

Written Public Comments

**IACC Full Committee
Meeting**

April 9, 2013

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Cathie

March 19, 2013

Subject: Denial of care issues for autism

This has happened to my child and now more. We know of a case now in Chicago. Why is this happening? Where are our rights and where is our govt.? We have filed complaints and not much seems to have happened. Where is your place in this big issue?

Thank you,
Cathie

Marian Dar

March 19, 2013

Subject: REMARKS: Upcoming IACC Conference Call - March 19, 2013

Some remarks following today's conference call, the discussion of "medical co-morbidities" (gastrointestinal (GI), immune, metabolic...) and upcoming panel:

- Recent New York (NY) medical conference cited studies that found that individuals with food
- "Sensitivities" as well as those with clear immune diagnosis had gut permeability issues;
- Dairy and sugar, in addition to wheat, are big offenders; getting nutrient value from food, etc. involves both the upper and lower gastrointestinal (GI); false negatives and incomplete analysis;
- Effective Feb 2013, Boston has an autism/ gastrointestinal (GI) research center.

Marian Dar

María Luján Ferreira

March 21, 2013

Subject: Upcoming IACC Conference Call - March 19, 2013

Unfortunately, with 1 in 50 after the last Centers for Disease Control (CDC) numbers, I do think there is no needed sense of urgency in this IACC to be at the requirements of the historic situation - even from an international perspective: no concern, no real answers, no real interest to go to the root of the situation and neither a bit of true progress.

M.L.Ferreira

Argentina

mom of a child diagnosed with Autism

Marian Dar

March 22, 2013

Subject: REMARKS: Upcoming IACC Conference Call - March 19, 2013

Ok -- but I am wondering if somehow these issues -- "immune, gastrointestinal (GI), metabolic" -- could be woven into the May 26 session "when should I be concerned" The tendency is to focus on the behavioral, and perhaps we need to be more deductive in our analysis.

The presumption is that ALL symptoms are visible.

What about a subclinical, sub-functioning immune or gut (permeability) system?

Marian D

Susan4Autism

March 25, 2013

Subject: Autism Statement

Please take notice of the numbers

Please develop a plan to treat these children in an affordable way.

Aba therapy is the only chance these folks have at independent living, they

María Luján Ferreira

March 28, 2013

Subject: IACC News Update: IACC Recommends Public and Private Health Coverage for Early Behavioral Intervention for Children with ASD

With the catastrophic proportions of the epidemics we around the world are facing this is the only action this committee considers appropriate? I am sorry , but everything that is done is too little, too late....What about the medical biological problems our children have- the only way they can learn whatever is if FIRST these medical biological problems are tested properly, diagnosed correctly and treated appropriately...otherwise is not helpful.. Where the situation is going to be addressed with the needed sense of urgency...?

M. L. Ferreira
Argentina

Linda Fravel

March 28, 2013

Subject: IACC News Update: IACC Recommends Public and Private Health Coverage for Early Behavioral Intervention for Children with ASD

To be candid, it is about time...I petitioned this group repeatedly for this position years ago when our grandson was diagnosed and denied coverage....

Linda Fravel

Patti Carroll

April 3, 2013

Subject: Public comments for April 9th meeting

My name is Patti Carroll, and I am the mother of a severely vaccine-injured child. I cannot attend the IACC meeting on April 9th, but I have some important questions for IACC, and specifically Mr. Guttmacher. Mr. Guttmacher testified before congress on November 29, 2012. When Mr. Guttmacher was sworn in, he vowed to tell the truth, the whole truth, and nothing but the truth. During the hearing, there were several questions asked by the Oversight and Government Reform Committee that Mr. Guttmacher did not answer, but under vow stated he would provide data for after the hearing. Many of those questions are incorporated into my questions for IACC. These are not rhetorical questions. I actually expect the committee to ANSWER them.

Mr. Guttmacher spoke of “remarkable advances” in autism research made by IACC, and all the money you have spent. Since IACC was enacted, however, the autism rate has more than doubled. Since the goal of the Combatting Autism Act (CAA) is to COMBAT autism, the only acceptable advances would be in stopping or slowing the exploding rate of autism.

Question 1: What are these “remarkable advances” Mr. Guttmacher claims have been made?

When chairman Issa asked if we can rule nothing out, Guttmacher blathered about how we can rule “certain things” out for the vast majority of the population. I suspect that he was talking about vaccines, as vaccines appear to be the one subject IACC will not honestly address. As this group undoubtedly knows, the multiple rulings of vaccine-induced autism in the NVICP clearly show that vaccines are the one thing we know cannot be ruled out.

Question 2: What are the “certain things” Mr. Guttmacher was referring to when he claimed that they can be ruled out as causative factors? And if his answer includes vaccines, didn’t Mr. Guttmacher lie under oath?

Mr. Guttmacher stated that IACC invites public comment and holds town halls so all have a voice in the room, but a review of public comments submitted to IACC shows that the public has begged IACC to study VACCINES more than any other possible cause.

Question 3: Will IACC actually give the public “a voice in the room” by doing the one study most requested by the public – a health outcome study comparing individuals who were vaccinated fully on the recommended U.S. schedule to individuals who have never received a single vaccine? And if IACC never intends to support this study, did Mr. Guttmacher again lie under oath?

Representative Kucinich spoke of mercury emissions, and the University of Texas study showing higher autism rates in those living near coal-burning power plants. When Rep. Kucinich asked Mr. Guttmacher if he knew of any other similar studies, Mr. Guttmacher referenced an auto emissions study. When Rep. Kucinich said “I’m speaking of coal-burning power plants”, Mr. Guttmacher replied that he would be happy to look into them and provide them for the record.

Question 4: What other studies related to mercury emissions did Mr. Guttmacher find and submit to the committee? And if IACC is not studying mercury emissions, what other “environmental” factors are being studied – since Mr. Guttmacher claimed in his testimony that both environment and genetics are being looked at?

When Representative Buchanan asked Mr. Guttmacher what the cost of autism is to the U.S., Mr. Guttmacher could not or would not answer at the time.

Question 5: What is the current cost of autism to the U.S., especially now that the prevalence numbers indicate that one out of 50 children has autism?

Representative Burton asked why the FDA took thimerosal out of most vaccines if it wasn't dangerous. Mr. Guttmacher responded that he is not a vaccine expert, but that he would follow up with an answer on that.

Question 6: Why did the FDA take thimerosal out of many vaccines?

Question 7: Does Mr. Guttmacher believe it is absolutely safe in every instance to inject mercury into humans?

These are some pretty simple questions, many for which Mr. Guttmacher should already have provided his belated answers to the congressional committee. It is important that the answers to these questions are also made available on the IACC website, so the autism community will know whether IACC is actually accountable to the public, as you claim to be. It is also extremely important for the public to know whether a member of a federally funded committee perjured himself under oath. Thank you for your anticipated responses.

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

Kathleen Helppi

April 3, 2013

Subject: April 9th 2013 Interagency Autism Coordinating Committee Written Comment for the Record

[PII redacted]

Joseph and Kathleen Helppi

Howell MI

April 3, 2013

We are the parents of [PII redacted], a 5th grade, 11 year old boy. He is the oldest of our 4 children. He is very handsome, has many interests, is humorous, and active. He is also a challenge behaviorally, in social situations, and educationally because he has autism.

My husband spent 5 ½ of [PII redacted] 11 years going to college in the northern most part of Michigan and we now live in lower Michigan hoping to access better services for our son, and also for a better paying job. We have seen firsthand the need for unilateral access to services across a state, from diagnosis, to education, to accessing therapies.

As my son is getting older I am starting to get a glimpse into even more challenges that lie ahead with puberty setting in, and learning more and more about possible comorbid conditions that may go along with autism, like for instance anxiety. Autism affects my son's life each and every day, but also the lives of everyone in my household. Not having the therapists available, or at least without costing us greatly (losing our house, car, 401k, savings, not being able to pay our college loan) we are at a loss on how to help our son in the way that he needs it NOW, and not later, when our whole family is torn apart from the stress of trying to figure it out ourselves. How much more will the bill be later? I ask myself daily.

Autism therapies should be covered in ALL 50 states, and not just state mandated insurances. It is one thing to fund research, but the families that are being impacted by the 1 out of 50 kids being diagnosed with autism need help TODAY! In Michigan on October 15, 2012, legislation changed to cover autism, but only 25% of kids have been able to access the therapies as of today.

Thank you for the chance to provide my comment. Please consider the impact you and your committee could have on so many lives!!

Sincerely,

Joe and Kathleen Helppi

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

Eileen Nicole Simon

April 4, 2013

Subject: Comments for the IACC Meeting - April 9, 2013

I wrote and sent the comments on March 31 (Easter Sunday) in a state of despondency. Since the late 1960s I have been spending hours in the library (before internet) looking up everything I could find on brain damage, language development, and what little there was in the early years on autism. I went back to graduate school, and was a student at the BU School of Medicine when Dr. Insel was. I published my research, and would have continued working in research, except I ran up against terrible resistance against my ideas that anoxia at birth could cause brain damage that might impede language development. I gave it up, hoping that other more established researchers would discover the same seminal papers that I had found in the medical literature.

That the auditory system of the brain is damaged by a 6 to 8 minute lapse in respiration has been in the literature for over 50 years now, and the research on blood flow and metabolism. Only Dr. Allan Mirsky did more research on this subject. I did my postdoctoral year working in his lab at BU.

Would it be possible to contact Dr. Louis Sokoloff, who is still at NIMH (emeritus)? He was a student of [PII redacted]. He and [PII redacted] started the Journal of Cerebral Circulation, and a lot of articles in that journal use blood flow and metabolism in the auditory nuclei the inferior colliculi as reference points in investigations of other areas of the brain.

The purpose for establishing the IACC, with heads of all the big NIH agencies, was to promote scientific investigation of what might be causing the brain damage that leads to autism. I feel this understanding should have been clear decades ago. Why have so many children and their families had to suffer this in increasing numbers during the 1980's, 90's, and 2000+ decades? Dr. Guttmacher's comment at the government reform hearing on Nov 29, about progress being painfully slow was painful to hear.

The scientific members of the IACC should be discussing the scientific evidence submitted by stakeholders who know the field. I applied to be included in the IACC, but as in the case of my postdoctoral research, evidence of obstetric error is probably taboo. That's why actuarial scientists should become involved, especially if insurance companies are ordered to pay for treatments with no evidence of efficacy.

The comments I submitted on Easter Sunday outline my sense of discouragement going back to the Autism Summit in 2003 and before. Too much taxpayer money is going to the IACC with very little to show for it.

I'm sure you hear from other disillusioned people.

Sincerely,
Eileen Nicole Simon
[PII redacted]
Lexington MA