

CONVERSATIONS WITH MIKE MILKEN



David Panzirer

Trustee, Helmsley Charitable Trust

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Mike Milken: David. Thank you for joining me today.

David Panzirer: Mike, thanks for having me.

David, I cannot congratulate you enough for your knowledge of how to focus on philanthropy and how to get a return, how to achieve objectives, governance, and how to keep people focused. But I think for our listeners around the world, let's talk about the mission of the Helmsley Trust for a moment.

Thank you for the kind words. I've had the privilege of working with you now for I think, 12 years. I'm a parent and a husband first; that's what matters to me most. I have three children, they're all teenagers, which just means that I'm wrong every day, everything I say. But my oldest daughter, Morgan, was diagnosed with Type 1 diabetes back in 2007 at the age of six. Five months later, my grandmother, who was the Leona Helmsley, passed away and named me as one of five trustees of what's now a \$6 billion trust.

I had absolutely zero experience in philanthropy. I had zero experience in nonprofits, but I knew that these two things being put together were not such a subtle hint as to what I

should be doing with my life. I really started to travel and learn; I traveled with Dana Ball who was working for Lee Iacocca at the time. We came in, saw you very early on. And I traveled for 18 months before we ever wrote the first check, because I needed to be able to understand the landscape that we were trying to impact.

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For me, there is no shortcut in doing the diligence. Quite frankly, I had a daughter with this disease, and fear is a really good motivator. When we think about the mission, most people don't really understand that Type 1 diabetes is an autoimmune disease; your body attacks and kills its insulin-producing cells. Without insulin, it's just a matter of time. It's not a lifestyle choice. It has nothing to do with diet. The way I like to frame it so that people understand is, Type 1 diabetes is the only disease that I'm aware

of where patients and caregivers make dosing decisions with a drug that can kill them. They make those decisions 24/7 without the benefit of a clinician. And if they get it right 60% of the time, they're doing amazing. You never get a break. I'm not trying to equate this to cancer or anything else, but it is a relentless, grueling disease. I just say that because I think it's really, really important.

My grandmother left 99.9% of her wealth to the charitable trust. She left a ton of money with a pretty broad mission statement for the trustees to go out and do good work. I think a lot of organizations use broad mission statements so that there is some latitude to do some good work. You avoid things that, unfortunately, we went through; we had a dog charity suing us because everybody thought that my grandmother left all the money to the dogs, which was complete bunk. Quite frankly, in my grandmother's lifetime, she gave a, a grand total of zero dollars to dog charities. So it was a quirk, but we had to deal with this; we had to defend this in court.

It is amazing David, when we think about misinformation. I was at an event, I think it was in the mid-to-late eighties with Kevin Costner. And he turned to me and said, ‘have you ever read anything about yourself that was accurate?’ Linking your grandmother to dogs became the significant interest of the media, regardless of if it had any value or any truth in it.

They wanted no part of the truth because it doesn't sell stories.

Our mission really is broad and I think it was meant to be broad. We have focused in on a mission the trustees have bought in on. We were originally five trustees, now we're three. I'd say we are 99.5% focused on health and medical research, and we really stay in our lanes. I had the privilege of meeting Patty Stonesifer very early on. Patty was the first CEO of the Gates Foundation. When we met her very early on, she said two things to me that I will never forget. She said, 'we're the Gates Foundation and we don't have enough money to solve anything.' At that point, I don't know, they were 10 or 12 times the size of us. And the second thing she said is 'you have to take every single dollar and be laser focused. Is this the best way to have impact on what you're trying to impact?' I have never forgotten those words. They have always resonated with me and the other trustees.

I also think it's crucial to understand, and I know you know this really well, the role of philanthropic dollars as compared to nonprofits and the public charities. The public charities have to fundraise every year. We are blessed with not having to fundraise. We don't have to perpetuate ourselves every year, starting over and spending what we take in. In my mind, that obligates philanthropy to think about things differently and think about the long game, and think about things that the public charities cannot do: high risk, high reward. So for us in the Type 1 diabetes space, we started doing diligence and realized there was no data outside of a few academic silos to show how people were really doing with this disease. So we built the [T1D Exchange](#), which ended up spinning off into its own five 501c3.

“COVID has been a great accelerator in a lot of instances, certainly telemedicine. All the barriers to telemedicine would have taken years to come down, yet they came down in days. We have to seize this opportunity to level the playing field and really begin to truly give equal care no matter where you live. There's nothing from a technology standpoint that can prohibit that. Shame on us if we ever go back.”

For the first time ever, we were able to go to the FDA, and go to the payers with data across 27,000 patients with Type 1 across 65 clinics in the United States, and show them that outcomes were not just not good. They were horrible. The percentage of people that had had a severe event requiring 9-1-1 to be called within the last 12 months was almost 10%. I presented that data myself to the FDA; they were on the floor. They had no idea; the payers as well. I think it's an example of where that project cost us upwards of a hundred million dollars. It took more than two and a half years before it was anything of value came out of it. It's just very tough for the public charities to take

something on like that because there's no patients, there's no long game. It's not a knock on them, it's a knock on the model. To my way of thinking the model was flawed. It is shortsighted and it perpetuates a short game.

Our mission, quite frankly, just to answer your original question, which I realize I haven't done really well, is really to have a positive impact on people in the areas that we care about. We believe very strongly similar to the lesson that Patty Stonesifer taught us – you have to stay in your lane. It's very easy to get scattered. It's very easy to get distracted, and we work really hard at trying not to do that.

I think the purpose of our [Center for Strategic Philanthropy](#), that you have been involved with from day one, is we find everyone wants to reinvent the wheel. One of the challenges with HIV and AIDS at the beginning was everyone wanted to set up their own group, but eventually it coalesced. One of the challenges today with Alzheimer's is that the disease is so devastating that everyone with financial resources wants to set up a new Alzheimer's foundation rather than trying to focus. I think your efforts were to try to understand everything going on in a particular area. At the beginning, I think it took us a year and a half to two years to do that. I think we now have it down to three or four months. The staff at the Center for Strategic Philanthropy is increasingly individuals who have MDs or background in molecular biology or other types of things as requests have increasingly fallen in this area.

When we set up these organizations we required anyone we gave money to share information – to collaborate. I think the discipline you've had in this area has been significant in setting the rules. You have changed the status quo by suggesting, as we did, that unless you share we're not going to give you any money. I know you've been very focused on governance, not only governance of private foundations, but public charities and those that were so set in their ways that their decision process was really a function of who happened to be on the board at that time. So talk to us about the lessons learned.

When I first started out, quite honestly, we were treated like pariahs by the public charities. They basically were like, 'write us a check, we got it covered.' From a very cynical point of view, I was naive and I was brash. And I said, 'you've been around for 30 years. And your one job is to put yourself out of business. Clearly you're doing something wrong.' Although that's not fair, that is what I said to them. I think over the years they have gotten to know us and we have learned the ecosystem. They have learned that we're not a funder; we are a partner, and it's very different. We don't write a check and walk away. We have a team in the Trust of 100 people, 14 of them specifically on Type 1 diabetes that bring expertise to the table. So we're not going to

write a check and say, 'come talk to us in three years.' It's never going to happen. We are going to be involved.

When you talk about the collaboration, I have learned – and we tried – but you can't buy

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collaboration. You have to have like-minded people who are willing to share. There are some folks who will yes you to death and tell you what you want to hear and take your money. For me, I always start a conversation with anybody who we may be thinking about staking money and saying, 'listen, here's our mission. We want to deliver a drug or a device or a therapy to people. If your mission is not aligned with that, don't take our money period, full stop, because we're going to do everything in our power to ensure that things move that way.'

So, to get back to your point about the boards and the public charities, this has been something I felt very strongly about. I personally think the public charity model is completely flawed. What I mean by that is if you look at boards on public charities, when you want somebody on a board and I know people try and ask me to be on board with them, it's not because I'm good looking, it's because I have access to some money, right? That's just the way it is. So boards tend to end up with people who have a passion for the disease and have either money or access to money. And what that model does is, it skews those who have lower socioeconomic status that probably need the help more and who never get a seat at the table. What we're left with is a very vocal minority with access already deciding what to do with public charities. We never get the full voice and points of view of those who really need the help the most.

I'll give you a for instance; you bear with me for two minutes. Over the last few years, we've spent quite a lot of time in sub-Saharan Africa, and I'm a newbie there. I went there the first time about four years ago; I've been back a few times since. I went twice last year within a month, which I highly don't recommend – it's way too much time on an airplane. But we went with this consulting group Dahlberg and Dahlberg whose point of view is to understand the experience. So what that really means is, don't assume what people want. Don't start building stuff and think, okay, if you build it, they will come. We went to really rural Malawi. It was a 37-hour trip door-to-door; the last four hours we're in a four-wheel drive vehicle, to go talk to people with non-communicable diseases and

also some with diabetes. Unfortunately, a good chunk of them are dead before they're ever diagnosed with diabetes, which gets mistaken for malaria. But we wanted to understand what do they really need? We went in there with preconceived notions that technology is the way forward, and there's so much of it available to them.

Yet, when you sit and you talk to them and you listen to what their needs really are, in most cases their problem was food insecurity or poverty. They were afraid to take their insulin, because with the insulin that they use there, you have to eat at certain times of the day or your blood sugars will plummet. So these people with food insecurity, it's a medicine that absolutely does not work. If you don't know that you have a meal to eat in three hours, you can't take your insulin. We would never have known this without truly going there and understanding the voice of the people. What I'm telling you is that that model does not exist for the most part on public charity boards. I've attended organization events where there's 200 or 300 rich white people in the room trying to decide what to do with the public charity money. It's a fatal flaw.

What else did you learn from the people?

Honestly, the most important thing I think that I had learned is perspective. We all walk around with our preconceived notions and our own perspective. I'd say mine was permanently adjusted. The very first time I went to Rwanda, and each and every time I go back to sub-Saharan Africa, you meet and you talk to these people. There's just no way that you could see the extreme poverty and talk to these people and not be impacted. It was my first trip to Rwanda that really got me thinking, who's the voice for these folks at a public charity? Whether it's non-communicable diseases, Type 1 diabetes, anything, where's their voice? For me, that was the start for me. My program director, Gina Agiostratidou, was with me and we both got on a plane ride home and we looked at each other and we said, 'we have to do something.' This is completely unacceptable.

"If you go into a hospital in the middle of rural North Dakota, your chances of having a doctor there to help you are slim and none. So we equip these tertiary hospitals with equipment. They hit a button on a wall and they're videoed into Sioux Falls, where there's a team on call 24/7; trauma docs, nurses, anesthesiologists, etc. The people in Sioux Falls help that person on the frontlines get whomever they're dealing with stabilized so they can get them airlifted to a hospital."

And to her credit, she's been a main driver of this. What we complain about in the United States is kind of a joke, right? Compared to what they're dealing with? Ironically, I would say the problems that exist in rural America are very similar to what exists in sub-Saharan Africa, to a lesser extreme for sure, but the issues that are the same. How do we decentralize healthcare so that people in rural America, rural sub-Saharan Africa, have equal access to specialists, to specialty care, that you have in an urban city like New York.

Telehealth. A number of the people that I've done podcasts with, whether they're Providence, the third-largest health system, whether it's Cleveland Clinic, UCLA and some others have had more telemedicine visits in one day than they did in all of 2019.

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It's increased a hundred-fold from what it was. It's increased 200-fold. There are actually operations that have occurred where the doctor is not even in the city where the operation is performed. We will never build the healthcare infrastructure in sub-Saharan Africa that we've built here in major cities like New York. We need another solution. Let's focus on the lessons that we've learned in telehealth and how we can apply them.

The Helmsley Trust has actually been on the cutting edge of telehealth since 2009. We started when my brother, Walter,

who lived out in South Dakota, headed up and took charge of what's called the Rural Health Care Program at Helmsley. We have an office in Sioux Falls, South Dakota. In a nutshell, what they started out doing, and they've done so much more, is equipping all of these tertiary hospitals with the ability to hit a button on the wall. If you go into a hospital in the middle of rural North Dakota, your chances of having a doctor there to help you are slim and none. So what they do is they equip these tertiary hospitals with equipment. They hit a button on a wall and they're videoed into Sioux Falls, South Dakota, where there's a team on call 24/7; trauma docs, nurses, anesthesiologists, etc. The goal is for those people in Sioux Falls to help that person on the frontlines get whomever they're dealing with stabilized so they can get them airlifted to a hospital. We've equipped I don't know how many hundreds of hospitals across nine different states in the upper Midwest. In addition to telehealth, there's this E emergency as it's called. We have also equipped them with the equivalent of vending machines for pharmaceuticals. So if you need morphine to be dispensed to that person, the guy in Sioux Falls can prescribe it and dispense it in a machine in North Dakota. They give it to the person, get them stabilized, and get them out of there.

We've spent more money per-capita than any other developed country, almost twice as much as any other developed country, and I will never question you on factoids because you are the King of Factoids, but we have spent at least one and a half times more than any other developed country in this world and our outcomes remain mediocre at best. In this day and age, if you think about it, the whole premise of where you live dictates your access to specialty care, dictates your outcomes, dictates your access to tools to manage your disease. That's absurd in this day and age.

I'll give you a really example that hit very close to home. Three months ago before COVID, my daughter who was still in college wanted to switch insulin pumps. We went through the process and people came back to us within three days and said your insurance won't pay for it. I said, why not? And he said, well, your daughter hasn't seen the doctor in more than six months. I said, well, my daughter has been on a continuous glucose monitor and I can send you six months logs of her glucose. You can see she's in really good control. It's going to be more data than you will ever get out of the doctor's office or out of the charge for that matter. And they said, 'nope, she has to go see the doctor.' They forced her when she came home on spring break to waste a day and go to New York City to see a doctor with whom she spent 15 minutes. It was a complete, utter waste of time, and not to mention the waste of time of the payer and the wasted of time of the clinician. As far as the payers and personalized medicine, nobody walks the walk. What we're trying to do now is create a virtual specialty clinic.

“When you look at chronic diseases, there's a comorbidity of a mental health condition, whether it's anxiety or depression something like 40%, 45% of the time. And I'm sure that's grossly underreported. The goal is to layer in mental health, front and center. Let's stop just treating symptoms and start taking care of the whole person.”

We did a small pilot where we enrolled 35 patients remotely out of rural America. They were being cared for a primary care physician. And I know you understand this, but primary care physicians are the most overworked, overtaxed people in the healthcare system. And there may only be one or two people within their practice that you're dealing with. So, what we need to create is this virtual specialty clinic. Could we onboard people remotely? Could we successfully teach them how to use a continuous glucose monitor? Can we teach them how to use the data?

The short answer was a hundred percent, yes. We onboarded all 35 people. We supported them for 90 days. Every single one of them used a device for 95% of the time.

Every single one of them had improved clinical outcomes, an A1C, which is our outcome measurement. Significantly, every single one of them felt more confident about their disease. They all went back to their primary care physicians with the data and showed them amazing outcomes. We're in the middle of doing a much larger study that is actually going to start recruiting next month. I'm here to tell you if you're willing to play the long game, this is the way to take care of people.

What COVID has done for us has been a great accelerator in a lot of instances and certainly telemedicine and all the barriers to telemedicine would have taken years to come down. They came down in days. We have to seize this opportunity to level the playing field and really begin to truly give equal care no matter where you live. And there's nothing from a technology standpoint that can prohibit that. Shame on us if we ever go back.

I'd like to turn to another area related to COVID, but related to the population at all times, and that is mental health. We started to see is that mental health visits were dropping 50%, 60%, 70%, 80% because people didn't want to go, nor did the psychiatrist or clinician want to interact during COVID. I know this is an area that you've been heavily involved with and the challenges of mental health in the system. How is this COVID-19 crisis affecting this area? What have you learned in dealing with mental health over the years?

You have been saying this for many, many years. One of the first interactions I had with you, you said the biggest kind of mental health issue is loneliness. That has resonated and stuck; a lot of what you say, Mike, I actually listened to.

Well, no, no, David, you do a lot more than listen.

I try. Thank you.

You are unique. And that whether you're listening to me or whether you listen to someone in Malawi, you take action and take it to a new level.

I will strive to continue to live up to those words. Right now in the United States, we treat symptoms. We don't treat the person. When you look at chronic diseases, you know this better than I, there's a comorbidity of a mental health condition, whether it's anxiety, depression something like 40%, 45% of the time. Like everything in mental

health, I'm sure that's grossly underreported. The goal is to layer in mental health, front and center. Let's stop just treating symptoms and start taking care of the whole person.

I'm just going to take Type 2 diabetes as an example, because it's an easy one that'll resonate with a lot of people. There have been nutrition apps, there have been diet apps, and there have been coaching apps over a decade. We have not made one dent in slowing down that epidemic. My hypothesis is quite simple: the reason why we haven't made a dent is because we haven't solved the underlying issues with people. When you look at nutrition apps and coaching apps, all of these things are the equivalent of a fad diet. Fad diets don't work. You get some near-term data and eventually people revert back to the mean. What works is the lifestyle change. In mental health, the lifestyle changes solving your underlying mental health condition so that you will be more proactive with your disease. We have to start treating the whole person, right? To me, it's common sense. There's no health without mental health. What COVID has done is

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put this front-and-center on every news channel now. We're starting to hear it all over the place, about mental health for our children and our people.

We have really been trying to take these shortcuts forever. And the payers are

thankfully starting to listen. At least the larger ones who understand 100% of us are going to have a mental health issue at some point in our lives. There's that organization, One Love, that I'm very involved with. They're trying to approach it a different way: instead of the stigma of mental health or spousal abuse, they're trying to teach people the differences between healthy and unhealthy relationships. To me, those are the foundational building blocks of mental health care that we need to get to our children in grade school. That's my hope for One Love, that they will become an educational arm that destigmatizes this and teaches people the basics from grade school on up, because we've never done that. In the past you were stigmatized if you went and saw a therapist. Today, I feel like the younger kids, it's a badge of honor, it's generational.

I really have been impressed on how you've gravitated to these areas: mental health, diabetes, telemedicine. You've taken us on a journey today, David. What advice, 12 years later, would you give someone who might be thinking of setting up their own foundation today and lessons learned over this period of time?

I think the first thing I'd say is, start with a goal, make it clear and focus, focus, focus. All of these things I've kind of alluded to, there is no shortcut for diligence. I started out and I wanted a cure for my daughter like anybody else in my position. As a society, we have

never cured an autoimmune chronic disease. Cure, to my way of thinking, is you walk away as though you'd never had the disease. We've taken some things and we've turned them into managed diseases. But my point is, it's not easy. If it were easy, we'd be done. There's been billions upon billions of dollars spent.

And I would be remiss if I did not plug my daughter's book. My 19-year-old daughter wrote a book called "Actually I Can." It's about her experiences with Type 1 diabetes and I'll leave it at that, but she would kill me if I did mention that. So I'm mentioning it.

In closing, I want to go back to a couple of things you've said for a person focused on philanthropy. As I said to you the first day we met – passion, have passion for something. And I think being a partner makes the other organization better, not just yourself. As one of the most effective philanthropists in the world, you and the Helmsley Trust have made a significant contribution. It's been an honor to work with you all in these years and an honor to learn from you, Dave.

Mike, right back at you. I mean, honestly hearing those words from you, somebody I have a tremendous amount of respect for, and somebody has really been a pioneer in venture philanthropy and what we're talking about means a lot. Thank you.
