

**SENATE APPROPRIATIONS SUBCOMMITTEE ON  
LABOR, HEALTH AND HUMAN SERVICES,  
EDUCATION  
HEARING**

**COMBATING AUTISM:  
UNDERTAKING A COORDINATED  
RESPONSE**

Testimony

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Good afternoon, Mr. Chairman. I am Bob Wright, Chairman of the Board of NBC/Universal and Vice Chairman of the Board of the General Electric Company. But I appear before you today in another capacity, as co-founder of Autism Speaks and as a grandfather of child with autism.

Our grandson, Christian, was diagnosed with autism in 2004. Helpless, we watched him slip away into the cruel embrace of this disorder. My wife, Suzanne, likens it to a kidnapping, as if someone had taken away the life Christian was meant to live. We all want nothing more than to have him back where he belongs, restored to his family.

Since the diagnosis, our family has been on a mission to learn all we could about autism, and to help ensure our grandchild received the best therapy and treatments available. What we discovered, however, was just how scarce the resources are for parents dealing with autism, and how thin the knowledge. We had so many questions, and instead of answers, we confronted a bewildering array of theories and guesses.

Here's what we do know about autism.

According to a recent CDC report, autism is now diagnosed in 1 in 150 children in the U.S., and a shocking 1 in 94 boys.

A decade ago, experts estimated the prevalence of autism to be 1 in 2,500.

This year more children will be diagnosed with autism than with AIDS, diabetes and cancer combined.

Autism costs society the American economy more than \$35 billion in direct and indirect expenses each year, according to a Harvard School of Public Health study. And caring for a child with autism can cost over 3 million dollars over the person's lifetime.

Frankly, Mr. Chairman, we were shocked that a disorder as prevalent as autism commands so little in terms of resources devoted to research and treatment, when compared to other, less common disorders.

For example, leukemia affects 1 in 25,000 people but receives research funding of \$310 million per year;

Pediatric AIDS affects 1 in 8,000 children; its funding, \$394 million per year;

And then there's autism, which affects 1 in 150 children and yet NIH research funding is a paltry \$108 million.

To help close this gap, we launched Autism Speaks in February 2005 to help raise the funds that will quicken the pace of research. Mr. Chairman, we also worked together with thousands of families affected by autism to introduce, pass and have the President sign the Combating Autism Act. This historic act is considered by some to be the most comprehensive piece of single-disease legislation ever passed by the U.S. Congress. It authorizes appropriations of \$920 million over 5 years

for autism research, surveillance, awareness and early identification, authorizing a 50 percent increase in the Department of Health and Human Services' spending on autism.

For Fiscal 2008, the Combating Autism Act authorizes a total of \$168 million to the HHS Secretary for autism activities and within that total provides for three distinct autism-specific line items:

\$16.5 million for the Centers for Disease Control and Prevention to conduct its Developmental Disabilities Surveillance and Research program;

\$37 million for Health Resources and Services Administration to carry out an Autism Education, Early Detection, and Intervention program; and,

\$114.5 million for NIH-funded autism research.

Mr. Chairman, let me elaborate on each of these items.

For the NIH, the funding increases are incremental. Most important, the Act directs NIH to spend those dollars more wisely, according to a Strategic Research Plan devised by an Interagency Autism Coordinating Committee, with consumers and advocates comprising a third of its membership. The Act also directs NIH to ramp up its investment in research into potential environmental causes of autism.

With these new funds CDC can expand its awareness and intervention activities, to reach new parents, health care professionals and health care providers.

Previous investment in CDC has produced the largest-ever surveillance study which established a baseline to measure autism prevalence trends in the United States. These studies need to continue so that we can measure the true changes in autism prevalence over time. It is also critical that funds be appropriated to CDC to fully fund the SEED study, which is the first epidemiological study to search for environmental exposures and exposure-gene-immune interactions.

The Combating Autism Act also creates new and innovative state-based programs in autism education, detection and early intervention. Early intervention can lead to profound improvements in speech, relating and learning. Right now, we consider getting a diagnosis and intervention for a three year old child a success. But we can do better. Through new diagnostic instruments we can reduce the age of diagnosis to within the first year of life. Service provision must keep pace.

Mr. Chairman, the funding increases recommended by the Combating Autism Act are relatively modest at only \$25 million more than the Congressional Budget Office's baseline estimates for HHS's autism activities. But the impact this Subcommittee would have by not just matching those increases but dictating how those funds would be spent would be historic. And by doing so, Mr. Chairman, this Subcommittee would take a giant step toward fulfilling the promise offered to hundreds of thousands of children and their families when Congress passed the Combating Autism Act.

The public health crisis posed by autism requires an extraordinary response. With every new child diagnosed with autism costing an estimated \$3 million over his or her lifetime, we cannot afford to rely on standard, "business as usual" practices. The autism crisis demands a focused, coordinated, and accountable response by our public health agencies, similar to the federal response to the AIDS crisis in the 1990s, with line-item appropriations for autism intervention, surveillance and research tied to a strategic plan.

I am fully aware that the autism community is asking this Subcommittee to do something which many claim to oppose in principle — namely, to appropriate by disease. In fact, Congress already took that extraordinary step when it passed the Combating Autism Act. That act, by authorizing the creation of autism-specific line-item appropriations, recognized that autism deserves, no, requires, this approach because of the combination of autism's high prevalence, coupled with historical neglect exemplified by the failure of the NIH to appropriately prioritize autism within its portfolio.

Last year, the House and the Senate unanimously passed the Combating Autism Act. We urge you to make funding the implementation of the CAA an equally bipartisan and universally supported effort.

Thank you, Mr. Chairman.