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Introducing Michael Mittelman 00:56

Neither last week's podcast guest, Janice Tufte, or I identify as a patient advocate – a person advocating on behalf of a disease state. I have multiple sclerosis but don't identify as a multiple sclerosis advocate. We identify as patient partners or patient/caregiver activists. We're generalists. Not so, today's guest Michael Mittelman. Michael received three kidneys via transplant, his current kidney from a living donor, his mother. He identifies as an advocate for organ donation, specifically, living organ donors. For this episode I'm going to test calling our work as advocates, activists, and partners, an Independent Community Benefit Practice. I know it's too long to stick, but I'm trying it anyway. I've chosen it because it is descriptive. Many of us work alone, we benefit the community, and it's a professional practice. Many of my guests tell an external story of how they found their way into an Independent Community Benefit Practice. I tell the story of Health Hats, patient, caregiver, nurse… You've heard it. It makes sense that I'm a generalist - lots of hats. As we become seasoned in independent community benefit work, we have internal stories, stories we share about the private practice of our work - our business with a mission, strategy, plan, revenue, and expenses. So, in addition to the role of CEO of our health, we have the position of CEO of our Independent Community Benefit Practice. Janice, Michael, and I are CEOs of our Independent Community Benefit Practices.

Michael Mittelman and I took some time away from the PCORI (Patient-Centered Outcomes Research Institute) Annual Meeting in Washington, DC, to talk about his journey growing into CEO of his practice. As usual, we began with me asking him how he introduces himself.

Michael Mittelman: It depends on the situation. Sometimes I will say that I'm a three-time kidney transplant recipient. Other times, I will say that I am a health care professional who also happens to be a long-time chronic patient in the health system. Yet other times I will say I'm the former patient editor the BMJ (British Medical Journal). And I'm the chairman of a national nonprofit that works with living donors, and before that, I was the CEO of a tech company and worked in the health insurance industry.

Health Hats: Wow. That's a lot.

Michael Mittelman: And occasionally, I'll throw in the fact that I'm single and may be looking for a date.

Health Hats: I'll be sure to include that. Where were you when you first realized that health was fragile?

Michael Mittelman: I was actually at the hospital as a little kid, where I found myself quite often, and I found myself missing a lot of things in life.

Health Hats: How old were you?

Michael Mittelman: I got sick when I was three. My first memories of this were when I was about four, four and a half. Also, when I was in kindergarten my memories are forming. I have some very vague memories from when I was maybe three three-and-a-half and being in things, but they start to crystallize a lot more. I remember very clearly back to a time when I was stuck for an IV at the Pediatric Institution. And they kept missing my veins. I was wearing this matching outfit of sweatshirt and sweatpants, which were popular back in the early '80s for children. I remember blood getting all over it. I remember my arm turning purple. I remember my mom stepping in and my dad stepping in and tell the phlebotomist and the IV team to stop. I remember being upset that my matching sweatshirt sweatpants outfit was ruined by blood.

Three kidney transplants 05:36

Health Hats: This was the beginning of kidney disease for you?

Michael Mittelman: This was the beginning of kidney disease. They were still trying to figure out what was wrong with me. They knew I had kidney disease, but they didn't know exactly what. They were searching. I had been in and out of the hospital for different reasons. It's very strong in my mind that the professional expertise wasn't there at the time. Did I know that as a kid? No. But I was in and out of hospitals seeing different doctors in the diagnostic process. I liken it to a TV show that I watched which went off the air a couple of years ago, House. In that show he's this expert diagnostic physician, but he goes through almost everything under the sun before they come to what's wrong with the person. Often it seems like that didn't happen in the show until maybe the person was coding on the table or having a reaction from some other medication that I was given. I liken it to that where there was a lot of experimentation and trying to figure out what's wrong with this otherwise healthy a little kid.

Health Hats: When did you have your first kidney transplant?

Michael Mittelman: I had a lot of biopsies between the ages of three and five. I had my first transplant in January of 1988. That was from a deceased donor.

Health Hats: How old were you?

Michael Mittelman: I was not yet seven. I was six and a half. I was turning seven in the spring of '88.

Health Hats: You were having dialysis at that time?

Michael Mittelman: I was on home peritoneal dialysis. My mom was doing that at home for me with no infections mind you. She was very adamant about that when the clinicians warned if you do home dialysis and with peritoneal dialysis, particularly, there's a high risk of getting an infection. My mother said absolutely no way, not my son. And she learned to do this type of treatment at home.

Health Hats: So, seven years old.

Michael Mittelman: I started on dialysis when I was a little over five and transplanted at seven. The reason I started on dialysis was that both of my kidneys were giving me extremely high and problematic blood pressure. I was getting migraines as a kid. I was in and out of the hospital. I remember one point it felt like there was an elephant stampeding on my head. That was how I described it. They took out both of my original kidneys when I was a little kid. They go through the back. Obviously, then I had to start dialysis right away. I had no more kidneys at all. Forget about maybe slightly functioning kidneys; I had zero kidneys in my body

Health Hats: Wow, I can't even imagine.

My multiple sclerosis is progressing very slowly, but it's progressing. My neurologist prescribed an infusion twice a year that costs $100,000 a dose. I asked my neurologist if I needed to get it. I understood every word he said. But my brain couldn't put all the words together. Thankfully, I had my Abridge recording app turned on. I had pushed the big pink button. I went home. My wife and I listened to the transcription several times. We decided it was worth it. I'm grateful that we could take time to make an informed decision. Thank you Abridge. Abridge was created by patients, doctors, and caregivers. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Starting a business, the American Living Donor Fund 09:47

I first spent time with just Michael several years ago. I was in Philadelphia for a meeting. It was my first flying trip going solo with my electric wheelchair. I'm a calculated risk kind of a guy, so I called Michael motor with me through a strange city. We went from the hotel down some very busy streets with intermittent curb cutouts and many pedestrians and people spilling out of bars and cafes onto the sidewalks. We ended up in a restaurant. Michael impressed me, telling me about how he saw a need and started a business, the American Living Donor Fund. I asked Michael what led him down this path.

Michael Mittelman: We have to go back to senior year of high school, where I was starting to get sick again. It became apparent that I was most likely going to need another transplant. I was either going to go back on dialysis or maybe get a transplant from somewhere first. Because in between the first and the second transplants, I was not back on dialysis. I had a second transplant only a few years after the first one. The third time around, we could see it coming. We knew that I was going to have to be on dialysis and I was going to be sick. We didn't know if it was going to happen during my senior year or if it was going to happen afterward. So that's when I also decided to stay locally for college, and I had to start on dialysis again. The search began for a living donor or being on the waitlist. I got put on to the transplant waitlist again. I was at the University of Pennsylvania as a freshman. I was doing dialysis a couple of days a week. I had been doing this now for about a year and a half. I was not getting any better. Looking back on it, I can see how sick I was, even though maybe at the time I didn't feel it. I did realize that I was having a lot of problems. That was when I was diagnosed with another autoimmune disease. They found it because I was on dialysis. They thought some of the challenges I was having were related to dialysis. But they didn't know. At that point I had already been on the transplant list a while.

We started looking around for living donation. We didn't know a lot about it beforehand because my first two kidneys were from deceased donors. A lot of people started putting out the word to our family, the synagogue. Mike needs another kidney, does anyone want to get tested for him? We always knew my mother was a good match for me. She had always wanted to donate to me when I was a kid. The challenge is that if you think back to genetics you have to have the same blood type to be a donor to somebody. You also have to have some antigen matches to be a donor to somebody. My mother was always a terrific match for me, perfect match. But she always had a different blood type. Obviously, you don't change your blood type. Maybe if you have a bone marrow transplant, it's possible. But she had a different blood type than I did, so she could never donate to me. In the summer of 2001, my mom read an article about some new experimental procedure that was going on at Johns Hopkins where you could cross the blood barrier with a transplant. So, we had been investigating living donation, and my mom stumbled upon this. It was highly experimental at the time. We went to get evaluated. We asked a lot of people if they knew anything about the procedure. We thought we were good candidates. They said we were good candidates. We asked a surgeon family friend who was my pediatric surgeon and he said, "what do you have to lose? Go ahead and do it." So, we did it. My mom donated to me. We went through the procedure. But then about 12 months after donating to me, she was diagnosed with stage 4 ovarian cancer. She fought it for a couple of years, and she ultimately lost the battle to cancer. That was in winter of 2005. Several years passed. I had always wanted to do something to honor her gift to me. I started learning a lot more about living organ donation and challenges that donors undergo. As recipients we look at donors as people that can save our lives. We often don't think about the challenges that these heroic people undergo in their journey to help us. So, I met somebody. She and I saw a very eye-to-eye about what we can do directly to help people. Not in theory, but direct action. What can we do? We said one aspect that we can help is financially, especially on the non-medical side. I believed that living donation should be cost-neutral. So, we set out, and we did a project of sorts. Then we were raising all this money. We needed to be a non-profit because this all this money coming in. That's when the American Living Organ Donor Fund was born. It's been five and a half years. We've helped a tremendous number of people. It's never been about the number of people we help. It's always about the quality of what people are getting from us. Since then we've expanded the number of programs that we offer to people because we continue to see more challenges.

Health Hats: Could you give us some examples of some of those programs?

Michael Mittelman: We have a free Mental Health Services Program now. That's not just for people that are considering living donations. But it's also for people that have already donated, so post-donation. A need that I didn't know existed until people were tagging us on social media or referring people to me and saying you guys work to help donors. This donor needs some help, and we're the only ones out there that are working just for living donors. So, we said well, why can't we do this? How could we do it? Still to this day we're a volunteer-run organization. I hope that will change at some point. But our Mental Health Services Program has grown in the same way through a board member overseeing the program and us being able to offer this to people when they need help.

The road to an Independent Community Benefit Practice 16:43

Clearly, the Fund was not the beginning of Michael's advocacy work. The road to his Independent Community Benefit Practice started earlier. His parents must have found community support along the way and included their son. I asked Michael to tell that story.

Michael Mittelman: I was involved in advocacy for a long time. I was not involved in the advocacy side of the world for living donation. My family and I have been involved in organ donation advocacy and kidney advocacy for a very long time. We got involved in the local organ procurement organization in Philadelphia, which has been which is the Gift of Life. The Gift of Life is the local organ procurement organization (OPO). They handle deceased donation. If you're waiting for a transplant or somebody passes away. They are a cornea donor or kidney donor. All that goes through them in the Greater Philadelphia area. We had been volunteers with them for a long time. I would talk at places as a kid, even when I was younger before I knew how to do my own meds. There was a program that started up called the Transplant Games. Philadelphia put a team together called Team Philadelphia. It was one of the earliest transplant games in the United States. I was the youngest kid there at the time. It was a small team, very intimate. We all got to know each other transplant recipients' families. It was so small that every team was in one hotel. That's not the case anymore. It was held in Indianapolis. I got involved as a kid even younger. After my first transplant, we started doing stuff for the National Kidney Foundation, walks. In high school, we held a fundraiser for the National Kidney Foundation. I was the president of the school. It was just something I've always been doing. I was alive because somebody donated to me. I was very aware of that. That was something our family always pushed forward. *Don't take your organs to heaven. Heaven knows you need them here.* That was a bumper sticker that went around for a long time.

Social media impact on advocacy 19:05

Health Hats: How have you seen advocacy change in the years? Let's start with your adult life through the eyes of an adult as opposed to an eight-year-old kid. How have you seen it change?

Michael Mittelman: I would say that with the advent of the internet and social media has changed it drastically. I can't recall a time when it was better to be a patient advocate or advocating for someone else. I say that because not only from the perspective of being able to story-tell. Society is more open to who you are as a person. Whether or not that's saying, I have cancer, or I have an eye problem. Or whether or not that's saying you have a physical manifestation that people can see, or you have kidney disease. It seems that we're living in a time where society is more accepting. It used to be that I hid from the working world that I ever had any sorts of health challenges. It was never on social media. My and my father's feeling was stuff is out there. You can't take it back. You never know if an employer, particularly when I was in college and I was looking at medical schools. I was looking at jobs, what they're going to think about you? If you're public about being an advocate or you put things on a resume, that you volunteer. Then they can say, why do you volunteer there? So, I think society is more accepting of that. When I decided to be more of a public advocate, my father and I got into a little bit of it because my opinion is people are more accepting these days. His opinion is you still never know what people are going to think.

I can relate. I was diagnosed 12 years ago. Soon after that, I got laid off. In looking for the next job, I landed many first interviews, but no second interview. My grown sons said, "Dad, you are awful public *about your multiple sclerosis. Is that really what you want to do? Is that preventing you from getting the second interviews." It was a great question. But I am who I am. Sure, I wear my life and challenges on my sleeve. I eventually found another job.*

Pay for professional practice 21:45

I asked Michael about the challenges of his Independent Community Benefit Practice. One of the stories he told reflected common experiences of CEOs of Independent Community Benefit Practices. We discussed misaligned expectations and lack of clarity about the value of the professionalism and expertise brought to the table. You'll hear in the conversation that I can't settle on whether we're advocates or citizen experts or what. Labels!!

Michael Mittelman: I could say that frustrations have been around speaking engagements. I tend to think that every speaking engagement has, whether or not you're on a panel, whether you're just speaking on your own in front of an audience, has an impact on your reputation. You're out there publicly talking. Recently, I've been asked a lot to be a part of things, and then sometimes I want to know why I should take part in it? Especially, the busier we get as Patient Advocates who are also living as much of a normal life as we can. I'm trying to go out on a date one night, or I'm just trying to go to a Philly's game with some friends or an Eagles game do the things that people do. I tend to think about well, why should I do this? What well, how will I benefit? One, maybe that's a little selfish. But I tend to think how I will benefit from this versus the people that I care about the communities that care about? How will they benefit from this? Are you going to value me, or am I going to be used as a prop? We've talked about this a lot. Especially as your experience becomes more valuable, do you want to give your time to something? Everybody's time is limited. Sometimes you need to be selfish about it and say what's in it for me? The more I begin to look at things and see that I get promises that are not kept. That's the biggest frustration. A huge frustration of mine all the time is people committing to things that they say. Maybe it doesn't just have to do with advocacy and being a patient. It's just general life. But I think just treating people with respect and being honest and truthful about your interactions with people can alleviate a lot of that. I can't say that I had friends that understood where I was coming from on things. So even though you and I, Danny, had very different patient experiences, I feel like we can talk about almost anything and I have a lot of other Patient Advocate friends that I have met over the years or family caregiver Advocates that I have met that really we can talk about these things on a deeper level.

Michael and I participate in a periodic call with other Independent Community Benefit leaders. Michael offers wisdom on those calls about expectations, contracts, rates, and negotiation. I so appreciate his generosity. We next spoke about this.

Health Hats: I've learned a lot from you about my own value and to monetize it; to think about my time. What my time is worth, how to contract for our time whether that's formal, meaning its legalese, or it's an email that says, "I understand that you're going to do this and I'm going to do that." Having that written expression. I've always been a person who does service agreements in my work as a quality management professional. I was a service department in an organization and people would expect things of me. It was a way to make sure that I understood what was expected and that I had a deliverable and a time frame. But before I met you, I hadn't thought about that in my advocacy work. That's added an important dimension. It also made me much more mindful of my pro bono time. You were saying, “what problem am I trying to solve? What's in it for me? What do I think of this organization?” Would I rather hang out with my grandkids? You know, life. So that's a thank you. I would say when I think of you, besides that you started a foundation which I admire so much, thanks. And personally, thankfully, I'm not in need of an organ. But my managing myself as an expert, a citizen expert, I feel like you've added a real dimension to that

Michael Mittelman: I appreciate that. Too often, we in the patient community and caregiver family community, are continually asked and asked and asked and asked. At some point, people say no to things. A lot of us don't know how to say no, which is a big challenge. But in it the idea that people have jobs, people have lives, and if you're continually asked to do things time and time and time again, then at some point you have to begin to ask, ‘why am I doing this or what's in it for me?’ I think about my professional life a lot, where I'm not a patient advocate. I try to bring advocacy to, and sometimes that works and sometimes that doesn't work. I can think of many times where I have butted heads with Executives in a job situation where I was trying to push certain ideas. I think beyond that, a lot of people don't like the idea of thinking about bringing a business aspect to advocacy. It's a challenge. Often patients in the community don't want to think about what's the tit-for-tat. They may be happy to be out in the community. I'm always happy to be out in the community. I'm not being paid to be here at PCORI. I enjoy it. I love it. I love the community. But I'm also learning a great deal. Every time I come to a PCORI meeting or meet new PCORI Ambassadors or researchers, I learn something new. That's a gift. The idea that I could be hired to do something because of my education and my knowledge and have it be just a regular job. But then I could be asked to do another job that requires the same knowledge and the same expertise, but I should be doing it for free all the time. It’s a challenge. How do you balance the two? How do you balance doing advocacy work versus not doing advocacy work? So, I think it will always be a challenge for people, and some people will never be comfortable thinking about things in certain capacity versus others may think about all the time. Maybe I think about this stuff more because my father is an attorney and maybe because of my prior professional experiences. I think about it. Yeah.

Health Hats: Thank you for joining me. It's been great.

Michael Mittelman: I've been happy to do it. I've enjoyed listening to your podcast before. I'm excited to be a part of one.

Reflections 30:20

At one of the calls with other people consulting in this space, Michael asked us to think of ourselves as lawyers. How would we manage our practice? Shortly after that call, I asked a potential client for a monthly retainer. We agreed on one as soon as I asked. No explanation needed. Who knew? I was at a meeting recently, and someone suggested that grant offering organizations – government, philanthropy – write in their specs that a block of money be reserved for the grantee to hire patient experts. Build in the expectation upfront. PCORI has specific criteria for funding applications for patient engagement. A proposal can’t be funded without that engagement. The stronger the engagement, the stronger the proposal. Patient engagement is necessary but not sufficient. Naturally, scientific merit and fill a gap in clinical knowledge weighs heavily as well. What do you think? Independent Community Benefit Practice? What about *Freelance* Advocate or *Freelance* Activist or *Freelance* Patient Partner? *Let me know in the comments or email me.*

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