

SPECIAL REPORT

Autism Speaks: the United States pays up

In recent years, autism has become the golden child of the fund-raising circuit. **Meredith Wadman** looks at a US public-relations success that is driving research funds and expertise towards this childhood condition, and asks who is missing out.

Toni Braxton, Matthew Broderick, Bill Cosby — perhaps not names you would associate with social or communication difficulties, and yet in one night, they helped raise \$1.45 million at a fund-raiser for research into one of the least-understood disorders affecting children: autism.

Star-studded events such as that fund-raiser at New York's swanky Lincoln Center in April are the latest front of a public-relations battle to raise money for research into childhood diseases. In the United States, it's a battle that autism seems to be winning.

"I was sitting in the nosebleed section and it was \$1,500 a ticket up there," recalls neurologist Gary Goldstein, president of the Kennedy Krieger Institute in Baltimore and chair of the scientific advisory committee for Autism Speaks, the group that organized the event. Goldstein recalls a 2005 Hollywood fund-raising concert featuring Jerry Seinfeld and Paul Simon. "Every four months there's something like that, and that doesn't count all the golf classics," Goldstein says.

In less than three years, autism has emerged from relative obscurity on the fund-raising circuit to become the disease *du jour*. The 1,000 biggest US private foundations nearly doubled their autism-related giving to \$2.7 million between 1998 and 2005, according to the New York-based Foundation Center. The Autism Society of America, the founding father of autism groups, has also seen its budget grow steadily to \$20 million. More striking are the contributions of two newcomers: Autism Speaks alone raised more than \$33 million in 2006, its first full year of operation, and it is well on target to meet its goal of \$55 million in 2007. And the lower-profile Simons Foundation, which began funding autism research

in 2003, has spent more than \$40 million and plans to spend another \$100 million over the next five years.

The commonly held belief that the prevalence of autism is rising may be partly responsible for the cash flow. Previously reported as affecting fewer than 1 in 2,000 children, studies over the past five years have found a dramatically increased prevalence: 1 in 150 eight-year-olds in the United States, according to a February report by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia; or 1 in 86 nine-to-ten-year-olds, according to research in one UK region (G. Baird *et al. Lancet* 368, 210–215; 2006). Experts attribute much of this rise to better diagnosis and reporting and to a broadened definition of autism that includes milder forms of the disease.

The purported link to childhood vaccines (see *Nature Med.* 13, 896–897; 2007) — which has since been denounced by scientists — has also raised the public profile of the condition.

But in the past two years, two people have had perhaps a greater impact on autism's visibility — and coffers — than any other single force, essentially rewriting the book on how to raise money for disease-specific research: Bob and Suzanne Wright, who founded Autism Speaks in 2005 after learning that their grandson had the poorly-understood condition.

Bob Wright, then chairman and chief executive of media and entertainment conglomerate NBC Universal, provided his business savvy and his extensive connections to a *Who's Who* of American stardom. He also brought urgency. "I know how devastating this problem is to families. I am reminded of it daily," says Wright.

In 2004, Goldstein pre-



Making moves: performances from stars such as Toni Braxton have raised the profile of autism.

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Paul Simon and Jerry Seinfeld took part in a 2005 fund-raising concert.



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the rate the group is growing, I'd be shocked if five years from now it's not raising \$100 million a year," observes Goldstein.

Although there are other private groups focused on research and treatment, in the past the public's awareness of autism has not been as high as it could have been. "We were really out there by ourselves on awareness," says Wright. A public-relations coup changed that: last year, the group won a three-year campaign of free, slick publicity from the Advertising Council.

The New York-based Simons Foundation is a very different player. Formed by Jim Simons, a mathematician and hedge-fund billionaire who has an autistic daughter, the organization is spending tens of millions funding individual researchers. It's also financing a \$12-million collection of genetic information and cell lines from 2,000 affected families that will be made freely available to other scientists. The database is called the Simons Simplex collection, and is to be stored at Rutgers University, New Jersey.

In 2006, Simons recruited Gerald Fischbach, the former director of the National Institute of Neurological Disorders and Stroke, as his scientific director. Taking the job, says Fischbach, was "a chance to focus on just the very best science".

Terrific scientists

According to Fischbach, the swell of interest in the disease has been boosted by new genetic techniques and imaging tools. He notes that 11 of the 18 scientists to whom the foundation will soon make three-year grants of up to \$3 million are new to the field. "You couldn't attract terrific scientists if there were no good ways to approach the disease," Fischbach says.

The upward trend in money and interest has been mirrored at the National Institutes of Health (NIH), where funding for autism research has grown from \$22 million in 1997 to \$108 million this year — with 16% of that growth happening since 2003, while the rest of the NIH has been essentially flat-funded.

At the CDC, which in 2000 spent just over \$1 million on epidemiological research on autism, spending has soared to \$15.1 million in 2007. Even the Department of Defense is getting in on the act, spending \$7.5 million on autism



Autism Speaks has rewritten the rules on fund-raising since it was founded by Suzanne and Bob Wright in 2005.

research this year, largely thanks to Autism Speaks, which successfully lobbied Congress for the money on the grounds that autism in military families costs more than \$200 million to treat annually.

The most recent legislative achievement of the autism-research advocacy groups is the Combating Autism Act, which was passed in December 2006 after intense lobbying. It guarantees that the spotlight will stay on the disease, requiring for the first time that the government draw up an annual strategic plan for autism research, identifying gaps and opportunities, all with the input of affected families.

"The advocacy groups here have had an enormous impact," says Tom Insel, the director of the National Institute of Mental Health, which with its \$62-million spending in 2006 made the largest financial contribution of the five NIH institutes that fund autism research. Insel, who also chairs an inter-agency committee that coordinates autism research for the fed-

"There is a dark side to the surge in autism funding."

eral government, says of the advocates: "They hold our feet to the fire, and make sure we are relevant and accountable."

But something distinguishes autism advocates, especially Autism Speaks. "They are actually raising very substantial amounts of funds to do a lot of the science themselves," adds Insel.

Bigger share

That fund-raising prowess has generated both admiration and envy from disease groups that could be considered competitors. For example, since the doubling of the NIH budget ended in 2003, NIH's cystic fibrosis funding has fallen from \$117 million to \$85 million; funding for childhood leukaemia from \$70 million to \$53 million; and funding for Down's syndrome, which is about one-fifth as prevalent as autism, from \$23 million to \$13 million.

"Why is Down's syndrome funding low? Autism I think is a big contributor," says Jon Colman, the chief operating officer of the National Down Syndrome Society. "It's dominating priorities."

Fischbach concedes that what's good for autism has to be bad for others that rely on NIH funding. As long as the biomedical agency's budget continues to be frozen year after year, he argues, pouring new NIH millions into autism necessarily means funding less research on some other diseases. "There is a dark side" to the surge in autism funding, he admits.

But other disease groups say that they have benefited from the rise in autism's profile — some by learning from Autism Speaks' example, and others because autism can coexist with other, lesser-known diseases such as tuberous sclerosis and fragile X syndrome, which causes mental retardation. "People are beginning to talk about the probable genetic basis for most autism. And then often, if not always, they mention fragile X as an example," says Robert Miller, the executive director of the National Fragile X Foundation in Walnut Creek, California, who was pleased when a recent cover story on autism in *Newsweek* made a passing mention of fragile X.

But despite its new visibility and funding, autism remains a little-understood and untreatable disease, and it is unclear how much this well-managed public-relations exercise will change that. Insel is optimistic, though. "Autism has attracted the attention of the most stellar geneticists and neuroscientists," he points out. "So I'm hopeful." ■

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