



Autism Speaks, It's Time to Listen

An Interview with Suzanne and Bob Wright, Co-Founders, Autism Speaks

EDITORS' NOTE Bob Wright is Senior Advisor at Lee Equity Partners and Chairman and CEO of the Palm Beach Civic Association, and served as Vice Chairman, General Electric, and Chief Executive Officer of NBC and NBC Universal for more than 20 years. He also serves on the boards of the Polo Ralph Lauren Corporation and the New York-Presbyterian Hospital. Bob is a graduate of College of the Holy Cross and of the University of Virginia School of Law.

Suzanne Wright is a Trustee Emeritus of Sarah Lawrence College, her alma mater. She has received numerous awards such as the Child magazine Children's Champion Award, Luella Bennack Volunteer Award, the Spirit of Achievement award by the Albert Einstein College of Medicine's National Women's Division, and the Women of Distinction award from Palm Beach Atlantic University.

ORGANIZATION BRIEF Founded in 2005 by Suzanne and Bob Wright, Autism Speaks (www.autismspeaks.org) is the world's leading autism science and advocacy organization. It is dedicated to funding research into the cause, prevention, treatment, and to finding a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

How has the vision for Autism Speaks evolved? Where is the work focused today?

Bob: We started with the premise that we could make things happen if we built awareness. As a result, we have benefitted to the tune of \$370 million in donated media from our partnership with the Ad Council. We have since tripled the awareness level in the U.S. for autism.

Suzanne: We will be launching a new Ad Council PSA campaign called Maybe, which is aimed at underserved communities whose children reach the age of six or seven years before getting diagnosed. This new campaign will empower young parents to talk with doctors about the signs of autism.

Bob: Our autism prevalence estimates now are 1 in 88 in the U.S.; when we started, it was 1 in 166 – a 78 percent increase in six years.

After getting people to recognize the prevalence of autism, it became about asking for early diagnosis and early treatment, which can improve the lives of these children by a margin of 50 percent in terms of academic ability and IQ.

Does the awareness really bring about action?

Bob: Awareness helped get the Combating Autism Act passed in 2006. We worked with Congress and President Bush to create a \$921-million program over five years, most of which went to the NIH earmarked for autism research. In 2011, we worked with Congress and President Obama to gain a three-year \$720-million extension. In addition, President Obama included more than \$100 million for autism in his stimulus program.

Suzanne: So far, \$1.7 billion has been committed, but the frustration I have is in getting the focus put back on mental health. President Obama pledged he would take a serious look at mental health in light of the Newtown shootings. We need the federal government to act on that promise and we have to rally our troops and start a campaign demanding it. No one in this country wants to face that issue.

Bob: We have also had great support globally, from countries like Bangladesh, Qatar, the Arab League, Albania, Jordan, and Panama.

Medicine outside of the U.S. is overseen by the World Health Organization, which doesn't have a presence in the U.S. but is funded by the U.N. We got them into the autism business and with their help, a resolution was passed recently for all governments to take urgent action to improve access to long-term health care, education, training, intervention, and programs for autism spectrum disorder and other developmental disorders.

We also have 32 states with autism insurance reform laws on the books, which is partly due to national awareness.

We funded a study in South Korea with scientists from Yale, Canada, and South Korea. They concluded that the autism prevalence there was 1 in 38. They had examined school and medical records but then went into the schools and provided autism screening to children who had not been suspected of having autism. In the U.S., the CDC has not taken that extra step of screening the general population to monitor prevalence. We offered to pay the CDC to do a version of the South Korea study in South Carolina, utilizing their methods. It's underway now and will take a few years to complete. I predict the resulting prevalence numbers will be closer to one in 38 here, as well.

The Chinese government was also really interested in the results coming out of South

Korea, so they committed \$5 million to a study on prevalence in China. They came to us to discuss the Beijing Genomics Institute, an organization utilizing whole genome sequencing, and said they will sequence all 10,000 participants for whom we had collected histories. We anticipate having a paper on this soon.

The genome sequencing allows for a breakdown of autism genes – it shows that there are at least a dozen or so individual autisms as opposed to one.

If we can develop and show the phenotyping and genetic make-up of a bunch of different autisms, the scientific community will get access to all of this for virtually nothing, and they will be able to drill down in these areas where cellular work has already been done and learn much more about the genetics and biology of autism.

Does the corporate world support these efforts?

Bob: Home Depot, Microsoft, and some others provide insurance. Our biggest corporate sponsor is Toys "R" Us – they have raised more than \$16 million for us since 2007. TJ Maxx has been a strong supporter – they raise about \$1.5 million in their stores every year. White Castle is doing roughly \$500,000 a year now. Dollar General has raised \$2 million over the past few years. However, in general, getting corporate support has been a challenge.

Is the research moving forward with the speed you had hoped? How much real progress has been made?

Bob: Science at the international level is very slow.

The NIH is the world leader in this sector and while every country tries to do something, the U.S. with its \$35-billion budget exceeds that of the rest of the world. Out of that \$35 billion, cancer receives \$5.5 billion, AIDS receives \$3 billion, and we're getting about \$169 million a year. Yet all evidence suggests that autism is actually more prevalent than HIV/AIDS in the U.S. and globally.

It's tough to move these people along because certain diseases and conditions have been around a lot longer than we have and they all have advocates inside the walls of the NIH.

Suzanne: If autism was contagious, it would be on everybody's radar.

What is a realistic end goal?

Suzanne: If AIDS advocates can get as far as they have gotten, why can't we do the same thing for kids and adults living with autism? We need a national plan for this national health crisis. ●