

## A Race Against Time

An Interview with Daniel L. Doctoroff, Founder, Target ALS

**EDITORS' NOTE** Having lost both his father and uncle to ALS, Dan Doctoroff founded Target ALS in 2010 in collaboration with Bloomberg Philanthropies and financier and philanthropist David Rubenstein to discover and accelerate treatments for ALS, an always fatal disease where there had been virtually no progress made since it was discovered 140 years before. Doctoroff and his team created a new collaborative model of research that has been a major catalyst to understanding the genetics and biology of ALS and has lowered the barriers to entry for new scientific discovery, and has helped to induce over 100 biotech, pharmaceutical, and venture capital firms to demonstrate interest in the disease.

Then in the late fall of 2021, Doctoroff was diagnosed with ALS. He stepped down as the Founder and Chief Executive Officer of Sidewalk Labs, an Alphabet company that accelerates the integration of digital technology into urban environments, and as the Chairman of The Shed, the innovative cultural institution on the Far West Side of Manhattan that he led since inception, to spend his last act on dramatically scaling up Target ALS.

Prior to forming Sidewalk Labs, he was President and CEO of Bloomberg LP, the leading provider of financial news and information, and before that he was New York City's longest-serving Deputy Mayor for Economic Development and



Daniel L. Doctoroff

Rebuilding. Prior to serving as Deputy Mayor, he was a managing director at Oak Hill Capital Partners. He serves on the boards of the University of Chicago and Bloomberg Philanthropies. He is the author of *Greater Than Ever: New York's Big Comeback*.

**What was your mission and purpose in creating Target ALS and will you discuss its work?**

My father died of ALS in 2002, and eight years later, in 2010, I watched my uncle die of ALS, so it was clear that in my family it was hereditary. I knew I had to do something. I was not so much thinking about myself, but I was thinking about my brothers, my cousins, my children, as well as the one in 400 people who will die of the disease if something isn't done.

I started by bringing on board a few advisors, primarily researchers who had some experience in ALS and other neurodegenerative diseases, to analyze why there had been so little progress and to learn the positive lessons from successes in other diseases. We concluded a number of things: first was that this was a very complex disease, requiring a multi-disciplinary approach and most research was done in silos. We developed a concept of funding consortia around important problems and hypotheses in ALS research. Since 2013 we have funded 41 consortia, 25 of which have led to continuing industry drug discovery programs, six of which have already led to clinical trials, and five biotech companies have already

been formed as a result of the research we have funded. The second thing we realized is that you needed to bring new talent into the disease and to do that, you must provide researchers with tools, resources and data to do their work – things like biofluid samples, postmortem tissue, animal models and stem cells. So we established and funded eight core scientific resources that anyone in the world can easily access and all they have to do is pay handling costs. Those resources have now been used on 500 projects by scientists all over the world. The third thing is that, as you know, there is no treating or saving lives if there are not drugs, and drugs need to be developed by pharma and biotech companies. We set out right from the very beginning to engage industry in everything we do since we knew that this engagement would be critical to making real progress.

We have seen an explosion of engagement in and understanding of this disease, and I am very proud that we have played a material role in that. We have become a respected neutral party in the ALS research ecosystem, which enables us to bring diverse coalitions together on projects like developing a toolkit of biomarkers, which are critical to early diagnosis, and better evaluation of clinical trials. We brought together 14 companies, 10 academic centers, 6 ALS organizations, and two venture capital firms to develop a process for identifying and using biomarkers.

We have also built three partnerships with other diseases, one related to Alzheimer's and two related to frontotemporal dementia. There is significant overlap on many dimensions among

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neurodegenerative diseases and we believe partnerships can bring in new talent and teach the ALS field new approaches.

To be clear, I am not the person who is leading our scientific efforts. We have a fabulous CEO, Manish Raisinghani, who has been the driver of our success, and a wonderfully committed board of directors and an Independent Review Committee, which selects and oversees the projects we fund. Both are comprised equally of eminent scientists from academia and industry who volunteer their time because they believe that what we are doing together is so essential.

**When you are addressing a disease like ALS that requires a long-term focus and commitment, how important is it to have metrics in place to track the progress and impact?**

At the end of the day, this is a pipeline game, and you need to fill the pipeline with as many potential targets, based on strong science, as possible. This is why you need to bring in new talent, technologies and funding in order to gain a deeper understanding of the genetics and biology. Ultimately, when you find those potential targets, they get handed off to pharma and biotech companies. Our goal over the next ten years is to play a material role in dramatically increasing the number of clinical trials, some of which will be successful in saving the lives of ALS patients. You need to have a big pool of targets to do that. No lives have been saved yet, but it is definitely coming.

We believe that lives will be saved, which are likely at first to be the genetic

forms of ALS, which represent 10 percent of the cases. But our goal is that within ten years we will be in sight of everybody living.

At Target ALS and across the entire ALS field, we are in a race against time.

**Do you feel that there is still an education process that needs to take place to build a deeper understanding and awareness of ALS?**

There is a constant education effort needed. There are organizations that have been very effective at activating the community of ALS patients and their families which has turned into political power since this has resulted in pushing legislation and action. You can make a real impact with the right audiences by making people understand the disease in a more complete way. There is a large opportunity to better educate people. With one in 400 people dying of the disease, a lot of people are touched by ALS.

**You are known to be an optimistic person. How has your ability to stay positive and to focus on opportunities helped as you face this disease?**

I am always optimistic. I think I am also realistic, and I am aware that 80 percent of the people with this disease die within five years, and 95 percent will die within ten years. I watched my father die of ALS; my uncle die of ALS; my college roommate, Stephen Winthrop, died of ALS, so I am very aware of the likely course for me, but my nature is to look on the bright side of things. I do think that my optimistic nature is really helpful in this difficult situation.

I have been this way throughout my career. When I started New York's Olympic bid, people thought it was crazy. I thought it was a great idea so I pursued it, and while it ultimately did not happen, many other good things happened in New York as a result of this effort.

One of the reasons why I think that I have been able to handle this diagnosis is because I have been the beneficiary of such love and support from so many people. When I announced that I received this diagnosis back in December, I received so many incredibly personal notes – about what I meant to people, about the impact I had on their career and lives. I felt that I went to my own funeral. As morose as that sounds, it actually sustains me.

I've been really lucky in my life. I have a wonderful family, tons of friends, have done what I wanted in my career and have started new institutions like The Shed. I have been very fortunate. I do not have any regrets. That helps to keep me positive. The reality is that I have probably only had one down hour cumulatively since this whole thing started.

**With all that you have accomplished in your career, do you feel that your effort with Target ALS is your most important work?**

There is nothing more important than saving lives. If Target ALS leads to that, then it will be the most significant thing I do in my life. It is also extremely personal because, forget about me, it is about my family. ●

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