Tammy Kremer (00:00):

Combating STI stigma is at the core of the work of expert guest host Dr. Ina Park. She talks with Courtney Brame, founder of the podcast, Something Positive for Positive People. Breaking down stigma is especially important now as there are more cases of monkeypox. We'll be doing a follow-up on monkeypox for our next episode. Welcome to Coming Together for Sexual Health, where we talk about enhancing sexual healthcare.

Ina Park (00:28):

For most of us, having sex is easier than talking about it.

Rosalyn Plotzker (00:32):

This is not related necessarily to the people who have the infection. It's related to the healthcare system in which they exist.

Duran Rutledge (00:43):

What can I do? What can I learn that impacts change for the people that are in my sphere of influence?

Rosalyn Plotzker (00:50):

This is so, so, so preventable.

Tammy Kremer (00:54):

These conversations are brought to you by the California Prevention Training Center at the University of California San Francisco. It's time. Let's come together for sexual health. Just to note, all views expressed are those with the person speaking and not of their employer or the CAPTC. And a trigger warning. This episode includes discussion of suicide ideation.

Ina Park (01:18):

Welcome, everybody. My name is Dr. Ina Park. I'm a professor at the UCSF School of Medicine and the medical director of the California Prevention Training Center. One of my passions is actually trying to combat STI stigma. To that end, I'm the author of a book called Strange Bedfellows: Adventures in the Science History and Surprising Secrets of STDs. Through that work, I encountered lots of folks on social media who are doing wonderful work combating stigma. One of those people is actually Courtney Brame, who is the founder and podcast host of Something Positive for Positive People. It's a 501C3 nonprofit organization and it's advocating for the integration of mental health resources and STD prevention efforts. Courtney provides lots of support to people who are dealing with diagnosis and dealing with disclosing their STI status to folks. I strongly support Courtney's mission. So much so, in fact, that I recently joined the board of directors of Something Positive for Positive People because the podcast has been really helpful to quite a few of my patients. Actually, Courtney has released over 200 episodes of the podcast since it started in 2017. So, Courtney, welcome to the podcast.

Courtney Brame (02:31):

Thanks for having me. I'm happy to be here. I was sitting here and I had my fingers crossed. I was like, I hope she says she's on the board. I hope she says she's on the board.

Ina Park (02:41):

Tell me a little bit about the podcast. How it got started and then how you decided to shift it over into a nonprofit. And focus also on what is your mission behind it? Why are you doing this?

Courtney Brame (02:53):

To begin, I am someone who tested positive for general HSV-2, the herpes simplex virus that primarily presents symptoms genitally in 2013. I am on the ninth year of my diagnosis now. For the first four years or so, I just navigated it the way that I knew how. I Googled how to minimize the outbreaks. I found that there were three main things. One of which was to focus on your eating, one was to exercise, and then the other one was to manage stress. I began to incorporate things into my life that allowed for me to have a new baseline for what healthy meant for me. In doing so, I didn't think I needed much other than those three things for myself.

As I continued on through navigating life with herpes... dating, disclosing... it got to a point where I got tired of feeling like that conversation was always just lingering in the back of my mind. About having to tell someone I have herpes. And so I began to explore alternatives to dating sites and various ways of finding out. There had to be other people out here with herpes. I stumbled into some spaces and platforms that there were people who were living with herpes. When I got there, I didn't have to worry about that anymore. That lingering thought of when or how to disclose and worrying about potential rejection. It was just so much easier for me to be myself.

I assumed that would've been everyone's experience in the space, but it actually wasn't. There were people who wanted to end their lives because of their diagnosis because they thought that no one wanted to have sex with them again. They were unable to find partners and love. I saw that a handful of times to a point where I was like, all right, this isn't a normal thing. Maybe it's one off. And then it took for it to hit home when someone that I had become friends with who was in a relationship, their partner was accepting... They still one day opened up to me and said that they too had thought about ending their lives. When this person said it was, that's when it hit me that it wasn't exclusively about being in a relationship, not being in a relationship, finding love or not finding love. This was about something else.

So, when this person brought it to my attention, I began to reach out to the communities that I was in for people who were living with herpes and just asked if anyone would be open to recording an interview and then me sharing it with the people who were struggling with their diagnosis to the point of suicide ideation. After interviewing one person and then sharing it directly with a few people and getting feedback, I began to ask if more people wanted to participate. As I began to share them within our communities for other people to share with their people, it began to turn into something that I didn't foresee, which was so many people being willing to share their experiences for something especially so stigmatized. It became a lot easier for me to just put the recordings up onto a podcast platform. That was essentially the birth of Something Positive for Positive People.

As a podcast, it began to be a unique resource in the sense that anyone who has internet access is able to access this platform and really be able to hear people who are living with herpes intelligently speak about the virus. Now, that conversation began to expand into other STIs. I've also interviewed health professionals, nurses, sex education professionals, as well as mental health professionals for the sake of bringing all of these useful resources into one space where people are able to consume the information in a way that is safe for them without having to compromise their anonymity, if you will.

What caused me to make this into a nonprofit was... Over two years of interviews, maybe around episode 100 ish, was when I began to see this ongoing pattern of how people's mental health was impacted by their sexual health status change. I learned that many of the people who I interviewed had this identity about themselves. Once their diagnosis came through, it was like that image they had of themselves was completely shattered. And the shattering of that identity was what led them to looking for resources, what led them to looking for and ultimately stumbling into Something Positive for Positive People. After connecting with this space and seeing all of the different ways that they can go about navigating their diagnosis, navigating stigma, learning how to disclose, learning that there's so much more to their being than just exclusively their sexual health status or ability to merge genitals with somebody without there being any potential, quote, consequences, that really where healing started to occur for people. And so, while that was just one hub of resources, one of the things that I wanted to also be able to offer was therapy and counseling services for people who were struggling most with potential suicide ideation or depression even. That's where the nonprofit mission came in to be able to support people navigating stigma by paying for them to get into therapy or group counseling services.

Ina Park (09:08):

Some things that you've said have really resonated with me and my experience caring for folks who are living with HSV, which is this identity crisis that you refer to. There is the way someone views themselves prior to having HSV and then the way that someone views themselves after having HSV. The clash of those identities can be really destabilizing for folks. I think part of the issue is the fear and anxiety around disclosure and the fear of rejection. I'm wondering if you underwent some of these identity crises yourself when you received your diagnosis or, because you poured yourself into this work, whether or not you were able to kind of avoid the intensity of the response that I have seen in some folks.

Courtney Brame (09:56):

I will say that, in hindsight, yes. Once I got the information of how to not have outbreaks, it was enough for me to manage moving forward. I was more concerned about the embarrassment of being the guy who gave someone else herpes than I was having herpes myself. After checking in with my most recent partners and hearing that they didn't have herpes, there was a sense of relief for me. And so getting to the point of recognizing how much bigger this whole thing was... herpes stigma... I saw that it really wasn't about my experiences alone and it wasn't really about me. It was about some sort of an emotional or mental response that I was having to my STI diagnosis and the stigma of what it means to carry this virus moving forward.

Now, going into the space of advocacy, as I began to talk to people, I realized that they were getting something from just being able to share their experience and I was getting something from holding that space. The more people I talked to, the more experiences that I had to draw from. It helped me with my creativity when it comes to disclosing my status. My creativity and how I decided to bring it up or talk to partners about their status. As I was so involved in this work, I think that it, in hindsight, was a way for me to avoid having to deal with my own diagnosis. This was something that came up for me in therapy. When I reached out to a therapist, I was like, "Hey, I do this work and I want to avoid burning out or having compassion fatigue." At the end of my session that day, the first day, he said to me, "I don't think you dealt with your own diagnosis." And my response was, "I don't think you know who I am. You must not know what I do."

Lo and behold, a year later when we had one of our closing sessions, he asked me. He was like, "Do you remember the first thing I said to you?" And it was just a laughing moment for me because I was like, wow, that came back full circle. You don't want to share this with anybody, but when you do, it offers that space of really being able to connect and be vulnerable with people. I think that this was really good practice for me to get to the core of what my [inaudible 00:12:22] issue was, which ultimately came down to being avoidance of rejection. That was something that Something Positive for Positive People offered me. I'm open about this. It's my work. If you Google Courtney Brame, you'll see everything associated with herpes. When it comes to dating, someone not wanting to move forward with me because of that, then I don't have to hear from them. I kind of created this screening mechanism for weeding out anyone who would not be okay with being intimate with me because I have herpes.

Ina Park (12:56):

This entire process that you've gone through, and now coming to a place of wellness and acceptance around herpes, is something that millions of people do have to go through. For the folks in our audience, many of whom are providers or health educators or folks who are working with clients, I just want to point out that herpes is so incredibly common. For HSV-2, which is the viral type that you're talking about, we used to be as common as one in four in this country and, now, it's closer to maybe one and eight folks who is living with HSV-2. But with HSV-1, almost half the population between the age of 14 to 49 has this. Many more people are actually having a genital HSV-1 as their first herpes outbreak. And yet I think there is still so much stigma around herpes specifically even though it is so common. Just a story on my end, Courtney, is I saw a patient the other day who I was testing for HSV well as HIV. The HIV result came back quickly because we have a rapid test. He said, "Okay, that's great that I don't have HIV, but I really don't want to have herpes." For him, herpes was more stigmatized than HIV. I'm just wondering. Why do you think that there is so much stigma around herpes specifically?

Courtney Brame (14:18):

There's a couple of reasons. I've had a similar experience with people who have HIV. They've talked to me in confidence and they're like, "I am so scared of getting herpes." People don't make HIV jokes anymore. People make herpes jokes. You're not gross or disgusting anymore because you have HIV because of the awareness, the understanding, the science around it. It's not stigmatized like it was before. It's not the gay disease. The way that people have shown up in allyship for people living with HIV is a way that we need people, but we won't be able to get people, to show up for people who have herpes. The reason being that people who have herpes don't want people to know that they have herpes. And there's no need for people to know that they have herpes. Whereas during the time of the AIDS epidemic, people were dying. People had to get treatment. People had to get help right away. People had to tell the people around them. The people around them where people who now... Oh, okay. I know someone who has HIV. I love them, I want to care for them, and I want to support them.

People who have herpes... I could be sitting in a room. There could be 12 of us in a room. Five of us could have herpes. Someone in there can make a herpes joke and none of us will speak up. Everyone will laugh. The self stigmatization and just being a bystander of something like that that clearly makes people have their reaction. Now, those people who are in the room who were laughing are going to go home and probably cry because they hate the fact that they have herpes. They hate the fact that they didn't say anything. They hate the fact that someone so close to them is so willing to make them feel that way, but they just don't know.

When we get to a point where we realize that everyone knows someone who has herpes, I think that we'll begin to see a shift in what stigma looks like. But we have to be willing as people who are living with herpes to create allies for ourselves. If we are struggling with dating and relationships, we don't need to just say, oh, I'm not interested or they just ghosted or something's not right. We can tell them. Hey, I have herpes and I don't want to tell this person I have herpes. And you never know. The friend that we're opening up to about something like that may also know someone who has herpes. They may know some resources. They may have herpes themselves and be able to speak to you in a way that's like, well, hey, let's go through this together. But so many people are definitely afraid of going to the people that they claim to be friends and trustworthy figures, partners even, to say, hey, I have herpes and this is what I'm struggling with. That is something that contributes to stigma. Whereas with HIV, we have a medication now, PrEP, that if partners of someone who is HIV positive is on and that a positive person's viral load is undetectable, then they can't transmit the virus. We don't have anything like that for herpes.

Ina Park (17:22):

That's right. And this whole concept is called U equals U. Undetectable equals untransmittable. For the HIV positive person, they can really confidently say, I cannot pass on HIV to you sexually. And for the HIV negative person, they're able to take highly effective prophylactic medication that's going to prevent transmission. We don't have a PrEP for herpes simplex virus. We don't have a U equals U for HSV. So, I agree with you. I think that would certainly help in reducing the stigma. I guarantee that everyone listening to this podcast either has HSV themselves or knows someone that has HSV. I have HSV-1. Right now, that's two out of two of us on this podcast that has herpes simplex virus. I think it's important for people to realize how common it is. One of the things that I want to own as a healthcare provider myself, Courtney, is that I know that many people can be traumatized by their provider because of how their provider handles the diagnosis and the conversation. The way I deliver the diagnosis might impact how someone views their future conditions. I'm just wondering. From your conversations with folks, can you share some dos and don'ts for our audience about delivering a diagnosis? What are good things to say and definitely things not to say when you're talking to someone?

Courtney Brame (18:46):

Well, you said a very interesting thing too, Ina. That the healthcare provider influences how a person perceives their own diagnosis. I want to add to that and say that a person will choose to or not to disclose based on how they're delivered the diagnosis as well. I can't tell you how many people I've heard from whose healthcare provider just completely gave them wrong information. Saying that they don't have to disclose their status if they're not having an outbreak. All they need to do is wear a condom. If they're taking medication, then they don't need to tell their partners. It's a way of alleviating any guilt because a person is looking for someone, especially from a credible resource like a healthcare provider, to give them permission to not have to further traumatize themselves by disclosing to someone and potentially receiving a rejection as a result of having herpes. When providers are giving that false information, probably no fault to their own because this is probably the last bit of information that they received in their training, this gives people permission to move forward with the justification of, oh, the doctor said dot, dot, dot.

And so some dos... Many people who've had positive experiences expressed that their healthcare provider saw them as a human and that they didn't use any stigmatized language. Trauma-informed care is a very popular buzzword right now. Going into it with that and understanding that your interaction will validate or invalidate a person's identity. Being able to see that there is a person sitting across from you when you deliver this diagnosis. Being able to just simply even ask them what do they feel like they need? Not do you have any questions? That is very standard. It's, hey, I know that this a lot. What do you need right now? And then being able to just guide them to something that's going to be useful rather than a pamphlet that says how many people have herpes. Because that is probably the most useless bit of information to someone who's diagnosed with herpes and doesn't know any of these people who are diagnosed with herpes.

That's probably the bigger thing is just to validate the person in front of you and just remind them the only thing that will change is how they choose to respond and react to this and, in a way, many people... despite how traumatizing it can be to receive a diagnosis... go on to become much better communicators about their sexual health. It's unfortunate that it takes something like this to make someone indulge themselves into sex education that we should have been given prior to our diagnosis, but it helps us become much more efficient communicators. Encouraging partners to share their STI status. To go and get tested and provide results before a sexual encounter takes place. There are so many positives that come out of this interaction.

Now, you don't want to tell a person that right then and there when they're going through the emotions, but just having the understanding of how valuable that first contact point of receiving any information about their diagnosis... This might be the first that someone's heard of herpes. This might be the first that someone has received an STI diagnosis. Especially something that doesn't go away. The primary concern for people is how do I tell other people? It's not really how do I live with this? People understand that herpes is not something that kills you. It's annoying. It's something that many of us have probably made fun of in the past. We see the jokes in the media. Aside from that, it's just a matter of, okay, well, it is how we live with it. Many people often have a question of how do I inform other partners about my diagnosis? And then that's where you offer a tool like Something Positive for Positive People for them to start their journey of looking for information rather than going home, Googling, and just being thrown all over the place.

Ina Park (23:08):

I think the Googling process is more isolating. Especially if you're by yourself and then you're just sort of spinning off down into rabbit holes on the internet. That is the moment, actually, when... After someone recovers from the initial, I think, shock of hearing me disclose to them, when I say that this can be isolating, I do offer Something Positive for Positive People as a resource. Even though you don't know the person who's on the podcast. Just the fact that you're hearing a real person. And as a communication tool for folks who talk about disclosing to partners. Talk about disclosing to other people in their community. I think your work really supports that and it is a tool that I utilize with patients after I diagnosis. I just want to put a plug in for the podcast right here.

Courtney Brame (23:55):

Hey! Thank you.

Ina Park (24:04):

One the things I know that you also do is you actually conduct surveys of your listeners. Really taking a landscape of how their mental health has been affected by HSV. Obviously, it's a little bit different from pure research, but I'm just curious. What are some of the highlights from some of the surveys you've conducted? Because I think lots of folks listening here may work individually one-on-one with people, but you work with a much larger sample size of people who are living with HSV.

Courtney Brame (24:34):

If you go to the Something Positive for Positive People website, www.spfpp.org, you'll see 2021 survey results. What this was is 1140 something people who are living with HSV, herpes simplex virus, participated in a survey that was put together from people with herpes about things that people who have herpes wish they would've known, what they're learning, and what they found out late. This is something by the herpes community for the herpes community that is, to my knowledge, the only thing out there like it. Especially with such a large sample size. Some of the things that stood out to me on this survey is that herpes was the first STI that... Roughly 70% of people, herpes was their first STI diagnosis.

Not only that, but 70 something percent of people have not tested positive for a second STI since their herpes diagnosis. What this speaks volumes to is that education piece that comes with it. If you test positive for an STI, you now have to go on and learn about that. Especially herpes being incurable, we're learning to better navigate the communication aspect of living with herpes. Being able to talk to partners and get partners to get tested prior to being intimate with one another.

Another interesting one was that, of this 1140 something people, 3% of people had attempted suicide and then 30 something percent were having suicide ideation. That's a third of the participants who experience suicide ideation after their herpes diagnosis. That just tells us that we absolutely need to be able to get these lived experiences and resources out there. Because 91% of the people who took the survey expressed that they didn't know what useful resources they need until they found them themselves. With something out here as useful as Something Positive for Positive People, there's no reason that healthcare providers aren't able to point those people into the direction of something that could, at the most extreme end, potentially save their life and, on a low end, just be able to support them with a tool to navigate disclosure. I also want to just drop that I believe most people who are living with herpes are perfectly fine. They don't need to look for resources. They don't need to come across Something Positive for Positive People. When I do these surveys, these are people who have struggled. These are people who have been looking for information. They heavily depend on some of the resources that we provide here because it's literally giving them whatever it is that they need in order to get to the place that people who have herpes and it's not a big deal for are.

Ina Park (27:51):

I think that's a really good point, Courtney. That this isn't traumatic for everybody. For some people, they shrug and say, okay, what do I need to do next? They kind of accept it and move on. For those folks that do experience this trauma from getting this diagnosis, I think we know that the podcast and connecting with others in that way reduces the sense of isolation. What have you seen that's been helpful for healing trauma with these issues related to getting a diagnosis?

Courtney Brame (28:23):

Some of the most useful and healing things have been just having community. When you're able to have an interaction with someone that has known you prior to your diagnosis and you're able to sit down with them and just tell them, I have herpes, and you see yourself seen the same way that they've always seen you, I think that's a big aha moment. Because what happens upon diagnosis is that any internalized stigma becomes activated. Whatever it is that I may have thought about people with herpes, when I receive a herpes diagnosis, that's what becomes of me. It takes for me to have a new point of reference communicating about that with someone who I know or someone who knows me and then they not treat me any different. I don't think that people trust their support systems, their friends, enough to be able to go to them right away in all cases, but the community aspect of being around people who also have herpes and understanding that you can live with this and then being able to sit in on conversations about this... I think that expands a person's perspective beyond what they just think about herpes because now they're tapping into a whole new world because they've grown up in a world where people didn't talk about herpes.

Ina Park (29:55):

Yeah, and I think being alone with your own thoughts is probably one of the most isolating and anxiety provoking things that you can do. So, yes. Creating community, creating connection, and hopefully getting support from those who knew you and loved you before the diagnosis.

Positive for Positive People did start off as a podcast exclusively, but I know that it's moving into other areas, which you've alluded to earlier. Where would you like to go next with this endeavor? What other areas and arenas would you like to go into with the organization?

Courtney Brame (30:35):

I would like to be able to pay myself and I would also like to be able to pay a full-time therapist. Whenever people reach out... I talk to everybody, but there's only so much that I can do. Sometimes people just need to vent. And sometimes people just need me to hype them up a little bit to go into a disclosure. They come back and they're like, "Yeah, I'm in a relationship now." That's something that I will never stop getting joy out of. I would also like to be able to support people that are beyond my help. There are genuinely people who need a therapist, who can't afford a therapist, who don't want to talk to their therapist about their diagnosis.

I know that people feel safe with me because I'm just a dude with a podcast, but I'm speaking at conferences, I'm seeking funding, and I'm putting the messaging out there. While we wait for a vaccine or we wait for a cure, my angle is to combat stigma and give people the tools that they need in order to navigate stigma long enough to stick around. Because at the end of the day, if we're not willing to speak up, put our names out there, and say, "Hey, we need better treatment. We need better testing. We need a vaccine. We need a cure," then we're never going to get those things. It's stigma that keeps us silent.

There's a whole campaign right now running. Penny for your thoughts campaign. The guy who runs that campaign is simply asking people for signatures so that we're able to expedite the process of getting this possibility of a vaccine out there. But people are deathly afraid of putting their name out there or they think, oh, it's just not worth it because they're feeling hopeless. I've been hearing about cures and vaccines and research since I was diagnosed. And here we are, nine years later. I've chosen to put my focus here on supporting people and dissolving any and all internalized stigma. When we get those allies, who knows? Maybe these people will step up with us for us to advocate for vaccines themselves and we've got 10 times the number of signatures that we would've been able to get just from people who have herpes. I'm really seeing that to be a major issue. It's just this lack of allyship.

Ina Park (32:58):

Because we're not dying, because we're not visibly ill necessarily, I think people don't feel that sense of urgency necessarily to speak up. I think that's a really, really good point. It sounds like... Yes, it would be wonderful. Full-time staff, full-time licensed therapist, I think could go a long way, and then also making this a career path for yourself. I think we're going to wrap up here. I just want to thank you so much, Courtney, for being on the podcast. The title of this podcast is Coming Together for Sexual Health. I'm wondering. What are your hopes? What can we create by coming together for sexual health?

Courtney Brame (33:35):

I think that we create allyship. Sexual health is mental health. It's not exclusively locked into the acts that we perform with our genitals. It's an overall state of being and your identity and who you are. Our whole concept of sexuality, really, is something that is a part of the whole human. And so when we're coming together in sexual health, it means coming together in terms of those internal identities and conflicts that we may have as individuals trying to separate ourselves from our sexuality and our sexual expression to see that this is something that directly impacts how we think, how we feel. When we can begin to embody all of this, we have whole humans who can go out into the world and also aim to de-stigmatize not just STIs, but also topics around sexuality. Seeing just how interconnected all of these things are, we begin to encourage that wholeness. That integration among one another so that we can have an army of allies that are advocating for people to experience their fullest expression of themselves.

Ina Park (34:55):

Thank you so much, Courtney. Thanks everyone for listening to this episode of Coming Together for Sexual Health with myself, Dr. Ina Park, and Courtney Brame. I just want you to know that, if you want to donate to Courtney's organization, Something Positive for Positive People, you'll see a link in the description of this podcast so that you can go and check out his website and donate to his organization into the cause of reducing herpes stigma. Thanks. Until next time.

Speaker 1 (35:23):

Thanks for listening and check out the show notes for the resources mentioned in this episode. You'll also find the link to the transcript of the show. Please follow and rate us wherever you get your podcasts. This will help more people find us. Connect with us on Instagram @comingtogetherpod and learn more about us and get in touch at comingtogetherpod.com. This podcast is brought to you by the California Prevention Training Center, where we build the capacity of healthcare professionals working in sexual health and emerging infectious diseases. Check us out at californiaptc.com and follow us on Twitter @CaliforniaPTC. This podcast is produced by me, Tammy Kramer, with Laura Morilazar and Catalina McDonald. It is edited by Leila Mohimani and Isaiah Ashburn with original music by Leila Mohimani. We're based at the University of California San Francisco and would like to acknowledge the Ramaytush Ohlone people, the traditional custodians of the land that UCSF sits upon. Thank you for coming together for sexual health.