and his level 1 waiver will fund 5 hours per week! No person wants a job that is 5 hours per week. So my husband is a stay at home dad! less income in the household! His diagnosis qualifies him for social security which would cover these costs, but because I work they say MY income is to high! I have other children as well so they all must be taken care of. I live in Delaware county Ohio

Maria Lujan Ferreira

November 9, 2013

Dear Staff of NIMH

I honestly do not understand why the contribution of the public is still being requested when no consideration of the suggestions are taken into account with the required sense of urgency that this situation needs.

There is a strong need of protocols, guidelines for the average pediatrician and clinic and consideration of the non-genetic, acquired gastrointestinal, metabolic, biochemical, nutritional, toxicological (by bioaccumulation), endocrinological (including the HPA axis), mitochondrial dysfunction, immune (as dysfunction), autoimmune (PANDAS/PITAND/PANS) conditions or medical problems, viral-fungal-parasitic.- bacterial infections (Gastrointestinal or not, acute or chronic, subclinical or not), oxidative stress, inflammation (systemic, organic peripheric or in brain) and microglial activation and the consequences of them in particular and in combination that are present in different subgroups of ASD.

Unfortunately nothing of this is being done in the context of the paradigmatic kuhnian change we are living that it requires, in the framework of the world. Until the single controlled case (SCC) as a research gold standard to be properly accepted, applied and studied in ASD due to the individual complexity, later the case series with proper and safe characterization to be considered for children teens and adults, no true translational progress is going to be met in terms of widespread applied and useful research and nothing is being done in that direction.

Recent research

<http://www.ncbi.nlm.nih.gov/pubmed/23915542>
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3751071/>

and the last work on gastrointestinal issues in autism , confirmatory
[Gastrointestinal Problems in Children with Autism, Developmental Delays or Typical Development.](#)
Chaidez V, Hansen RL, Hertz-Picciotto I.
J Autism Dev Disord. 2013 Nov 6. [Epub ahead of print]
PMID:

24193577

[PubMed - as supplied by publisher]

[Related citations](#)

Select item 24188502 []2.

[Increased abundance of Sutterella spp. and Ruminococcus torques in feces of children with autismspectrum disorder.](#)

Wang L, Christophersen CT, Sorich MJ, Gerber JP, Angley MT, Conlon MA.
Mol Autism. 2013 Nov 4;4(1):42. [Epub ahead of print]

and even researchers in the genetic field, strongly rooted in the genetic field, are noting this even when the analysis is biased

Autism. 2013 Oct 8. [Epub ahead of print]

The association between emotional and behavioral problems and gastrointestinal symptoms among children with high-functioning autism.

Mazefsky CA, Schreiber DR, Olinos TM, Minshew NJ.

Source

University of Pittsburgh, USA.

Abstract

This study investigated the association between gastrointestinal symptoms and a broad set of emotional and behavioral concerns in 95 children with high-functioning autism and IQ scores \geq 80. Gastrointestinal symptoms were assessed via the Autism Treatment

Network's Gastrointestinal Symptom Inventory, and data were gathered on autism symptom severity, adaptive behavior, and multiple internalizing and externalizing problems. The majority (61%) of children had at least one reported gastrointestinal symptom. Emotional and behavioral problems were also common but with a high degree of variability. Children with and without gastrointestinal problems did not differ in autism symptom severity, adaptive behavior, or total internalizing or externalizing problem scores. However, participants with gastrointestinal problems had significantly higher levels of affective problems. This finding is consistent with a small body of research noting a relationship between gastrointestinal problems, irritability, and mood problems in autism spectrum disorder. More research to identify the mechanisms underlying this relationship in autism spectrum disorder is warranted. Future research should include a medical assessment of gastrointestinal concerns, longitudinal design, and participants with a range of autism spectrum disorder severity in order to clarify the directionality of this relationship and to identify factors that may impact heterogeneity in the behavioral manifestation of gastrointestinal concerns.

And I have to say 1) the body of research is not small and 2) GI issues treatment are key to make progress and learning possible

Now, how many decades are going to be spent until what parents have to tell be heard, and worse, to be confirmed but with decades lost?

Thank you in advance

M. L. Ferreira

Argentina

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

Eileen Nicole Simon

November 12, 2013

Subject: Comments for the IACC workshop, Nov 15

I have been listening to the conference call on risk factors today. The list of strategic plan objectives needs to be reworked. The current objectives appear to be focused on epidemiology, and “autism” as an overgeneralized term.

The major objective should be to understand brain systems that underlie language development, and maturation of the language association tracts in the cerebral cortex. Language development is the most serious handicap for children with autism. How can this be so badly overlooked?

The last two objectives, to collect data on environmental factors in the perinatal period should have been discussed in terms of neurologic injury. Risk factors? Oxygen insufficiency at birth and head trauma (concussion), and their specific effects on the brain should be the focus of discussion.

Evidence has been available in the medical literature for more than 50 years now that the auditory system is vulnerable to damage by asphyxia at birth. This should have been recognized long ago as a handicap for language development. I have been trying to point this out to the IACC for 10 years now, since the Autism Summit in 2003.

I hope at some point to hear discussion of the comments I have submitted for this and many previous meetings of the IACC.

Eileen Nicole Simon, PhD, RN
[PII redacted] Lexington MA
[PII redacted]

Jill Rubolino

November 14, 2013

Attached please find my public written comments to enter into the record. Also attached, to accompany them, is a survey result regarding discrimination in healthcare against patients with autism. While I realize this submission will be too late to enter into the comments prepared for review for the meeting participants prior to the meeting, let's be honest. I'm quite sure they have not in the past, and currently don't make it a point to review those comments since it is just a "suggestion" rather than a requirement. The committee members seem painfully unaware of the scope and breadth of this issue and oblivious to their obligation to "discuss public comments" as stated in the core values statement.

Please submit these previously written oral public comments as my written comments. I was not able to attend the meeting tomorrow due to the schedule change.

Thank you,

Jill Rubolino

OCTOBER 8TH 2013

GOOD AFTERNOON,

MY NAME IS JILL RUBOLINO AND I AM THE MOTHER OF A TEN YEAR OLD SON WHO IS RECOVERED FROM AUTISM. I AM HERE TODAY TO SPEAK TO YOU AS A PARENT, A HEALTH CARE PROFESSIONAL, AND A PATIENT ADVOCATE.

WHILE I AM FULLY AWARE OF THE TIME CONSTRAINTS REGARDING PUBLIC COMMENTS, I ASK YOU FOR SOME LEEWAY. LAST MEETING WE TOLERATED UPWARDS OF 45 MINUTES LISTENING TO THE MOST PAINFULLY INAPPROPRIATE AND INACCURATE DESCRIPTION OF "CATATONIA" I CARE TO EVER WITNESS. I HAD TO ENDURE A DESCRIPTION OF CHILDREN WHO CLEARLY SUFFERED IN SOME WAY AND WHO WERE OBVIOUSLY DEMONSTRATING THE NEED FOR MEDICAL INTERVENTION, BUT WOULD RECEIVE NONE. INSTEAD, THEY WOULD RECEIVE A LABEL OF "CATATONIA". THE FACT THAT COMMITTEE MEMBERS THOUGHT THAT PRESENTATION WAS A VALUABLE ADDITION AND APPROPRIATE USE OF TIME AND RESOURCE IS OVERSHADOWED ONLY BY THE PAINFUL REALIZATION THAT AUTISTIC CHILDREN WERE BEING MEDICALLY NEGLECTED UNDER THE GUISE OF RESEARCH. I COULD HAVE THOUGHT OF A HUNDRED BETTER USES OF THAT TIME, AND THIS AUDIENCE. IN ADDITION, I CANNOT GO FORWARD WITHOUT MENTIONING THE OUTRAGEOUS SUGGESTION THAT AUTISTIC CHILDREN WEAR A FLOTATION DEVICE AROUND THEIR NECKS, AND SUBSEQUENTLY THEIR AIRWAY, ON A CONTINUAL BASIS SO THEIR LIVES WOULD BE SPARED FROM THE DROWNING THAT MAY OCCUR IF THEY SHOULD ELOPE FROM THEIR HOME AND ENTER A BODY OF WATER. I DON'T MEAN THIS COMMENT TO BE FACETIOUS AS DROWNING DEATHS ARE TRAGICALLY THE NUMBER ONE CAUSE OF DEATH FOR AUTISTIC CHILDREN THAT WANDER. I SAY THIS TO DEMONSTRATE THE ABSURDITY THAT THIS COMMITTEE, A FEDERALLY FUNDED COMMITTEE, CHARGED WITH MAKING RECOMMENDATIONS ABOUT IMPORTANT ISSUES AFFECTING THE AUTISM COMMUNITY, WOULD NOT LOOK AT THAT SUGGESTION AND TAKE PAUSE. THOUSANDS OF PARENTS ARE OUT THERE, STRUGGLING EVERY SINGLE

DAY TO KEEP THEIR CHILDREN SAFE. I'M SURE THEY WERE ALL APPALLED, AS WAS I, BY THE RIDICULOUS AND REPEATED SUGGESTION OF SOMETHING SO ABSURD. IT BEGS TO QUESTION THE VALIDITY OF THE PARTICIPANT'S QUALIFICATIONS AND UNDERMINES THE ENTIRE FORMAT WHICH SHOULD FOCUS ON REAL WORLD, REAL TIME ISSUES AND NEEDS WITH APPROPRIATE, WELL THOUGHT OUT, MATURE SUGGESTIONS. I DO NOT NEED AN INTERAGENCY COMMITTEE FOR A SUGGESTION OF THIS CALIBER. THAT COMMENT WAS AN INSULT, AND A MOCKERY OF THE SERIOUSNESS WITH WHICH THE DEATH OF AN AUTISTIC CHILD SHOULD BE DISCUSSED.

AUTISM STATISTICALLY OUTNUMBERS ALL OTHER PEDIATRIC ILLNESSES AND CONTINUES TO DO SO. THIS PROBLEM IS OF A MAGNITUDE THAT IS ALMOST UNBELIEVABLE. WHERE DO WE GO FOR HELP? THIS COMMITTEE MAKES RECOMMENDATIONS AND DETERMINES WHAT ISSUES GET ATTENTION AND FUNDING IN THE COMING YEARS. WHILE THERE ARE HUGE MEDICAL ASSOCIATIONS, ORGANIZATIONS AND ENTIRE HOSPITALS DEVOTED TO OTHER PEDIATRIC POPULATIONS, AUTISM HAS A COMMITTEE WITH NO OVERSIGHT AND NO ACCOUNTABILITY, THAT MEETS FOUR TIMES A YEAR TO ADDRESS THE NEEDS OF OVER 1.5 MILLION CHILDREN AND ADULTS. THE RESPONSE CERTAINLY DOESN'T MATCH THE NEED. THERE SHOULD BE AN ENTIRE STAFF DEVOTED SOLELY TO AUTISM AND HUGE MEDICAL CENTERS ACROSS THIS COUNTRY WITH MULTISPECIALTY CLINICS THAT ARE TREATING PATIENTS AND DOING CONSTANT RESEARCH, BUT THERE ISN'T.

CERTAINLY, WE ARE NOT THE FIRST SET OF PARENTS TO ENDURE THIS NEGLECT. WHILE YOU EXPECT US TO ACCEPT THIS AS AN APPROPRIATE RESPONSE, THESE FORMER PARENTS, CALLED "REFRIGERATOR MOTHERS", HAD TO ENDURE FAR WORSE. NOT ONLY EXCLUSION, AND DISCRIMINATION, BUT OPPRESSION BY A MEDICAL COMMUNITY THAT'S VERY EXISTENCE IS MEANT TO SERVE THE PATIENT AND FAMILY. A DISGRACEFUL, EPIC FAILURE OF HUMANITY AND ABUSE OF POWER, INFLUENCE AND DISCRIMINATION BY PHYSICIANS. IN THE EXTRAORDINARY FILM "REFRIGERATOR MOTHERS", DOROTHY GROOMER, AN AFRICAN AMERICAN MOTHER OF AN ADULT SON WITH SEVERE AUTISM TALKS ABOUT HER EXPERIENCE WITH PHYSICIANS DIAGNOSING HER SON AS "EMOTIONALLY DISTURBED". HE WAS EXCLUDED FROM THE DIAGNOSIS OF AUTISM BECAUSE, AS SHE STATED, "WE DID NOT FIT THE CLASSIC MOLD FOR AUTISM", WHICH AT THE TIME, WAS CHILDREN OF WHITE, UPPER MIDDLE CLASS, EDUCATED PARENTS. HER DOCTORS TOLD HER THAT HER SON, STEPHEN, COULD NOT BE AUTISTIC BECAUSE HE WAS NOT WHITE, AND THEY ASSUMED SHE WAS NOT EDUCATED, AND THEREFORE HE WAS DIAGNOSED AS "EMOTIONALLY DISTURBED" INSTEAD. UNFORTUNATELY, WE HAVEN'T COME VERY FAR. WHILE PARENTS CONTINUE TO ASK THEIR DOCTORS TO INVESTIGATE THEIR CHILD'S PHYSICAL SYMPTOMS, THEY ARE REPEATEDLY TOLD THOSE CAN ONLY BE ATTRIBUTED TO THEIR CHILD'S AUTISM AND MEDICAL DIAGNOSTIC TESTING AND TREATMENT ARE WITHHELD. JUST AS WE LOOK BACK AT THAT TIME AND SEE THE RESPONSE AS BARBARIC, WE WILL LOOK BACK ON THIS TIME IN THE SAME LIGHT. WHILE OTHER PARENTS OF CHRONICALLY ILL CHILDREN ARE ABLE TO ACCESS HEALTH CARE, COMPREHENSIVE TEAMS AND ASSISTANCE, OUR PARENTS HAVE TO GO IT ALONE. POLICIES TO DISCRIMINATE AGAINST OUR CHILDREN ARE IN PLACE. WHILE MANY PARENTS, LIKE ME, KNOW THAT THEIR CHILDREN HAVE ADVERSE REACTIONS TO VACCINATIONS, PEDIATRICIAN PRACTICES ACROSS OUR NATION HAVE CREATED POLICIES TO DISCRIMINATE AGAINST PARENTS WHO CHOSE TO NOT VACCINATE OR NOT VACCINATE ACCORDING THE RECOMMENDED SCHEDULE. TEXAS CHILDREN'S PEDIATRICS ASSOCIATION HAS 48 LOCATIONS IN THE HOUSTON AREA AND IS ONE OF THE LARGEST PEDIATRIC PRACTICES IN THE NATION. SEVERAL OF THEIR OFFICE LOCATIONS HAVE "OFFICE POLICIES" THAT STATE THEY WILL NOT TAKE ANY PATIENTS WHOSE PARENTS CHOSE NOT TO VACCINATE OR NOT TO VACCINATE ACCORDING TO THE RECOMMENDED SCHEDULE REGARDLESS OF THE REASON INCLUDING BOTH RELIGIOUS EXEMPTION AND MEDICAL CONTRAINDICATION. THEY REFUSED TO ACCEPT MY CHILD AS A PATIENT AND IN CALLING MULTIPLE LOCATIONS AS WELL AS TEXAS CHILDREN'S

HOSPITAL BOTH PATIENT RELATIONS AND THEIR LEGAL DEPARTMENT, I COULD NOT BE PROVIDED WITH A WRITTEN POLICY, AN EXPLANATION, OR ANY LEGAL FRAMEWORK TO SUPPORT THIS DISCRIMINATORY POLICY, AND YET IT CONTINUES. IN ALMOST TWENTY YEARS OF BEDSIDE NURSING I HAVE NEVER WITNESSED ANOTHER PATIENT POPULATION BEING DENIED HEALTHCARE BASED ON THEIR VACCINATION STATUS. IN FACT, A LARGE MAJORITY OF PATIENTS ARE NONCOMPLIANT WITH THEIR PLAN OF CARE AND YET STILL RECEIVE IMMEDIATE, COMPREHENSIVE CARE. DENYING CHILDREN ACCESS TO HEALTH CARE BASED ON VACCINATION STATUS IS AKIN TO NOT SEEING A DIABETIC PATIENT BECAUSE THEY DON'T FOLLOW THEIR DIET OR A RENAL PATIENT WHO MISSES DIALYSIS.

FURTHERMORE, DENYING ANY CHILD ACCESS TO A MEDICAL HOME PEDIATRICIAN BASED ON VACCINATION STATUS RELATED TO RELIGIOUS EXEMPTION IS, IN FACT, RELIGIOUS DISCRIMINATION. THE DISCRIMINATION AGAINST THIS PATIENT POPULATION BY PEDIATRICIANS AT THE LOCAL LEVEL, PHYSICIAN ORGANIZATIONS AT THE NATIONAL LEVEL, AND AGENCIES RESPONSIBLE FOR DETERMINING THE RESPONSE AT THE FEDERAL LEVEL WILL HAVE THE SAME LEGAL ACCOUNTABILITY AS OTHER HEALTH CARE DISCRIMINATION. FOR THESE REASONS, WE REQUEST A RECOMMENDATION FOR A FULLY FUNDED LEGAL ASSISTANCE NETWORK TO ENSURE THESE CHILDREN RECEIVE APPROPRIATE CARE, RECOMMENDATIONS FOR MANDATORY INVESTIGATION OF DISCRIMINATORY PRACTICES OF ANY HEALTH CARE ORGANIZATIONS RECEIVING FEDERAL FUNDS THROUGH MEDICAID PROGRAMS, AND AN IMMEDIATE INTERVENTION BY THIS COMMITTEE TO FORMULATE A PLAN TO EVALUATE YOUR OWN LACK OF RESPONSE TO THIS VERY SERIOUS MEDICAL NEGLECT OF AN ENTIRE PEDIATRIC PATIENT POPULATION.

FROM A CLINICAL PERSPECTIVE THIS LEAVES A LARGE GROUP OF MEDICALLY COMPLEX CHILDREN WITHOUT BASIC MEDICAL CARE, WITHOUT REFERRALS TO SPECIALISTS, AND THE TASK OF COORDINATION OF CARE RESTING SOLELY ON THE PARENTS. IN ADDITION TO LACK OF ACCESS, THOSE CHILDREN THAT DO ENTER INTO THE HEALTHCARE SYSTEM, RARELY GET DIAGNOSTIC TESTING AND CERTAINLY ARE NOT OFFERED THE SAME SERVICES AS OTHER PEDIATRIC PATIENTS WITH CHRONIC ILLNESS INCLUDING BUT NOT LIMITED TO AUTISM SPECIALISTS, CHILD LIFE SERVICES, PEDIATRIC SUBSPECIALTIES, THERAPY SERVICES, SOCIAL WORK, CASE MANAGEMENT, NUTRITION AND PARENT SUPPORT GROUPS. HERE IS A LIST OF JUST A FEW OF THE THINGS AUTISM PARENTS ARE FACED WITH INSTEAD:

- LACK OF INFORMED CONSENT
- VIOLATION OF PATIENT RIGHTS
- UNLAWFUL NOTIFICATION OF CHILD PROTECTIVE SERVICES
- FAILURE TO TREAT
- FAILURE TO DIAGNOSE
- UNLAWFUL SECLUSION, RESTRAINT AND SEDATION
- FAILURE TO MEET FEDERAL MANDATES IN REGARDS TO DISABILITY AND COMMUNICATION ACCOMMODATION
- DISCRIMINATION AGAINST A DISABLED POPULATION
- FAILURE TO KEEP THE PATIENT SAFE FROM HARM
- FAILURE TO ASSESS AND TREAT PAIN
- NOT INVESTIGATED PHYSICAL SYMPTOMS THAT OCCUR IN ANY PATIENT, REGARDLESS OF THEIR AUTISM DIAGNOSIS, IS ALWAYS MEDICAL NEGLECT. WHETHER THE PRACTITIONER REGARDS AUTISM AS A PSYCHIATRIC DIAGNOSIS, A MEDICAL DIAGNOSIS OR HOLDS THE OPINION THAT

AUTISM IS PSYCHOLOGICAL WITH MEDICAL COMORBIDITIES DOES NOTHING TO CHANGE THAT. IF A PATIENT PRESENTS TO THE EMERGENCY ROOM WITH ABDOMINAL PAIN, DIARRHEA AND VOMITING, THE PROCESS OF DIAGNOSTIC INVESTIGATION BEGINS THE SAME WAY WHETHER THAT PATIENT IS NEUROTYPICAL, AUTISTIC, SCHIZOPHRENIC, ALCOHOLIC, AN IV DRUG USER, MORBIDLY OBESE, DIABETIC, HIV, RENAL FAILURE, MAN, WOMAN, CHILD, EVEN A FEDERAL AGENCY EMPLOYEE.....IT ALL BEGINS WITH THE FIRST STEPPERFORM A PHYSICAL ASSESSMENT AND DIAGNOSTIC WORK UP. WHEN A PRACTITIONER FAILS TO ADDRESS THE PATIENT'S SYMPTOMS BASED ON THEIR DISABILITY, IT'S CALLED DISCRIMINATION.

NO OTHER CASE OF MEDICAL NEGLIGENCE, MALPRACTICE AND DISCRIMINATION ILLUMINATES MY POINT BETTER THAN THE CASE OF [PII redacted]. ALEX WAS A 14 YEAR OLD BOY WHO SUFFERED FROM SEVERE AUTISM AND WAS HOSPITALIZED SEVERAL TIMES FOR AN ACUTE CHANGE IN STATUS RELATED TO AGGRESSION AND GASTROINTESTINAL SYMPTOMS. HE WAS KEPT IN FOUR POINT RESTRAINTS FOR 22 CONSECUTIVE DAYS WITHOUT AN APPROPRIATE DOCTOR'S ORDER. HE WAS GIVEN A COCKTAIL OF PSYCHOTROPIC DRUGS THAT WAS EVER CHANGING AND INEFFECTIVE. HE HAD GASTROINTESTINAL DISEASE THAT WAS NEVER INVESTIGATED. HE WAS DISCHARGED HOME FROM ADVOCATE LUTHERAN GENERAL HOSPITAL, IN PARK RIDGE, ILLINOIS AND NINE DAYS LATER WAS FOUND DEAD AFTER AN APPARENT MURDER-SUICIDE ATTEMPT. HIS MOTHER, [PII redacted], AND GODMOTHER FOUND UNCONSCIOUS AT THE SCENE ARE CURRENTLY INCARCERATED IN ILLINOIS. I CAUTION YOU TO MAKE A REBUTTAL COMMENT ABOUT THE IMPRESSION THAT ANYONE IN OUR COMMUNITY PERPETUATES THE IDEA THAT TAKING YOUR CHILD'S LIFE IS EVER ACCEPTABLE NO MATTER HOW DIFFICULT YOUR ROAD. A PRISTINE EXAMPLE OF EVERLASTING DEVOTION, DEDICATION AND METICULOUS CARE GIVEN TO HER CHILD IS [PII redacted] AND HER SON [PII redacted], NOW 19, WHO AT AGE 18 MONTHS EXPERIENCED A VACCINE INJURY AND NOW SUFFERS FROM RELENTLESS SEIZURES AND SEVERE AUTISM. ALTHOUGH SHE AND I LIVE IN HOUSTON, THE LOCATION OF THE LARGEST MEDICAL CENTER IN THE WORLD, SHE CANNOT GET ADEQUATE HEALTH CARE FOR HER CHILD. IT IS ONLY BECAUSE OF HER DEVOTION TO HIM, HER FAITH IN GOD AND HIS WARRIOR SPIRIT, THAT HE IS ALIVE TODAY. THIS IS THE PATH WE ENDORSE, AS DIFFICULT AS IT IS. [PII redacted] DID NOT FOLLOW THE SAME PATH. AND BEFORE YOU SPEAK OUT ABOUT CALLING FOR A HATE CRIME, I SUGGEST YOU CHECK YOUR EMAIL INBOX. WERE YOU CONTACTED TO HELP THIS CHILD, AND DIDN'T? YOU SEE, THIS CHILD WAS NOT HIDDEN AWAY FROM EVERYONE; HE WAS RIGHT UP IN OUR FACES. HE HAD BEEN IN AND OUT OF THE HOSPITAL FOR MONTHS WITH COUNTLESS REQUESTS BY HIS MOTHER FOR INVESTIGATION OF HIS MEDICAL PROBLEMS AND REPEATED REFERENCE TO HIS GASTROINTESTINAL SYMPTOMS IN HIS MEDICAL RECORD, ALL GOING UN-INVESTIGATED. HIS PATIENT RIGHTS WERE VIOLATED, HIS CIVIL RIGHTS WERE VIOLATED, HIS DISABILITY RIGHTS WERE VIOLATED AND HE WAS A VICTIM OF MEDICAL NEGLIGENCE AND MALPRACTICE. EVERY LOCAL, STATE AND FEDERAL AGENCY WAS NOTIFIED. EVERY RESOURCE WAS CONTACTED. EVERY SINGLE AGENCY AVAILABLE KNEW ABOUT THIS CHILD, AND YET, HE WAS SENT OUT INTO THE WORLD WITH NO SUPPORT AND DISCHARGED TO HOME WITH HIS MOTHER TO CARE FOR HIM ON HER OWN. WITHOUT EVER RECEIVING MEDICAL TREATMENT. WHY AREN'T ANY OF THE SAME ORGANIZATIONS CALLING FOR A HATE CRIME, ASKING THE HOSPITAL HOW THEY COULD SAFELY DISCHARGE THAT PATIENT? WHY ISN'T THE STATE AGENCY THAT WAS SUPPOSED TO BE MONITORING THIS CHILD BEING INVESTIGATED? BECAUSE THIS MOM IS IN JAIL FOR KILLING HER CHILD. THAT DOESN'T CHANGE THOSE FACTS. WE KNOW THOSE FACTS, WE HAVE THOSE FACTS, AND I AM HERE TO TELL YOU, WE WILL NEVER GO AWAY. YOU CAN'T CHANGE THE TRUTH, NO MATTER HOW HARD YOU TRY. [PII redacted] SUFFERED THE SAME MEDICAL NEGLIGENCE THAT ALL OF OUR KIDS DO. HIS MOTHER SUFFERED THE SAME FATE, WHEN TRYING TO ADVOCATE FOR HER CHILD'S HEALTH, DOCTORS CALLED CHILD PROTECTIVE SERVICES.

AND THIS IS THE FATE OF SO MANY PARENTS. NO SUPPORT, NO REAL HELP, AND EVERYONE COVERING UP THEIR PART IN IT; THEIR PART IN CONTRIBUTING TO THOUSANDS OF CHILDREN BEING SENT OUT INTO THE WORLD WITH PARENTS WHO CANNOT KEEP THEM SAFE, OR HEALTHY BECAUSE THERE IS ABSOLUTELY NO APPROPRIATE HEALTHCARE. [PII redacted] WAS HOSPITALIZED MULTIPLE TIMES OVER A PERIOD OF SEVEN MONTHS AND YET NOT ONCE, DID HE RECEIVE A COMPREHENSIVE DIAGNOSTIC WORK UP. HE RECEIVED COPIOUS AMOUNT OF PSYCHOTROPIC DRUGS AND UNLAWFUL RESTRAINT. AND MAY I REMIND YOU THAT RESTRAINING A PATIENT WITHOUT A PHYSICIAN ORDER, AND CONTINUING A RESTRAINT THAT IS ALREADY IN PLACE WITHOUT A DOCTORS ORDER IS CONSIDERED ASSAULT AND BATTERY, EVERY INSTANCE, EVERY TIME. BUT THOSE HEALTHCARE PROVIDERS WON'T BE PROSECUTED, BECAUSE ALEX'S MOM IS IN JAIL. BUT WE WON'T FORGET. THIS WAS A POLARIZING EVENT FOR OUR COMMUNITY. SINCE [PII redacted]'S DEATH, THERE HAVE BEEN MORE CHILDREN KILLED BY THEIR PARENTS. WHEN WILL IT BE ENOUGH? WHEN WILL IT BE ENOUGH DEVASTATION FOR THIS COMMITTEE TO STAND UP AND MAKE SOME REAL WORLD RECOMMENDATIONS THAT ADDRESS OUR NEEDS?

THE LAST IACC MEETING I ATTENDED WAS JULY 9TH. DR. FRYE AND DR. BUIE GAVE WONDERFUL PRESENTATIONS COVERING THE NEED FOR MEDICAL INVESTIGATION AND TREATMENT FOR OUR CHILDREN'S MEDICAL ISSUES. BOTH PHYSICIANS STATED IN THEIR PRESENTATIONS THAT SOME CHILDREN SHOW TREMENDOUS IMPROVEMENT AND EVEN COMPLETELY RECOVER WITH TREATMENT. MY CHILD IS ONE OF THOSE. WHAT I CAN'T FIGURE OUT IS WHY WOULDN'T YOU WANT THAT? WHY WOULD YOU NOT WANT TO INSTITUTE A COMPREHENSIVE PLAN TO MEDICALLY TREAT THESE CHILDREN TO IMPROVE THEIR OUTCOMES? DR. PERRIN FROM THE ATN AND PRESIDENT-ELECT OF THE AMERICAN ACADEMY OF PEDIATRICS WAS ALSO IN ATTENDANCE. HE STATED THAT WITHIN THE AAP THERE WAS A TASK FORCE ALREADY IN EXISTENCE WORKING ON ALL THINGS RELATED TO AUTISM. HE EXPRESSED INTEREST IN WORKING WITH BOTH DOCTORS, YET STILL NO WORK HAS BEEN DONE. SINCE THAT MEETING, NEITHER PHYSICIAN HAS BEEN CONTACTED BY ANYONE FROM THIS COMMITTEE, THE AAP OR THE TASK FORCE. LYN REDWOOD STRESSED THE IMPORTANCE OF ADDRESSING OUR KIDS' MEDICAL ISSUES AND SUGGESTED A WORKING GROUP; STILL NO WORK HAS BEEN DONE. PARENTS HAVE COME HERE TIME AND TIME AGAIN REQUESTING THE NEED FOR ADDRESSING MEDICAL ISSUES; STILL NO WORK HAS BEEN DONE.

I BRING TO YOU TODAY THE STORIES OF MANY CHILDREN, WHO LIKE THOUSANDS OUT THERE, HAVE PARENTS WHO BROUGHT THEM TO THE DOCTOR AND TO THE HOSPITAL LOOKING FOR HELP, BUT RECEIVED NONE. YOU SEE THEIR PICTURES UP ON THE SCREEN AND THEIR STORIES ARE IN MY COMMENTS. I ENCOURAGE YOU TO READ THEM. THEIR CHILDREN SUFFER FROM SEIZURES, ABDOMINAL PAIN, DIARRHEA AND CONSTIPATION, SELF- INJURIOUS BEHAVIOR, RELENTLESS FEVERS, METABOLIC AND MITOCHONDRIAL DISORDERS, IMMUNOLOGICAL DISORDERS, ATAXIA, UNIDENTIFIED RASHES AND A WHOLE HOST OF OTHER SYMPTOMS. THEY ARE SUFFERING, AND YET THEY RECEIVE NO MEDICAL CARE. THEY ARE BEING DISCRIMINATED AGAINST BECAUSE OF THEIR DISABILITY. THIS WILL STOP. WE WILL MAKE IT STOP.

I PUBLICLY REQUEST YOU MAKE A RECOMMENDATION TO FORMULATE A COMPREHENSIVE PLAN, INCLUDING A WORKING GROUP, TO ADDRESS THE MEDICAL NEEDS AND MEDICAL NEGLECT OF ALL AUTISTIC PATIENTS, CHILDREN AND ADULTS. I REMIND YOU THAT AS MEMBERS OF THIS COMMITTEE YOU HAVE A MORAL, ETHICAL, AND LEGAL OBLIGATION TO UTILIZE THE RESOURCES AVAILABLE TO YOU, INCLUDING FEDERAL FUNDING, TO ADDRESS THIS NEED ON AN EMERGENT BASIS. WE WILL CONTINUE TO ADVOCATE FOR THIS PATIENT POPULATION AND WILL SEEK ASSISTANCE FOR FUNDING AND LEGAL REPRESENTATION TO ENSURE OUR CHILDREN AND ADULTS WITH AUTISM RECEIVE THE SAME ACCESS

TO MEDICAL CARE AS ALL OTHER PATIENT POPULATIONS. FAILURE TO MAKE THIS A PRIORITY FOR THIS COMMITTEE IS UNACCEPTABLE.