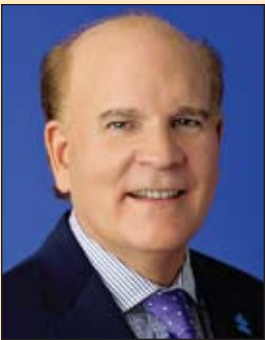


# Making a Difference

## A Voice for Autism

An Interview with Bob Wright and Suzanne Wright, Cofounders, Autism Speaks



Bob Wright



Suzanne Wright

**EDITORS' NOTE** In addition to his post with *Autism Speaks*, Bob Wright is Vice Chairman of General Electric. Formerly the CEO of NBC for more than 20 years, Wright has received numerous awards and accolades for philanthropy and community service, most recently the 2005 Humanitarian Award from the Simon Wiesenthal Center. He is a member of the board of directors of the Damon Runyon Cancer Research Foundation, is on the board of governors of New York-Presbyterian Hospital, and is a member of the Society of New York Hospital Inc. He is a graduate of the College of the Holy Cross and received his LLB degree from the University of Virginia School of Law.

An active philanthropist, Suzanne Wright serves on the board of directors for several organizations, including the Make-A-Wish Foundation of Metro New York, the Laura Pels Foundation, the Inner-City Foundation for Charity and Education, and the Philadelphia-based Champions of Caring Project. She is a graduate and member of the board of trustees of Sarah Lawrence College.

**ORGANIZATION BRIEF** *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. The organization was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism.

### What is Autism Speaks' mission as an organization?

**Bob:** First, it is to build awareness because, when we founded Autism Speaks in 2005, it was simply insufficient. Nothing could account

for the most significant children's developmental disorder in the nation not being recognized. There was a huge gap between reality and perception. So awareness was the first goal. Awareness leads to the ability to raise funds for scientific research to improve our understanding of autism. Third, we provide family services, dealing on a day-to-day basis with parents of autistic children and addressing their needs, as well as those of adults with autism. That gets us into areas like lobbying for health insurance and educational rights. It gets us into the areas of governmental spending, the National Institute of Health [NIH], the Department of Health and Human Services, and legislation at the state and federal levels. We touch all of those areas.

**Suzanne:** We got involved because of our grandson, Christian, who has autism. When he was diagnosed, it was the worst day of my life. We found out that one in 166 children had autism, and I thought to myself, "Why is no one screaming about this? Why hasn't the medical establishment drawn our attention to this – the worst thing that's happening to children today?" We then spent a week working with NBC News and CNBC and MSNBC to tell the country about this epidemic. We went on the *Today Show* to announce the creation of Autism Speaks. Bernie Marcus, the cofounder of Home Depot and the Marcus Institute in Atlanta – gave us \$25 million to get the organization off the ground.

### How has Autism Speaks addressed the stigma associated with the disorder?

**Bob:** I think we've come a long way, but people are still generally reluctant to come out and talk about it. It's important that people who are successful in any sphere speak out, because others will listen to them. So, whether you're a musician, an actor, a writer, a publisher, or whatever, you have to get out there. So many people are hanging back, and it's damaging. They think their children, grandchildren, or other relatives won't get better any faster if they speak up. But by getting involved they might be able to prevent this from happening to other children. It doesn't seem to click with people as much as it does with more traditional diseases.

**Suzanne:** That said, there is progress. Due in part to our efforts, the UN has proclaimed April 2nd, in perpetuity, World Autism Awareness Day [WAAD]. This is a global epidemic. It's no longer a secret. Now we have a global stage, and we're going to stand on that stage and have the world help us.

### Do you currently have enough funding for all of the organization's initiatives?

**Bob:** Oh no. The funding is not even close to where it needs to be. The NIH's autism-related funding is three tenths of 1 percent of its budget – and this is the most significant childhood developmental disorder. So it's totally out of proportion. We need a push from the government, and awareness drives a lot of that. It has to come from all corners, because it is a bit of a club. Once you're in, you get funded. If you're not in, you don't get funded.

**Suzanne:** There's no sense of urgency at the NIH.

**Bob:** While they recognize the seriousness of autism, they believe other matters are more urgent.

**Suzanne:** Back in the '50s, one in 3,000 were getting polio, and it became a national health crisis, led by Franklin Delano Roosevelt and the March of Dimes. We have Autism Speaks, and it's not just speaking anymore – it's roaring. Our country has to do for autism what it did for polio.

### It has to be frustrating to not yet see the results you need and the attention autism deserves.

**Bob:** We need substantial resources – probably just shy of \$1 billion a year from the NIH. That's what it would take to have a major program. The good news is we have some wind behind us now, due to the lowered cost of genetic studies. That allows cell biology work to take place much faster and cheaper than it could have 10 years ago. Alzheimer's, Parkinson's, and autism have all suffered a great deal due to the high cost of genetic research. But that's getting a lot better. We're also picking up some very well trained and novel researchers. Autism is a tricky one, because multiple genes are involved. A quick answer isn't going to pop out, but we're starting to see motion. That said, we need financial support.

**Suzanne:** The presidential candidates are also making pledges. Hillary Clinton said she'll dedicate \$700 million to autism research if she's elected. Barack Obama announced that he would dedicate \$1 billion and appoint an "autism czar." We'll see what John McCain will promise.

*Suzanne Wright with Sarah Jessica Parker, one of Autism Speaks celebrity supporters (above); Suzanne Wright with her grandson Christian, who inspired Autism Speaks (facing page)*

**Before your grandson was diagnosed, did you ever dream that autism would be such a part of your life?**

*Bob:* We never dreamed we'd be doing this, but today we have 180 full-time employees at Autism Speaks. They're on the ground, doing regional and local work. We want our fundraising to be tied to awareness. So we have local activities through which lots of people make smaller donations. That helps rid the disease of its stigma. We need people in Cheyenne, Wyoming, for example, to talk about autism with their elected officials and make the disorder prominent in their region.

**After working in the private sector, Bob, what is it like to petition corporate leaders to join this cause? Have they responded in positive ways?**

*Bob:* If people don't have a direct touch with autism, it's hard for them to make large gifts. We have a wonderful sponsor in Toys 'R' Us. Last year, they launched a fundraiser, slated to raise \$250,000, which ended up raising over \$1 million just from employee gifts. Toys 'R' Us CEO Jerry Storch was overwhelmed. Why wouldn't businesses react to this epidemic? It affects women of all ages, particularly new mothers. This is particularly a women's issue, because these children need so much maternal care.

*Suzanne:* There is a very high divorce rate among parents of autistic children.

*Bob:* It's a destructive disorder on many levels.

**Why can't we make more progress? Is it a political issue, as you implied earlier?**

*Bob:* Autism is discriminated against by most group insurers. They feel it's very hard to underwrite the reimbursement for therapies and care unless there's an adequate history of benefit. And there isn't, to their satisfaction. So they exclude it from their policies. Hospitals can't get much reimbursement for caring for a child with autism if they're addressing an autism-related issue. Even the diagnosis of autism is restricted in reimbursement. It's not like juvenile diabetes or leukemia – fully insured people are happily invited into hospitals for those conditions. Autism is not that way. Hospitals have very stringent rules about the inability of doctors to take on patients whose diagnoses aren't reimbursable. So that's a fundamental issue that we are addressing on a state-by-state basis. How can someone decide that one person's tragedy is insurable, while another's is not, based on underwriting capabilities? The underwriting capability wasn't there for AIDS either 20 years ago. But now that billions of dollars have been poured into it, things have changed. So we need momentum.

*Suzanne:* Generally speaking, the community of parents with autistic children is desperate; they're broke and powerless. I've never seen a community more desperate. They have second and third mortgages on their homes or they're moving in with their in-laws, because they have to pay for their autistic children's health care and education. That's why we started Autism Speaks: The community was so isolated, they were like lepers. Now, we have a charter school for autism in New York City, but it's just two years old and there are thousands of children on the waiting list.



**Obviously, the end goal is a cure for autism. But how do you evaluate your incremental success along the way?**

*Bob:* If a child is diagnosed with autism before the age of two and a half, and given significant behavioral, occupational, and speech therapy through the first grade, there is a 50 percent chance that that child will be able to matriculate through grammar school into high school at relatively appropriate age levels in an in-place class with some help. If the child is diagnosed in first grade, there's very little chance that child is going to be able to matriculate through a public school. The child will be assigned to special education programs and may never go anywhere. That child might drop out altogether. First grade is the average age of diagnosis for African Americans, Hispanics, and people whose first language is not English, as well as the very poor. Of the 320 million people affected by autism, 120 million fall into those categories and they're at a severe and unfair disadvantage. So early diagnosis is one metric we use to measure our success, but it's going to require insurance. Most people can't afford the therapies I outlined, because of the quantities in which the child will need them. People need to be able to afford the diagnosis and the therapy. So we've turned this around a little bit, but we need the school districts to start screaming at the legislators with us. We would be relieving them of one of their most significant problems which, knowing the statistics, is having to make the diagnosis in first grade. Every time that diagnosis is made, they know they're in for a long winter. It's too late for that child and they have a difficult problem on their hands, which could have been avoided in half the cases. That would take an enormous burden off the school district.

**Is autism a global issue?**

*Bob:* Autism knows no geographic, economic, or social boundaries. We'd love to be able to point to an environmental issue, but we don't know enough about autism. Most countries have some form of a national health organization, and you'd think they'd be able to knock out the data collection process, but that doesn't happen. Of course, when you talk to people in national health organizations, they nod and tell you it's a huge problem.

**Autism, if anything, has seemingly strengthened your family.**

*Bob:* It's as rough on our family as it is for everyone else's. Unfortunately, autism is not a uniter; it's a separator. It takes so much time and attention that people become exhausted with it. That's why marriages break down. It's generally not the fault of either party, but the circumstances are challenging, particularly for the siblings. They don't have a brother or sister like other people do, and they have trouble explaining what the problem is. It's very difficult to handle.

It's important to say that autism is a no-blame condition. If people ask me what a young mother can do to prevent autism, there is nothing I can tell them. I could not answer that question in any concrete way. We don't know what causes it. So if we could remove the blame from the situation, it would help things a lot. It isn't the mother's fault or the father's fault; it isn't that simple at all. Guilt can hurt a lot.

*Suzanne:* I hear many mothers blame themselves for waiting too long to have their children diagnosed.

*Bob:* We have probably helped the awareness effort, but we can't measure it yet. Hopefully we'll see the percentage of children being diagnosed in the first grade go down. That would mean we have accomplished a lot. But we need a little more time to collect data.

**It must be difficult to remain objective in this line of work.**

*Bob:* It's hard, because it's an emotional issue, and emotions can burn you out. Plotting our success helps us sustain our energy for longer periods. We just keep working hard, and we end up getting somewhere. We don't have to cure autism to achieve something big here.

Sometimes I see a child with autism, and I wonder if we've done anything to help that particular child today or yesterday – and if we can do anything for that child tomorrow. That is the sad thing about being in this line of work.

**Do you ever take a moment to step back and appreciate the impact Autism Speaks has already had? Or are you constantly looking forward?**

*Suzanne:* You were pretty excited about the Combating Autism bill. We got that. It was pretty exciting when the UN announced World Autism Day, as well.

*Bob:* The best moment is when we accomplish something and I can evaluate it. We committed to putting in five years on this issue. You need a boundary – something to get to. Our goal is to have this organization run like a corporation. We want it to be so well established and staffed with the right people that it can perpetuate itself beyond its founders, much like the March of Dimes has. That would be a real accomplishment. ●