

A Strong Voice



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

EDITORS' NOTE Bob Wright is Senior Advisor at Lee Equity Partners, 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, RAND Corporation, and the New York-Presbyterian Hospital. Bob is a graduate of College of the Holy Cross and of the Law School of University of Virginia.

Suzanne Wright is a Trustee Emeritus of Sarah Lawrence College, her alma mater. Suzanne 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.

In 2008, Suzanne and Bob were named to the Time 100 list of most influential people in the world for their commitment to global autism advocacy. They have also received numerous awards, including the first Double Helix Medal for Corporate Leadership, NYU Child Advocacy Award, Castle Connolly National Physician of the Year Award, and The American Ireland Fund Humanitarian Award. In May of 2010, they received Honorary Doctor of Humane Letters degrees from St. John's University in Queens and delivered the commencement address as the first married couple to be bestowed such an honor.

ORGANIZATION BRIEF *Autism Speaks* (www.autismspeaks.org), founded in 2005 by Suzanne and Bob Wright, is dedicated to increasing awareness of autism spectrum disorders; funding research into the causes, prevention, and treatments for autism; and advocating for the needs of individuals with autism and their families.

What progress have you made in addressing the stigma about autism?

Bob: The awareness we have generated has been positive in that regard. We always say, this is a "no-fault" disorder. People with autism in their family now feel comfortable acknowledging it and seeking support.

One in every 110 children is now diagnosed with autism. Why has the number of children diagnosed with autism increased so drastically?

Bob: Our Chief Science Officer, Dr. Geraldine Dawson, has publicly stated that better diagnosis, more awareness, and more people coming

forward probably can account for up to 50 percent of the increase, but no more. So there is still an inability to explain the full scope of the increase in autism.

It may have something to do with aspects of the lifestyles we all live today versus 50 or 60 years ago, including environmental "triggers" – anything that isn't genetic that might impact underlying genetic factors. But it is challenging to explain and cannot be pushed aside simply based on diagnosis – that just doesn't fly. That's why we're funding a wide range of research to look at a variety of potential causes. There are many "autisms" – similar, in many ways, to cancers – and they likely have different causes. That makes this an especially daunting task.

Has enough attention been paid to this cause and is the funding coming in at the levels you had hoped?

Bob: The Combating Autism Act was the declaration of a formal war against autism and it formalized a lot of work being done at the National Institutes of Health (NIH). It has produced over \$1 billion of research for autism.

We have to get it renewed because it expires this year. There is great support for renewing it even though we're in a challenging fiscal period. We need at least \$250 million per year to keep up the level of activity. The NIH will hopefully take more of a leadership role in outlining its plans and expectations for the money, and will be cheerleaders for us in Congress as they explain the benefit of all of the work that has been done.

In addition, Autism Speaks has committed \$160 million, most of it on medical and science research. We have provided substantial encouragement to other private sources to fund programs, which has brought in several hundred million dollars.

For every dollar we put into medical and science, we actually get a 10-to-1 return in terms of funding. So our money is very successfully leveraged with the help of other foundations and the government.

Is enough being done to address the growing needs of adults with autism?

Suzanne: Children with autism grow into adults with different, lifelong needs, from housing and transportation to job training and

placement. As a society, we simply aren't equipped to meet the needs of the growing number of adults with autism. We need to give them the tools and opportunities to maximize their potential and lead fulfilling, productive lives.

We're leading a consortium of groups called Advancing Futures for Adults with Autism to create and advance a policy agenda to address these important issues.

As the organization has evolved, have you increased your global focus?

Bob: Suzanne has driven this initiative with the United Nations and the establishment of World Autism Awareness Day on April 2. Autism is in every country – some prevalence is measured, but a lot is not.

We're an NGO authorized and supported by the UN, and that facilitates us going to other countries to try to develop screening, diagnostic, and treatment programs.

We have also been able to get the World Health Organization to focus on autism. That means a country can talk to them about autism and apply for a grant, because it's now an acknowledged issue.

Suzanne: At the opening of the United Nations every year, I invite the women of the world to talk about autism, which has been very successful.

Globally, it's not so difficult because people get it. For instance, we had a seminar on April 6 at the United Nations sponsored by the Bangladesh mission. We invited all of the UN missions to participate in a global discussion of autism. We also have strong support from Sheikha Mozah in Qatar. Autism knows no borders and the world is starting to finally address this global health crisis in a meaningful way.

In the early days, could you have imagined Autism Speaks would have had the type of impact it has had?

Bob: Creating awareness has stimulated public and foundation spending, and has fostered a unity among people across the country affected by autism. It has produced great satisfaction as we have been able to get people talking to their communities, politicians, and the media, as well as to potential corporate sponsors, about autism. That is how you build strength.

Suzanne: All of the families facing autism didn't have a very strong voice – they were on their own. Now they are part of a big movement, which gives them hope. But it is their strength, passion, and determination that will always drive this movement. ●