Oral & Written Public Comments

IACC Town Hall Meeting

May 3, 2008

List of Oral & Written Public Comments

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

Christina Bogert

May 3, 2008

Thank you for this opportunity to share with you today.

There are two fundamental issues to be addressed with autism:

1. How do we avoid new cases?
2. How do we help those who have it?

I have some comments concerning both of these questions. First, how do we help those with autism?

1. The condition which behaviorally defined by the term autism is clearly physiologically heterogeneous! Research study constructs which are not based on reality will be fruitful. Statistical interpretation of data needs to be based upon this heterogeneous reality.

2. These individuals are damaged in many places. They are each damaged in varying degrees and vary combinations of places, with many commonalities. Some of the Defeat Autism Now! (DAN) clinicians have been grouping the damage into 5 areas-oxidative stress, methylation & transulfation damage, immunologic, toxicity, and other metabolic damage (good presentation at http://www.icdc.org/Presentations/Biomarkers_HongKong.pdf). These mechanisms are complex and interdependent. Different individuals have different predominant problems. Study constructs must take this into consideration. In almost all cases, addressing just one specific damaged capacity in one of these areas of functionality will not be enough to turn this broken "System-of-System" (SOS) towards long term healing. Most of these individuals must have simultaneous treatment of most or all of the above mentioned broken areas in order to allow their bodies to enter a sustained state of healing. Based on this, the classic allopathic research study construct of a single variant approach, double blinded, placebo controlled will fail to create meaningful outcomes. It is a construct that is not appropriate for the SoS multivariate problem at hand! Research Study constructs must be based upon the concepts of functionalities and interdependencies of the different functionalities.

3. In support of what I have previously described I would like to strongly encourage you to select a certain number of these individuals (hopefully at least multiple dozens) and measure everything likely to be relevant that you can think of in each individual and build a physiology story for each individual. So far science's approach has been very 'stove-piped', actually thought it is more like looking at little pieces of this complex physiology through very narrow pixie straws. It makes me think of the 5 blindfold men each experiencing a different part of the elephant. I suggest we need to step back, with all the data on the table, look at everything we can know about for each individual and we will then be able to describe the 'elephant' that one individual is, and that another is actually a camel, and another is a leopard, and so on…Autism research needs to get back to what medicine used to do a much better job of thoroughly study the individual patient in front of you!

4. With all of the different dysfunctions that have been published, and based upon my experiences with my own son and talking with many other parents and autism biomedical doctors, there is one important observation that I don't believe has been appropriately appreciated. In most of these kids, their neurological capabilities are not static! They definitely have days and weeks of better functioning and days and weeks of worse functioning-this points to a mechanism with flux.

5. Of the various areas of physiologic dysfunction, my own opinion of which areas are likely to be most fruitful for treatment is the area of immune dysfunctions. These include of course the deregulations, particularly in the T-cells, the inflammation, the inability to fully suppress pathogens and the autoimmunity. At least some parts of these immune problems are closely tied to their gastrointestinal status. With my son, when his stool gets worse, he starts getting a big pregnant belly late in the day. He gets spacier and talks less. When this is getting quite bad his cheeks become fatter and bumpy on the inside surface, and his face changes shape-his eyes look deeper-set and his forehead protrudes more-he looks like Herman Munster. Figure out how to normalize their immune function. This would be closely tied to improving their GI condition and their levels of toxicity.

How do we avoid new cases?

The two most important things to study in the immediate term are:

1. Developmental disorders incidence in children that are not vaccinated

2. Developmental disorders incidence in children that have been vaccinated at an older age.

The autism population looks toxic and like they got screwed up at very key points I development-particularly for the brain and the immune system. By the way, many of these kids had chronic otitis media as babies and lots of oral antibiotics, possibly interfering with immune development. They couldn't get rid of their earaches…but we kept on vaccinating them.

Public confidence in the immunization program will continue to erode until this autism epidemic truly ends. Continued stalling and avoidance of a rigorous investigation of our vaccine program will just contribute to increased loss of confidence in the program and our public health leaders, and of course 1,000's more damaged children.

Specific comments concerning our current vaccine program:

Day of birth vaccination: Science's understanding of how the mature human immune system functions is…far from complete. The understanding of immune development in a newborn is very poor. The understanding of how the Hepatitis (Hep) B vaccination affects the developing immune system has not been addressed. No studies were done when vaccines were moved up to day-of-birth. Hepatitis B is transmitted by sex, IV drug use and blood transfusions. Risk for this disease in babies is extremely low. We have absolutely no business vaccinating on day of birth.

Multiple vaccines given simultaneously. There have been no studies to investigate the effect of multiple vaccine products given simultaneously. This is also an absolutely incredible deficiency from

a safety standpoint. Much higher amounts of adjuvant potentially creating much higher immune dyregualtions.

There are other serious deficiencies in our immunization program. I will not cover any others at this point.

Our public health leaders have failed us in a fundamental capacity to provide an appropriately safe vaccine program. We must fix this! Fixing it sooner is a much better idea than fixing it later.

I appreciate the opportunity to share with you today. If you would like to talk to me further about this, I can be reached as described below.

Thank you,

Christina Bogert
Mom to [PII redacted], 11 yr boy w/autism
San Jose, CA
[PII redacted]

Joseph Herr

May 3, 2008

Subject: Letter to the Editor

Autism–Ear Infections–Glue Ear–Sleep Disorders

Joseph Herr's attachment can be viewed here:
Attachment (PDF – 335 KB)

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

Joseph Herr

May 3, 2008

http://www.nlm.nih.gov/medlineplus/ency/article/000250.htm

The symptoms (Of **ulcerative colitis**) vary in severity and may start gradually or suddenly. **Attacks may be provoked** by many factors, including **respiratory infections** or physical stress.

Respiratory infections include MMR and DpT which just happen to be mandated

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Rigas A, Rigas B, Glassman M, et al. Breast-feeding and. maternal smoking. in the etiology of Crohn's disease and ulcerative colitis in childhood. AnnEpidemiol. 1993 Jul;3(4):387-92

"Breast...feeding was negatively associated with Crohn's disease (P approximately 0.04) and ulcerative colitis (P app.roxiJ11ately 0.07), with relative risk point estimates around 0.5 and **with evidence of duration - dependent trends in both instances."**

"Breast feeding's negative association with Crohn's and colitis" translates to "Bottle feeding promotes colitis and Crohn's disease. Don't bottle feed your babies."

About one fifth of autistic children have high levels of **uric acid**. **Gout** is for older overweight men and women after menopause. High levels of uric acid in children **does not compute!** Something has changed.

Obstructive sleep apnea is for older overweight men and women after menopause. Autistic children have sleep problems. Again it **does not compute.**

Palmer B. Breastfeeding: Reducing the risk for obstructive sleep apnea. Breastfeeding Abstracts, 1999 February; 18(3):19-20. (On Internet) http://www.brianpalmerdds.com/bfing_reduces.htm

Bottle feeding predisposes the infant to- obstructive sleep apnea.

Joseph H. Herr
[PII redacted]

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

Joseph Herr

May 3, 2008

Obstructive Sleep Apnea (OSA) and Birth Autism by Joseph R. Herr

[PII redacted]

Some autistic children develop normally only to regress following some event while other autistic children seem to have autism at birth. Researchers studying autism in twins suggests that an environmental factor underlying autism could be brain injury caused by 6 minutes or more of perinatal apnea or delayed birth of 20 minutes.[1] This suggests that lack of oxygen is involved. Reduced levels of oxygen is a characteristic of obstructive sleep apnea. The working hypothesis of this paper is obstructive sleep apnea underlies birth autism.

Obstructive sleep apnea background

An apnea can develop if the pressure difference between the tip of the nose and the interior of the lung is insufficient to overcome airway resistance and the tendency of the airway to collapse. One factor in the pressure difference is the excursion of the diaphragm. The pressure difference is related to the excursion of the diaphragm. The diaphragm, while its excursion would normally be directly related to the magnitude of respiratory drive, may have its excursion limited by the bulk of the fetus, primarily in the last trimester of pregnancy.

Autism at Birth

Autism evident at birth seems to occur in at least four circumstances: 1) Apnea for 6 minutes at birth, [1] 2) Hypoxia due to gestational apnea, 3) “in utero rubella” causes autism and 4) Fetal alcohol syndrome.

Actually circumstances 2 through 4 above are variations on the cause of gestational apnea with transient fetal hypoxia having an adverse effect on the fetus.[3] Circumstance # 1A paper on autism in twins suggests that an environmental factor underlying autism could be brain injury caused by 6 minutes or more of perinatal apnea or delayed birth of 20 minutes.1 Circumstance # 2 During pregnancy OSA may be initiated in the mother or become exacerbated.4-6 The symptoms associated with OSA increase during pregnancy.[4] Transient fetal hypoxia may have an adverse effect on the fetus.3

During the third trimester of pregnancy, the bulk of the fetus may reduce the effective respiratory drive by limiting the diaphragm’s excursion sufficiently to initiate OSA. If the mother‘s airway has been compromised by bottle feeding the likelihood of the mother developing OSA is increased.

Circumstance # 3 It is postulated that the etiology of autism secondary to ‘in utero rubella’ is: 1) The mother may have a compromised respiratory system, 2) Nasal congestion develops as the result of rubella, 3) The nasal congestion causes OSA7 and 4) OSA induced hypoxia injures the fetal brain.

The immediately above describes OSA caused by rubella. Others have described autism as the result of congenital cytomegalovirus.[8] It is postulated that cytomegalovirus (CMV) induces OSA by the same etiology as rubella and the reduced levels of oxygen again results in fetal brain damage.

4. Fetal alcohol syndrome is caused by a pregnant woman consuming alcoholic beverages. In this case the muscles necessary to avoid apneas relax under the influence of alcohol. The resulting apneas reduce the oxygen available to the fetus resulting brain damage.
Discussion: The common factor in birth autism is the reduced levels of oxygen. Only the circumstances leading to low oxygen levels vary.

References

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3. Pien GW, Fife D, Pack AI, Nkwuo JE, Schwab RJ. Changes in symptoms of sleep-disordered breathing during pregnancy. Sleep. 2005 Oct 1;28(10):1299-305. [abstract]

4. Kowall J, Clark G, Nino-Murcia G, Powell N. Precipitation of obstructive sleep apnea during pregnancy. Obstet Gynecol. 1989 Sep;74(3 Pt 2):453-5.

5. Roush SF, Bell L. Obstructive sleep apnea in pregnancy. J Am Board Fam Pract. 2004 Jul-Aug;17(4):292-4.

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8. Yamashita Y, Fujimoto C, Nakajima E, Isagai T, Matsuishi T. Possible association between congenital cytomegalovirus infection and autistic disorder. J Autism Dev Disord. 2003 Aug;33(4):455-9. [abstract]

Joseph R. Herr

[PII redacted]

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Keri and Robert Horan

May 3, 2008

WHAT ARE THE VARIOUS SUBSETS OF AUTISM SPECTRUM DISORDER? Where is the mention on this list of the need to identify the AUTISMS (plural).

Some audience members spoke eloquently about this issue. It must be a research based exploration and will undoubtedly help guide treatment protocols. Without identifying the various kinds of autisms, no one can accurately determine what specific treatments might be of benefit to the child. If all cancer patients were treated with the same modality, a great portion of cancer patients would accrue no benefit because their type of cancer was not a type that was specifically identified, and therefore a treatment could be overlooked.

We need to look at NOT whether a treatment works or not, but AT WHY CERTAIN TREATMENTS WORK FOR SOME INDIVIDUALS IN WHOM THEY WORK, AND WHY THEY DON'T SEEM TO WORK/HELP IN OTHER INDIVIDUALS... I didn't see that listed anywhere.

Not enough emphasis on vaccine connection. So many parents talked about that...there are only two items listed here? There was talk of the effect of multiple vaccinations being administered to babies and toddlers. The synergistic effect of the various viruses.

Not enough emphasis on environmental impact....at all. That was a huge concern.

Best practices?? The one woman with the black hat had a great point - what were best practices 20 years ago (Lovaas and corporal punishment) only ended up damaging her son....we need to be careful about what we call best practices and why.

Early intervention: what exactly does that look like and how is a particular treatment chosen for a particular child and/or subset?

Why list "Train Defeat Autism Now! (DAN) physicians in research design?" What is that? Many DAN docs (Wakefied, Bradstreet, James, etc.) already have published peer reviewed research articles. Seems like an insult, a waste of dollars, etc. The only person I recall mentioning something to this effect was [PII redacted], the guy who seemed to insult most people in the room that day, including panel members.

Thank you.

Robert Krakow

May 3, 2008

Dear Members of the Interagency Autism Coordinating Committee

A-CHAMP respectfully submits this response to your "Request for Information" referenced above. A-CHAMP is comprised of thousands of "ASD stakeholders", i.e., parents who every day confront the challenges of caring for a child with a vaccine injury that presents itself with symptoms often identified as "autism" or "autism-like." We are parent-advocates whose only concern is the welfare of our children. Our constituency includes parents from every walk of life. We have repeatedly submitted to governmental authorities our view that research must focus on vaccines and environmental factors; treatment must focus on physiological factors that cause ASD symptoms; diagnosis must go beyond labeling to identify the host of biomedical diagnoses that comprise the syndrome we call autism; and, that underlying all this are biological pathways that are primarily non-genetic in origin, although genetic susceptibility must be understood to allow us to effectively bring our children back to health.

Put succinctly, the foregoing is our view of the health issued afflicting our children. We offer our specific suggestions to "advance research" with a high degree of skepticism born from extreme frustration with the public health response to the autism epidemic. Over many years we have repeatedly made our suggestions known, both as an organization and as individuals, only to be visited with one bureaucratic effort after another, such as "autism summits", "roadmaps", conferences, councils, roundtables and the like, that yield little help. We welcome your effort to reach out to the stakeholders – while skeptical, we issue a challenge that we expect results. You must demonstrate that your only responsibility is to the only "stakeholders" who truly matter in this effort: the very sick children who are suffering every day, and their families. They need results NOW!

We offer A-CHAMP's specific statement of the "high priority questions and issues for advancing research on ASD". Our suggestions are not abstract or hypothetical; they are rooted in specific findings clinical testing. We have not sorted our request based on you 5 categories, as there are multiple areas of overlap; e.g., the "biology of autism" implicates "treatment" options, "risk factors" and methods of "diagnosis". We have limited our submission to two pages, pursuant to the RFI, although we can elaborate on any specific suggestion, and offer additional areas of inquiry.

Suggestions for Areas of Research on Autism

With respect to research, we recommend the inclusion of the following areas into a research agenda on autism spectrum disorders:

1. Research recognizing that autism is a "treatable" or "reversible" condition. Specifically, a research focus must regard autism as a chronic impairment, resulting from oxidative stress. For example, there exists evidence showing that autism is characterized by the presence of "sick" neurons rather than "dead" ones or even impaired development processes (e.g., gamma-aminobutyric acid (GABAergic) neuron migration). This type of research highlights the inherent reversibility of the disorder and must be pursued with urgency in order to develop and validate treatment of the disorder.

2. Research evaluating the mitochondrial status of children diagnosed with autism. For example, in multiple sclerosis mitochondrial impairment has been shown to play a strong role – research suggests a similar role in autism;

3. Research investigating the capability of exposure to xenobiotics, including thimerosal in vaccines, endotoxins in vaccines, antigens in vaccines, among others, to induce deficits in cellular energy metabolism or cause conditions that are similar to what have been termed deficiencies in mitochondrial function, resulting in symptoms that have features of autism spectrum disorder.

4. Research of large cohorts of children to determine their status based on testing for urinary porphyrins, urinary toxic metals, urinary amino acids, organic acid test, immune panels, cytokine testing, chemokine testing, etc.

5. Research of the use in treatment of autism of anti-inflammatory medications such as Actos, Celebrex or Singulaire in quelling inflammation in the gut and brain and in reducing level or pro-inflammatory cytokines and chemokines;

6. Genetic research should be focused on single nucleotide polymorphisms and their relationship to metabolic and other mechanisms that create vulnerability to environmental toxins (including vaccines) rather than the latest genetic research focusing on genetic anomalies or copy number variants (CNVs) that have not been tied to a biological mechanism affecting more than a tiny number or children;

7. Thorough investigation of the role of heavy metals, including mercury, aluminum, lead and arsenic, from any source, in any form (including thimerosal), specifically including vaccine exposures in the etiology of autism;

8. Complete access to the Vaccine Safety Datalink data by independent researchers outside the government;

9. Recognition in developing a research agenda that vaccine sourced exposures may be a contributing factor in many cases of autism alone or in conjunction with other environmental exposures;

10. Funding of research of the biological mechanisms that may contribute to autism;

11. Thorough investigation of the role of viruses, bacteria and other infectious agents independently or in conjunction with other environmental exposures in the etiology of autism;

12. Research investigating environmental factors, including the mumps measles and rubella (MMR) vaccine, as they relate to gastrointestinal symptoms and histopathological findings and treatment of underlying bowel problems;

13. Investigation of the effects of various metals, viruses, toxins with each other and other environmental agents – also know as synergistic toxicity – in the etiology of autism;

14. Research investigating the role urinary porphyrin profile analysis can play in measuring heavy metal toxicity – and the relationship of such measures to the existence of “autistic” symptoms in children.

15. Research of the role of mercury and other toxicants in ambient air pollution, including toxicants emitted from coal burning power plants, in the etiology of autism;

16. A thorough analysis of the role of thimerosal, heavy metals, and other toxins play as mutagens and how this mutagenicity may play a role in autism;

17. Research examining the role of the hypothalamus – pituitary-adrenal axis in the etiology and treatment of autism.

Respectfully Submitted,
Robert J. Krahow
President, A-CHAMP
(on behalf of thousands of parent-advocates)

Isabella Tan

May 3, 2008

My son as diagnosised with Autism at 2.5 years old, and my life was devastated by this. As you may have heard from other sources that it took 5 times of efforts, stress and money to raise such kind in today's society.

The government is spending billions of dollars in war and cut the little money they give to children especially those in bad need. And insurance company is denying any expense for autistic children by claiming they are not curable. And we know that thy can be recovered, we have seen many of them and my son is 60% recovered by homeopathy! Please spend your project on the proved success, and we are all waiting for your involvement as the nation's top government health organization.

It is so sad to see so many parents and children suffering for so long with no helping hand.

Thanks for your prompt attention,

Isabella Tan

Carolyn Weissberg

May 3, 2008

Replicate Dr. Jill James glutathione study. Glutathione processes heavy metals.

Tylenol depletes glutathione because of a shift from aspirin, we were told to give Tylenol before vaccines. We were told to mix Tylenol and ibuprofen when fevers happened.

Also we need standards in diet etc. Families break up over controversies on treatment. In shared custody they don't treat or feed consistently. Also our son turned out to have severe sleep apnea. He slept normally until the mumps measles and rubella (MMR) [vaccine]. Stop criminalizing parents for speaking our truths.

Anonymous

May 3, 2008

Bransfield RC, Wulfman JS, Harvey WT, Usman AI. The association between tick-borne infections, Lyme borreliosis and autism spectrum disorders. *Med Hypotheses.* 2008;70(5):967-74. [PMID: 17980971]

Anonymous

May 3, 2008

Subject: Sulfation Issues

My daughter has high urinary sulfate issues, low plasma sulfate, how do we correct this?

- Balancing GABA/Glutamate levels
- Reducing high ammonic levels

Anonymous

May 3, 2008

Please see attachment for submitted comments

The attachment can be viewed here:
Attachment (PDF – 224 KB)