AUTISM SPEAKS™
It's time to listen.

Written Testimony Provided for the
House Committee on Oversight & Government Reform

Bob Wright
Co-founder, Autism Speaks

November 29, 2012

Good afternoon, Chairman Issa, Ranking Member Cummings, and members of the committee. I am Bob Wright, co-founder of Autism Speaks. Thank you for inviting me to testify.

More than seven years have passed since my wife, Suzanne, and I founded Autism Speaks. During that time, we have seen the prevalence of autism in America nearly double – from 1 in 166 children in 2005 to 1 in 88 today, including 1 of every 54 boys. The prevalence of autism has increased by 1,000 percent over the last 40 years. This year alone, approximately 46,000 children will be diagnosed with an autism spectrum disorder – that's more than pediatric AIDS, juvenile diabetes, and childhood cancer combined. Yet even these alarming statistics may understate the true picture – the most comprehensive study to date, completed last year in South Korea, found a prevalence rate of 1 in every 38 children. The methodology used in this study is now being replicated in South Carolina, with funding from Autism Speaks, and may well yield similar findings. There is no getting around the facts: autism has become an epidemic.

The incremental lifetime cost of caring for a single person with autism is staggering – as much as $2.3 million. The annual cost of autism in the United States is now estimated at $137 billion – a figure that exceeds the gross domestic product of 139 countries. These spiraling costs are borne not just by families but by taxpayers at the federal and state level, as well as by localities. Consider as well the cost to our economy – when one of every 54 boys is diagnosed with autism, 2 percent of the productivity of our nation's male workforce is diminished. The toll on our families, however, is unimaginable. A diagnosis of autism too often leads to divorce, personal bankruptcy or shattered careers. A spouse in Michigan has to give up working in order to care fulltime for a child with autism at home. A family from Alabama is uprooted as they search for jobs in states where treatment for their child with autism will be covered by insurance. Parents in Utah are forced to surrender custody of their children to the state because they cannot care for their needs. And most shamefully, we see the U.S. Marine back home in Texas after being wounded in combat in Iraq having autism treatment denied to his son.

These burdens on families can be addressed, the costs can be reduced, and the quality of life for individuals with autism improved. But it will require new thinking, engaged leadership, and a concerted effort bridging all sectors of our society.

Autism Speaks began as an idea to give a voice to millions of struggling families around the nation and has materialized into the world's leading autism science and advocacy organization. We are dedicated to funding research into the causes, prevention, treatments, and for those who desire a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Since our founding seven years ago, Autism Speaks has committed more than $180 million in private funding to research and has supported innovative scientific and clinical programs such as the Autism Speaks Autism Treatment Network, a network of hospitals, doctors, and researchers across the United States and Canada dedicated to improving the care of children with autism. Our research efforts also have led to improved screening tools that can be used by pediatricians and more effective behavioral and medical treatments for people with autism throughout the lifespan. Our awareness activities include the worldwide "Light It Up Blue" project on World

Autism Awareness Day (April 2nd) and the “Learn the Signs” campaign with the CDC and Ad Council which has generated over $316 million in donated media.

Autism Speaks provides resources and support for families in the autism community, handing out thousands of free tool kits and awarding hundreds of thousands of dollars in grants for community programs, camp scholarships, and families in crisis each year. In 2012 alone, our Autism Response Team and Autism Treatment Network have responded to over 25,000 phone calls and emails from families looking for assistance. Recently, our AutismCares program allocated $120,000 in private funding to help families impacted by Hurricane Sandy.

Through the work of our government relations team in state capitals and on Capitol Hill, individuals with autism have better access to applied behavior analysis (ABA), the most widely used behavioral intervention for treating autism, and other critical health care services. Thirty-two states, representing 75% of the US population, now have comprehensive autism insurance coverage, and beginning in 2013 many federal civilian employees will gain access to behavioral health treatments through the Federal Employees Health Benefits Program.

We are incredibly proud of what Autism Speaks has accomplished. We cannot, however, go it alone. We need a strong federal partner.

Our families are not asking for a blank check from the federal government. We are asking for real help that delivers meaningful results more quickly to our community and with a transparency that provides accountability to taxpayers. We are asking our elected leaders to recognize that there is a public health crisis racing across this nation and we are not keeping pace. We need a plan and we need it now.

Autism Must Be a National Priority

I want to say this again: the rate of autism in America is now 1 in 88 children, including 1 in 54 boys. It has become alarmingly apparent that we are no longer dealing with just a public health crisis, but a public services crisis as well. As this population continues to grow, our ability as a society to care for people with autism falls further behind.

Real families struggle every day with autism and those struggles do not end when a child with autism becomes an adult. A recent study found that more than one-third of young adults with autism have no paid job experience or post-secondary education in the first six years after high school. In other words, they most likely live at home with nothing meaningful to do during the day. That is a sobering statistic when you consider that more than half a million children with autism will reach adulthood within the next decade.

But with this sobering reality comes a meaningful opportunity for this country. We know that there are effective therapies that will improve the life-trajectory of people with autism. This means that with more effective translational research and better access to supports and services for the individuals I described, we can help them lead more independent lives and in some cases join the workforce. The trend that contributes to the $137 billion in annual costs can be reversed dramatically for the country as a whole and for the people affected. In the current fiscal crisis, this potential reduction in current and future costs should be appealing to both sides of the aisle and across the ideological spectrum.

Clearly, we have a long way to go in meeting the needs of people with autism and their families. The status quo isn't working. We have to do better, and we have to act now. It is time we commit to a **comprehensive national strategy** for autism.

A Comprehensive National Strategy is Essential

First*, we must continue to fund a robust research effort but should do so more smartly.*
We are only beginning to grasp the complex connections between genes and environment in autism. There is now growing evidence that certain environmental factors, including chemicals, toxins, infections during pregnancy, maternal nutrition and parental age, can affect brain development in combination with an underlying genetic predisposition. Recent studies are pointing the way to the development of medicines that could reduce the core symptoms of autism and help improve communication and social skills. Novel behavioral health interventions are being tested that can be started with young infants, as well as implemented later in life to help adolescents and adults develop the skills they need to be successful, productive adults. These new treatments have the potential to significantly impact lives and reduce the burden of autism to families and society. The federal commitment to autism research through the Combating Autism Act (CAA) has been an important first step in better understanding the causes and underlying pathology of autism. Autism has historically received a fraction of the research funding of many less prevalent disorders, and even under the CAA, autism research comprises about one-half of one percent of total NIH research funding. The research into environmental factors I have noted is an example of an area of research that was mostly neglected prior to the CAA. Further, the Interagency Autism Coordinating Committee (IACC) established by the CAA has served as a convening function for scientists and autism advocates to have a dialogue with the National Vaccine Advisory Committee on the important vaccine safety issue.[1] These steps have been important, but much more can and needs to be done. What continues to be lacking is a policy that directs funding according to a strategic plan, measures meaningful progress, operates with a sense of urgency, and assures accountability. We need a national commitment – much the way the country has committed to address the AIDS crisis or Alzheimer's disease – to invest the resources needed to solve this growing public health crisis. We must demand results that improve the lives of people with autism today, not just in the future. Through a smarter investment in research we can unlock the door not only to autism, but a variety of brain disorders.

Second*, we must commit to diagnosing children with autism, regardless of background, no later than 18 months of age, and increasing access to early intervention.*
Five years ago, the American Academy of Pediatrics recommended that all children be screened for autism at 18 and 24 months, and that appropriate referrals be made if autism is suspected. This is crucial because we know that early intervention can alter the life trajectory of children with autism. Today the average age of diagnosis remains close to five years. Geography, ethnicity, and race may place a child at a particular disadvantage in getting a timely diagnosis.

---

[1] Louis Z. Cooper, Heidi J. Larson, and Samuel L. Katz, *Protecting Public Trust in Immunization*, Pediatrics 2008:122; 149

Research shows that children from ethnic minority backgrounds must go to the doctor many more times before receiving a diagnosis and thus, they begin receiving services at a much older age. Autism is not something that a child outgrows. We must develop new and better ways to increase access to early diagnosis for all children no matter what their background is.

***Third**, we have to develop and make available effective medicines and treatments for the debilitating aspects of autism.*

Too often, scientific discoveries gather dust on laboratory shelves or are entombed in the pages of academic journals. We need to speed to market products that improve the lives of people with autism. For our part, Autism Speaks recently established a not-for-profit affiliate, ***Delivering Scientific Innovation to Autism (DELSIA)***, to help do this work. From Washington, we are looking for the National Center for Advancing Translational Sciences (NCATS), NIH's newest center, to take a key role in fostering collaboration between public and private efforts at real world solutions. This committee can be instrumental in providing oversight for this opportunity.

As we develop the technologies of tomorrow, we must fully utilize the treatments and interventions of today. Right now, autism is considered a treatable disorder. But ten years ago, many experts didn't believe it was. Today, we can change the course of a child's development and outcome. Research has shown that early intensive behavioral intervention significantly increases IQ, language abilities, and daily living skills, while reducing the disabling effects of autism and the demands on taxpayers for avoidable costs, such as special education. Autism is not a static disorder; we can treat it and help those affected lead better, more fulfilling lives.

***Fourth**, we must recognize and address the disparities in access to proven behavioral health treatments.*

We have long known the benefits of behavioral interventions in autism, including the use of ABA. In 1999, the Surgeon General of the United States reported that "[t]hirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." Yet today families across the country continue to fight for behavioral health benefits, negotiating a complex maze of state and federal laws and insurance company practices.

Consider this – civilian employees of the federal government who for the first time in 2013 will gain coverage for ABA through the Federal Employees Health Benefits Program because administrators finally came to acknowledge the therapy as a valid medical intervention. But over in the military, the administrators of the TRICARE program view ABA differently and offer only benefits limited to active duty personnel. Even wounded warriors who retire because of combat-related injuries cannot get ABA treatment for their children.

Here is a classic example of two agencies within the same government heading in opposite directions on the same issue. It is appalling that our military families end up with the short end of the stick. Getting help for any child, let alone the child of a parent who has honorably served our country, should not be so difficult. We can do something right now to help these families – we can enact a National Defense Authorization Act (NDAA) that clarifies the coverage of behavioral health treatment for autism. The House passed a version of the NDAA that assures all Department of

Defense members of the military, regardless of their duty status, will receive autism insurance benefits for their dependents. Now it is time for the Senate to pass a bill with the same provision.

This same incongruity can be found all across America. Repeatedly, we find families overjoyed to gain coverage for ABA when their state enacts autism insurance reform. They are happy because they have the good fortune to work for an employer with a state-regulated health plan. Their neighbors, however, may not be so fortunate. Because many employers self-fund their health plans, they are exempted from following state insurance laws. Their plans are regulated by the federal government under ERISA. Two families, same problem, but different outcomes. This is fundamentally unfair, illogical and, with autism prevalence on the rise, unsustainable.

***Fifth and finally**, we need to address the needs of adults with autism for continuing education, employment, housing, and community integration.*

With early identification and intensive intervention, some children with autism can lose their diagnosis, but most children with autism become adults with autism. To be frank, we do not know very much about the life experiences of adults with autism; only 2% of total autism research funding is spent on lifespan issues. Young adults with autism face real challenges. The majority of adults with autism are unemployed or underemployed, a tragic waste of potential. Hiring people with autism is smart business – just ask Walgreens, TIAA CREF, AMC Theatres or any of the other national employers who have made the investment in our community.

Executive Order 13548, which has increased the percentage of disabled workers in the federal workforce, has been an important step in the right direction, as has been a proposed rule calling on federal contractors to set a goal of hiring people with disabilities for at least 7 percent of their workforces. People with autism generally follow rules and pay close attention to details. They want to work. Give them the support they need and they will succeed. It's time for corporate America to recognize the potential of employing people with autism. They will find a partner at the National Governors Association, whose chairman, Delaware Governor Jack Markell, has made his top initiative increased employment opportunities for people with disabilities.

Like all Americans, adults with autism should be able to choose where they live, with whom they live, and how they live. But the great demand for housing among people with developmental disabilities and the lack of appropriate support services often force families to decide whether to make their own housing arrangements or wait indefinitely for an adult child with autism to move out of the family home. A broad range of housing and support options must be available to meet the needs of people with autism. These options must not be limited by government-imposed restrictions. Where people choose to live should drive where the government directs our money.

People with autism and their families should have the ability to save and plan for the future. The Achieving a Better Life Experience (ABLE) Act would allow tax-advantaged savings accounts for employment support, housing, and other life needs of people with disabilities. These accounts would be subject to much the same rules as 529 college savings accounts and would not jeopardize eligibility for Medicaid and other means-tested federal programs. A bipartisan majority of House members and 40 Senators have signed on to co-sponsor ABLE. This is readily achievable in the current Congress and would bring relief to parents who face their own financial cliff – what happens to their child with disabilities when they are no longer around to support them? I ask the members of this committee to help pass ABLE in this Congress. In this time of fiscal cliffs, this is a common sense solution that will help disabled individuals and their families achieve even greater independence.

If the list of what must be accomplished seems long, it is because the stakes are very high. On a personal scale, there is this harsh reality: ten years ago, even five years ago, many people in this committee room would have known autism only from what they read in the newspaper or saw on television. Today, they are the parents, grandparents or relatives of affected children. Autism has become ubiquitous. Autism has changed our lives, and it continues to change the lives of millions of Americans. We must face up to the crisis. We are ready to join you as a partner. One in 88 can’t wait.

Committee on Oversight and Government Reform
Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(5)

Name: Bob Wright

1. Please list any federal grants or contracts (including subgrants or subcontracts) you have received since October 1, 2010. Include the source and amount of each grant or contract.

Not applicable.

2. Please list any entity you are testifying on behalf of and briefly describe your relationship with these entities.

Autism Speaks, Co-founder and Board Chairman

3. Please list any federal grants or contracts (including subgrants or subcontracts) received since October 1, 2010, by the entity(ies) you listed above. Include the source and amount of each grant or contract.

See attached schedule.

Robert C Wright

11-27-12

I certify that the above information is true and correct.

Signature: Date:

AUTISM SPEAKS INC.
SCHEDULE OF EXPENDITURES OF FEDERAL AWARDS
October 1, 2010 to November 2012

	Contract Number	Federal CFDA Number	Governmental Revenue
			Federal
FEDERAL AWARDS			
Agency - Program Grant Title			
U.S. Department of Health and Human Services			
Pass-through Regents of the University of California, Los Angeles			
Mental Health Research Grants			
The Autism Genetic Resource Exchange Program	1RO1MH081754-A	93.242	$ 378,820
Pass-through University of Southern California			
Mental Health Research Grants			
The Autism Genetic Resource Exchange Program	5U24MU081810-04	93.242	$ 1,329,496
Pass-through Massachusetts General Hospital			
Mental Health Research Grants			
Autism Treatment Network Program	UA3MC11054	93.110	$ 668,697
Pass-through Washington University			
Mental Health Research Grants			
The Autism Genetic Resource Exchange Program	5R01HD042541-09	93.242/93.865	$ 29,000
National Institutes of Health			
Mental Health Research Grants (NDAR)			
The Autism Genetic Resource Exchange Program	5RC1MH089707-02	93.701	$ 465,471
National Institutes of Health			
Mental Health Research Grants (NDAR-ATP)			
The Autism Tissue Program	3RC1MH089707-01S1	93.701	$ 141,029
Pass-through University of Southern California			
Mental Health Research Grants (ATN/Biorepository - AS)			
Autism Treatment Network Program	3U24MH081810-04S1	93.242	$ 307,964
Pass-through University of Southern California			
Mental Health Research Grants (ATN/Biorepository - Pass-Through)			
Autism Treatment Network Program	3U24MH081810-04S1	93.242	$ 254,661
TOTAL FEDERAL AWARDS			$ 3,575,138

Suzanne and Bob Wright are Co-founders of Autism Speaks, the world's leading autism science and advocacy organization. Inspired by the challenges facing their grandson who suffers from autism, they launched the foundation in February 2005.

Since its inception, Autism Speaks has made enormous strides raising over $325 million . committing over $180 million to research and developing innovative new resources for families. The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. In addition to funding research, Autism Speaks has created resources and programs including the Autism Speaks Autism Treatment Network, *Autism Speaks Autism Genetic Resource Exchange and several other scientific and* clinical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2, which Autism Speaks celebrates through its "Light It Up Blue" initiative. Also, Autism Speaks' award-winning "Learn the Signs" campaign with the Ad Council has received over $338 million in donated media. Autism Speaks' family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit, a Grandparent School Kit, and a community grant program. Autism Speaks has played a critical role in securing federal legislation to advance the government's response to autism, and has successfully advocated for insurance reform to cover behavioral treatments in 32 states thus far. Each year *Walk Now for Autism Speaks* events are held in more than 95 cities across North America. To learn more about Autism Speaks, please visit www.autismspeaks.org.

Bob Wright served as Vice Chairman and Executive Officer, of the General Electric Company and also Chairman and Chief Executive Officer of NBC Universal. Bob joined NBC as President and Chief Executive Officer on September 1, 1986, and served as Chairman and Chief Executive Officer of NBC Universal until May 1, 2007. Bob had one of the longest and most successful tenures of any media company chief executive, with more than two decades at the helm of one of the world's leading media and entertainment companies. He has a strong history of philanthropy and community service, for which he has received numerous awards and accolades. He serves on the boards of Polo Ralph Lauren Corporation, Mission Product, LLC, AMC Networks Inc., and is a Trustee of the New York Presbyterian hospital. He is also Chairman and CEO of the Palm Beach Civic Association and Senior Advisor of THL Capital. Bob Wright is also the former member of the Executive Committee of Rand Corporation and a former Board of Director of EMI Group Global Ltd. He is a graduate of the College of the Holy Cross and of the Law School of University of Virginia.

In 2008, Suzanne and Bob were named in Time 100's Heroes and Pioneers category, for their commitment to global autism advocacy. They have also received the first ever Double Helix Award for Corporate Leadership from Cold Spring Harbor Laboratory, the NYU Child Advocacy Award, the Castle Connolly National Health Leadership Award, the American Ireland Fund Humanitarian Award, the Citizens United for Research in Epilepsy 2011 Leadership Award, the Eugene M. Lang, Lifetime Achievement Award from the I Have A Dream Foundation and Moffly Media's Light a Fire Lifetime Achievement Award. In the past few of years the Wrights have received honorary doctorate degrees from St. John's University, St. Joseph's University, Fairfield University and UMass Medical School– they delivered respective commencement addresses at the first three of these schools. The Wrights are the first married couple to be bestowed such an honor in St. John's history.

The Wrights have three children and six grandchildren.