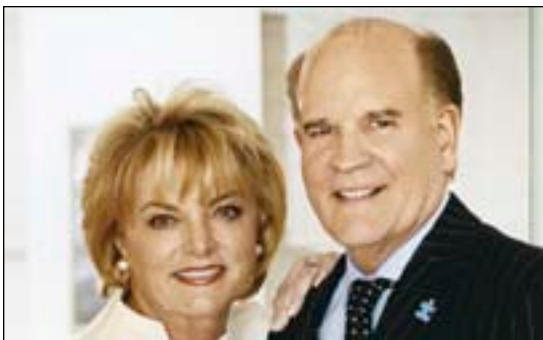


# How To Make a Difference

## Autism Speaks. The World is Listening

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



Bob and Suzanne Wright

**EDITORS' NOTE** Bob Wright served as Vice Chairman and Executive Officer of the General Electric Company, and also Chairman and Chief Executive Officer of NBC Universal. He 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. Bob serves on the board of directors of the Polo Ralph Lauren Corporation, and is a Trustee of RAND Corporation and of the New York Presbyterian Hospital. He is also a Senior Advisor of THL Investment Capital. Bob is a graduate of College of the Holy Cross and of the Law School of University of Virginia.

Suzanne Wright has an extensive history of active involvement in community and philanthropic endeavors, mostly directed toward helping children. She serves on the boards of several non-profit organizations and is also 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, and the Spirit of Achievement award by the Albert Einstein College of Medicine's National Women's Division.

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.

**ORGANIZATION BRIEF** Founded in 2005 by Suzanne and Bob Wright, Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)) 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.

**When you initially founded Autism Speaks in 2005, based on a very personal experience with your grandson, were you surprised at how much needed to be done in this regard?**

**Bob:** We were surprised at how little there was being done. We could not believe the prevalence. We also recognized that when we saw what was being done and we realized what had to be done for Christian, we couldn't figure out how other people could possibly afford this, especially since insurance didn't play any role in it.

We began to travel around the country to find out more, and every time we showed up some place, we got more agitated. We let people know that we were interested in trying to make a difference. Bernie Marcus (co-founder of Home Depot and founder of Atlanta's Marcus Autism Center) expressed interest in getting involved and sat down with us and Dr. Gary Goldstein (President and CEO of the Kennedy Krieger Institute in Baltimore). He had put a ton of money into autism, but was disappointed that he could not get any laws changed, especially insurance reform, and he was overwhelmed with people coming to his clinics who he could not fully service. So this frustration formed the basis for our partnership. He gave us \$25 million to establish Autism Speaks.

We knew we could help our grandson, but we were worried about the other families that were going through this. We saw low-hanging fruit all over the place – in science, in medical treatment, in care, in diagnosis, and in the lack of hospital resources.

**Suzanne:** I've never seen a group of parents and people in such desperate shape. Autism was taking a terrible personal toll on these families, there was no insurance coverage for their children's treatments, the school districts were denying them help, and the medical establishment was denying them – they were discriminated against on all levels. The Centers for Disease Control (CDC) was putting out the

prevalence numbers, but as the public health crisis was growing, they weren't even making parents aware of the early signs of autism. The American Academy of Pediatrics now recommends that all babies be screened for autism at 18 and 24 months, which is a huge accomplishment.

**Bob:** The CDC showed us a track of increasing prevalence, which was statistically shocking. Twenty years ago, it was approximately one in 2,500; now, it's one in 110 and it's one in 70 boys.

We have accomplished a great deal, but we've also increased the breadth of what we're trying to do, which makes it more complicated. We have moved beyond awareness, trying to get pediatricians more aware and engaged, and from getting the NIH involved in a major way. Now we're into education, the discriminatory practices of insurance companies, and dealing with teenagers and young adults, including getting housing for adults. All of those things are extremely troubling and require small armies of people to address each of those areas because they all have a lack of funding and enormous liabilities associated with them.

**Suzanne:** We have been very successful in the effort to change state insurance laws. Now 15 states require insurance companies to cover behavioral therapies for autism, including diagnosis and other critical services. There is also similar language in both the proposed House and Senate health care reform bills. That is one of the biggest things Bob and I feel we can do for this community, because their insurance is not good – people are paying significant amounts for insurance coverage, but the expensive treatments their children desperately need are not covered. It's an abomination.

**You're now five years down the road and you've had so much impact in so many areas, but you still have a lot of progress to make. Is it frustrating that things don't always happen in a more timely fashion?**

**Bob:** I am used to dealing with the government and with products that take a long time to develop as a result of my time with GE. But we have to build out an organization that is solid enough to address these various points. We're fighting wars on different fronts now, and we're accomplishing a lot. I've worked with bureaucracies all my life and it can be very frustrating, because they do not like to move quickly.

**Is the stigma associated with autism starting to fade?**

*Bob:* I certainly hope so, because I've moved past it. When I meet people, I'm pretty aggressive with them. If they want to help, I suggest they stand up and be counted. If you're concerned about your child with autism, act, because the best thing is to be in front of the cause and not behind it and hiding.

Hollywood has been a very big disappointment on this issue, and there are a lot of people who have positions of power in science, medicine, and business who are not doing their share. I constantly look for folks like Duncan Niederauer, Mel Karmazin, and Phil Geier – people who stand up and recognize that this has to be addressed.

The stigma is still there, but at the more basic level of young people and parents, it's not there anymore. They talk about it among themselves and with their pediatricians – it's not a bad word; it's a condition that needs to be addressed. So we're getting through, but there are people who have a position of power that are still a little bit on the hard-to-get game.

**Today when you're having a child, there are mixed opinions on things like getting vaccines. Is the information being streamlined enough where we're getting a consensus on what is right?**

*Bob:* The vaccine schedule has dramatically changed over the past fifteen years. Our position is that vaccines save lives, and we certainly believe in childhood vaccines. But parents have to be alert; every child is different and all the vaccines are the same. People over 40 don't understand the number of vaccines being rushed into the under-two-year-old category. The American Academy of Pediatrics is recommending 34 vaccine injections from birth to age 6, and many of these doses are given at the same time. This is compared to 15 years ago when it was closer to fifteen. Most people who are now over the age of 50 did not receive any vaccinations before they were two years old. I always tell parents to use common sense. If your child has any potential immune condition, then you should talk to your pediatrician and ask to spread these vaccinations out over a longer period.

**Initially, there was very little funding going into this cause. Is there a better understanding now of the type of dollars that are needed?**

*Bob:* We're not there yet. We need to be in a situation where we have a program with a strategic plan that is spending somewhere in the neighborhood of \$600 or \$700 million dollars a year – that's just on basic research. We need another chunk on treatments, especially centers of excellence and things of that nature. So we're trying to get there, but we have more work to do. President Bush signed the Combating Autism Act in a Republican Congress and President Obama has authorized an additional \$116 million of NIH spending for autism as part of the stimulus plan, and

he is also supportive of both health bills in Congress, which provide significant benefits for people with autistic children. I hope this bill passes, because the areas we're concerned about are not controversial and would be given the attention. But our goal is to see \$1 billion a year spent, between private and government money, on science and treatment.

**Is it difficult to get corporate funding?**

*Bob:* It is hard to get the corporate sponsorships we need. One company that has jumped on the bandwagon and touts what a big success it has been for them is Toys"R"Us. Because their customers are mothers and their kids, the



*NBC News' David Gregory, Bruce Springsteen, Suzanne Wright, Jerry Seinfeld, and Bob Wright at the Fifth Concert for Autism Speaks at Carnegie Hall in Manhattan on November 17, 2009. The event, featuring performances by Seinfeld and Springsteen, raised nearly \$1.7 million to support the work of the world's largest autism science and advocacy organization.*

salespeople and store managers have been very appreciative of it, and we've raised quite a bit of money working with them. There is no reason why others can't do this.

**Has it been challenging as Autism Speaks has grown to maintain that control or have you had to broaden the reach and grow the organization from a people perspective?**

*Bob:* We have nearly 200 people full time, and we have thousands of volunteers. It is a challenge, as it is in any business, when you're growing rapidly to make sure you're being as thoughtful and efficient at spending your money as you were when you only had a few people. We have very good people, but there is always a tendency to become bureaucratic, and that can kill any organization, especially in a growth area. So we have to be efficient, but we can't be rigid. We need people with passion who really want to see something accomplished, and we have to be very careful as an organization that we don't end up just counting beans, because that doesn't get anything done.

**Have there been any advancements in education that are helping to create the right environment for the kids?**

*Bob:* Some of the awkwardness here is that institutions – and education is an institution – tend not to look beyond their own gates. You would think they would be our biggest partners because they're the biggest beneficiaries. If a child is diagnosed in first grade, which is far later than they should be, the school district is

going to be faced with huge difficulties dealing with that child that, most likely, they will not be able to handle and that will probably end up in some type of litigation with the parents. The school districts should be working with us ahead of time to develop special daycare programs, so when the children get into the educational environment, they're better diagnosed and we know more about them so we can place them in appropriate classroom situations, which will make their lives at the elementary school level a great deal easier.

*Suzanne:* If a child is fortunate enough to get into one of the private schools, many have hundreds on the waiting list. I was very fortunate to know Cardinal Egan when the Diocese in New York was closing some schools. I told him we needed a larger space for the McCarton School for children with autism, which my grandson attends. It took us a few years, but now they have 30,000 square feet in a 100-year-old school with five stories that is perfect for our children. But they still can't take on many more kids because they don't yet have the infrastructure. They need therapists, speech pathologists, and occupational therapists. We're trying to develop our resources, but in the meantime, it's a very difficult situation for the parents.

**Is it challenging to take the time to appreciate the progress you've made, or is there so much left to do that you can't look back?**

*Bob:* You have to. In business, you have to go back periodically and assess what you've done in order to give yourself the energy to go forward.

*Suzanne:* We're currently putting our five-year anniversary synopsis together summarizing what we've accomplished, and it will make everybody in our organization, as well as our sponsors, feel very proud and energized to keep moving.

*Bob:* If you don't look back, you're apt to make the same mistake over and over again. But I also think looking back invigorates you; you can see that if we were able to accomplish those things, we ought to be able to accomplish the goals we have in front of us. So looking back and going forward go hand in hand.

*Suzanne:* Our international involvement has been a big plus for us. We have an agreement with Qatar, Albania, the Philippines, and Ireland, and are working with Saudi Arabia. We worked with Qatar to encourage the United Nations to establish World Autism Awareness Day, which is now celebrated annually on April 2. We're declaring the Decade for Autism awareness and action with the goal of having countries raise a combined total of \$100 million to fund research and services in their countries to take autism on in a full-scale effort. Autism is a growing public health crisis, not only here, but around the world. This devastating disorder knows no boundaries, and it doesn't discriminate. It is going to take a global collaboration to win this fight. ●