Oral Public Comments

IACC Full Committee Meeting

May 12, 2008

List of Oral Public Comments

Dr. Vicky Debold

May 12, 2008

Subject: Interagency Autism Coordinating Committee's Strategic Plan for Autism Spectrum Disorders Research Policy Recommendations

Good Afternoon. My name is Dr. Vicky Debold and I represent SafeMinds, a private charitable nonprofit organization founded to investigate and raise awareness of the risks to infants and children of exposure to mercury from the environment and medical products, including thimerosal in vaccines. Additionally, SafeMinds supports research on the potential harmful effects of mercury and thimerosal.

We appreciate the opportunity to provide recommendations for the Interagency Autism Coordinating Committee's (IACC) strategic plan for autism spectrum disorders research. To that end, eight recommendations are offered. Specifically, SafeMinds recommends that the IACC do the following: 1) acknowledge autism as a national emergency and epidemic; 2) allocate sufficient resources to fund autism research; 3) shift the research focus from genetics to the environment; 4) develop a leveraged research agenda; 5) regard autism as a dynamic disease process that is amenable to treatment; 6) reclassify autism as a multi-organ disease; 7) establish an NIH-driven research agenda that is not driven by researchers; and 8) create a formal mechanism for ongoing public-private research agenda.

1. Acknowledge Autism As A National Emergency and Epidemic.

In reviewing the overall autism research portfolio at the National Institutes of Health (NIH), we sense a lack of urgency in addressing the growing epidemic of autism in our country. The Centers for Disease Control and Prevention (CDC) has reported that the prevalence of autism spectrum disorders has risen to alarming levels, affecting at least 1 out of every 150 children in the United States. Such profound numbers demand immediate attention and action from all of our Federal agencies. Therefore, we request that the NIH respond to autism as a **national emergency** and appropriately allocate the critical resources necessary to respond to this pervasive epidemic before it affects and even greater proportion of the nation's children.

Specific recognition of autism as an **epidemic** is needed to both highlight the preventable environmental cause and the urgency of needed governmental action. This is a political necessity both inside and outside the community to stimulate a more rapid and stronger response that is appropriately and sufficiently funded. To that end, we recommend that NIH immediately direct resources and launch calls for proposals for environmental studies that will find answers to specific urgent questions.

2. Allocate Sufficient Resources To Fund Autism Research.

The IACC strategic plan must make a case that sufficient funds need to be spent on autism research, whether derived from Congress or as part of the overall NIH funding allocation. A sufficient funding level is justified due to rapidly increasing direct and indirect autism costs incurred by families, schools, insurers and other payers. In response to the statement that the community has heard in the past --- there will be "no new money" spent on autism research --- is an unacceptable answer to the urgent and unmet needs and true national health crisis.

Would we say this if 1 out of every150 children were injured, kidnapped or otherwise harmed?

3. Shift The Research Focus From Genetics To The Environment.

Acknowledging the epidemic demands that the research focus shift. Specifically, the focus of autism research must be shifted away from an exclusively genetic model to one that investigates the role of environmental factors combined with a genetic vulnerability as a potential culprit behind this otherwise unexplained epidemic. The role of the environment was recognized by the expert panel in the report as an understudied area that was given insufficient attention in the first iteration of the NIH autism research matrix. The absence of a well-developed environmental research agenda impedes the discovery of etiologic factors responsible for the development of autism. It also impedes identification of effective treatment strategies. SafeMinds respectfully requests that a research plan specific to the environment be created and incorporated into the overall IACC autism research agenda.

To that end, the IACC's strategic research plan must include a special emphasis on vaccines and their components as a possible cause of autism. This topic is the only specific research priority mentioned in the Combating Autism Act (CAA) legislative history. Otherwise, the CAA spoke only of cause, prevention, and treatment in general. To meet this requirement, the research plan should include specific extramural funding for a rigorous and prospectively conducted and randomized trial that will establish differences in health outcomes, including autism spectrum disorders, among vaccinated and unvaccinated children.

4. Develop A Leveraged Research Agenda.

The NIH should develop a leveraged research agenda focused on identifying etiologic factors driving the epidemic of autism to prevent its occurrence and to devise effective treatments for those already afflicted with this devastating disorder. The guiding principal should be to pursue research and treatments that will beneficially affect the greatest number of lives and families as quickly as possible and follow clues provided by evidence-based treatments. Such an agenda would be best served by a translational research protocol where clinicians who care for children with autism determine which areas of research are linked to the most promising areas of intervention.

It should be understood that research on cause and prevention does not disrespect autistic persons or cultures any more than does research to eliminate the causes of deafness or blindness interfere with the dignity and worth of these individuals and cultures. Congress identified the strategic plan goals for research and stipulated that they be directed at cause, prevention, and treatment. Those who seek answers related to treatment and prevention are not the enemy of those who are autistic.

5. Regard Autism As A Dynamic Disease Process That Is Amenable To Treatment.

Currently, funded research perpetuates a belief system that autism is fixed pre-natally and immutable post-natally, rather than as a condition that arises from preventable pre- or post-natal exposures and is amenable to treatment after birth. Continuing to support this belief impedes research initiatives to identifying effective treatments. SafeMinds is also concerned that current treatment strategies are targeted at ameliorating symptoms rather than

understanding the underlying biology and pathologies responsible for symptom manifestations. Such an approach does little to reduce the morbidity associated with autism. The latest research points to a genetic susceptibility that is environmentally triggered. As a result, the perception that autism is lifelong and incurable should be abandoned to follow the line of reasoning that autism is indeed preventable and thus, treatable. Hopeless becomes hopeful. A cure is possible in those suffering now and steps can be taken to make sure no others will become ill.

6. Reclassify Autism As A Multi-Organ Disease.

Recent clinical investigations have identified numerous co-morbid disease states in children with autism. These include abnormal gastrointestinal function and inflammatory bowel disease, evidence of increased oxidative stress, severely disordered serum chemistries, methylation disturbances, increased body burdens of metals and microglial activation in the brain. Studies must be initiated as soon as possible to increase the focus on the identification of co-morbid disease states, since many biomedical imbalances are amenable to medical and nutritional interventions as reported by clinicians treating autism. Additional investigations into these associated disease states also offers the promise of the identification of biomarkers and more effective clinical interventions targeted on identified abnormalities.

7. Establish An NIH-Driven Research Agenda That Is Not Driven By Researchers.

An area that is not addressed in the report that we feel is critical to advancing the science related to autism spectrum disorders at NIH is the way the research matrix is developed and studies are implemented. It is our understanding from discussions with staff at NIH, that the current research agenda is currently being driven by investigators, i.e. the NIH funds a research proposal and then retrofits the project into the matrix. This is best evidenced by the fact that investigations into the characterization and screening for autism are flush with research, whereas areas of research into identifying specific treatments for those suffering with autism is severely lacking. The research goals and activities outlined in the autism research matrix would be more likely to be implemented if NIH research goals and activities were used to set funding priorities and score proposals. Specifically,
NIH should:

a) include NIH goals as items to be scored when reviewing grant proposals;
b) announce NIH goals as program project grants; and
c) require Autism Centers of Excellence to address NIH goals as part of their center designation and to consider such project proposals when scoring center proposals.

Additionally, the strategic planning process must embrace a re-engineered funding process to ensure that the best and most focused science is performed and accountability is increased. To ensure that this mechanism is strengthened, the strategic planning process and evaluation should be formally turned over to the Autism Advisory Board, which has specific recognition in legislative history.

8. Create A Formal Mechanism For Ongoing Public-Private Research Agenda.

Throughout the draft matrix, reference is made to a public/private partnership regarding autism research activities. The overall research budgets for private autism research funders are

equivalent to or surpass that of our federal agencies. To enhance the potential for improving knowledge, prevent undue repetition in research activities and fill in research gaps, a formal mechanism needs to be established to coordinate and benefit from collaborative public/private efforts. Formal collaboration can be achieved with conference calls, email or in-person meetings. This mutually beneficial approach to the latest research and ideas will provide a synergistic effect and channel scarce research funds into the most critical areas. Establishing strategic and specific research agendas as well as funding decisions must have direct consumer input on both science and relevance, similar to the process used by the Department of Defense to carry out the Congressionally Directed Medical Research Program on Autism.

Thank you for the opportunity to provide a statement and recommendations.

Paula Durbin-Westby

May 12, 2008

My name is Paula Durbin-Westby. I am an autistic citizen and taxpayer.

I spoke at the March 14 meeting about the need for research models that include autistic people at every level of the project.

Funding should be allocated to research that will have practical applications for autistic people and our families.

As I mentioned last time, community-based participatory research is a promising avenue for exploration. With community-based research, members of the community being studied are full participants at every stage of the research process.

Since I last spoke to you, I have learned of a promising new project that exemplifies how the academic and autistic communities can partner together to conduct research to improve the lives of autistics.

AASPIRE is the Academic Autistic Spectrum Partnership in Research and Education. The partnership adheres to the principles of community-based participatory research.

The mission of AASPIRE is:

To encourage the inclusion of autistic people in matters that directly affect them. To include autistic people as equal partners in research about autism. To answer research questions that are considered relevant by the autistic community. To use research findings to effect positive change for people on the autism spectrum.

AASPIRE team members come from three interrelated communities:

The autistic adult community
The academic community, and
The support and service community

The autistic community partner is The Autistic Self Advocacy Network. Academic partners include health services, disability, and autism researchers from multiple institutions. Team members from all three communities work as equal partners to design, implement, and disseminate the research. The inclusion of autistic individuals in all phases of the project ensures that the research is relevant to the autistic community, that the methods are feasible and respect the rights of autistic adults, that the questions are clear, that the conclusions are valid, and that the findings will be used directly to benefit the autistic community.

A strong literature exists documenting health care disparities for people with developmental and intellectual disabilities including increased mortality, increased morbidity, and lower quality of life. AASPIRE is currently undertaking an initial pilot project to address these disparities.

The first pilot project will examine the experiences and recommendations of autistic adults as consumers of health care, and the experiences and recommendations of primary care clinicians as providers of health care services to autistic adults. The project will use a variety of methods to obtain and analyze data, including surveys, semi-structured open-ended interviews, and data-mining of information shared through public online communities.

The purpose is to obtain pilot data for an NIH proposal, to develop and evaluate practical tools that can improve patient-provider communication and make health care more accessible to health care consumers on the autism spectrum.

Using AASPIRE as an example, I urge high-priority funding for studies utilizing community-based participatory research. Results are based in the real-life experiences of people on the autism spectrum and will have practical application.

Mike Frandsen

May 12, 2008

I'm Mike Frandsen from www.coachmike.net. I tutor kids and adults with autism.

I believe that the NIMH discriminates against people with disabilities in its hiring process.

NIH and NIMH are doing some good work in autism research, but there has been some discussion that NIH should do more research on ***services*** and coordination of research with services for people with autism. I believe that they should.

One example of how this disconnect between research and real world services can be **partly** bridged – rather than having completely separate silos for each area – is greater federal employment for people with disabilities.

I believe that one area that is deeply ingrained in the NIH culture that needs to be changed is the insistence that NIH is **solely** a research organization whose responsibilities **completely end** at conducting research. This shows a reckless disregard for doing research on the services that are desperately needed today to improve the lives of people with autism and **other** disabilities. This attitude is at best short sighted, and at worst, a mind-set perpetuated by academics who sit in ivory towers rather than work in the trenches and help people with autism and other disabilities.

During each of the past 5 years I advocated on behalf of a person with impeccable credentials and great experience, who has a **psychiatric** disability, to get a job interview at NIH, through the Schedule A hiring authority. Schedule A is a federal program used to "appoint persons who are certified that they are at a severe disadvantage in obtaining employment."

This Schedule A program, specifically set aside to help reduce the more than 70% unemployment rate of people with disabilities – these are people who want to work and are more than capable of working - is severely underutilized and virtually ignored by NIH.

While the person who I advocated for **does not** have autism, Freedom of Information Act Requests I sent to NIH have shown, that as of a year ago, not one of NIH's employees hired in the previous five years was hired using the Schedule A authority for people with disabilities. And there is **no evidence** that during that timeframe this **program** was **ever** used at NIH to hire someone with autism.

Information was sent **each** of the past 5 years, **multiple times per year**, to the NIH Director, HR contacts, EEO contacts, the Selective Placement Coordinator, Communications Directors, and the Ombudsman. Even years after NIH was notified of the problem – the lack of Schedule A hires - they refused to do anything. NIH's response has been insensitive, ignorant, and dismissive and I left my job at NIH in protest a year ago.

It is ironic and disappointing that an organization whose mission to "work to improve mental health through biomedical research on mind, brain, and behavior," (the National Institute of Mental Health) does not have an equivalent program to ensure that those disadvantaged with disabilities can fairly contribute to advancing that mission.

I believe that NIH and other agencies should not only **develop** policy on making the hiring process as **inclusive** as possible, but should also be **accountable** to those claims by ensuring that the policies are **effectively implemented** in a way that will mutually benefit the agencies, the public whom they represent, and the employees who conduct work for these agencies.

NIH and other agencies need to do more than just say, "there must be many people who happen to have disabilities among our 17,000 employees." NIH needs to be **proactive** in hiring people. And other Operating Divisions of the Department of Health and Human **Services** need to take a role in outreach and awareness.

In conclusion, given its position as the "steward of medical and behavioral research for the Nation," NIH should be particularly sensitive to attracting and retaining people who are traditionally underrepresented, including those with disabilities, whether they be physical, psychiatric, cognitive, or developmental. Incidentally, the government doesn't even have a category for developmental disabilities in its Schedule A program. A failure to proactively include employees from **all** segments of society in the hiring process threatens to leave these people languishing with difficulties and frustrations.

This is based partly on what I have written on my website, coachmike.net.

Thank you.

Carol Hoernlein

May 12, 2008

I am a former food process engineer who has spent the last 16 years investigating the cause of sensitivity to neurotoxic food additives. Since the February 2007 study implicated areas of the genome which code for glutamate synapses in ASD, I believe we should investigate the effects of both ingested and INJECTED excitatory free amino acids (glutamic acid and aspartic acid) on children with the "autism genes". This position is based on the startling similarities of ASD symptoms and reported symptoms of sensitivity to excitatory amino acids present in the diet.

If ingested and injected excitatory free amino acids affect ASD children adversely, it would explain the positive impact of gluten-free – casein-free diets AND a vaccine link. Vaccines have free glutamic acid added to preserve the virus. I have created a chart showing where free glutamic acid comes from. It is found in extremely high amounts in processed wheat and dairy products – to the extent that food manufacturers use these two items to produce MSG effects with a "clean label".

However, a child may not improve on a GF-CF diet alone, because it doesn't limit all potential sources of free glutamic acid – like soy. Children are tested at birth for PKU and phenylalanine is limited until the brain is hardwired by the age of 7. Why not treat the predisposition for autism similarly and limit the glutamic and aspartic amino acids in the diets of children with autism genes?

ASD includes errors of metabolism for sulfur containing amino acids – like cysteine. Cysteine is converted to taurine and glutathione by the liver. Taurine regulates heartbeat and osmotic balance as well as bile production and was found to be low after a seizure. In ASD, symptoms include arrhythmias, digestive disorders and a high rate of epilepsy – suggesting that taurine production may be compromised. Glutathione levels are also lower in ASD leading one to conclude that possibly, cysteine metabolism may be responsible for the myriad and seemingly unrelated additional symptoms of ASD. It should be noted that glutamate interferes with the handling of cysteine. When cysteine metabolism is compromised, homocysteine levels may increase. The lower levels of glutathione may put ASD individuals at risk of mercury poisoning, since it is how the body eliminates mercury from the body.

Excitatory amino acids activate the amygdala, which in ASD causes gaze avoidance. It should be noted that the NMDA receptors that respond to both glutamate and aspartate are found in the amygdala - part of the limbic system involved in the perception of taste and smell as well as fear. ASD children may over-react to smells and tastes and face to face encounters can overwhelm them with fear. Limiting excitatory amino acids that target the amygdala may help.

Japan consumes more MSG, and fish (a dietary source of mercury) than nearly any other country. Compared to the amount of mercury consumed in fish and the amount of MSG consumed in the diet, the MMR contribution was probably small compared to a typical Japanese diet. In Japan, the MMR vaccine was stopped in 1993. Autism rates in Japan still increased. Perhaps in Japan, the diet plays more of a role in autism than the vaccines. Children from other countries with a lower consumption of fish and MSG may find a stronger correlation between vaccines and autism.

New research studies into ASD should include people who are sensitive to the food additives MSG and aspartame. MSG-sensitive persons have reported a distinct lessening of symptoms by using taurine,

ibuprofen, CoQ10, Vitamins B6 and B12, sugar, foods high in butyric acid – like butter, and Magnesium. Perhaps they share some of the same genes that predispose a child to ASD. New treatment studies should look into these easily available, inexpensive and relatively safe compounds.

Based on what I have observed, here are my recommendations:

1. Treatment of ASD?
REMOVAL of excitatory amino acids (glutamate, aspartate) from VACCINES, glutamate and aspartate restricted diet (similar to treatment for PKU) in addition to GF/CF diet, supplementation of taurine, glutathione, vitamins B6, C, magnesium, CoQ10, increased carbohydrate, labeling of free glutamic and aspartic acid on food labels, glutamate blockers, anti-histamines and leukotriene blockers for children already suffering or getting vaccinated.

We should calm their surroundings, encourage quiet tasks and less-threatening contact to enhance communication. We need to give them space and not overwhelm them.

2. Diagnosis of ASD?
Test for autism genes preferably AT BIRTH like PKU Tests for aspartic acid, glutamic acid, glutathione, taurine, cysteine, homocysteine

3. Risk factors for ASD?
Autism Genes, sensitivity to excitatory amino acids, low taurine, low glutathione, sulfite sensitivity, vaccines with glutamic acid as a preservative, damage to the microglia, overactive immune system, "Junk food" diet, aspartame in medications or vitamins or foods

4. Biology of ASD?
Excess CNS sensitivity, inability to handle sulfur-containing amino acids, overactive immune response – linked to Nerve Growth Factor

5. Other areas of ASD research?
Common genes in Alzheimer's, Parkinsons, ALS, MS, and excitatory amino acid sensitivity.

Study persons without ASD who suffer from overactive CNS or neurodegenerative disease and sensitivity to excitatory amino acids. See if they share same genes. Could Alzhemier's sufferers simply be ADS children whose brains were hard-wired before damage by the environment?

Thank you for this opportunity to share my ideas on this very important topic,

Sincerely,

Carol Hoernlein
Founder, MSGTruth.org

John Erb

May 12, 2008

I am here before you today to give you an update on my mission to end Autism. On November 4th I informed you of the connections I have found between the food and vaccine additive Monosodium Glutamate and Autism. I also told you that I would have MSG removed from the food supply, thereby reducing new cases of Autism.

In January I received a letter from Dr. Van Eschenburg, Commissioner of the FDA, inviting me to Petition the FDA to remove MSG form the food supply. I have since done just that and my petition is now on the Docket at the FDA and open for public comment. I have also done further research into the connection of Autism and MSG and have the following findings:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

In the NIMH press release of February 18th, 2007 the Genome Project was reported to produce the following findings:

"Clues emerged adding to evidence that implicates components of the brain's glutamate neurotransmitter system in autism. Glutamate increases neuronal activity and plays an important role in wiring up the brain during early development. Since autism likely stems from faulty wiring, a genetic blueprint gone awry in this pivotal neurotransmitter system is a prime suspect. Some key genes associated with the glutamate system are located in chromosome regions previously associated with autism, note the researchers.

Previous studies have also linked abnormal glutamate functioning to disorders such as Fragile X syndrome and tuberous sclerosis, which share some symptoms with autism. It's not unusual for individuals with either syndrome to be diagnosed with autism."

What will it take to make the Autism community wake up and take notice? I would like someone on your committee to be bold enough to make a motion that a special task force be created to closely examine the research that I have brought forward, and to take a serious look at the possibility that MSG in food and vaccines is triggering the massive epidemic of Autism.

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

Who on this committee is interested in finding the likely cause of Autism? Who among the members of this fine committee is willing to make the motion to create the MSG task force?

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

Judith Ursitti

May 12, 2008

My name is Judith Ursitti and I reside in Dover, Massachusetts. I am a Certified Public Accountant, but have been inactive in the profession since the birth of my second child, [PII redacted], who was diagnosed with severe autism just after his second birthday.

[PII redacted]'s diagnosis spurred me into action. Prior to moving to Massachusetts last summer, our family lived in Dallas, where I was a founding member of the Dallas Chapter of Cure Autism Now and was extremely active in advocacy and community outreach. Since moving to Massachusetts, I have served as Chapter Advocacy Chair for the Boston Chapter of Autism Speaks and have been appointed to the steering committee of Advocates for Autism of Massachusetts. I sit on the Special Education Parent Advisory Council of Chickering School in Dover, Massachusetts and also served as a member of the Parent Advisory Council for the development of the100 Day Kit that was recently released by Autism Speaks. In 2006, I ran the Chicago Marathon to raise funds for the Organization for Autism Research and just last month, I ran the Boston Marathon to raise funds for Nashoba Learning Group, the wonderful school for children and young adults severely affected by autism that my son [PII redacted] attends. I also write a blog for Parents.com called Autismville.

Admittedly, I sit before you, the token "Autism Mom", a cliché if you will. But I would contend that the fact that I am a cliché lends credence to the notion that autism is affecting our nation in alarming numbers.

Since that indelible day in November of 2005, when the pediatric neurologist scribbled the word "autism" in Sharpie across [PII redacted]'s medical record, I have been motivated to try to make things better for families dealing with the challenges of autism. Sometimes when my husband [PII redacted] is digging through the laundry basket, attempting to locate a matching pair of clean socks, he rolls his eyes at me and mumbles "You know … you can't boil the ocean…." I know in my heart that he is right, but as this committee has already recognized, the needs of the autism community are incredibly immense and diverse.

The Combating Autism Act of 2006 took a huge leap forward in addressing those needs by creating a congressionally mandated roadmap for a federal war against autism. Part of this roadmap, as you already are aware, was the reauthorization of this committee, whose primary charge is to develop a strategic plan for the conduct of autism research. There are numerous crucial issues to be dealt with, but the most fundamental issue of all remains the long unanswered question, just what is autism? What causes it? What can be done to treat it?

This question lies heavily on the hearts of thousands of parents and caregivers to those debilitated by autism. In the year 2007 alone, over **a quarter of a million** of them walked to raise funds for autism research at Autism Speaks' Walk Now events across the country. **2,000** attended the national conference for the Autism Society of America.

1,100 attended the Defeat Autism Now conference in New Jersey. [PII redacted] was interviewed by [PII redacted] and [PII redacted], selling just a few books in the process.

Parents are desperate for information. Since my son's diagnosis not quite three years ago, I have searched for answers myself in any form available. I've scoured the internet; I've attended conference after conference. The results of my efforts have been much like following the yellow brick road. Even the greatest of the wizards don't possess the elusive answers.

I sit before you today as the mother of a son who I love unconditionally. Our family is doing all we can to make sure he knows that and that he receives the best care and support available. But like so many families just like ours, we are worried sick. We realize there is a reason that across the vast spectrum of nature, parents seek to prepare their children for a life of independence. The frightening reality is that [PII redacted] more than likely will spend more time living on this earth *without* our care than with it. It is crucial for his future well-being, that we identify the biology behind his disorder and develop treatments that will lead him to a life of health and happiness.

A life of independence.

I leave you with the words of [PII redacted], a nonverbal teenager profoundly affected by autism who communicates with a keyboard. In a recent interview with ABC News, [PII redacted] states, "Autism is hard because you want to act one way, but you can't always do that. It's sad that sometimes people don't know that sometimes I can't stop myself and they get mad at me. If I could tell people one thing about autism it would be that I don't want to be this way."

My son [PII redacted] is nonverbal, just like [PII redacted]. I think if he could type he would tell you the same thing. The challenges before you are great. But you possess the talent, energy and compassion to see this mission through. As you work on our behalf, please be reminded, you can't boil the ocean. Be wise. Work hard. Focus on one thing at a time. Develop a research plan that will serve as a gateway to finally finding the answers families like mine so desperately need.

Thank you.

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

[Name of minor redacted]

May 12, 2008

Oral public comments presented by [name of minor redacted], May 12, 2008.

The written statement is provided in the accompanying slide presentation that can be viewed here.
(PDF – 546 KB)

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

Theresa Wrangham

May 12, 2008

Good afternoon. I am Theresa Wrangham and the parent of a 17 year old daughter with autism. I want to thank the IACC for the opportunity to voice my concerns and hopes for autism research.

My hopes spring from the fact that my daughter's health and autism symptoms have improved more in the three years since pursuing biomedical interventions than the previous 9 years of speech therapy and social skills intervention. All progress, whether behavioral or biomedical, has been realized well over the age of early intervention, giving every parent hope and science many possibilities to pursue. Our story is one of fighting to reclaim our daughter's health - the same story that many parents consistently tell in the ASA chapter I co-founded, during the five annual state conferences I have coordinated and support groups, of which I am a part, in Colorado.

In 1990 [PII redacted] was a normal baby in every way and met all her developmental milestones up to about age three. We vaccinated on schedule and thus began her exposure to high levels of dangerous toxins such as mercury and aluminum. Her immune system continued to be assaulted while living in the Middle East under blackened skies from Kuwaiti oil field fires and toxins from weekly pesticide fogging of our compound. She is an example vaccine injury and product of her environment. An environment that is globally polluted and effecting children in the United States, as evidenced by the recent University of Texas study published this year on increased autism risk and mercury emissions in proximity to pollution sources.

[PII redacted] went from being a normal and social infant to a toddler with periods of vacant stares and playing by herself when surrounded by children. At 2 ½ [PII redacted]'s language acquisition had plateaued and by 5 ½ she was echolalic. On our return to the United States in 1996 [PII redacted] was diagnosed on the spectrum at over 6 ½ years of age.

Under the care of [PII redacted], a former Chief of Medical Operations for NASA, and [PII redacted], biomedical treatments have yielded success. Medical test results indicated that [PII redacted] suffered from heavy metal toxicity, significant oxidative stress, impaired detoxification, hormonal imbalance, mitochondrial dysfunction, intestinal inflammation and malabsorption.

These impacts to health are not unusual and recent clinical investigations have identified numerous co-morbid disease states in autistic children that also include severely altered serum chemistries, methylation disturbances, and microglial activation in the brain.

What helped [PII redacted]? Inositol, a B vitamin, allows her to sleep through the night. Chelation therapy is removing toxic heavy metals such as mercury, aluminum, arsenic, tin, lead, cadmium, antimony and thallium. Herbal supplements taken for 3 months have fully regulated [PII redacted]'s menstrual cycle and diminished associated pain experienced for 3 years, as well as decreasing her anxiety levels. Intestinal abnormalities have markedly improved with enzyme therapy and probiotics. Most significantly, after 80 hyperbaric oxygen treatments in conjunction with subcutaneous Methyl B12

injections over a period of 4 months, [PII redacted]'s IQ has shot up 10 points, language has increased and her reading level has increased by 3 grade levels.

My concern is that research into biomedical interventions will not be pursued. Societal costs of autism today are $35 billion annually, with parents covering treatments almost exclusively without assistance or insurance coverage. Autism is a public health crisis that requires far more urgency than it is currently receiving. Research must shift from being primarily genetic in focus to a thorough investigation on the role environment and vaccines that continues to be understudied in order to identify the factors driving this epidemic. Policy must change to insure that bias and conflict of interest cease to invade the scientific process and that a balance of views is represented in the research agenda.

Many afflicted individuals cannot communicate their needs and desires and this body must fulfill their mandate to assure that one day they will. This truth must be pursued no matter where the path leads us. The promise of prevention and cure has roots in successful biomedical interventions and my family requests that the agenda include clinicians treating recovering children, scientists focused on environmental triggers and toxicology and family members of those afflicted.

We believe that no stone should be left unturned in finding the truth. Health and prevention must be the priority and research into - and standardization of - biomedical interventions to stem this disorder's growing and disastrous health consequences require your immediate action. [PII redacted] is a prime example of how medical treatments of abnormalities that occur in autism have improved her health, the autism symptoms and have greatly reduced the burden to special education and future adult services. More importantly this progress has given her the ability to express herself and greater self-determination. This success must be extended to all affected individuals.

My family asks that you consider the progress of children like [PII redacted] who are in recovery and those who have recovered. They are the beacon for the many who struggle daily with autism; their progress mile markers in the destination to health, prevention and cure.

Thank you.