

Andy Shih, PhD
VP Scientific Affairs
Autism Speaks

Hearing Date: May 31, 2011

House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights

Prepared Remarks

Thank you, Chairman Smith and members of the subcommittee for this opportunity to share with you Autism Speaks' global perspective on autism.

I am Andy Shih, VP of Scientific Affairs at Autism Speaks, where I oversee the etiology portfolio, including research in genetics, environmental sciences, and epidemiology, as well as lead our international scientific development efforts. I am a molecular biologist by training, and have had the honor and the pleasure of serving the autism community for the past decade.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social behavior and communication, and a restricted range of activities. Autism symptoms vary by person from mild to severe. Some individuals have strong intellectual and language abilities, whereas others are cognitively impaired and require life-long care.

ASD transcends geographic, economic and cultural boundaries. Current scientific consensus is that 67 million people, or about 1% of the world's population is affected with some form of ASD—a prevalence that is higher than AIDS, diabetes, and cancer combined.

While there is currently no known medical cure for autism, behavioral treatment programs can be quite effective, particularly when the diagnosis is made early and subsequent interventions are begun. This growing recognition around the need for better screening with treatment has lead groups, such as the American Academy of Pediatrics, to mandate autism screening for all children between 18 and 24 months of age. The success in improving care in both North America and Europe also makes it clear that these approaches can be adapted and extended to countries around the world.

Unfortunately, today, for most of the world, early autism diagnosis and intervention remains more an aspiration than reality. A major barrier to improving the health and wellbeing of individuals and families touched by autism is the lack of expertise and capacity to diagnose the disorder and deliver appropriate interventions. Without expertise and capacity, solutions that improve the quality of life for individuals with ASD and their families remain out of reach. In many countries, there is little awareness and simply no autism service providers. As a result, affected children and families do not receive proper

care and support, and opportunities for a better outcome and improved quality of life for the families are lost.

To address this global public health challenge, in 2008, Autism Speaks launched the Global Autism Public Health Initiative (GAPH), an ambitious international advocacy effort to provide support to other countries in order to enhance public and professional awareness of autism, and to increase capacity to enable early detection and intervention as well as research.

Built around the core values of a sense of urgency, scientific excellence, and benefits to individuals and families touched by autism, GAPH provides technical expertise and support to our partners to help realize their vision of progress. We collaborate broadly and inclusively with stakeholders at all levels, such as health and education ministers, expert clinicians and scientists, as well as parents and families, because we recognize the development and implementation of meaningful and sustainable program solutions require local leadership and ownership. GAPH strategies and content are continually informed by the latest research in clinical and dissemination science. In addition, the experience we gained and the data we collected from GAPH programs will help us advance and refine autism science, and inform future policy and service development. Indeed, benefits from GAPH-related activities are expected to be reciprocal—with greater international collaboration there will be new insights into ASD causes, including environmental factors, socio-cultural influences on diagnosis and treatment, education, and service development, answers that will help affected individuals and families the world over, including those in the United States.

Autism Speaks currently supports GAPH-related activities in 23 countries on 6 continents, and these collaborations are already yielding impressive returns for our community both here and abroad. We have assisted countries like Brazil, Mexico, and Qatar in developing their own awareness campaigns and establishing research collaborations with US scientists. We are supporting governments like Albania and Ireland in their review and development of autism-related national health policies and programs. As an official NGO partner of the WHO, we are working with Geneva and a number of health ministries in Southeast Europe and Southeast Asia to develop and implement regional collaborative health networks focusing on awareness and training. In fact, Autism Speaks and the WHO are collaborating with the Bangladesh Prime Minister's office, as well as Ministries of Health, Education, and Social welfare, to host an international conference this July to officially launch GAPH-Bangladesh, and to bring together likeminded stakeholders from India, Thailand, Sri Lanka, Bhutan, and Maldives to explore regional coordination and collaboration. Finally, the recently published first ever autism prevalence study in South Korea reported a stunning prevalence of 2.6%, with many previously unidentified cases found in the mainstream schools. In addition to the potential implications for environmental sciences research, the differences between the case-finding methodology used in the Korean study and one deployed by the CDC to monitor prevalence in the US raise important questions about the robustness of our statistics, and if we are actually underestimating autism prevalence in these United States.

It is important to note that prevalence and other public health data on autism that can guide policy and services development is not available for most of the world. By one recent estimate, over 90% of autism research is conducted on about 10% of the global community. By supporting GAPH-related activities and research like the Korean study worldwide, Autism Speaks is helping to bridge that knowledge gap, to inform policy and development, enhance evidence-base, and as result, narrow the service gap.

In South Africa, for example, we've funded a prevalence study in a region where AIDS is endemic, to help establish basic public health statistics and explore the potential risk posed by a compromised immune system on brain development. Simultaneously, we are working with stakeholders from that country, including government officials, to develop consensus community priorities that will inform upcoming policy and program discussions with federal agencies. It is worth noting that one of the recurring themes we've encountered working with health officials in low resource countries like those in Africa is how best to prioritize autism and developmental disabilities when so many life-threatening diseases or conditions, such as AIDS, malaria, and malnutrition, compete for limited public health resources.

While we understand that perspective, we believe such public health policy-making is overly simplistic. As child mortality decreases, simple math predicts an increase in number of children with developmental disabilities. So instead of seeing mortality and developmental disorders like autism as two distinct public health challenges, they should be tackled as parts of the same problem. Autism Speaks and our partners around the world believe that by addressing autism and related disorders now, South Africa and other developing countries can get ahead of the curve, help maximize outcomes for affected individuals and families, and minimize long term costs to society.

In conclusion, the unmet needs of the global autism community mirror the daily challenges that are familiar to any individual or family in this country struggling with autism spectrum disorders. By sharing our experience, expertise, and translating and adapting current best practices into feasible and sustainable health solutions, we believe we can make a difference in communities with less knowhow and resources. Just as important, we can also learn valuable lessons from these collaborations that can help improve the quality of life of our families here. But we need help. Our work with WHO and other international partners have confirmed the power of collaboration in accelerating progress and speeding the delivery of answers to our families. We welcome suggestions and recommendations about how perhaps we can work with other US government agencies to further our global efforts. Thank you.

United States House of Representatives
Committee on Foreign Affairs

"TRUTH IN TESTIMONY" DISCLOSURE FORM

Clause 2(g) of rule XI of the Rules of the House of Representatives and the Rules of the Committee require the disclosure of the following information. A copy of this form should be attached to your written testimony and will be made publicly available in electronic format, per House Rules.

1. Name: Andy Shih	2. Organization or organizations you are representing: Autism Speaks
3. Date of Committee hearing: May 31st 2011	
4. Have <u>you</u> received any Federal grants or contracts (including any subgrants and subcontracts) since October 1, 2008 related to the subject on which you have been invited to testify? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	5. Have any of the <u>organizations you are representing</u> received any Federal grants or contracts (including any subgrants and subcontracts) since October 1, 2008 related to the subject on which you have been invited to testify? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
6. If you answered yes to either item 4 or 5, please list the source and amount of each grant or contract, and indicate whether the recipient of such grant was you or the organization(s) you are representing. You may list additional grants or contracts on additional sheets. Please see attached appendix I	
7. Signature: 	

Please attach a copy of this form to your written testimony.

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Appendix I to 112th FAC Truth In Testimony Form

Grants, Contracts, and Subcontract Funding Support Autism Speaks Receives from US Federal Agencies 2008 to Present

Responsible Autism Speaks staff: LAJONCHERE, CLARA M., VP Clinical Programs

1 UA3MC11054-01-00 J. Perrin (PI) 9/1/2008 – 8/31/2011 2.4 calendar months
HRSA \$400,000/yr

Autism Intervention Research Network for Physical Care

The goal is to develop research projects and practice parameters in collaboration with Autism Speaks' Autism Treatment Network that will serve to develop standards of care for children and adolescents with autism spectrum disorders.

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

1U24MH081810-01 C. Lajonchere (PI) 9/28/07-9/27/2012 2.4 calendar months
NIMH

Center for Genomic and Phenomic Studies in Autism \$1,569,460

The goal of Center will be to facilitate genetic and environmental studies on autism, thereby improving diagnosis, accelerating our understanding of its etiology and pathophysiology, and facilitating discovery of new therapeutics.

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

1R01MH081754-01 D. Geschwind (PI) 4/1/2008-1/31/2013 2.4 calendar months
NIH/NIMH

A Comprehensive Approach to Identification of Autism Susceptibility Genes \$123,736

The goal of this grant is to expand the existing data on the relationship between autism-related genes and physical traits (phenotype) by identifying rare genetic variants, mutations and abnormalities that affect a person's risk for autism.

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

1RC1MH089707-01 C. Lajonchere (PI) 9/30/09-9/29/11 .6 calendar months
NIH/NIMH (ARRA) \$372,733

Linking Data Sources from the Autism Genetic Resource Exchange (AGRE) with NDAR

The goal of this grant is to federate large scale genetic and clinical data on autism to accelerate our understanding of its etiology and pathophysiology, and facilitate the discovery of new therapeutics, diagnostic tools and biological models of autism spectrum disorders.

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

3RC1MH089707-01S1 C. Lajonchere (PI) 6/1/2010-5/31/2011 .6 calendar months

NIH/NIMH (ARRA)

\$102,940

Supplement - Linking Data Sources from the Autism Genetic Resource Exchange (AGRE) with NDAR

This supplement will enhance the breadth of data that will be made available to NDAR by facilitating the inclusion of clinical, genetic, and imaging data from the Autism Tissue Program in the current data integration plan.

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

1RC1MH088600-01

C. Lajonchere (PI)

9/30/09-9/29/11

.6 calendar months

NIH/NIMH (ARRA)

\$308,614

Disseminating Scientific Information about Autism to the Latino Community

This project represents a proof of concept study that will serve to increase health literacy and access to research among Latino families with children affected by autism spectrum disorders (ASD)

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

RC1-HG005787

Laura Beskow (PI)

9/30/09-6/30/2011

.3 calendar months

NIH/National Human Genome Research Institute

\$6,853

Ethical Approaches to Genotype-Driven Research Recruitment

The goal of the project is to explore attitudes about being recontacted for genetic studies among families of children with autism spectrum disorders.

Role: Co-Investigator

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.

1R18HS019271-01

C. Tanner (PI)

9/1/10-8/31/13

.6 calendar months

AHRQ

\$1,486,234

Innovative Adaptation & Dissemination of CER Products: Autism (iADAPT-ASD)

The goal of this project is to increase the impact, use and application of two AHRQ comparative effectiveness research (CER) products that reference autism and autism spectrum disorders (ASD) by adapting both their content and delivery mechanism to improve their penetration and use at the health and educational systems, clinical practice, caregiver, and family levels.

Role: Consultant

OVERLAP

There is no scientific or budgetary overlap with any of the other awards.