

Oral Public Comments

**IACC Full Committee
Meeting**

November 30, 2007

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Erin Lopes Bak

November 30, 2007

My Name is Erin Lopes and I am a mother of an 8 year old boy with an autism spectrum and an epilepsy diagnosis. I am a board member Pervasive Developmental Disorder (PDD)/Autism Spectrum Support Group near my home in Delaware County, Pennsylvania, a parent advisor on the Philadelphia Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) team and a Community Advisor for the Early Autism Risk Longitudinal Investigation (EARLI) Network with Drexel University. None of these titles were intended.

To the members of the Committee from the National Institutes of Health

In June, 2006 I attended the International Meeting for Autism Research (IMFAR) in Montreal. Dr. Insel was the keynote speaker at that conference. During his keynote address, Dr. Insel stated several research objectives for autism that included characterizing the various autism phenotypes, recruiting researchers from a wide range of fields to study autism and finally to make research work to alleviate the burden of disease. Although I left that conference feeling hopeful, two years later I still see the need for the research community to make progress in understanding autism.

As a parent leader in our local autism support group I speak with parents, mostly mothers, of children with autism on a daily basis. From parents of newly diagnosed children to veteran parents who have been struggling with the issues related to raising a kid on the spectrum for many years. My experience working with these families leads me to say the following – when it comes to treatment of children of autism there are too many cooks in the kitchen and no shortage of charlatans. It's outrageous to me that years after recognizing the increase in prevalence the medical community has yet to issue a set of standards for the treatment of autism. There are still too many mothers with a new diagnosis coming into our support group saying "I don't know what to do. Where do I go for services? How do I get help for my child?"

I came here to emphasize, as someone living on the front lines of autism, the importance of the previously stated research objectives. Many families I know are struggling to treat, what is clearly a neurological disorder, solely with behavior based interventions, not knowing what else may be available to them. We need to distinguish between the different phenotypes in autism and develop appropriate medical treatments that can reach families from all backgrounds. I speak from experience that families need options for treatment – treatments that are effective and can be covered by insurance.

One autism phenotype seems to have been defined – 25 to 40 percent of children with autism have seizures. My son is one of those children. Kids with autism, particularly, those who have shown regression should be screened with an electroencephalogram (EEG) and seizures should be treated.

To the members of the Committee from the Department of Education

Treatment of autism extends into the school setting. Education itself becomes a treatment.

Children with autism are entitled to free appropriate public education (FAPE). Although, I believe in FAPE, it is clear that for school districts to adequately meet the educational needs of the growing number of children on the spectrum they're going to need more state and federal dollars. I've worked extensively with my local school district. Throughout my home state school districts are strained by special education budgets with no relief in sight.

In many cases the regular education classroom simply cannot meet the educational needs of a child on the spectrum. A parent in this situation understandably (and often reluctantly) opts for a private placement, with the school district footing the bill. Four children in private placements can cost a school district up to \$200,000. I may be in that situation someday. If you ask my son, he wants to go to his neighborhood school. He wants to be ordinary.

Thus, I see the need to increase funding for public schools to meet special education costs. Encourage school districts to use funds to build state of the art in-house programs to educate children with autism. Encourage states to follow New Jersey's example and establish grant programs for constructing new classrooms and for the purchase of materials for new classrooms designed to meet the educational needs of children on the spectrum.

In Conclusion

The news media is quick to cover high profile people who claim to have championed autism and unlocked their children from the disorder. Those situations, if real, are rare. There many more of us who can claim no triumph over autism and continue to struggle everyday with it – we need help. I ask that you please consider my statements. I thank you very much for your time and for this opportunity to speak.

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

Kristina Chew

November 30, 2007

My name is Kristina Chew and I am an Assistant Professor of Classics at Saint Peter's College in Jersey City, New Jersey. I am the mother of [PII redacted], who is 10 1/2 years old and who has autism. I write a weblog about autism, Autism Vox, that attracts some 4,000 visitors a day from around the world, from autistic adults and parents of autistic children, to doctors and teachers and journalists, and many more members of the public.

According to some autism organizations, parent advocates, and the media, it is most important to find the causes of autism and to find treatments for autism. But finding out whether or not there is something in vaccines or in the environment that is causing autism is only one among many concerns in the autism community. Families with autistic children and autistic persons have other issues than what we hear about on [PII redacted] and [PII redacted] and from [PII redacted]. Families also want to know about education, about schools, about daycare and after school care for autistic children. They want to know how integrate autistic children not only into classrooms, but into all aspects of every day life in a community. They want to teach their children to be as independent as possible so that their children can learn how to get jobs, take care of themselves, and lead fulfilling lives.

We need research to find out what are the best educational methods to teach autistic children to communicate, to interact with others, and simply to learn. We need to figure out what are the best types of school environments that autistic children can learn in and how best to train teachers and therapists, and also how to maintain autism programs over time. I know that it is possible to create a high-quality education for autistic children in the public schools; my son attends a public school program that some autism experts say is as good as the best autism schools in the country. Further, we need research to find out how to prepare autistic children to get and keep jobs and to live as independently as possible, and how to best integrate autistic persons into our communities. Films such as *Autism is a World* (<http://www.cnn.com/CNN/Programs/presents/index.autism.world.html>, IACC Note: URL is not valid.) and *The Key of G* (<http://www.lateralfilms.com/keyofg/>) show how autistic adults, even with severe disabilities, can live as full-fledged members of a community. Books such as *Unstrange Minds: Remapping the World of Autism* by Roy Richard Grinker and *Reasonable People: A Memoir of Autism and Adoption* by Ralph Savarese also provide perspectives about autism than you will hear in the mass media.

Autistic adults tell me that they want to have their voices heard and their experiences about life with autism understood. Other perspectives about autism can be found in the words of autistic adults like Ari Ne'eman, the President of the Autistic Self-Advocacy Network (<http://www.autisticadvocacy.org/>) and a college student studying politics and economics, and like [PII redacted], who can be heard speaking at a conference autism and advocacy at Fordham University in October of 2006, at <http://www.fordham.edu/cs/media/autism.shtml> (IACC Note: URL is not valid.). Rather than focusing so much on preventing and curing autism, we need to turn our attention on how to make the world better for autistic persons, through education, jobs, and understanding, by listening to the full range of voices and perspectives on life with autism.

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Nancy McPartlin-Gardella

November 30, 2007

As a hospital administrator, former county health department spokeswoman, and the parent of a child who is recovering from autism, I am not here to debate the cause of autism. This is not about who is right. This is about what the right is and how we need to move forward and begin creating solutions to help these children.

My suggestions are:

1. We need to understand that to medically treat a child with autism is almost the antitheses of the managed care health model. Our children are not an assembly line of cars.
2. We need to model our children's healthcare after our country's acquired immunodeficiency syndrome (AIDS) and human immunodeficiency virus (HIV) hospital based programs, such as the one that exists at Jacobi Medical Center in New York City.
3. There not only is the child's immune system treated, but the entire family receives their health care, emotional support, and various other support services.
4. We need parity with AIDS funding for autism, which is currently \$95 billion annually.
5. We need community hospital-based organic food pantries, managed by specially-trained holistic nutritionists who will advise parents on how to help their children prepare for recovery.
6. We need diagnosis related groups (DRGs) for our children's healthcare. Hyperbaric Medicine, Chelation, intravenous immunoglobulin (IVIg), IV Glutathione and phospholipids, titers, immunoglobulin G (IgG) blood tests, IV B vitamins (B-vits), just to start.
7. Parents need to be able to choose whether or not to vaccinate their child without retaliation from their pediatrician, the practice, the schools and the health department.
8. We need to return to the day when the parent and the physician made the healthcare decisions, not insurance companies. Insurance companies especially healthcare management organizations (HMOs) should not dictate that a doctor must vaccinate in order to be paid for a well baby office visit. A physician's bonus should not be dictated by how many vaccinations she gives to her patients. She should not feel threaten with losing her job if she doesn't make her "quota."
9. Parents need respite care for their children.
10. We need supplemental security income (SSI) for all our children so we might be able to pay for medical treatments which are currently not covered under our insurance.
11. We need compounded medicines available in community hospitals.
12. We need to remember the words of [PII redacted]. "Listen to the parent. Observe the patient. And never vaccinate a sick child."

Katy Beh Neas

November 30, 2007

Thank you for the opportunity to speak today. My name is Katy Beh Neas and I am Vice President for Government Relations at Easter Seals. Easter Seals is the leading non-profit provider of services for individuals with autism, developmental disabilities, physical and mental disabilities, and other special needs. For more than 85 years, we have been offering help and hope to children and adults living with disabilities, and to the families who love them. In addition to providing direct services, Easter Seals is engaged in research efforts across the country, partnering with universities and medical centers to help find effective interventions and to hasten the gap between research and practice. Easter Seals is also part of an effort sponsored by the National Institute on Mental Health (NIMH) to explore the efficacy of an intervention that hopefully can augment the limited choices of evidence-based interventions that are currently available to individuals with autism.

Easter Seals strongly encourages the Interagency Autism Coordinating Committee (IACC) to promote research on direct services for children and adults with autism. People living with autism today and the individuals who teach them, provide their health care and assist them to work and live with independence in the community need evidence based interventions. This need is especially critical in communities of color. While Easter Seals does not favor separate education, health, housing, employment programs for people with autism, each one of these systems needs to the knowledge to provide individualized and appropriate services to people with autism. Research must also be applicable to a large volume of individuals with autism if we, as a nation, are going to be able to appropriately address the demand for services that the growth in the prevalence rate indicates will be necessary in the future.

Finally, Easter Seals encourages the IACC to prioritize research that will build the scientific evidence for some of the new models of intervention that have been noted to be promising practices or have the beginnings of supportive evidence. Families need more choices to fit the varying needs of their family members. We also cannot focus exclusively on children, but rather we must address supports for adults with autism and look for ways that allow them to work, live and play in their communities.

Thank you for considering our views.

Ari Ne'eman

November 30, 2007

Thank you for this opportunity to give comment on the IACC's important work. My name is Ari Ne'eman and I am here today in my capacity as the President of the Autistic Self Advocacy Network (ASAN), a volunteer non-profit organization run by and for adults and youth on the autism spectrum. ASAN works to promote the autistic culture movement and other opportunities for individuals on the autism spectrum to interact with each other as well as work to improve the representation of the autistic community in public policy deliberations about autism and disability affairs.

As an individual on the autism spectrum myself – I am an Asperger's autistic – I am heartened to see the interest and resources being directed towards the autism spectrum as of late. Unfortunately, as positive as the strong awareness campaign about the autism spectrum could be, it is counterproductive without an equally strong commitment to autism acceptance. Upon the passage of the legislation authorizing this committee – the Combating Autism Act – a prominent parent-lobbyist announced "a federal declaration of war on the epidemic of autism." The problems with that statement are many. A "War on Autism" approach is not in the interests of people on the spectrum. It offends and alienates the autistic community. This is the community of verbal and nonverbal individuals on the autism spectrum – distinguishable from the autism community of the parents, professionals and others who often claim to speak on our behalf. We are usually the last to be consulted on autism policy; the autistic community should be the first to have input into policymaking about our own futures.

While the rhetoric surrounding autism has focused on the idea of cure, many people on the autism spectrum are not interested in pursuing as a goal making autistic individuals normal. Instead, we agree with the opening language of the proposed Expanding Promise for Individuals with Autism Act, which states "Autism is a natural part of the human experience." This is NOT to deny in any way the very real and pressing hardships placed on families and people on the autism spectrum. Instead, it is to promote research that will truly do something about it. We encourage the IACC to re-focus its research exclusively on how to improve the quality of life, communication, independent living and educational opportunities of America's many autistic citizens.

The promising research leads are already present and are not being followed up on, due to a misguided belief that the goal behind autism research and advocacy should be to, "make autism a word that we only see in the history books." The Autistic Self Advocacy Network encourages the IACC to make the focus of the federal research agenda Augmentative and Assistive Communication (AAC) technology, positive behavioral supports, restraint reduction methods, adult supports, educational inclusion, employment and independent living services and other possibilities that provide tangible improvements in our lives. If one-tenth of the attention and funding now focused on finding a cure was put towards the promising possibilities in assistive communication technology, many people on the autism spectrum today viewed as "low-functioning" would be communicating successfully today.

I applaud the IACC for beginning to fulfill its moral obligation to have autistic representation on the Committee. The inclusion of Stephen Shore, a respected self-advocate with a long history of contributions to the autistic community, is a great first step. At the same time, I note that there remains a distinct under-representation of autistic representatives on IACC as compared to the number of parent

and professional organizations and individuals represented. I hope to see the inclusion of autistic self-advocate organizations in the near future, such as Autism Network International and the Autistic Self Advocacy Network.

We must also express concern over one of the public members appointed: Alison Tepper Singer of Autism Speaks. Ms. Singer's comments in the fundraising video Autism Every Day where she discusses [offensive language redacted]. Many self-advocates and parents believe Autism Speaks to be [offensive language redacted].

We live in a society where the lives and opinions of individuals with disabilities are viewed as less valuable and less deserving of basic human respect than those of other citizens. The IACC must break with that mindset and we encourage the Committee to pursue a new direction in autism research to maximize quality of life and opportunity for every person on the autism spectrum, not by insisting that we attempt to become what we are not but by recognizing that – with the right services, education, and a supportive environment - we can succeed as we are.

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John Erb

November 30, 2007

Good afternoon, ladies and gentlemen. Thirty years ago, autism, one in 10,000; today, one in 140. At this rate, 30 years from now, one in two. Global warming? We have more to worry about than just global warming. Autism is much, much bigger than anyone suspected.

I have been working with autistic individuals front-line for 20 years, over 200 of them, and one thing I have noticed is that in many cases they were smarter than me. This perplexed me. How could they be smarter than me? Yet I knew some with multiple languages, abilities beyond in skills of math and music.

I came up with a theory and published it four years ago when I was researching something called monosodium glutamate (MSG), an excitotoxin that overexcites neurons of the brain. Glutamate is an amino acid which is one of the predominant building blocks of the human brain. I theorized about MSG in diet. If we are getting too much, what if our brain is growing because of it.

I did notice that recently they have discovered that autistic individuals have larger brains more densely packed with neurons. So I did more research, and I found out that over 12 vaccines have monosodium glutamate or glutamate as an additive. This was quite alarming to me, and I published a 24-page report which is now before the World Health Organization in the hands of the director of food safety, Dr. Yorgin Schlent. It also has been passed by the director of food safety at the Food and Drug Administration (FDA), Dr. Laura Tarentino, to the Food Safety Committee, where it is sitting right now.

What is interesting to note is that glutamate is in many things: Doritos, all your Campbell's soup, Top Ramen, Hamburger Helper, your processed foods, and it is not just labeled as MSG, it is labeled as autolyzed yeast extract and hydrolyzed vegetable protein. In the 1970s they were all concerned about the Chinese Food Syndrome. They were blaming the Chinese food for having the MSG. Well, what was happening was Kentucky Fried Chicken and other corporations were using massive amounts of MSG but they had a lobby group called the Glutamate Association. The Chinese restaurants were family-owned and had no lobby group, so the large corporations pointed the finger.

Before 1950, 13 cases of autism. After 1950 with the introduction of MSG by [PII redacted], we have an exploding amount. This is my concern. I have presented this to the FDA. I'm not waiting for further research. What I'm going to be doing is I'm taking the Capitol.

I'm going to demand that and pressure the FDA to remove MSG from the food supply. Hopefully, in a few years I will come back and say, "Got MSG out of it. Maybe we will see a drop in autism." But I'm certainly going to try because prevention is what we are all about. If MSG could be the cause of autism, then it is one less thing our children should be eating.