

A Urologist, PrEP, and Discriminatory Disability Insurance Practices: Dr. Paul Sax Interviews Dr. Philip Cheng

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Hi, this is Paul Sax, and I'm editor-in-chief of *Open Forum Infectious Diseases* or OFID, and this is the OFID podcast. Today joining me on this podcast is Dr. Phillip Chang. He's a fifth-year urology resident here at Brigham and Women's Hospital. And why, you might be wondering, are we interviewing a Urologist for an infectious disease podcast?

It is not to go over treatment approaches to prostatitis, but instead to discuss Phil's very distinctive experience as a physician who was applying for disability insurance—and then getting rejected since he was receiving Truvada for pre-exposure prophylaxis for HIV.

This experience made national news, and Phil is kind enough and really courageous enough today to come on this podcast to share what happened and to answer some additional questions. Phil, thank you very much for joining me today.

Thank you for having me, Dr. Sax.

No problem, and by the way you can call me Paul. Saying Dr. Sax makes me feel old. All right, before we get to what happened, please let us know a little bit about yourself. Where do you call home? Where did you grow up? Do you come from a medical family? All those things.

Absolutely. I grew up in Princeton, New Jersey. My parents had moved from Taiwan after college and I was born and raised in New Jersey. I ended up going to college and medical school in Houston. After college and medical school I decided to return back to the Northeast.

My parents aren't doctors, but both my grandfathers are. One was a general surgeon. Another one was an OB/Gyn, and it seemed to skip a generation because my sister and most of my cousins are all in medicine.

Oh really. It is funny how being a physician often runs in families. My family is just filled with doctors, but my children are not going into medicine, which is just fine. Obviously, not everyone can be a doctor or wants to be a doctor.

So, you ended up deciding to become a doctor. Maybe because of your family. Any other particular reasons?

Yeah, I think what pushed my sister and I into medicine was that when we were very little, my father got sick. He was diagnosed with a rare brain tumor. It was a chordoma of his brain stem, and after witnessing someone deteriorate over time...

He ended up passing away when we were both still very young. That definitely had a big impact on both of us. Ultimately, I think that was one of the main motivating factors, and my sister is a current fellow in colorectal surgery. So we both decided to go to the surgical route.

Surgical route. Yes, so now we'll get into your choice of specialty. You are a urologist. You're obviously a surgical subspecialist. There are all these things you could do, and this is what you chose. How come?

The million-dollar question. Sometimes I still ask myself that.

You've already gotten into residency so you don't need to come up with an answer. That's very clever.

I made the decision of surgery over medicine when I was in medical school after a few rotations. Surgery and medicine were both my early rotations, and after making that decision I just explored a lot of different subspecialties. Urology was the one that I felt like had the range of surgeries that I liked and the personalities, it's mainly the people. But honestly, looking back it felt somewhat arbitrary. But, I don't regret it. I do enjoy urology.

Okay. Now, let's talk about what happened. When did you first hear about pre-exposure prophylaxis or PrEP? And what were your initial responses to the research, etcetera?

I first heard about PrEP maybe around five years ago. I honestly can't pinpoint exactly where I heard it from, but in the gay dating world it's something that was pretty prominent where you heard about people on it, then you wondered what it was, and then I did more research into it.

PrEP and Truvada were the two words that I had heard. I looked into what exactly Truvada was, what medication it was, the side effects, why people were taking it.

Then I looked up studies that were done on it. There was certainly that article in *The New England Journal of Medicine*, that study IPrEx. That definitely was really convincing data to me. I felt like it was just something that was such an important drug from a public health standpoint for the gay community, for anyone at risk of HIV/AIDS.

Since I'm an HIV specialist within infectious disease, I first heard about it, and I confess I first was a little skeptical. I thought it would work, but I wasn't sure how broadly applicable it would be.

But, it wasn't until seeing not just the IPrEx study but a couple of other studies done that I realized just how effective

it is. I think somewhere you were quoted as saying it's as effective as an HIV vaccine. It's extremely effective, so therefore something that really people should consider if they're at risk of getting HIV.

Absolutely. I just felt like after looking into it, reading about it some more, it's the closest thing to an HIV vaccine that we have right now. It definitely seemed like the responsible thing to do for anyone at risk of getting HIV to be on the medication.

Now, some people had trouble getting their healthcare providers to prescribe PrEP. What was your experience?

I do think that's one of the biggest barriers. One is just knowledge of the drug. Another one is access. There certainly is stigma. I think a lot of gay patients may not feel comfortable asking their providers, and thankfully I felt comfortable asking mine because I went through Fenway Health here in Boston, which treats a huge population of LGBT patients. I specifically sought out Fenway Health for a primary care physician to get it.

And he or she was very responsive to your question?

Yes. One of the barriers for me for going on PrEP was I was afraid of coverage, how much it would cost me. And another one was side effects. I actually didn't start taking PrEP until I was taking it for postexposure prophylaxis.

You had an exposure in the hospital, needle stick or something like that?

Exactly. I had an exposure in the operating room to an HIV-positive patient, and I was put on Truvada for a month and had no side effects whatsoever. That exposure happened right after I got out of a long-term monogamous relationship so I was single and it was perfect timing.

So after that month of taking Truvada I ended up finding a primary care physician through Fenway Health and going on the medication long-term for PrEP.

Any side effects?

No side effects.

Did you have trouble remembering to take it every day?

I'm very anal retentive about that, as a medical resident.

I think it can go both ways.

Yeah, it actually goes both ways.

Some residents are incredibly compulsive about things and others, they are so busy that they can't take care of themselves at all.

Yeah, I actually never missed a dosage while I was on it.

Wow. Good.

I was always very attentive to it and took it the same time every day.

You might be one of those people who even when you change time zones you still take it at the same time. I don't know if you're that compulsive. Now, just shifting the topic a little bit.

Surgical residency, surgeries in general, and applying for disability insurance—is that something that most surgical residents do, or is that something that all surgical residents do and when do they do it?

I definitely think most surgical residents will apply for disability insurance during their residency. I had seen my senior residents apply usually during their fourth or fifth years of residency.

Some had given me tips for what type of insurance to get. I think that in any field where you work so hard to get to a certain point, we're using our bodies, our hands. In urology and in surgery, I hear a lot of stories about physicians getting injured and not being able to operate anymore because of a back injury for instance.

So, very early on in residency I knew that I wanted to do it, and I ended up going to a financial advisor that one of my coresidents had gone to. I just decided at the end of my third year that I was going to apply.

So what happened?

I applied in May of 2016 at the end of my third year. I met a financial advisor, I told him exactly what type of insurance I wanted. He went through my medical and surgical history. I told him that basically I have no past medical history, no past surgical history, no hospitalizations or surgeries. I don't take any medications besides Truvada.

I'll just fill in the listeners that I'm looking at you and you're not overweight, to put it mildly. You look like you stay pretty fit, and very few doctors smoke cigarettes, so you're a healthy person.

Yes, so it made his job easier because he didn't have to go through any sort of algorithms. He's able to look at quotes from different insurance companies based on age and as healthy as you can be basically.

He was looking at all these different companies and we went over different plans, what they would offer, and we went with the cheapest one. He said, "This is what you should get. Applying is just a formality at this point."

So, I applied to the insurance company that gave the best plan for the cheapest rate, and it was probably about a month later that I heard back. He had emailed me, told me to go into his office. We set up an appointment, and he told me that from this company I wouldn't be getting the full plan, and I couldn't get it solely because I was on Truvada.

What was your response?

I was pretty livid. I was very shocked. It's not something that I thought about at all when I was applying. I didn't really think that it was a barrier. I was a little bit naive in that sense.

When he told me that I didn't get it, before he told me the reason why, I did have a kind of light-bulb moment where I was like, "This is because I'm on Truvada, isn't it?" And he confirmed that. So, I was very upset with it. He was a pretty new financial advisor. This wasn't something he had ever heard of. He had never heard of the drug. He had never had a client that was rejected because of something like this.

So, he ultimately got me in touch with more experienced advisor who recommended other companies, and I had asked

him to go back to the insurance company and see if they would offer me the full plan, one if I stop taking Truvada or two if I put an HIV/ AIDS rider on my insurance, so to speak. So that if I ever were to contract HIV or AIDS, then I wouldn't be able to benefit from the policy, and they rejected both requests.

It's very interesting. I think I heard this analogy before. They were almost rejecting you for taking something that was likely to be preventive, kind of like wearing seatbelts or getting a vaccine.

I think in their mind, they're probably using it as a proxy for other risks and just not really wanting to investigate it further.

Exactly. My initial reaction was that this is discrimination because I'm gay, and they're making assumptions based on my sexuality, that I engage in high-risk behavior, and because of that I shouldn't get disability insurance.

So, something happened between hearing this news and *The New York Times* piece. So, how did it become public? What went through your mind when you decided to go public with this particular story?

A lot happened actually. It was about a year and a half before I was contacted by *The New York Times*. Immediately after it happened I called my family, my sister first. She was extremely supportive, and she was just as livid as I was.

She couldn't believe it, and then I started contacting anyone that I could reach. I didn't really know where to start, but I contacted my primary care physician at Fenway Health, Dr. Kenneth Mayer, an HIV physician.

Well known to us. Ken Mayer has been involved in HIV prevention research for years.

I Googled everything I could about this. I found one case online where there was a lawsuit filed here in Boston actually regarding a gay man who was rejected for long-term care insurance solely because he was on PrEP.

The lawsuit was public record. I was able to read the lawsuit and contact the lawyer Bennett Klein. I found his email address online. I emailed him. I got on the phone with him, and that was actually the best lead, Bennett Klein. Kenneth Mayer actually told me that was the right person to speak with.

And, a little-known fact, which is that Ben Klein's father is an infectious disease doctor.

Yeah. I had no idea.

We ID doctors like to keep track of the famous ID doctors in the world. There aren't that many of us.

He was extremely supportive of what happened. He told me that filing a lawsuit was certainly something that I could do. That's something that he obviously had some experience with.

Earlier on in our conversation, I told him that's not something I was interested in. I didn't want to get caught up in litigation, that's a lot of time and resources for a resident. But, I asked him, "What do you think I should do? Do you think it would

be helpful at all if I wrote an op-ed about this, or got any sort of press?"

And he felt like that would be helpful, and he was extremely accommodating. He said, "If you want to write anything, I'd be happy to read it and help you out." I'd spoken to a couple other people as well about this, and one of them was Dr. Mark Litwin, who is the Chairman of Urology at UCLA.

He is a gay urologist, and he was recently at the Brigham as a visiting professor, and that's how I met him. I emailed him about my situation about month after I had met him. And I asked him, "Urologist to urologist, do you think that if I got a lot of exposure, put my name out about this issue, if it would be detrimental at all to my career, or do you think it would be a good idea? Do you think that this could induce any change?"

His response I believe was, "You should complain as loud as you can and to anyone who'll listen." I really took that to heart. Ultimately, my goal was to get more press about this issue so that something could actually happen. Whether that's regulation or legislation, I really wanted this practice to change. And so there was a time gap, but, ultimately, I ended up not writing anything. I got bogged down with work.

Oh fancy that, a resident who is bogged down with work, I can't imagine. I'm just kidding.

But Bennett Klein called me and left a message and said that *The New York Times* had contacted him, they probably found him the way I had through the lawsuit online, and asked him if there's anyone that'd be willing to be part of a story about this, and he remembered me and called me about it, and I immediately said, "Absolutely, this was more than I could have hoped for."

How was the experience dealing with *The Times*?

It was a great experience. I interviewed with Donald McNeil, Jr. who writes for the health and science section, and he was very knowledgeable about PrEP. I was impressed with how much he knew, and the sorts of questions that he asked me, and the questions that he asked the insurance companies just to get more background information.

But he asked me about how this whole thing happened, he asked for a timeline, how I felt about it, what my goals were, and we had a few conversations about this issue, and then he set me up with a *New York Times* photo editor and a photographer, which was a really interesting experience for me. First time being part of a photo shoot. And then a month and a half later, the article came out.

Did you have some fair warning the article was going to come out?

About a month after the interview I'd actually emailed him asking what the status of the article was, because he thought that it would be out in a couple of weeks, and I was just waiting around for him to contact me. This entire year and a half the news cycle has been dominated by politics.

He kept saying that it kept getting pushed back because Donald Trump was quoted for doing this or that and that it just wasn't the right time, and they really wanted this article to be prominently featured in The Times.

Well it really was.

I definitely respected that.

And even my brother who works in finance—he really couldn't have a job more different than mine— and yet when this appeared, he contacted me that day and he said, "You hear about this?" And of course, all of us in our field heard about it because it became big news within the infectious disease world very, very quickly. Was the reaction what you anticipated?

It was bigger than I expected because he didn't give me any warning in terms of where it would be in the paper or how big the article would be. I had no idea it would be on the front page and that my picture would be so big.

The print version, it's different than the online version, but I went and picked up a copy and never thought I would see my face that big anywhere. It made me a little embarrassed, but I was definitely happy that it got so much press.

Immediately when it came out I heard from a lot of friends, a lot of colleagues, everyone was extremely supportive, and then a lot of online news sites, other newspapers picked up the story, and I was really happy that it was getting the press that I wanted it to get.

Actually, and I've said this to you before as did our social worker that has worked in our clinic for a long time, it's both incredibly brave of you do this, and also incredibly important because it is a form of discrimination that really is not fair, and really I want to thank you again.

Absolutely.

I want to ask you if you've had any negative repercussions from the experience.

I am lucky that I haven't experienced anything negative from this.

Great.

I was aware that it would probably get some press and a lot of it could be negative. Besides some negative comments online that I didn't really read [or] I stayed away from, I only heard about positive things.

If you Google my name, if you look in Doximity and those websites, it links the articles to it. There's a section that says, "Press Mentions." I didn't realize that at the time, but now I'm aware of that. If anyone Googles my name or looks at that site, associated with my career they'll also see those articles, which

I'd definitely come to terms with or I wouldn't have wanted to do this.

I'm very much comfortable being an "out" gay physician and using my voice to speak for change in any way possible. I almost felt like I had a responsibility to do this.

Great. So bring us up to date, what's going on now with disability insurance, if you want to share etcetera?

To backtrack a little bit, I did end up getting the disability insurance with a different company, thankfully. With regards to the article, a couple days after it was published, Donald McNeil Jr. wrote another article stating that New York State had started investigation of these cases, and they wanted gay men who have experienced anything similar to reach out to them.

They felt like it was a form of discrimination as well. And then a couple days after that, I had seen online that California had followed suit on something very similar. So I was very proud of that, more so than the original article because it meant that hopefully something can happen even if it is in two of the more liberal states in the country.

I've reached out to the Division of Insurance here in Massachusetts, and there is an insurance commissioner Gary Anderson. I have not been able to get in touch with him yet, but I have called and written emails, and I'm waiting to hear back. I'm told that they are looking into my complaint.

I've also reached out to the Attorney General's office, Maura Healey, and I've been in contact with the [Massachusetts] state senator Julian Cyr. He and Bennett Klein have written a letter to the Division of Insurance as well.

Julian Cyr is looking into getting in touch with them, seeing if they can pass some sort of regulation, and if not then he's looking to pursue legislation, which is really great to hear.

That's terrific, and this is obviously all things that take time, and residents don't have a lot of time so you're really to be credited. Any last comments? Anything else you want to mention?

No. I'm just really grateful to all of the people that read the article, that shared the article, that are as outraged as I was and still am about what happened.

You do your outrage in a very controlled way, and I think that is one reason why it's so effective. Anyway, this is Paul Sax from OFID, and I've been talking with Dr. Philip Cheng who is a fifth-year resident in neurology here at Brigham and Women's Hospital, and he has been discussing his experience of being declined disability insurance because he was receiving Truvada for PrEP. Thanks so much for joining us, Phil.

Absolutely. Thank you, Paul.