

Leveraging Awareness Into Progress

An Interview with Bob Wright, Co-Founder, 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, AMC, and the New York-Presbyterian Hospital. Wright is a graduate of College of the Holy Cross and of the University of Virginia School of Law.



Suzanne and Bob Wright

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

How are we faring in the fight against autism today?

We've done a good job at trying to build awareness around autism. We started from scratch.

There were other groups that preceded us. But the level of awareness was minimal, and there was very little scientific and medical research being done by the NIH and other organizations.

Dr. Herb Pardes, former CEO of New York-Presbyterian Hospital, is on our board. He recently said that when you start an activity and you have very little going for you, you're going to have to do a lot of things to get the process moving that seem strange. Some of those things are going to work and those will become the cornerstones of your future success.

We started out with the help of the Ad Council and a lot of people in media and advertising, and got off the ground in a big way. We have significantly raised the awareness of autism in the U.S. and outside of the country.

We have had the help of thousands of volunteers. We have 100 walks in the U.S. with more than 400,000 people participating. Outside

of the U.S., we're an NGO with the United Nations. We are connected directly now to the WHO, which is the arbiter of health outside the U.S. We are able to reach out to developed and developing countries to create anchor posts in different parts of the world.

On the issue of research, we have spent over \$220 million that we raised, and we have leveraged that to approximately \$1.5 billion of medical and scientific research.

We have also used our political advocacy to drive significant federal and state legislation.

On the federal side, we drove the passage of the Combating Autism Act, which was set up in 2006 and extended in 2012. Those bills have generated \$1.7 billion of federal government health funding, of which \$1.2 billion has been direct NIH funding for autism.

We have also driven insurance bills in 34 states in the country that account for 75 percent of the population of the country for insurance to cover speech, occupational, and behavioral therapies, which are the critical elements of autism treatment.

In addition, our research has shown us that if we can get a diagnosis by age two-and-a-half and provide significant speech, occupational, and behavior therapy up until those children are elementary school age, they will have a 50 percent chance of matriculating through school at, or near, age level with the right support.

Now we're trying to work outside the U.S. to leverage the work that is being done there to help create faster progress.

We have an academic medicine mentality in the U.S. Everything is peer-reviewed but most grant requests are closely aligned with prior projects. We need to take some dramatic steps to accelerate the pace of discovery. The biggest step we are starting right now is whole genome sequencing.

We have agreements with Google to help us with this project using the Google Cloud for storage and Google engineering services to help with the bioinformatics necessary to process the six billion pieces of information that you get with the sequencing of each genome. Our program is designed to sequence 10,000 genomes from individuals with autism and their families.

Some say this is risky, but we're at a point where we need to take big risks to get big moves.

We have very good international relationships now and I am hoping to add significant Chinese support to our efforts. I could use a lot more corporate support and I always need political help, no matter which country it comes from.

We now also have 230 or so full-time employees with Autism Speaks.

It appears as if the numbers of those being diagnosed with autism are going up. Is that a result of the ability to detect it more readily today?

When people ask that, I always have to ask, does it make a difference?

The number the CDC uses is about 1.5 percent – at the end of the year, that number will be 2 percent. Some of the increase is that there is better diagnosis and awareness but a significant portion of it is unknown. This is a startling prevalence.

We have a situation that is being ignored statistically but cannot continue to be. It's tough to rally a Congress or government around something they're not personally familiar with, but we desperately need a national plan for autism.

Are you optimistic that you will get the support you need?

I predict that in two years, we will have identified at least six different autisms and we will have phenotypes for them.

When we go to a drug company with that information, they will be thrilled to see the phenotyping that matches up with each autism. This will put us on a fast track of development and, in turn, will significantly improve our knowledge of discovery treatment for all autisms.

Autism is a spectrum disease – we know that no two children are the same. Yet, they're in the same spectrum, so we have to break that down into different types of autism if we can. Whole genome sequencing is the fastest approach that we have.

Is it difficult to keep the effort at such a high level?

Sometimes, but my wife Suzanne works harder and longer than I do. We both are determined to keep moving quickly but also thoroughly. ●