Episode 6 – Living and Thriving with HIV!

Details: Welcome back to Real Issues, Real Talk: For Students, By Students! This week join students from the University of South Alabama as we sit down with AIDS Alabama South Director, Shey Thorn, to discuss living and thriving with HIV! For more information regarding all of the services offered by Aids Alabama South please feel free to follow this link: <u>https://www.aidsalabamasouth.org/</u>

Transcript

00:00:02 Podcast Host

Hi, everyone. Welcome back to real issues. Real talk. We are back with our season finale. Oh my gosh. I can't believe we are already done with the season. It's been a whirlwind. We've had amazing guests and great conversations and so exciting to hear back.

00:00:21 Podcast Host

After every single episode from you guys and get all of your love and support on them, it genuinely means a lot to us now. For this last episode, we wanted to bring back a very special.

00:00:33 Podcast Host

The man that started it all, that helped us kick off this season is no other than Shay Thorn from AIDS Alabama South here in Mobile. Jay, you want to go ahead and introduce yourself or anyone that might have forgotten.

00:00:46 Shay Thorn

Absolutely. Thank you so much for having me. Connor. My name is Shay Thorne. I am the Co executive director and clinical executive director at AIDS Alabama South and Shell Health Services.

00:00:56 Podcast Host

Awesome. Now just in case people don't quite understand that everything that AIDS Alabama's health has going on right now, you want to take a few minutes to talk about AIDS Alabama South as a whole.

00:01:08 Shey Thorn

Yeah, absolutely. So AIDS Alabama South is the only AIDS service organization between Pensacola, FL and New Orleans, LA. We cover 12,545 square miles of southwest Alabama. We provide essential life sustaining services to individuals who are living with or affected by HIV, and that includes social services.

00:01:28 Shey Thorn

Such as rental payment and assist.

00:01:30 Shey Thorn

Since utility assistance housing, we believe that housing is healthcare, food boxes, medical transportation. We also have full STI testing services, HIV, gonorrhea, chlamydia trip and syphilis, and a full service comprehensive sexual health clinic that offers treatment for HIV.

00:01:50 Shey Thorn

It is as well as prep the pill.

00:01:52 Shey Thorn

That prevents HIV.

00:01:53 Podcast Host

Wow. You know what's so crazy is we've filmed a lot of episodes, especially with your colleagues.

00:02:00 Podcast Host

And you know, every single one is diving really deep into these services that is offered by your organization and it just it blows me away when you lay them all out. By that, I mean, as our episode was titled, you know, All This in Our Little Town. And then, of course, surrounding areas too. But it's just. It's incredible. I mean, huge kudos to you for being able to do what you do.

00:02:19 Shey Thorn

Thank you so much. It means a lot to me.

00:02:21 Podcast Host

Of course. Well, today.

00:02:24 Podcast Host

You know, aside from all the wonderful things that your organization does, we really wanted to focus this episode on what it's genuinely like to live with HIV. And going

through that process now, thank you so much for coming on this episode and being willing to talk about your status. We know that's something that.

00:02:45 Podcast Host

Not a lot of people are comfortable with, so you know, just once again, thank you. Thank you. Thank you. This is really vital information for our listeners and for the Community.

00:02:55 Podcast Host

Now you know first and foremost, I want to ask you.

00:02:59 Podcast Host

What was it like getting diagnosed with HIV? Could you kind of walk us through the day? What was going through your head and, you know, I assume it wasn't the easiest time for you?

00:03:09 Shey Thorn

No, not at all. I hate to laugh. I'm very thankful to be in a place that I can laugh at it now. So January will be my 13 year.

00:03:19 Shey Thorn

Mark of living with HIV.

00:03:22 Shey Thorn

So I'm very, very happy about that and actually I'm considered a person now that is aging with HIV, which is weird to think about. I'm only 31, so I was 18, had just turned 19 whenever I was diagnosed with HIV, I was living my best life. I was a freshman at the University of Alabama. I was studying.

00:03:41 Shey Thorn

Dance performance and Health Sciences. I thought I had everything laid out for me and all of these opportunities in front of me that I was just gonna tackle straight on.

00:03:52 Shey Thorn

Coming from a family that was very open and talked about sexual health a lot, I came out at the age of 13 and my mother had always been my biggest supporter and whenever I became sexually active, I opened that conversation up with her to seek advice and in her motherly fashion, the very first thing she said was.

00:04:12 Shey Thorn

Every three months you need to.

00:04:13 Shey Thorn

Tested and little did I know that that was also the CDC recommended guidelines for anyone between the ages of 13 and 64, so I did. I maintained testing every three months and I just so happened because I was a freshman at the university to have skipped my normal three-month checkup and.

00:04:33 Shey Thorn

I went about my life that fall semester.

00:04:36 Shey Thorn

And then I went home for the Christmas holiday, and I went to our family physician and got tested and I got a call as I was walking around the quad at the University of Alabama. And it was my physician letting me know that I needed to come home so that he could talk to me. And I'm like, what are you talking about? You know, I don't have a car.

00:04:56 Shey Thorn

I didn't have a job at that time. I come from a pretty poor family. I was living off of scholarships and grants and what have you. And I was like, whatever it is I need you to just tell me over the phone. Basically, I didn't know I should say this, but you have my full consent. Tell me right now.

00:05:12 Shey Thorn

And that's when he told me that I had tested positive preliminary positive for HIV and then needed to run additional blood work. And since I had lived so far away that he would attempt to connect me to another physician in my local area in Tuscaloosa so.

00:05:32 Shey Thorn

I feel like in that moment I lost control. I was way too young to have handled or tried to attempt to even handle something like this on my own, but I did it for about three to six months. The very first thing I did was go to my dorm room and just unload all of those feelings and I think.

00:05:52 Shey Thorn

I was in pure fear and depression and crying for about 3 weeks before I came to terms with the fact.

00:05:59 Shey Thorn

That I needed to do something about this.

00:06:02 Podcast Host

Go.

00:06:03 Podcast Host

I can't imagine what you would be going through during that time, especially so young and as a freshman and you know, just getting started in your collegiate career, did you have, you know, like a wide array of familial support with your diagnosis or your friends there, or did you?

00:06:20 Podcast Host

Kind of just.

00:06:21 Podcast Host

Say like, hey, this is something I have to figure out on my own.

00:06:24 Podcast Host

Like I can't tell everyone yet until I get it under control. What did that process look like for you?

00:06:31 Shey Thorn

So HIV then is it's still the same HIV, but our world was so much different. Stigma was so much more prevalent. Misunderstandings and MIS education surrounding HIV were a lot more rampant. And so even myself, I was so under educated regarding HIV at that time. I definitely thought it was my death sentence.

00:06:51 Shey Thorn

I thought that that was going to be the way that I left this world and being young, I kind of gotten that mindset of what can I do to experience this life?

00:07:03 Shey Thorn

I did not. I did not open up to my family at that time. I thought it was way too early on. I knew I needed to learn more. I needed to speak to doctors and and and my providers and get on treatment and kind of see what this life looked like. And I knew that I had to be pretty careful and protect myself too. So my main goal in that was to put myself 1st and protect myself.

00:07:24 Shey Thorn

About six months after diagnosis is whenever I started treatment and that was when I learned a lot more about HIV and the and the real facts about it. And that's whenever I kind of had enough courage to go speak to my mom and she was the first person that.

00:07:39 Shey Thorn

Told and she was right there. Oh, gosh, I could cry.

00:07:42 Shey Thorn

About her right now.

00:07:43

Hmm.

00:07:44 Shey Thorn

She was right.

00:07:45 Shey Thorn

There with me through the whole time and she.

00:07:49 Shey Thorn

Told me how scared she was and she kind of spoke some of those fears that we thought were reality, and I eliminated those. And then she went to one of my very first doctor's appointments with me, actually.

00:08:01 Shey Thorn

And asked a ton of questions to the doctor and her motherly fashion, and she's been my support throughout this, this, this whole 13 years. And it wasn't until.

00:08:14 Shey Thorn

Sometime over these past five years, working at the agency and you know, talking about HIV daily and working to eliminate stigma that I became brave enough to even talk about it and be open about it within my community and for a short period of time, I was shunned from our local gay community because of that. And so I got to experience first hand exactly why people don't talk about it openly.

00:08:35 Shey Thorn

And so I just made it my mission to fight against that and work against that and change it for those of us that are living with HIV here in mobile.

00:08:42 Podcast Host

Wow, I mean.

00:08:44 Podcast Host

Gosh, I'm just honestly taken away. Thank you for opening up about this and I know we got emotional there for a minute, but it's still extremely important that we're sharing this story in the 1st place you mentioned as soon as you first got on treatment. Could you walk us through what that process was like? What was around at the time that you were diagnosed, things like that?

00:09:06 Shey Thorn

Yeah. So my experience was not very different from other people and still some people to this day, and it's sad.

00:09:14 Shey Thorn

That so?

00:09:17 Shey Thorn

My the provider from mobile had to connect me to an infectious disease specialist in the Tuscaloosa area, and they explicitly only took patients in that had insurance and I had just lost my insurance and insurance was different back then. So if you had a preexisting condition whenever.

00:09:37 Shey Thorn

You did get insurance then?

00:09:40 Shey Thorn

You know, they could deny you completely, and that's exactly what happened to me. And so for about a year or two, actually, almost three years, I lived without without insurance as I was going through my collegiate career, my undergraduate career.

00:09:55 Shey Thorn

It took a lot of steps and processes. I had to go see case managers at the local health department. I had to answer hundreds of questions, give them any connections of sexual partners from my past so that they could reach out to them and notify them in a confidential manner. I had to have many doctor's visits and blood work.

00:10:15 Shey Thorn

All without insurance and so.

00:10:17 Shey Thorn

My medical bills began to pile up and the provider was very much so aware that I couldn't afford them. And so basically it was essentially understood that it.

00:10:25 Shey Thorn

Was.

00:10:26 Shey Thorn

Going to go, you know, this was going to be an ongoing debt for me and.

00:10:31 Shey Thorn

It wasn't until that six month mark that I was able to start treatment, which is absurd. People need to be, you know, now we know people need to be rapidly initiated as soon as possible on treatment and.

00:10:44 Shey Thorn

Whenever the the treatment options were pretty vast at that time, and even more so vast now, so, so many more options. The very first medication I took was Atripla, and it had horrible side effects. They were the worst. It would give me, like, very lucid, vivid dreams make me feel almost like I'd been drinking.

00:11:03 Shey Thorn

And it would make my emotions just fluctuate very, very heavily. It was crazy. It was absolutely crazy.

00:11:11 Shey Thorn

And then I moved to another medication about three years after that, whenever I talked to my provider at UAB 1917, which is where they actually provided me, the state issued health insurance that essentially saved my life and all of the resources and services that AIDS Alabama Southouth and Mobile offers to the Community now.

00:11:31 Shey Thorn

And I moved on to another medication called Triumeq, which was so much better. It was 1 pill once a day and then more recently over the past year a new treatment injection. 2 injections every.

00:11:46 Shey Thorn

Two months called Cabin Nuva came out and I I began that treatment and it's been going absolutely wonderfully. But I mentioned 1917 and the resources they provide and and the work we do and what we provide and it's so weird to go to like these

organizational meetings and statewide meetings and see my case manager from 10 / 10 years ago be there.

00:11:52 Podcast Host

Yeah.

00:12:07 Shey Thorn

And be at the same level with them, but I like to say that this life and this work has truly come full circle for me, for me, and that passion creates perfect purpose. So my passion for HIV created my purpose to do this work and it allowed me to.

00:12:23 Shey Thorn

Work and function and operate in a capacity to where I could create these programs and resources for our community and that in itself allowed my journey with HIV to truly come full circle.

00:12:34 Podcast Host

Yeah. I mean, it's incredible, especially how you've been able to utilize all the experiences that you've been through to really.

00:12:42 Podcast Host

Guide the work that you're doing today and give back to the community. We talked a lot about the progression of medication and there's been huge advancements with that.

00:12:53 Podcast Host

We all know that advancements are being made in medication on a daily basis that are making it much easier for people to live longer healthy lives with HIV. But one thing that remains pretty consistent is the stigma surrounding HIV. Have you noticed any change? You know, since you're diagnosis back in the day when you were at the University of Alabama?

00:13:13 Podcast Host

And now, in the stigma and perception of HIV and even HIV positive people, what they're thinking about, yeah, it's.

00:13:23 Shey Thorn

I have and I haven't. I think it's very situational, circumstantial for the individual and where they are in.

00:13:29 Shey Thorn

Their journey with HIV.

00:13:31 Shey Thorn

For me personally, whenever I was diagnosed and I had these conversations with my providers, I was on effective treatment. U = U which stands for undetectable equals untransmitted able came out.

00:13:43 Shey Thorn

Which means that someone who's on effective treatment for HIV and has a viral load that is undetectable below a certain number cannot pass HIV.

00:13:52 Shey Thorn

Along that understanding came out and allowed a lot of us to, you know, feel more free to live our life. And that also meant that some of us could now be just be very blatantly honest. It meant that some of us could have sexual lives again, essentially. And so whenever I would have a a new partner, someone that I was dating.

00:14:12 Shey Thorn

Before anything got serious, I would open up that door in that conversation and it was very.

00:14:17 Shey Thorn

You know worrisome for me because I was giving them information about myself that they could probably use against me and every single time it was like the door just shut. These people were not welcome. Interested open to having this conversation. They wanted nothing to do with me, so I spent a lot of years being single and by myself it was not that fun.

00:14:37 Shey Thorn

But it allowed me to better understand myself. And so for me, personal.

00:14:41 Shey Thorn

Actually, the very first time I saw this true progression and stigma reduction regarding HIV was whenever I met my now husband, which was eight years ago and we've been married for five years now and he is not living with HIV. He is negative, has been negative thanks to you, equals you and effective treatment. But our very first date.

00:15:02 Shey Thorn

We went to.

00:15:03 Shey Thorn

A restaurant in Pensacola on the beach and I was like, I like this man. I'm going to have a conversation with him. I'm going.

00:15:10 Shey Thorn

To.

00:15:10 Shey Thorn

Tell him. And so I opened up and I told him, and I was so hesitant to tell him. And right before I told him, I knew that it was the perfect time to say it because my grandmother growing up.

00:15:23 Shey Thorn

Always this is.

00:15:24 Shey Thorn

So weird my grandmother growing up always ate lemons and.

00:15:28 Shey Thorn

That she would put salt on them. And so I love doing that and people find that very weird. Obviously it's very bad for.

00:15:33 Podcast Host

Your teeth don't do it truly bad for your teeth, number one. But #2 I do the exact same thing, because that's my my Midwestern family. Everyone does it.

00:15:35

Nick.

00:15:39

No, wait.

00:15:43 Shey Thorn

Yes. So you never see. So whenever people find that they're or see someone doing that, they're like taken back. So he's.

00:15:48 Podcast Host

Yep.

00:15:50 Shey Thorn

Like he's like, wait, what are you doing? And I was like, I just grew up doing. I'm sorry. It's weird. I didn't want to look weird to this new man. And he was like, no, that's so sweet. My mom used to do that, and then he tells me that he lost his mom and his dad his senior year of high school. And so it's like that that door to kind of trauma relation opened up.

00:16:11 Shey Thorn

And then at the same time, in the most beautifully spiritual way, 3 little birds by Bob Marley started playing, and I had just lost my brother the year before, and that was his favorite.

00:16:25 Shey Thorn

And I was like, everything is lining up. This means that I can. I can just at least say something.

00:16:31 Shey Thorn

And so he had no knowledge of HIV other than what we, you know, knew in the Community, talked about in the streets type of thing and that he should get tested. And that's when I told him and he did not shun me. He didn't stop me. He didn't end the conversation. The whole vibe of what we had going on didn't change. He was like, I'll be honest.

00:16:51 Shey Thorn

I don't know enough. I really want to learn more about you and I need to learn more about HIV, so I'm willing to do it. And I was.

00:16:58

Like.

00:16:59 Shey Thorn

Heck yeah, let's do this. So that's where it started, really. That's where I saw stigma reduction truly take place within our community and essentially it just started with a conversation and being open, which I learned now is very vital, but sometimes a lot of our patients and clients still experience much worse.

00:17:19 Shey Thorn

And the other side of those?

00:17:23 Shey Thorn

Chances they they come to us and tell us stories of being shunned by their family and their family still has the perception that they can't use the same utensils or plates or toilets as them. They can't be in the same room as them and that literally just goes right back to why we do the work that we do to get out into the community and educate them and eliminate these stigmas.

00:17:45 Shey Thorn

And just have these basic conversations.

00:17:48 Podcast Host

Yeah, absolutely. You know, it's first and foremost incredible that your partner was willing to learn about HIV and, you know, kind of as you were learning about the disease and learning to live with it, he was willing to grow with you. That's beautiful. And of course, trauma bonding just made it all better, you know.

00:18:07 Podcast Host

Right now, for those that might not have like family or friends support, what would you recommend that they ensure they do to get the proper?

00:18:19 Shey Thorn

Take care of themselves first. I think a lot of times people in those situations find it easier not to get into treatment, not to get into care, not to see their.

00:18:28 Shey Thorn

Providers.

00:18:29 Shey Thorn

Not to have the essential conversations with the people that need, they need to be having them with the people that can truly help them. And so if someone in that position.

00:18:40 Shey Thorn

Were to, you know, self identify that they needed that help, that they were ready to begin treatment, that they were ready to just have a conversation.

00:18:47 Shey Thorn

And then go to your local aid service organization or comprehensive sexual health clinic. I know this podcast reaches a a very, very large region, but if you're in Mobile County, aids, Alabama S is the place for you. We can be those people for you. We have very knowledgeable providers. And I think understanding that treatment is 100%.

00:19:07 Shey Thorn

Essential and that it is not an option anymore because.

00:19:13 Shey Thorn

If you do not receive treatment, then HIV over a long period of time can become your death sentence, and there there is no reason that that should be your option anymore. Whenever treatment is available and it can get you to an undetectable viral load and you can live happy and healthy and normal.

00:19:30 Podcast Host

Beautifully said. And of course, as always, we'll have all the information surrounding AIDS. Alabama S LinkedIn. The description of this episode. So anyone that does need help, feel free to reach out. Now we're reaching towards the end of the episode here, so I want to ask you just real quick.

00:19:47 Podcast Host

As someone who has been living with HIV, what is one thing you want the people to know who are not living with HIV?

00:19:55 Shey Thorn

I get asked this question a lot and I sometimes don't always know the best answer to say because I think that like what I want to say is so over said. But now that I think about it, it truly can't be said enough for anyone that is living with HIV, I think.

00:20:13 Shey Thorn

You just have to know that you are not alone, and that is so important to truly understand and think about. Whenever we understand that we are not alone, then we can begin to make connections and build those relationships with people who may be experiencing the exact same thing that we are. And then we can help one another hold each other's hands.

00:20:34 Shey Thorn

And move through this sometimes all too harsh world together to create change.

00:20:40 Podcast Host

100% now, as always, our infamous question that I'm sure you're very aware of.

00:20:48 Podcast Host

Let's say for a minute that our listeners were walking around campus. They had their earbuds in and then Ohh popped one out to talk to a friend. Just put it back in. They're returning to this point in the.

00:21:00 Podcast Host

Episode.

00:21:02 Podcast Host

What is the one thing you want them to take away?

00:21:05 Shey Thorn

U = U undetectable equals untransmitted able if someone that is living with HIV is on effective treatment, they are seeing their provider. They are taking their medication as prescribed their viral load. The amount of HIV in their system will be so low that they cannot pass it along to anyone under any circumstance.

00:21:25 Podcast Host

Incredible. Absolutely. And that point just needs to be hammered into people over and over and over again.

00:21:34 Podcast Host

Shay, thank you so much for coming on the podcast. Thank you for everything that you do with your organization, not just for the Mobile County, but for helping ending the stigma surrounding HIV. It is truly incredible. All the work you do, and I hope that you continue to do it for the years to come. Well, I'm sure you will.

00:21:54 Shey Thorn

Anything else? Thank you.

00:21:55 Shey Thorn

So much for having me, Connor. I really appreciate it.

00:21:57 Podcast Host

Of course, for our listeners at home, if you need to ever find information out about AIDS Alabama South, feel free to check out the links in our description. We have had an incredible time throughout the season with you guys and.

00:22:12 Podcast Host

Interacting with you through all these episodes has just been incredible. As always, if you want to check us out, feel free to listen to us on any platform that you listen to podcast. Be sure to check us out on social media and we'll.

00:22:24 Podcast Host

Catch you in the next one.