Transcript: Secrets of a Long-Term Survivor

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Peter Staley talks with long-term survivor Matt Sharp at the 47th Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC) about his activism, his new regimen, and his facial lipo fix. To see the video click here.

PS: Hi, this is Peter Staley with AIDSmeds.com, and we're reporting from the ICAAC conference in Chicago—you can see Chicago in the background. And we're here with Matt Sharp, a longtime friend of mine, very longtime AIDS activist, and a long-term survivor of HIV. And you're currently the director of treatment at TPAN, which is based here in Chicago. It stands for Test Positive Aware Network. First off, Matt, thanks for joining us.

MS: Thank you. Thanks for talking to me.

PS: Tell about about TPAN. It's a strange name for an organization: Test Positive Aware Network. What do you do?

MS: Yeah, it sounds like we're a testing agency, and we actually do a lot of rapid testing right now. But it started as an AIDS treatment organization—at least education, information. It started in the living room of gay men back in the 80s when they wanted more treatment information, and support with each other, and they met together in a living room, and that's how the agency started, and it grew from there. A newsletter was devised, and from that newsletter came our magazine, which is *Positively Aware*. More people are familiar with *Positively Aware* than they are with TPAN, but the magazine came from TPAN.

PS: There's a Spanish version of the magazine as well, right?

MS: We do a Spanish version of the drug guide, which is our annual drug guide issue, which goes through all the medications that are available, and provides different perspectives on those medications. Side effects…a perspective from doctors, from pharmacists, and from patients.

PS: When I read the mission statement, it kind of reminded me of the People With AIDS Coalition. It's very peer-oriented. The staff is, what, 65% positive?

MS: That's right, yeah, and we pride ourselves on being probably one of the last peer-led organizations in the country. We strive to employ people who are living with HIV. All of our support

groups are peer- facilitated. Even our education—we have peer educators doing all our education work. And also, our testers—a lot of our testers are HIV-positive. So that provides a really amazing amount of support when somebody tests positive—they can immediately talk to somebody who's positive. It's a really good structure and I think we are getting a lot of support from the community because we're one of the few peer-led agencies left.

PS: Now, Matt, your story is pretty inspiring. You've been living with HIV a very long time, you're a long-term survivor. When did you find out you were HIV-positive? Where were you?

MS: I was in the heartland of the country, in Oklahoma city

PS: Where we first met.

MS: That's right. Should I say that we invited Peter to be a keynote speaker at our gay and lesbian event…?

PS: It was in the late '80s—I think it was, what, '89?

MS: It was '89. So I was tested in 1988 in Oklahoma City, and that's how I found out I was positive.

PS: You were one of the co-founders of ACT UP Oklahoma City, is that right?

MS: It was called STAT, which wasn't really an acronym for anything, but we liked the urgency of that word. But it was basically ACT UP.

PS: And then from there you went to San Francisco, is that right?

MS: Yes, I had a partner who passed way and a lot of people were dying then. It was a really hard time, as you know. I had friends in the Bay Area, and it's also someplace I always wanted to live so I got myself there, and I knew and I recognized that that if I was going to be aggressive with treating myself and being on top of all the current therapies, that I needed to be in a major urban center, and San Francisco…

PS: Major HIV center.

MS: Yeah. So San Francisco really led me there because it was a place I always wanted to live.

PS: Any major health scares?

MS: Yes, a few. I've been very, very lucky, I haven't had any major OIs—no PCP, no MAC. But I did have wasting syndrome- I was diagnosed with wasting syndrome so I did have to deal with that- I was one of the first people in the Human Growth Hormone study, And that's basically what turned me around and led me to the protease era. If it hadn't been for growth hormone, I probably wouldn't stair-step to protease inhibitors and HAART.

PS: Do you still take growth hormone?

MS: I do take it today to reduce my trunk fat, and it's really helped me for that.

PS: You recently became a poster boy for the drug that's probably going to be approved within weeks of now- the first integrase inhibitor, called Isentress (raltegravir). And you traveled to the FDA hearing, where they did ultimately recommend approval. And you testified on behalf of the drug, because you were one of the earliest users of it. First or second person on the expanded access, is that right?

MS: That's right. I tried to get into the study, and there wasn't a site—the last, large study I could get into—there wasn't a site in Chicago. And I had to sort of fight for that, but it never happen in time. So I waited for the expanded access to open, which is probably a good 4 or 5 month wait. And I wanted to just say that the drug development committee of the AIDS Treatment Activists Coalition, ATAC, sent me to the hearing. It wasn't totally on my own, although fortunately I was able to tell my own story without trying to promote or dissuade people from going for the drug.

PS: Now we should mention ATAC, AIDS Treatment Activists Coalition, is kind of a national coalition of AIDS treatment activists—from the Treatment Action Group, to Project Inform, to groups all over the country- it's really a wonderful network, and it lobbies industry and government, really pushing the drug approval process along.

MS: Right, follow drug development, and also access issues, too. We're also following immune-based therapies, as well.

PS: What was your experience on Isentress?

MS: The Isentress drug—as my history goes—came along at the perfect time for me. Because I was a failure on all the latest drugs—the new T-20 injectable treatment, I had already failed, I'd been on it 2 yrs. So I knew there was a new protease inhibitor I hadn't taken, the Prezista drug, and I had heard in the study design, after following the development of Isentress, I knew that the best way to take it was to add it with another new agent. So I waited that period of time, when I was waiting for the expanded access to open to take both Prezista and Isentress together, and for me, fortunately, that changed things around immediately. Within two weeks I had an undetectable viral load, now I've been on the drug almost a year and I've stayed undetectable and I've never been undetectable in my whole treatment history

PS: And you're highly treatment-experienced. You've been taking treatment for how long?

MS: I've been taking treatment since 1989, the year after I tested positive. And my story goes like a lot of other people who are like me we added a new drug—

PS: Started on monotherapy…

MS: —to older regimens, and that forced me into sequential monotherapy.

PS: Successive resistance.

MS: Absolutely.

PS: You develop resistance to each new thing you take because you're resistant to the stuff you've taken before, and this is one of the first salvage regimens—Prezista, Isentress—part of this new group of salvage therapies we've got now that are really changing people's lives—like yours.

MS: Absolutely, and that's one of the things I said at the hearing—that this drug is really saving lives. That set of people like myself who are completely out of options, in the salvage realm, and you know I think we're in a new stage—we're at this conference here, we're hearing two or three new drugs that are really becoming active and look very active for people like myself. So it's a very encouraging time I think.

PS: We should say that even for patients who may not have huge viral loads or complete treatment failure—people who have been coasting along maybe at 5,000 or 10,000 viral load on treatment—now that these are on the market, they might want to consider going undetectable because of this so that they don't become highly resistant to the therapies that they're currently on.

MS: Yeah, again, I think that this is another boost for people who have not been able to get to that undetectable level.

PS: What about side effects? Any on Prezista?

MS: None whatsoever, other that probably a little bit of the ritonavir part of Prezista that causes a little bit of side effects. But I'm telling you, my health is excellent, everything from regular bathroom to full energy. One of the things I told people at the hearing was that I've had a problem with skin warts—cutaneous warts—and one of the things that I noticed when I started on this therapy is that the warts started drying up and falling off. I had gone to a score of dermatologists, and everybody would throw up their hands—no success, no treatment, lots of pain in dealing with the treatment. Nothing was working, except just to get my immune boosted.

PS: You and I, besides sharing a long history together, also share the experience of taking trips to Tijuana, Mexico to get some face-filling done. I went after you and in fact I called you and asked about your experience because I was doing my research on whether the clinic down there was all its reputation was, which was good. It's kind of a face-filling factory down there. But they began to switch treatments right before I went down. I got PMMA injected in my face, which is slightly more permanent, I think, and smaller. What was your experience?

MS: Well, I'm glad you brought that up, because again, here's another thing that's going to make us live a good quality of life and not have all the stigma—or possibly not have stigma around—or being as recognized as someone who has HIV. Yeah, the new product that you tried is supposed to be- they call it a smoothing agent- it's supposed to be smoother than the Bio-Alcamid, which is the product that I used. So they're both apparently removable, they can take them out if there's too much done, but they are permanent. The problem with them is they're not approved yet, and so people, if they want them, they actually have to pay out of pocket for them.

PS: Let’s clarify, because from what I understand PMMA is not removable at all, and that’s kind of the difference with Bio-Alcamid, whereas if something that goes wrong, theoretically you can remove Bio-Alcamid, but PMMA is too small of a molecule, there’s too much integration going on, and it can’t be removed. Which is a little scarier, because if they screw up somehow, and you’ve got a lump somewhere…but they do a very fine job down there, and certainly I’m very happy with what happened. Matt, thank you for introducing me to Oklahoma City so many years ago. I finally remember the little barbeque that happened the night before the Gay Pride, where you kind of introduced me to the local activists down there. I think they had a lot of hot dogs, they called it something like…the invites said, “Enjoy wieners with Peter,” or something like that. It was hysterical, and we all had a good time.

MS: A wiener welcome to Oklahoma City.

PS: Exactly. Thanks very much for joining us.

MS: Okay, thanks, Peter.

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