## Labor Health and Human Services, Education, and Related Agencies Witness Disclosure Form

Clause 2(g) of rule XI of the Rules of the House of Representatives requires non-governmental witnesses to disclose to the Committee the following information. A non-governmental witness is any witness appearing on behalf of himself/herself or on behalf of an organization other than a federal agency, or a state, local or tribal government.

Your Name, Business Address, and Telephone Number:
Peter Bell Executive Vice President for Programs and Services Autism Speaks
1. Are you appearing on behalf of yourself or a non-governmental organization? Please list organization(s) you are representing.
Autism Speaks
Have you or any organization you are representing received any Federal grants or contracts (including any subgrants or subcontracts) since October 1, 2008?  Yes _X No
3. If your response to question #2 is "Yes", please list the amount and source (by agency and program) of each grant or contract, and indicate whether the recipient of such grant or contract was you or the organization(s) you are representing.
Please see attached
Signature: Date: March 23, 2012

## AUTISM SPEAKS, INC. SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS YEAR ENDED DECEMBER 31, 2008

	Contract Number	Federal CFDA Number	Governmental Revenue Federal	Program Expenditures from Governmental Revenue
FEDERAL AWARDS				
Agency - Program Grant Title				
MAJOR AWARDS U.S. Department of Health and Human Services Pass-through Regents of the University of California at Los Angeles Mental Health Research Grants The Autism Genetic Resource Exchange Program	1RO1MH081754-01	93.242	\$ 155,907	\$ 155,907
Pass-through Stanford University Mental Health Research Grants The Autism Genetic Resource Exchange Program	13487640-26578 <b>-B</b>	93.242	96,474	96,474
Pass-through University of Southern California Mental Health Research Grants The Autism Genetic Resource Exchange Program	1U24MH081810-01	93.242	956,838	956,838
Pass-through Cold Spring Laboratory  Mental Health Research Grants  The Autism Genetic Resource Exchange Program	25680112	93.242	68,076	68,076
Pass-through Harvard Brain and Tissue Resource Center/Partners Health System Mental Health Research Grants The Autism Tissue Program	5R324MH68855	93.242	224,210	224,210
Pass-through Massachusetts General Hospital Mental Health Research Grants Autism Treatment Network	UA3MC11054	93.110	<u> 147,859</u>	147,859
TOTAL MAJOR AWARDS			1,649,364	1,649,364
TOTAL FEDERAL AWARDS			<u>\$1,649,364</u>	<u>\$ 1,649,364</u>

## AUTISM SPEAKS, INC. SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS YEAR ENDED DECEMBER 31, 2009

Contract Number	Federal CFDA <u>Number</u>	Government Revenue Federal	Expenditures from Governmental Revenue
•			
1RO1MH081754-01	93.242	\$ 196,051	\$ 196,051
13487640-26578-В	93.242	31,631	31,631
1U24MH081810-01	93.242	751,325	751,325
25680112	93.242	41,706	41,706
UA3MC11054	93.110	189,743	189,743
2R01HD042541-06A1	93.865	14,500	14,500
IRC1MH089707-01	93.701	62,292 1,287,248 \$1,287,248	62,292 1,287,248 \$1,287,248
	Number  1RO1MH081754-01  13487640-26578-B  1U24MH081810-01  25680112  UA3MC11054  2R01HD042541-06A1	Contract Number  IRO1MH081754-01 93.242  13487640-26578-B 93.242  1U24MH081810-01 93.242  25680112 93.242  UA3MC11054 93.110  2R01HD042541-06A1 93.865	Contract Number         CFDA Number         Government Revenue Federal           1RO1MH081754-01         93.242         \$ 196,051           13487640-26578-B         93.242         31,631           1U24MH081810-01         93.242         751,325           25680112         93.242         41,706           UA3MC11054         93.110         189,743           2R01HD042541-06A1         93.865         14,500           1RC1MH089707-01         93.701         62,292 1,287,248

Program

#### AUTISM SPEAKS, INC. SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS YEAR ENDED DECEMBER 31, 2010

FEDERAL AWARDS	Contract Number	Federal CFDA <u>Number</u>	Government Revenue Federal	Program Expenditures from Governmental Revenue
Agency - Program Grant Title				
MAJOR AWARDS U.S. Department of Health and Human Services Pass-through Regents of the University of California at Los Angeles Mental Health Research Grants The Autism Genetic Resource Exchange Program	ROIMH081754-03	93.242	\$ 210,94 <b>5</b>	\$ 210,945
Pass-through University of Southern California Mental Health Research Grants The Autism Genetic Resource Exchange Program	SU24MH081810-04	93.242	742,175	742,175
Pass-through Massachusetts General Hospital Mental Health Research Grants Autism Treatment Network Program	UA3MC11054	93.110	353,758	353,758
Pass-through Washington University Mental Health Research Grants The Autism Genetic Resource Exchange Program	5R01HD042541-07	93.865	14,500	14,500
National Institutes of Health Mental Health Research Grants The Autism Genetic Resource Exchange Program	1RC1MH089707-01	93.701	510,172	510,172
National Institutes of Health  Mental Health Research Grants  The Autism Tissue Program	3RC1MH089707-01S1	93.701	68,271	68,271
Pass-through Duke University Mental Health Research Grants The Autism Genetic Resource Exchange Program	RC1HGD05787	93.701	<u>9,389</u>	9,389
TOTAL MAJOR AWARDS TOTAL FEDERAL AWARDS			1,909,210 \$1,909,210	_1,909,210 \$1,909,210

## FOR REVIEW AND DISCUSSION

Program

#### AUTISM SPEAKS, INC. SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS YEAR ENDED DECEMBER 31, 2011

	Contract	Federal CFDA	Government Revenue	Expenditures from Governmental
FEDERAL AWARDS	Number	Number	<u>Federal</u>	Revenue
Agency - Program Grant Title	•			
MAJOR AWARDS U.S. Department of Health and Human Services Pass-through Regents of the University of California at Los Angeles Mental Health Research Grants The Autism Genetic Resource Exchange Program	RO1MH081754-03	93.242	\$ 154,265	<b>\$</b> 154,265
Pass-through University of Southern California Mental Health Research Grants The Autism Genetic Resource Exchange Program	5U24MH081810-04	93.242	844,880	844,880
Pass-through Massachusetts General Hospital Mental Health Research Grants Autism Treatment Network Program	UA3MC11054	93.110	239,393	239,393
Pass-through Washington University Mental Health Research Grants The Autism Genetic Resource Exchange Program	5R01HD042541-07	93.865	14,500	14,500
National Institutes of Health Mental Health Research Grants The Autism Genetic Resource Exchange Program	1RC1MH089707-01	93.701	301,786	301,786
National Institutes of Health Mental Health Research Grants The Autism Tissue Program	3RC1MH089707-01S1	93.701	75,251	75,251
Pass-through University of Southern California				
Biorepository			342,415	<u>342,415</u>
TOTAL MAJOR AWARDS			<u>1,972,489</u>	1,972,489
TOTAL FEDERAL AWARDS	•		<u>\$1,972,489</u>	<u>\$ 1,972,489</u>

## Peter Bell Executive Vice President for Programs and Services

Peter oversees the foundations' government relations and family services activities and also serves as an advisor to the science division. Prior to his role at Autism Speaks, Peter was President and Chief Executive Officer of Cure Autism Now, which merged with Autism Speaks in February 2007.

Peter joined Cure Autism Now in 2004 following a successful 12-year marketing career at McNeil Consumer & Specialty Pharmaceuticals, a member of the Johnson and Johnson family of companies. As President and CEO, Peter led Cure Autism Now through a tremendous growth period and brought the foundation's funding total to more than \$39 million. In addition, Peter enhanced the foundation's research, education and outreach initiatives, and expanded its treatment portfolio.

Peter received a Bachelor of Science degree from Cornell University and holds an MBA from the Kellogg School at Northwestern University. Peter and his wife, Liz, reside in New Jersey with their three children. Their eldest son, Tyler, has autism.



# TESTIMONY PRESENTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES BY PETER H. BELL, EXECUTIVE VICE PRESIDENT FOR PROGRAMS AND SERVICES AT AUTISM SPEAKS

Chairman Rehberg, Ranking Member DeLauro, and members of the subcommittee, thank you for the opportunity to offer testimony on the importance of continued funding for autism.

My name is Peter Bell and I am executive vice president of programs and services for Autism Speaks. My responsibilities at Autism Speaks include overseeing the foundation's family services and government relations activities. I also serve as an advisor to our science division. Autism Speaks is the world's leading autism science and advocacy organization. Since its inception in 2005, Autism Speaks has committed over \$173 million to autism research as well as developing innovative resources for individuals with autism and their families. Our mission is to change the future for those who live with autism. We do this through funding science, raising awareness, helping families and advocating for those who live on the spectrum.

I am also the proud father of a child with autism. His name is Tyler and he recently turned 19. In 1996 when my wife and I first heard the words "your son has autism", we were stunned. Our only reference to autism at the time was from the Oscar-winning movie "Rainman". We had never known anyone with autism, nor did we know any families who had a child with autism. I

suspect this would have been true for most of you on this committee. However, today, I'm willing to wager that every one of you personally knows someone or some family who is touched by autism. Each year, nearly 50,000 families hear those same words -- "your child has autism."

Twenty years ago, the experts estimated that one of every 2,500 children had autism. The latest statistic is one in 110, one in 70 for boys. On Thursday March 29<sup>th</sup>, the Centers for Disease Control and Prevention (CDC) is expected to announce a new prevalence rate that we suspect you will find even more disturbing. Increasingly we hear the word "epidemic" associated with autism in America. But we at Autism Speaks are hearing something else from the families in our community and it is getting louder by the day.

And that is the question, "what is our government doing to confront this public health crisis?"

We are increasingly frustrated and frankly confused by what appears to be a lack of will from

Washington. When the number of people on the spectrum is going up, why would the dollars for autism research and prevention be going down?

When Bob and Suzanne Wright founded Autism Speaks in 2005, they were shocked that a disorder as prevalent as autism commanded so little in terms of resources devoted to research and treatment when compared to other, less common disorders. Working together with thousands of families affected by autism, we were able to enact the Combating Autism Act of 2006. Signed by President Bush, this historic act was considered to be the most comprehensive piece of single-disease legislation ever passed by Congress. Last year, working with many of you in bipartisan

fashion, the CAA was reauthorized when President Obama signed a three-year reauthorization into law on September 30<sup>th</sup>.

Autism Speaks and the one million plus members of our community are of course grateful for this funding. But we also recognize it provides but a fraction of the billion-dollar-a-year commitment that had been promised by President Obama, a commitment that better reflects the actual need for funding meaningful research, treatment and services. That disappointment has now been compounded by fears that the funding that was authorized just last September may now be in jeopardy as a result of this year's appropriations process.

Funding for the CDC to continue prevalence research under the President's budget request was \$700,000 below the \$22 million authorized funding level and then inexplicably incorporated within the Prevention and Public Health Fund created under the Affordable Care Act. As you know, recent legislation reduces the fund by 20% in FY 2013, further jeopardizing the CDC's autism surveillance activities. Since 2000, funding for this work has always been included within the CDC's total discretionary budget authority. It should continue there. Autism Speaks requests that you include \$22 million for autism activities within the National Birth Defects Center, within CDC's discretionary budget authority.

Further, we urge you to fully fund the basic and clinical research initiatives for autism at the levels called for under the Combating Autism Reauthorization Act. Specifically, we ask you to support at least \$161 million for the NIH's autism research programs and \$48 million for HRSA's autism research, treatment and training activities.

As I mentioned earlier, Autism Speaks has committed more than \$173 million through private fundraising to scientific research studies, fellowships, and scientific initiatives. Other private foundations have contributed in excess of \$125 million. But we can't do this alone. We ask that Congress restore full funding as authorized under CARA for autism research, surveillance and treatment. And we ask that Washington treat autism as the epidemic it has become.