

Impacting Disease Through Philanthropy



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My life changed dramatically on March 23, 2007, when my oldest daughter, Morgan, was diagnosed with type 1 diabetes (T1D). It was a couple of weeks after her sixth birthday. We immediately learned a new way of life that now incorporated insulin shots, pricking my daughter's finger 10 to 14 times per day, and the constant vigilance of being a full-time pancreas because my child's had failed her.

Five months after Morgan's diagnosis, I was named one of the trustees of the Helmsley Charitable Trust, which now has assets of about \$5.5 billion. I had the amazing opportunity to impact my own child's disease, which was extraordinary, but I had no clue how to play in the space.

So, I began learning and understanding the landscape of what I was trying to impact. I spent 18 months traveling and meeting with academics, clinicians, industry, the Food and Drug Administration, the National Institutes of Health's National Institute of Diabetes and Digestive and Kidney Diseases, payers, and other funders—not just in T1D but in other diseases as well. I found that many of the successful organizations that are impacting their diseases have some common themes.

What did I learn?

To make an impact, start with the end in mind. What is your goal? For us, it was to get a drug, device, or therapy to market to ease the

burden of managing T1D. This would allow people to stay healthy while we searched for that elusive cure. It is crucial to be laser-focused on obtaining your goal, and this requires knowing the opportunities and obstacles in your path.

A huge part of philanthropy's job, then, is to know the players in your field and understand their goals. In medical research, that means understanding the needs of the regulatory authorities as well as the payers because, without satisfying both, whatever you are funding will never reach a patient's hands. Engage early and often with both. Don't assume the people you are funding will do this on their own.

Similarly, understand what the market incentives are for the companies playing in the space you are trying to impact. Understand what is in their pipeline. Industry's job is to make money, and if a product is going to be successful, they will need to make money. That shouldn't be perceived as a bad thing; for them that is the ultimate goal. Indeed, if industry is making money, then a product has reached people's hands. Take, for example, the insulin pump and continuous glucose monitoring space: Despite

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the fact that people with T1D do better with these devices, market penetration is still quite low and costs for companies to enter this market are quite high. This is where philanthropy can and should come in.

Foundations and philanthropists have an opportunity to de-risk and align goals towards what we are trying to achieve. We have an obligation to think differently, to think in a long-term way and very far out on the risk curve. Don't be afraid to fail. If you are not failing 90 percent of the time, you are not taking enough risk. If curing a disease was easy, it would be done. Part of this means funding young investigators with wild ideas. After all, most inventions are at least conceived in the inventor's mind by the time they reach 30 years old.

That said, you should nevertheless run your grant program like a business. At the end of the day, bringing a drug, therapy, or device to market won't work unless it makes business sense to a company. A business approach to any investment entails a very active partnership with those who you are investing with. Every grant should have milestones that must be hit prior to the next payment being released. We are not just grantors; we are partners at the table with our grantees. For that reason, one should also retain some form of control of any intellectual property (IP) that is developed with philanthropic money to ensure the IP moves down the path towards commercialization and into the hands of people who need it.

In all of this, use common sense—if it sounds too good to be true, it usually is. Like everywhere else in life, there are unscrupulous people out there, so be wary. You cannot force collaboration; the mindset must already be in place or it will never work.

Finally, once you've done all this, don't assume that if you build it they will come. You must understand the wants and needs of the patient. It all comes back to goals.

