

Courtney Brame

My name is Courtney Brame, I'm the Founder, Executive Director of the nonprofit organization Something Positive For Positive People that also has a podcast by the same name which I host. On this podcast I interview people who are living with primarily herpes about their experiences from their diagnosis to dating to disclosure. For me I was diagnosed with genital HSV-2, I was living with my grandmother at the time, I was just out of college, probably 23 I believe. I'm 31 now, so yeah, it's been about 8 years. At age 23 I wake up one morning and I was under the covers, I got under the covers and I was like whoa, I'm really cold, whoa, I'm really sweaty at the same time. And I get up to go to the restroom for the first time and I go to urinate and I look down at my genitals and I screamed an obscenity, let's say that.

And my grandmother comes to the door and my grandmother's a nurse, I'd be sure to include that part here. And she goes, 'You okay in there?' And I was like, 'We need to go to the emergency room or somewhere right now.' And my mom just happened to be over this morning and so my mom drives me to an urgent care facility and we're in the waiting room, I'm not sure what's going on at this point. Having an STD never crossed my mind. So I get in there and the doctor looks at me and he goes, 'Alright, that looks like herpes.' He gives me a swab test, he gives me treatment for I believe gonorrhea and chlamydia and I get tested for the other common STIs at that point. And he sends me on my way.

I get a pamphlet that tells me a little bit about herpes and the different statistics and I get home and I immediately start messaging, texting, Facebook messaging my most recent partners just out of concern that I may have given it to them. So my immediate response was, 'Oh man, who else did I give this to?' And it was really weird how I worded each message because it was just, 'Hey, do you have herpes? You wouldn't happen to have herpes, now would you?' And everyone said no. So you can't really dwell on where you got it from or how you got it or how long you've had it or anything like that so I just kind of had to move forward accordingly with taking responsibility for myself.

The next 5 years are a huge blur for me because I kinda just stayed in my relationships with the women that I disclosed to early. Dating was a trip over these 5 years going through the process of having to first off understand the virus and then have to communicate that to another person because I already had my thoughts in my mind that okay, no one wants an STD. Nobody wants herpes and nobody wants to put themselves at risk for herpes. This is where we begin the origin story of something positive for positive people. I begin dating again and in my dating I just kind of got tired of keeping this thing to myself because it's really hard to talk about. It was kind of what led to my decision making for dating. It wasn't are we compatible, it was more so do you accept the fact that I have herpes? Okay great.

I stumbled across a dating website for people who are living with herpes and I get on that dating site and herpes isn't on my mind because everyone here has it or everyone here knows I have it, right. And so I get active in chat rooms, I'm meeting women, I'm dating, and life is great. So like where was this at for the last 5 years, right? And in these communities I find that people are saying on online forums and blogs that this herpes diagnosis is the worst thing that's ever happened to them, no one's gonna love them, they're never gonna find a partner, and they want to kill themselves. And that to me, the first couple of times I saw it, it wasn't really a big deal it was just kind of like, 'Huh, that's weird.' And then after someone I had become friends with who was in a relationship with a partner who was accepting, she told me that at some point she had suicide ideation. And so when she said it I think I started to notice it a little bit more, a lot more, and I felt like I had to do something.

And so I go to one of my communities and I just make a post. And the post was requesting people to anonymously share their experience and allow me to record it and then just send it to these people who were expressing suicide ideation. And so I got one person to do it and her perspective was one, it was the first episode of Something Positive For Positive People and over the conversation we got sad, we got angry, we cried a little bit, we laughed a little bit, and by the end of it there was this neutrality there, a sense of relief more than anything. And I think that me witnessing someone who went from holding this inside to finally having shared this experience for the first time, it really showed me that there's something to be said for the power of just expressing these experiences that we have. So after I shared this recording in the group, more people wanted to get involved.

So it went from that one interview to 4 to 8 to 16 and so many different people shared so many different experiences, there are no two experiences that are the same on the Something Positive For Positive People podcast episode archive. People expect to hear from people who have gotten herpes by being promiscuous and having multiple sex partners and being reckless and not taking any precautions and all of those things that people by default think of stigma and what people with STIs look like are completely challenged by so many different experiences of everyday people who are living their life that you would never hear from simply for the fact that they're living their life. These are people who have gone to to have families and they have businesses, these are models, these are celebrities, these are athletes, bodybuilders, people who have absolutely no reason to come up and say, 'Hey everybody! I have herpes and I don't fall under the stereotypes of the stigma.' These are the people who are sharing their stories from their diagnosis to dating to disclosure to the point where they are now.

So I often tell people Something Positive For Positive People is not necessarily a herpes resource that just happens to be a secondary effect from this actually being at its core a suicide prevention resource. It's becoming clear that there's a direct connection between an STI diagnosis as something that triggers mental health issues. As a nonprofit organization the business function of Something Positive For Positive People is to not only connect people with community resources but also a therapist in the event that they are struggling with stigma or struggling with their diagnosis, we're connecting them with a sex positive therapist who is capable of talking them through that. So one of the things that I wanna do is just put people in position to where they don't necessarily feel the need to come out and combat stigma or openly make a Facebook status that they have herpes. If that's what people wanna do, great, but they don't have to do that.

This is essentially a safe space for people to understand how they want to navigate the stigma. I have no intention of destroying stigma, eradicating it or whatever violent word you wanna insert to stigma, my purpose is to just give people the resources to navigate the stigma. It's not going anywhere anytime soon so until we're all on the same page about what this is gonna look like for us, we get the truth out there, consistent truth about this virus. Then I think that we can begin to focus more so on the important stuff which is how we process it mentally and emotionally and how we go about communicating to the people who need to know about it and how we deal with it ourselves.

TPWKY

(This Podcast Will Kill You intro theme)

Erin Welsh

You just heard from the amazing Courtney Brame who is the creator and host and editor and producer and everything of the nonprofit organization and podcast Something Positive For Positive People. You can find SPFPP wherever you get your podcasts and also on [SPFPP.org](http://SPFPP.org) or [somethingpositiveforpositivepeople.org](http://somethingpositiveforpositivepeople.org). Hi, I'm Erin Welsh.

Erin Allmann Updyke

And I'm Erin Allmann Updyke.

Erin Welsh: And this is This Podcast Will Kill You.

Erin Allmann Updyke: And today you've probably guessed we're talking about herpes.

Erin Welsh: Yes, HSV-1 and HSV-2.

Erin Allmann Updyke: That herpes simplex virus 1 and 2.

Erin Welsh: It's gonna be a really great episode in part because in addition to our incredible guest Courtney, we also had the wonderful opportunity to chat with Dr. Ina Park who is Associate Professor at UC San Francisco School of Medicine as well as Medical Consultant in the Division of STD Prevention at the CDC. And we chatted with her about her upcoming book titled 'Strange Bedfellows'. It's an incredible book and you guys are gonna love this interview. So Erin, should we jump to important business matters?

Erin Allmann Updyke: Oh yes, it is what time? Oh it's quarantini time!

Erin Welsh: It is. What are we drinking this week?

Erin Allmann Updyke: This week we're drinking The Simplex Sour.

Erin Welsh: Ooh yum. And what is in The Simplex Sour?

Erin Allmann Updyke: Well Erin, as you can probably describe better than me, it's a bourbon slush, right?

Erin Welsh: Yeah, it's a bourbon slush.

Erin Allmann Updyke: It's a very Kentucky drink.

Erin Welsh: It's so delicious, I feel like it's great, the last sort of throes of summer here as we wave goodbye to the beautiful sun and greenery that's been all around me here in Chicago. Anyway, so what's in a bourbon slush? It is essentially black tea, sugar, frozen lemonade, frozen orange juice, bourbon, ginger ale. I will warn you that it does take a bit of prep in that you make a big batch of it and you have to freeze it sometimes overnight but it's totally worth it cause it's delicious.

Erin Allmann Updyke: And we will post the full recipe for that quarantini as well as our nonalcoholic placeborita on our website [thispodcastwillkillyou.com](http://thispodcastwillkillyou.com) and all of our social media channels.

Erin Welsh: Awesome, all right. Well should we dive right into the episode?

Erin Allmann Updyke: Let's dive in right after this break.

TPWKY: (transition theme)

Erin Allmann Updyke: So HSV, herpes simplex virus, easy enough, we can learn a lot about this disease just from the name. We're dealing with a virus, specifically a DNA virus in the family Herpesviridae. That's right, this is a massive family of viruses, not just the two that we're talking about today. People are probably very familiar with a whole bunch of these herpes viruses, okay, because they're very famous and many of them cause disease in humans, not just HSV-1 and HSV-2. Do you know some of them Erin? You probably do.

Erin Welsh: Well there's herpes zoster.

Erin Allmann Updyke: Yep, that causes chickenpox and shingles.

Erin Welsh: Is CMV one?

Erin Allmann Updyke: Yeah it is, cytomegalovirus is a herpesvirus.

Erin Welsh: EBV?

Erin Allmann Updyke: Yeah, Epstein-Barr which causes mononucleosis is also a herpesvirus. I got at least a couple more.

Erin Welsh: That's all that I have.

Erin Allmann Updyke: Great job, Erin that was very impressive. Also Kaposi's sarcoma is caused by a herpesvirus, HHV-8. And then roseola or sixth disease which is common in small children can be caused by HHV-6 or sometimes 7. Then there are also hundreds of other herpesviruses that cause disease in other animals, other mammals but also birds, fish, molluscs, amphibians, reptiles, everybody's got herpesviruses!

Erin Welsh: Oh my gosh Erin, I think I have that same exact sentence in my notes. (laughs)

Erin Allmann Updyke: (laughs) That's awesome. It's so true.

Erin Welsh: Because I think I even put in molluscs and I was like whoa!

Erin Allmann Updyke: Cause when I saw that I was like, I'm sorry, molluscs? Really?

Erin Welsh: I know, I know.

Erin Allmann Updyke: Little clams with herpes? I love it. So yeah, this is a very big family of viruses but today we are focusing just on herpes simplex which is HSV-1 and HSV-2. So let's get specific on HSV. Transmission of HSV is pretty straightforward across the board, HSV-1 and HSV-2 are transmitted the same way, it's from mucus membrane to mucous membrane or from skin to skin. Easy enough. HSV can enter through any break in the skin, you can get it really anywhere, literally anywhere.

Erin Welsh: Yeah.

Erin Allmann Updyke: So in general the incubation period, so the time from when you first get infected to when you show symptoms is about 4 days but it can range from as little as 2 days to 12 days, I even saw up to a month in some cases. But one of the most important things about HSV infections is that a large proportion of them are actually completely asymptomatic.

Erin Welsh: Right.

Erin Allmann Updyke

So you can get infected with HSV-1 or HSV-2 and never show any symptoms of it. And that doesn't necessarily mean that you aren't infectious to other people because you can still be shedding virus even if you never knew that you were infected.

Erin Welsh

Right.

Erin Allmann Updyke

So let's go through the symptoms in a primary infection. Most often if you have any symptoms about 40% of the time you'll also have systemic symptoms, so you'll have fever, you'll have headache, you'll have body aches, those kind of general viral illness-type symptoms. The two most common places to get infected with HSV-1 and 2 are either the mouth or the genitals. So if it's a genital infection you can have kind of UTI-type symptoms if the urethra is involved, so urethritis, inflammation of the urethra. Or you can have vaginal irritation if you have cervicitis, so inflammation of the cervix. And if you get an oral infection then you can also get pharyngitis-type symptoms, so sore throat and things like that. And then it's also really common to have some lymph node swelling, so if it's an oral infection your lymph nodes in your neck might get swollen and tender, if it's a genital infection you have lymph nodes kind of in your groin that might get swollen and tender.

And then of course the herpes sores that everyone knows about, okay. So these lesions often start with an itching or burning sensation in the skin where the virus has entered and then these lesions appear. They start out as kind of a flat red just little spot and then they form vesicles, so kind of like little fluid-filled blisters, and then the vesicles will burst open and leave an open ulcer behind that will often crust over especially if these ulcers are on skin rather than mucus membranes. So if it's around the mouth or on the shaft of the penis or on the vulva, then they will crust over whereas if it's inside the vagina or something like that, then they just sort of heal slowly without crusting over, if that makes sense.

Erin Welsh

Gotcha, yeah.

Erin Allmann Updyke

Yeah. So they start out usually with this sort of itching and burning sensation but once these lesions come they are super, super painful. We talked in syphilis about the lesion that you get from that which is painless.

Erin Welsh

Right.

Erin Allmann Updyke

But these ones are quite painful. And in a primary infection they take a really long time to heal too, it's usually at least 8-11 days but it can be even longer. So you have these painful sores for a long time. So one of the questions is what's actually happening here? And that will lead us into how does this virus then hide out in our bodies, okay. So why does the virus actually cause these ulcers, these sores? When HSV enters your skin through a break in the skin or through the mucus membrane, the cells that they infect are your epidermal and dermal cells, so they don't have to travel far, right where they enter is where they start to infect cells and replicate. And as they do that, they cause direct damage to the cells of your dermis and epidermis. So that's why you have those blisters because those are actually from viral damage to the cells. Does that make sense?

Erin Welsh

Okay, yeah.

Erin Allmann Updyke

But then as they replicate and spread, they enter the axons of our sensory nerves.

Erin Welsh

Right.

Erin Allmann Updyke

What?

Erin Welsh

I know, it's wild.

Erin Allmann Updyke

It's so wild! Oh my goodness. So they enter the axons and then they travel, the axons are essentially the nerve projections, right, and they travel along these axons all the way back to the cell body which is in our spinal cord.

Erin Welsh

And trying to phrase this in a way that's not like, 'Why does the virus do this? Why is it so smart?' But the consequence of this nerve association or whatever, the fact that it goes into your nerves is that our immune system doesn't really like to mess around with that.

Erin Allmann Updyke

Yeah! We've talked about this a lot before but once a pathogen has made it past our blood-brain barrier, it's really hard for our immune system to do much about it. We have the blood-brain barrier there to prevent things from getting in in the first place, right. And so once a virus is already there in our spinal cord, it is very hard. And HSV, like many herpesviruses, well like all herpesviruses, is also just really good at evading our immune system even when it's not inside of our nerves, right. So it has all these adaptations to just make it harder for our immune system to fight it off essentially.

Erin Welsh

Interesting.

Erin Allmann Updyke

Yeah.

Erin Welsh

Very interesting.

Erin Allmann Updyke

And so that is how HSV can establish this latent infection essentially. Once it's in the cell bodies of our nerves, and usually that's in the trigeminal nerves which is one of your facial nerves if it's an oral infection or in the lumbar lumbosacral nerves which is if you have a genital infection, that's where HSV tends to hang out. Once it's there it just can hang out and 90% of people that present with a symptomatic primary infection will have at least one recurrence within the first year after being infected. So these recurrent episodes tend to start with a prodrome, so some kind of tingling sensation or burning sensation or sometimes even a shooting pain that can happen anywhere from hours to a few days before a new outbreak of these vesicles, so those same kind of ulcers that you see in a primary infection.

But one of the big differences if that recurrent episodes tend to be shorter in duration, so you would only shed virus for like 4 days compared to 11 days in a primary infection, and there also tends to be fewer lesions. So in a primary infection it's common to have 16 or more lesions whereas in recurrent infections you tend to have fewer, like maybe 4, 5, 6, something like that.

Erin Welsh

Gotcha. Okay so questions, many questions.

Erin Allmann Updyke

Great.

Erin Welsh

Number one is the difference between HSV-1 and HSV-2. Cause you said that either virus can infect any part of your body basically.

Erin Allmann Updyke

Yeah.

Erin Welsh

So how does that manifest clinically?

Erin Allmann Updyke: Great question.

Erin Welsh: And then the other question is sort of about if you were to plot viral shedding with time on the X axis and viral load on the Y axis, what might that look like over a number of years starting with the primary infection and then on?

Erin Allmann Updyke: Excellent questions, let's address them both. Okay so HSV-1 vs HSV-2. Commonly we say HSV-1 causes oral herpes, HSV-2 causes genital herpes, right. That's an easy way to be like boom, one and done.

Erin Welsh: Right.

Erin Allmann Updyke: It's not quite that simple. The majority of oral herpes are definitely caused by HSV-1 and HSV-2 tends to really only cause genital herpes, it's pretty uncommon to get HSV-2 outside of the genitals.

Erin Welsh: Interesting.

Erin Allmann Updyke: You can but it's much less common. However HSV-1 can absolutely and is becoming more common to cause genital herpes largely because of oral-genital sex because if you have it on your mouth, it's very easy to be able to spread to the genitals.

Erin Welsh: Right but not so much the reverse.

Erin Allmann Updyke: Yes. Yeah it certainly could, it's just less common. I don't really know the exact reasoning as to why but in general epidemiologically what we see is HSV-2 tends to only cause genital herpes.

Erin Welsh: Gotcha.

Erin Allmann Updyke: It could however infect anywhere. But what's very interesting is that HSV-2 infections of the genitals are associated with greater rates of recurrence than HSV-1 infections of the genitals and the opposite is true for oral lesions. So HSV-1 is more likely to cause recurrence if it's an oral infection than HSV-2 is if it's an oral infection. Isn't that fascinating?

Erin Welsh: That's very bizarre.

Erin Allmann Updyke: Why?

Erin Welsh: Why? Yeah, that was my question.

Erin Allmann Updyke: So I don't know. Are our nerves that different? I don't think so but I'm not great at nervous system stuff.

Erin Welsh: Well maybe there's a bit about the history of the virus or the evolutionary history that could shed some light on that in terms of just being a very, very, very old association with humans.

Erin Allmann Updyke: Right.

Erin Welsh: HSV-1 and 2 have been with humans for, as I'll talk about, millions of years. So yes, maybe that's part of it. It's just so highly specific.

Erin Allmann Updyke

Right.

Erin Welsh

Hey, this is how I do it, I'm not willing to change.

Erin Allmann Updyke

I'm not messing around. (laughs)

Erin Welsh

Before we go into the viral shedding timeline, another question about HSV-1 and HSV-2, concurrent infections. Can you be infected with both HSV-1 and HSV-2? And could you have oral herpes caused by both HSV-1 and HSV-2?

Erin Allmann Updyke

Great question. Absolutely you can be coinfectd, it's not uncommon to be coinfectd with HSV-1 and HSV-2.

Erin Welsh

Okay.

Erin Allmann Updyke

I know for example if you have oral HSV-1, you will not then get genital HSV-1.

Erin Welsh

Okay.

Erin Allmann Updyke

Does that make sense?

Erin Welsh

Yes.

Erin Allmann Updyke

But whether you could have say genital HSV-1 and genital HSV-2, that I'm not sure. I didn't see that anywhere but it seems like you probably could unless they somehow compete within the nerve. But I doubt it. So probably, probably could. Once you're infected with one, you have it and you just have it where you have it.

Erin Welsh

Okay. That makes sense.

Erin Allmann Updyke

Okay and then what was your second question? Timeline of shedding.

Erin Welsh

Timeline of shedding, yes.

Erin Allmann Updyke

Great, so glad you asked. So this kind of is what I wanted to talk about next which is the idea that this is a latent infection actually correct? So we know that HSV infections can show up, you have a period of no symptoms and then you can have symptoms, right, like discrete periods of time where you have symptoms. And we know that during those times you are highly infectious, so you're definitely shedding virus when you have an active cold sore or genital sore for example. However it turns out that up to 80% of the time that someone is shedding virus is when they're asymptomatic.

Erin Welsh

Okay.

Erin Allmann Updyke

So you don't have to have any active lesions that you know of to be infectious potentially. And in fact in some studies people who were HSV positive shed virus on about 25% of days regardless of their symptoms. And the viral loads will be much lower than if you have an active lesion for example.



Erin Welsh: Okay.

Erin Allmann Updyke: But it would still be from that same mucosal surface.

Erin Welsh: Gotcha.

Erin Allmann Updyke: For a long time we thought well if you just abstain from sex when you have active lesions or use a condom if you have visible lesions, then that's it, you're protected. But that's not true.

Erin Welsh: Right.

Erin Allmann Updyke: They absolutely reduce the risk but especially because you can shed when you're asymptomatic and you can have lesions that aren't covered by a condom, so condoms are not 100% effective in preventing transmission by any means.

Erin Welsh: Right.

Erin Allmann Updyke: But yeah, so that's kind of the overall general biology of HSV-1 and HSV-2. But that's not everything.

Erin Welsh: Yeah I wanna know about treatment.

Erin Allmann Updyke: Oh there's actually more to talk about in terms of the disease itself before we can talk about treatment.

Erin Welsh: Oh okay, great.

Erin Allmann Updyke: And that is because in general this disease, herpes, it can be extremely debilitating, it can be painful. As you heard in the firsthand account and as we'll talk a lot more about, I know you'll talk about it in the history Erin, we'll talk about it in the current events, the stigma associated with it is so severe in many cases. But in general it's a self-limited infection that doesn't have very serious complications if it's left untreated.

Erin Welsh: Right.

Erin Allmann Updyke: However there are kind of three exceptions to that. So one is that infection of the eyes, which is possible because your eyes are a mucus membrane, can happen, very painful, it can lead to scarring and blindness. So that's a pretty severe potential complication from an ocular infection with HSV.

Erin Welsh: Okay, two questions about that.

Erin Allmann Updyke: Oh gosh, okay.

Erin Welsh: Number one, what is the incidence of that?

Erin Allmann Updyke: Good question. I don't have a number on that, I do not know.

Erin Welsh: Okay. And then the other question is could that be from an oral HSV-1 infection just manifesting? Like the vesicles manifesting in your eyes?

Erin Allmann Updyke: It's such a good question, Erin. So I don't fully know. So let me answer that question in roundabout by talking about the other serious complication and that is encephalitis, okay.

Erin Welsh: Oh yeah.

Erin Allmann Updyke: So herpes encephalitis is very rare, we're talking between 2 and 4 cases per 1 million worldwide each year.

Erin Welsh: Wow, that is very rare. Okay.

Erin Allmann Updyke: It's very rare. However it is the most common cause of viral encephalitis in the United States and probably across the world but we just have good data for the United States.

Erin Welsh: Wow.

Erin Allmann Updyke: Yeah. So herpes simplex virus accounts for 50-75% of identified cases of viral encephalitis. A lot of viral encephalitis we're just like we don't know what caused this but when we can figure out what caused it, 50-75% of the time it's HSV. Okay? And we've talked about encephalitis kind of a lot actually on this podcast.

Erin Welsh: We actually have, we just did Triple E.

Erin Allmann Updyke: Yeah, we did Triple E, we've done encephalitis lethargica.

Erin Welsh: Encephalitis lethargica.

Erin Allmann Updyke: Yeah. So you know that that's an infection of your brain itself. In the case of herpes it tends to infect the temporal lobe and/or the frontal lobe. So it causes just kind of the same generic encephalitis symptoms, so mental status changes, confusion, behavior changes, headache, seizures, you can have neurologic deficits, but the good thing about HSV encephalitis is that we have treatment for it, right.

Erin Welsh: Oh cool.

Erin Allmann Updyke: Yeah. But it is super high mortality, like 70% mortality rate if it's untreated.

Erin Welsh: Oh my gosh.

Erin Allmann Updyke: So it's very serious.

Erin Welsh: Yeah.

Erin Allmann Updyke: But again very rare.

Erin Welsh: Yeah.

Erin Allmann Updyke: And what's interesting about encephalitis and this gets to your question about how you get the eye infection, you can get potentially HSV encephalitis from either a primary or from a recurrent infection.

Erin Welsh: Okay. Okay so it could just be random.

Erin Allmann Updyke: Yeah, yeah.

Erin Welsh: Is it more common with HSV-1 than 2?

Erin Allmann Updyke: Yes! Great question. It's absolutely the vast majority of cases are HSV-1.

Erin Welsh: Okay, that makes sense. That also makes sense that it's the number one cause because so many people, as you'll talk about, like everyone is infected with HSV.

Erin Allmann Updyke: Exactly, yeah. Exactly.

Erin Welsh: Like it's everyone. Yeah.

Erin Allmann Updyke: Yep. And then yeah, the other serious complication is neonatal infection, so that's when a baby gets infected. It is possible for a fetus to get infected in utero but it's quite rare actually, it's more common for a baby to get infected if there are active lesions during a vaginal delivery and this is most common if someone gets infected for the first time, so has their primary HSV infection during the last part of their pregnancy.

Erin Welsh: Gotcha.

Erin Allmann Updyke: Okay. Herpes is treatable, yay! Well, kind of. So herpes encephalitis and neonatal herpes infection are very treatable, often without any long term damage depending on how severe the infection was. Treatment for oral and genital herpes is acyclovir or valacyclovir or famciclovir, there's a few others too. But it does not eradicate the pathogen, period.

Erin Welsh: Right.

Erin Allmann Updyke: Okay. So there are a couple of different ways that you can go about treating it, like you can use just suppressive therapy and just always be taking this drug kind of like we do with HIV, just keeps your viral load down really low. Or you can also use it just if you are about to have an outbreak. So you know how you can have these prodromal symptoms like tingling or burning? So you can have enough aciclovir on hand to be like, 'Oop, I think I'm about to have an outbreak' and start taking acyclovir and that will help squash that.

Erin Welsh: Right.

Erin Allmann Updyke: No topical, it doesn't do anything, not recommended.

Erin Welsh: Interesting.

Erin Allmann Updyke: Yep. It exists but it really doesn't help, especially for genital herpes.

Erin Welsh: That's what it started as which is why I asked.

Erin Allmann Updyke: Yes, yeah. It really doesn't work. So oral is the way to go and then if you have severe infection it's IV actually.

Erin Welsh: Oh wow, okay.

Erin Allmann Updyke: Yeah. Isn't that cool? We have IV. I love it.

Erin Welsh: Are there side effects from acyclovir?

Erin Allmann Updyke: Pretty minimal actually, it's a pretty safe drug as far as they go, yeah.

Erin Welsh: Cool.

Erin Allmann Updyke: Yeah, yeah. So it's pretty good. And it's of course always possible that there will be resistance but at this point we don't see a lot of resistance to acyclovir or valacyclovir.

Erin Welsh: How does it work?

Erin Allmann Updyke: Oh okay. It's a nucleoside analog, okay. So in one of our COVID episodes actually we talked about remdesivir and it's the same type of drug as that. So it basically blocks DNA replication of the virus.

Erin Welsh: Oh.

Erin Allmann Updyke: So it can't eliminate it but it can stop it from replicating, so it stops you from having active infection.

Erin Welsh: That's very cool.

Erin Allmann Updyke: And it drastically reduces the chances of infecting others as well, so the infectivity.

Erin Welsh: Okay.

Erin Allmann Updyke: It doesn't eliminate it but it drastically reduces it.

Erin Welsh: Okay. And then what are some of the things that triggers outbreaks?

Erin Allmann Updyke: Good question. It really can depend on the person. It can be stress, it can definitely be an immunocompromised state, so whether that's an actual immunodeficiency or just another cold or another viral infection or bacterial infection that kind of gets your immune system out of whack, especially for oral herpes it can be UV light, so spending a lot of time in the sun can actually trigger a reactivation.

Erin Welsh: Interesting.

Erin Allmann Updyke: Yeah. And then I think for some people they can't really pinpoint any triggers, so it can really depend on the person.

Erin Welsh: Gotcha. Interesting. Cool.

Erin Allmann Updyke: Yeah. What else? You got anymore questions for me, Erin?

Erin Welsh: I think I might've set the record this episode with questions.

Erin Allmann Updyke: Maybe. I like it though. Actually I think caffeine, that whole biology section was actually just you asking questions.

Erin Welsh: And I still never got the answer that I wanted for why my hollow bones feel so hollow when I drink caffeine. (laughs)

Erin Allmann Updyke: Your hollow bones. (laughs) So yeah, that is the biology of HSV-1 and HSV-2. Erin, where did this thing come from? How did it get here? And why is it such a stigmatizing disease?

Erin Welsh: Oh I cannot wait to tell you, let's take a quick break first.

TPWKY: (transition theme)

Erin Welsh: As you mentioned Erin, herpesviruses are found in all of those animal groups that you named.

Erin Allmann Updyke: Yes.

Erin Welsh: I even have molluscs here again. And there are also probably a great deal of herpesviruses that remain undiscovered. And one of the major characteristics that herpesviruses share in addition to all of the ones that you listed is that they have a super high specificity to their host species of preference.

Erin Allmann Updyke: Yeah.

Erin Welsh: So there isn't a whole lot of species jumping. And due to this high host specificity, viruses that tend to cause lifelong infections can actually be very useful in teasing apart when one species diverged from another or studying genetic differences in strains can give us a lot of insight into things like when and where migrations happened. So as I alluded to earlier, Herpesviridae is a very, very old group, like millions and millions of years which makes sense given its wide host range and diversity. But the focus of this episode is not on Herpesviridae, it's not even just on human herpesviruses, it's just about HSV-1 and HSV-2. So where did these guys come from and what can they tell us about our own history?

Erin Allmann Updyke: Yeah.

Erin Welsh: Well molecular evolution research shows that HSV-1 probably came with humans as they split off from our last common ancestor with other primates around 6-7 million years ago.

Erin Allmann Updyke: What?

Erin Welsh: Yeah. 6 million years.

Erin Allmann Updyke: Literally as long as we've been humans.

Erin Welsh: Oh yeah, even before. And HSV-1 enjoyed its time as an only child for a few million years but then was joined by HSV-2 between 1.4 and 3 million years ago in an instance of cross-species transmission. So as early humans, we had HSV-1.

Erin Allmann Updyke

We had HSV-1 from the get go.

Erin Welsh

From the get go. And then we picked up chimpanzee herpesvirus but then it sort of evolved into HSV-2.

Erin Allmann Updyke

Fascinating.

Erin Welsh

Right?

Erin Allmann Updyke

Yes.

Erin Welsh

Okay. So where do we go from here?

Erin Allmann Updyke

Yeah.

Erin Welsh

Or rather where did HSV-1 and HSV-2 go from there?

Erin Allmann Updyke

Yeah.

Erin Welsh

Well wherever humans went, of course.

Erin Allmann Updyke

Yeah, okay.

Erin Welsh

And I think this is where it's really interesting to consider how the characteristics of different pathogens helped to shape their spread historically and even prehistorically. So in our past episodes when we've talked about the evolutionary origins of a particular infection, one of the themes that we always hit on is how large human settlements facilitated the spread of infectious diseases, particularly those transmitted by respiratory droplets or contaminated water.

Erin Allmann Updyke

Right.

Erin Welsh

Your basic crowd diseases.

Erin Allmann Updyke

Yeah.

Erin Welsh

For many of those diseases, the Agricultural Revolution was a tipping point. So a settlement had to reach a certain population threshold before those pathogens could be sustained, otherwise they would just burn through the population and die out.

Erin Allmann Updyke

Right.

Erin Welsh

But HSV-1 and HSV-2 both started their history with humans long before anyone even thought about domesticating cows or goats or horses. And the reason why the virus didn't just burn out is in its biology.

Erin Allmann Updyke

Yeah.

Erin Welsh

So it's these long lasting and very easily transmittable infections.

Erin Allmann Updyke

Right.

Erin Welsh

And so they could be sustained intergenerationally very well, like from a mother kissing a baby, from grandparents kissing grandchildren, etc.

Erin Allmann Updyke

Yeah.

Erin Welsh

Just close contact.

Erin Allmann Updyke

Plus they don't tell to kill you for the most part.

Erin Welsh

Yeah, that's why number two is that the infection is incredibly mild and so a lot of people don't even know that they have it.

Erin Allmann Updyke

Right.

Erin Welsh

No one even thought twice about it. So we know that humans and herpes have been hand in hand for literally millions of years but when did it first show up in writing? So when did people actually take note of it?

Erin Allmann Updyke

Yeah.

Erin Welsh

And the answer is that as per usual, we're not really sure. Okay so the word 'herpes' itself was used for hundreds of years to describe any kind of blistering inflammatory skin condition. And the word come from the Greek 'herpein' which means 'to creep or move slowly'.

Erin Allmann Updyke

Yeah, I saw that too and I was waiting for you to say it.

Erin Welsh

Oh yeah. And so when that word 'herpes' appears in ancient or historical writings, we can't know for sure whether it was referring to HSV outbreaks or something else like shingles or even smallpox or something like that.

Erin Allmann Updyke

Okay, that makes sense. Yeah.

Erin Welsh

But as always where there's uncertainty, there's somebody willing to venture a guess. So for instance in Ancient Rome, Emperor Tiberius who ruled from 14 to 37 CE supposedly banned kissing at public ceremonies and rituals during an epidemic of oral blisters throughout the empire.

Erin Allmann Updyke

Okay, all right. Maybe.

Erin Welsh

So oral herpes HSV-1 might have been the first descriptor. However the other complicating factor in determining what was described first is that there are other blistering rashes on your genitals that could have been confused with herpes and so we're not really sure.

Erin Allmann Updyke

Definitely.

Erin Welsh  
Okay so regardless of whether the kissing ban really happened or it was really Tiberius' way to try to control herpes, HSV-1 and HSV-2 do seem to have been pretty widely known throughout history. And there are early references on how to treat the blisters such as cauterizing open sores using an iron or rubbing gold wedding bands on the lesions.

Erin Allmann Updyke  
What?

Erin Welsh  
Yeah.

Erin Allmann Updyke  
Why?

Erin Welsh  
Gold, maybe it was partially symbolic, maybe it was partially just gold is valuable so it's gotta have medical properties.

Erin Allmann Updyke  
Yeah but if it's just gold wedding bands and not like a gold coin I feel like that's pure symbolism right there.

Erin Welsh  
I know, I know. Well it's better than the third one I'm about to say.

Erin Allmann Updyke  
Oh gosh.

Erin Welsh  
Which is that people also recommended the use of snail slime to treat lesions.

Erin Allmann Updyke  
No.

Erin Welsh  
Yes.

Erin Allmann Updyke  
What kind of snail?

Erin Welsh  
I don't know, it was referred to in Scotland so I don't know what species of snails are in Scotland or what the most common species are.

Erin Allmann Updyke  
Scottish snails. How much slime? I have so many questions.

Erin Welsh  
I know.

Erin Allmann Updyke  
Do you put the snails directly on it or do you just gather the slime?

Erin Welsh  
Right. I don't know, what kind of slime gathering equipment would you need?

Erin Allmann Updyke  
Great question.

Erin Welsh  
These are fantastic questions. I don't have the answer to any of them.

Erin Allmann Updyke  
Wow, snail slime. Don't try that.

Erin Welsh  
Don't try that, no. And then a mention of herpes even made its way into Shakespeare's Romeo & Juliet.



Erin Allmann Updyke

What?

Erin Welsh

Yep. In a speech by Mercutio in Act I Scene IV. And I don't know how to read in iambic pentameter so apologies in advance. "O'er ladies lips, who straight on kisses dream, which oft the angry Mab with blisters plagues, because their breaths with sweetmeats tainted are." So basically Mercutio is describing the Fairy Queen Mab who plays pranks on sleeping humans and he's describing her, one of the things that she does is places blisters on young women's lips because she's jealous of them.

Erin Allmann Updyke

Interesting, okay.

Erin Welsh

I think that's an interpretation. So for any listeners out there that has to read Romeo & Juliet for school this semester, you should definitely bring that up in discussion. Okay but except for these brief mentions of blisters or treatments for blisters, herpes didn't really take up that much space in historical medical texts, again not very surprising considering the infection is so relatively benign. And only beginning in the 1700s did physicians start to take a closer look at these blisters and when they did, they primarily concentrated on the genital herpes.

Erin Allmann Updyke

Interesting.

Erin Welsh

In fact the connection between cold sores and genital sores wouldn't really be realized until much later.

Erin Allmann Updyke

That's was gonna be my question. When, Erin?

Erin Welsh

Well I mean it was really when microscopy and virology had advanced enough to allow people to actually isolate different strains and say okay, this is the same virus.

Erin Allmann Updyke

Wow. It was that long.

Erin Welsh

And there were probably similarities noted like these lesions look very similar. Okay so the first recognized description of herpes was made in 1736 by French physician Jean Astruc in his book on what were then called venereal diseases from the word 'venery' which we don't use that term anymore for very good reason cause it's super judgemental.

Erin Allmann Updyke

Yes.

Erin Welsh

And this book came on the heels of the huge outbreak of syphilis in Europe that had begun in the early 1500s, so see our syphilis episode for more on that. And in an attempt to try to reduce the incidence of sexually transmitted infection, particularly syphilis, the French government ordered mandatory medical surveillance for sex workers which led to a rapid growth of information on all STIs. And so in this first description in addition to commenting on the size, the shape, and location of the blisters and a bit about the recurrent nature and sort of the timeline of infection, Astruc also suggested a connection between the appearance of the blisters and sexual intercourse. Although the link between sex and genital herpes seemed to be accepted by most physicians by this time, some insisted that it must be due to another reason because, 'Oh I had observed this in this young, recently married, very proper woman and there's simply no way it can be sex related.'

Erin Allmann Updyke

What?

Erin Welsh: And it was sort of like you had these preconceived notions of, 'Oh well my wealthy, well to do patients have these lesions as well and it can't be related to sex.'

Erin Allmann Updyke: So they couldn't be related to sex. Right, yeah. Cause wealthy, well to do people don't have sex?

Erin Welsh: They don't have sex. Yeah. And so some of the alternative reasons that were suggested ranged from congestion of the genitals and then they also claimed it was just nervous overstimulation or hot weather which is interesting about the UV radiation actually.

Erin Allmann Updyke: Yeah, yeah. But how much UV radiation are people getting on their labia and their penis? Probably not a ton, especially in the 1800s.

Erin Welsh: No. Right. Probably not very much.

Erin Allmann Updyke: Yeah.

Erin Welsh: Yeah.

Erin Allmann Updyke: Anyways.

Erin Welsh: Well the early 1900s brought some clarity to the situation via what was likely medicalized torture although I don't have enough info to say for certain.

Erin Allmann Updyke: Okay.

Erin Welsh: But basically in an offhanded little comment somewhere I read that material from blisters on the genitals was injected into the skin of some people, quote "human subjects" and that they subsequently developed blisters.

Erin Allmann Updyke: Jesus. Oh my. Nobody volunteered for that experiment.

Erin Welsh: No. I mean even the term 'volunteer' is problematic today in terms of coercion.

Erin Allmann Updyke: Yeah.

Erin Welsh: Anyway, okay. So in 1934 Albert Sabin, whose name might sound familiar from our polio episode-

Erin Allmann Updyke: Yeah, Sabin!

Erin Welsh: Along with two other colleagues, isolated a herpes simplex virus and then additional strains were detected in later decades. And during the first half of the 20th century herpes in general received a pretty good deal of research attention as scientists studied the natural history of the virus and discovered its ability to cause these quote unquote "latent infections" just hanging out in the nervous system. Cause it is a very interesting virus biologically.

Erin Allmann Updyke: Oh it's fascinating.

Erin Welsh: Yeah. But it wasn't until 1967 that researchers described the clinical differences between HSV-1 and HSV-2.

Erin Allmann Updyke: 1967?

Erin Welsh: Mm-hmm. But it was also around the same time that researchers discovered the tendency to cause infections on either the mouth or the genitals respectively, HSV-1 and HSV-2.

Erin Allmann Updyke: Yeah.

Erin Welsh: All right so in the story of herpes, Erin, we're already in the 1960s.

Erin Allmann Updyke: Yeah!

Erin Welsh: And there's one glaring piece of the puzzle that's missing: the stigma.

Erin Allmann Updyke: Yeah.

Erin Welsh: Yeah.

Erin Allmann Updyke: Everyone's just like, 'Yep, we all have this and it's fine.'

Erin Welsh: Yeah. And so the reason that I haven't brought it up is because it wasn't there yet.

Erin Allmann Updyke: What?

Erin Welsh: It wasn't there. Of course the transmission route of HSV-1 and HSV-2 was well established and many people were happy to point accusatory and judgmental fingers at those with other better known STIs such as syphilis, gonorrhea, chlamydia, etc. But herpes didn't receive very much social attention, I guess I'll call it, even in the most popular sex or sexual health books of the 1970s. Herpes barely gets a mention.

Erin Allmann Updyke: What?

Erin Welsh: Why was that?

Erin Allmann Updyke: Why?

Erin Welsh: And what happened to change this public perception of herpes to what it is today?

Erin Allmann Updyke: Yeah.

Erin Welsh: Okay so the first question, why herpes didn't garner that much attention, that could have been due to a number of different reasons. One could be that the other more common STIs with their potential to cause much more serious health issues had long overshadowed the mild infections caused by HSV. Another reason could be that since at the time there was no treatment for HSV, short descriptions primarily focused on the natural history of the viruses and there wasn't much more to say about it.

Erin Allmann Updyke: Okay.

Erin Welsh

Some healthcare professionals were even hesitant to label HSV-2 as a sexually transmitted virus since it could also be spread non-sexually. So that takes me to the next question, what happened to flip the switch on herpes?

Erin Allmann Updyke

Yeah.

Erin Welsh

Before I start to answer that I wanna say that for this part of the story I'm focusing on how the stigma of herpes grew in the US in the last few decades. I don't really know how herpes is perceived in other parts of the world but I would love to know more, so if you have any info or articles or personal experiences, please send them our way, I would love to know more about that. Okay so for hundreds of years and into today, sexually transmitted infections have been used by some people to drive a particular narrative. As Allan Brandt pointed out in a book I read called 'No Magic Bullet' which is about the social history of STIs in the US, these narratives fall into three basic themes. One is that sexually transmitted infections are considered punishments for immoral behavior. Another is that people use STIs to argue for a more conservative or restricted sexuality. And the third is that an STI is not simply an STI, it's a symptom of a much larger systemic issue and indicative of the decay of society as we know it.

Erin Allmann Updyke

Oh geez.

Erin Welsh

So those are the three primary narratives that had been used to make some sort of moral argument.

Erin Allmann Updyke

Yeah.

Erin Welsh

For a long, long time more prominent STIs like syphilis and gonorrhea were used as the cases in point. But then came antibiotics and these painful, deadly diseases that were delivered as divine punishment cleared up with a quick course of penicillin.

Erin Allmann Updyke

Oh this is fascinating, Erin.

Erin Welsh

And then the sexual revolution of the 1960s really changed the landscape in terms of normalizing sex, having all different kinds of it, talking about it, and most importantly enjoying it. And the sexual revolution deserves a much more nuanced history retelling than I can give it or than I'm going to give it right now but I'll recommend a book that covers some great ground. But casting off the puritanical attitudes about sex that had prevailed for hundreds of years provided a little glimpse into what it might be like to live in a progressive, non judgemental society. This social movement gained momentum with policy changes such as the legalization of birth control pills and abortion, 'Make Love Not War' was the motto and also the name of the book on the sexual revolution that I was gonna recommend.

But of course the sexual revolution wasn't the utopia that it is often described to be, some of the more prominent figures held racist or sexist or homophobic views and there were still clear boundaries on what was or wasn't acceptable and so on. But that glimpse looked great to some people, to others it looked dangerous. "The youth of America was destroying the natural order of things", quote unquote. And it's not like the stigma or shame surrounding sex or STIs disappeared during this time, it was just drowned out by louder voices for a little while. And when the sexual revolution started to wane a bit in the late 1970s for a number of reasons including economic downturn, commercialization of sex, sort of disillusionment overall with this movement, there were plenty of people ready and willing to take backup that mantle of 'sex is bad and you deserve to be punished for having it'. But they needed a new villain to fill the roles previously held by syphilis, gonorrhea, and chlamydia.

Erin Allmann Updyke

Cause those were treatable now.

Erin Welsh

Uh huh. Enter herpes.

Erin Allmann Updyke

What?

Erin Welsh

Herpes, despite being for the most part as you described a very benign infection that does not require sexual contact to transmit, herpes suddenly became the symbol of the consequences of sexual liberation.

Erin Allmann Updyke

Wow.

Erin Welsh

It became the evidence that opponents of the sexual revolution had long been looking for that any kind of sex outside of the narrowly defined one man, one woman, only after marriage was going against mother nature. The evangelist Billy Graham said, quote: "We have the pill, we have conquered VD with penicillin, but along comes herpes simplex 2. Nature itself lashes back when we go against god." Of course HIV was also used to drive these same repressive narratives, check out our HIV episode from way back in our first season for more. But in response to this moralistic interpretation of herpes, a commentator from 1982 said, quote: "If herpes did not exist, the moral majority would have had to invent it."

Erin Allmann Updyke

Whoa.

Erin Welsh

And then popular media fed into this too. So early 1980s news articles in like Time Magazine were titled, quote, "Today's Scarlet Letter, Herpes" or "Herpes, The New Sexual Leprosy".

Erin Allmann Updyke

The new sexual leprosy? See our leprosy episode if you'd like to know all about that.

Erin Welsh

Yeah.

Erin Allmann Updyke

Oh my.

Erin Welsh

And so these types of headlines and these types of fear mongering, all they did was increase the hysteria and stigmatization around the virus by telling the story of how Jim or Nancy or whoever and how their chance at love and happiness was forever ruined by their positive diagnosis. They weren't informative pieces of journalism.

Erin Allmann Updyke

Right.

Erin Welsh

They were scare tactics.

Erin Allmann Updyke

They're just like, 'Your life is ruined cause now you have herpes.'

Erin Welsh

Uh huh. And I think it's really important that people's stories are told and if someone feels like their life is ruined, let's tell that story but let's talk about why they feel that way and why we as a society have made them feel that way.

Erin Allmann Updyke

Not just be like, 'Yep, you're right. Look at you now!'

Erin Welsh: Yeah. And then there as a new word that was introduced into the conversation that further othered people who were HSV positive, 'herpetic'.

Erin Allmann Updyke: Herpetic.

Erin Welsh: Herpetic. Words, and we've kind of talked about this before on the podcast, but words that reduce a person's identity to one thing, herpetic, syphilitic, lepers, these do an enormous amount of damage and are incredibly dehumanizing.

Erin Allmann Updyke: Yep.

Erin Welsh: But in a way that was kind of the goal of the people using them. And so herpes rose to a position of notoriety in the late 1970s and into the early 1980s, helped along by these many, many news reports on the topic who knew how to get that readership up and the effectiveness of this new narrative around genital herpes can be reflected in some stats from this time. Between 1970 and 1985, the prevalence of HSV-2 in the US rose from 13.6% to 15.7%. But between those same years roughly, doctors visits for genital herpes increased 10 times over.

Erin Allmann Updyke: Okay, yeah.

Erin Welsh: Yeah. And that's not necessarily a bad thing because if you believe that you have an STI, you should go to a clinic or talk to your primary care physician.

Erin Allmann Updyke: Yeah.

Erin Welsh: But that lopsided increase is indicative of how awareness had crossed over into fear because it wasn't just that the number of doctor visits was increasing but it was also the response to a positive diagnosis. Shame, depression, self exile, loss of self worth, these were all very real and common responses to being diagnosed with herpes. And this was also reported in those news articles. But again, not in that, 'Hey, let's talk about why this is happening,' rather like, 'Well this is what you get, so don't have sex.'

Erin Allmann Updyke: Right. This is the consequences of...

Erin Welsh: Mm-hmm.

Erin Allmann Updyke: Yeah.

Erin Welsh: But who stood to gain from all of this stigma around herpes? Well certainly the opponents of progress, those who wanted to impose their moralistic beliefs over everyone else and control people's bodies and also news outlets who were generating these must-read articles. But there's a third group who had been waiting for their time to shine: pharmaceutical companies.

Erin Allmann Updyke: Oh.

Erin Welsh: In 1982 around the same time as the peak of herpes panic, the FDA approved aciclovir, the very first treatment for HSV-1 and 2, produced by the pharmaceutical company Burroughs Wellcome. Aciclovir was first introduced as a topical cream and sales were disappointingly low, probably because as we talked about, it doesn't really work.

Erin Allmann Updyke: Doesn't really work.

Erin Welsh: The development of oral aciclovir, so the oral pill form, that improved sales quite a bit as did the magazine ad campaign that Burroughs Wellcome launched in Cosmo, Rolling Stone, People, Playboy, and other popular magazines. And this may be where you go hey, I think I smell a conspiracy, or hey, I think I've heard this conspiracy theory before.

Erin Allmann Updyke: Ooh.

Erin Welsh: So there's a conspiracy theory, also I'm gonna start a petition to call these conspiracy hypotheses because this is not a theory.

Erin Allmann Updyke: Because they're not theories? Yeah, I know. It's part of the problem where people don't understand the word 'theory', it's because of things like that.

Erin Welsh: Exactly. So there's a conspiracy hypothesis that's all over the internet that claims that Burroughs Wellcome created the herpes stigma to sell aciclovir because of the early low sales.

Erin Allmann Updyke: Wow.

Erin Welsh: Let me just say that from what I've read, there doesn't seem to be a whole lot of truth or at the very least evidence in this conspiracy hypothesis. Did Burroughs Wellcome play into the stigma and fear mongering? Sure. Did they profit from it? Absolutely. But did they create it? Not likely.

Erin Allmann Updyke: Yeah.

Erin Welsh: If you look at the timing of when their promotional campaigns began, the stigma around herpes was well established by the time the first ads were out and even then the ads themselves didn't really buy that much into the herpes panic, they often represented someone who felt comfortable in their dating life or secure after talking to their doctor and getting treatment. So it was like they were for the most part from what I saw positive ads.

Erin Allmann Updyke: Interesting.

Erin Welsh: And also Burroughs Wellcome didn't need to create any STI stigma, if you look at the history of STIs there's always stigma, always, always, always.

Erin Allmann Updyke: It's not hard to have stigma around STIs.

Erin Welsh: Yeah. And when directly asked about it, not by me but in an article that I read, a representative denied any involvement in promoting the stigma which I know, what else would you expect them to say but whatever.

Erin Allmann Updyke: They go, 'Oh yeah sure, yeah we totally did, that was great marketing.'

Erin Welsh: (laughs) And I don't wanna sound like I'm defending Big Pharma because I'm definitely not, I'm just saying that in this particular instance, Burroughs Wellcome may be innocent of what they've been accused of.

Erin Allmann Updyke: We gotta say the facts, you know what I mean.

Erin Welsh: I like truth.

Erin Allmann Updyke: Yeah.

Erin Welsh: I just like it. Created by Burroughs Wellcome or not, the stigma around herpes never abated. When I earlier referred to the peak of the panic, I meant in terms of the number of news articles or made for TV movies about herpes. Since then the stigma has barely budged.

Erin Allmann Updyke: Yeah.

Erin Welsh: To this day it remains perhaps the most stigmatized of all the STIs. There's a Cards Against Humanity card about it, it's referenced in countless TV shows and movies as a joke, and all of that serves to further present silence and shame as the appropriate response to a positive diagnosis.

Erin Allmann Updyke: Yeah.

Erin Welsh: Somehow it is socially acceptable to make fun of this and to other or ostracize people who are HSV positive and I think that there's a lot of undoing that remains in terms of breaking down the stigma or examining it at the very least. And I really, really like the way that Courtney talked about navigating the stigma because it is so big that it is a bit maybe unrealistic to say you know what, in my lifetime let's end the stigma against herpes. So Erin, it's your turn.

Erin Allmann Updyke: Oh, is it?

Erin Welsh: It's kind of an abrupt end to the history but it's all that I've got. I mean I could talk about an unethical vaccine trial that happened a little while back but really I just kinda wanted to end by saying hey, the stigma is where it was in the early 80s more or less. So hit me with some prevalence stats, some social science stats, some psychological stats. Tell me what's going on with herpes today.

Erin Allmann Updyke: Would love to, right after this break.

TPWKY: (transition theme)

Erin Allmann Updyke: You wanted stats, let me give you some stats here Erin. Worldwide an estimated 3.7 billion with a 'B' humans under age 50 have HSV-1. That 67% of the global population.

Erin Welsh: Did you say under 50?

Erin Allmann Updyke: Yeah, okay. Here's a weird thing about all of the stats associated with HSV-1 and HSV-2, they end at age 50 as if after age 50 you don't exist. Isn't that bizarre?

Erin Welsh: Oh my god, it's the Hollywood of... Although if it were the Hollywood of whatever STIs then it would be males and females under 50 and males over 50.

Erin Allmann Updyke: Right, exactly, yeah. The World Health Organization also estimates that of those 3.7 billion with a 'B' people with HSV-1, somewhere between 120-190 million of those people have genital HSV-1 rather than oral HSV-1 and an estimated 491 million people ages 15-49 which is 13% of the global population have HSV-2. I mean come on.

Erin Welsh: It's extraordinarily common.



Erin Allmann Updyke: It is so, so common. And it really does bug me that you can't get numbers, like you still have it at 52 okay.

Erin Welsh: Maybe there's a legitimate reason for it.

Erin Allmann Updyke: Well okay, let's talk about some legitimate reasons for things cause I don't have a lot of them, I haven't found a lot of them. Okay, listen.

Erin Welsh: Wonderful.

Erin Allmann Updyke: So unlike other STIs, herpes is not a notifiable disease which means we don't have great state by state data and we don't have super great numbers on the incidence of infection. It's also not universally screened for. If you go into the clinic because you are symptomatic in any way or you have a partner who has tested positive or you have any type of concern and want to be tested, then absolutely any doctor would test you for herpes. But universal screening for herpes is not recommended the way it is recommended for some other STIs and the CDC as well as the USPSTF which is the US Preventative Service Task Force and a bunch of other task force guideline-generating organizations all agree on this idea to not recommend universal screening. So let's explore why.

Erin Welsh: Yeah, I wanna hear this.

Erin Allmann Updyke: In my opinion there's one good legitimate reason and then some others that they kind of throw in that I don't know how I feel about, okay.

Erin Welsh: Okay, yeah.

Erin Allmann Updyke: So largely our screening tests for HSV are super cruddy.

Erin Welsh: Which is not that surprising considering the history of the lack of funding or maybe not a big incentive for it.

Erin Allmann Updyke: Yeah. I think we're lacking incentive.

Erin Welsh: Yeah.

Erin Allmann Updyke: So at this point the false positive rate can be as high as 50% depending on which test is used and confirmatory testing, so not the screening test but confirmatory better testing is only done at a few labs in the country, so it's not widely available. I think it's also worth mentioning that even during pregnancy which we know could potentially be high risk because of the risk of neonatal transmission, we still don't recommend universal screening which is something that we do do during pregnancy for a lot of other STIs even though we know that people with vaginas are more likely to get herpes overall.

Erin Welsh: And again is this because the high rate of false positives and sometimes false negatives?

Erin Allmann Updyke: Yes, absolutely.

Erin Welsh: Okay.

Erin Allmann Updyke

And so I do wanna point out however that the CDC on its FAQ section which I think is the supposed to be accessible section of their website, they list a lot of reasons besides the false positive and false negative rate that they don't recommend universal screening. They say in part because the stigma associated with HSV is so great then that kind of goes along with we don't wanna give someone a false positive because there's so much stigma. It's also they say because we don't have treatment that can eliminate the infection.

Erin Welsh

But we do have treatment that can greatly reduce your viral load, okay.

Erin Allmann Updyke

We do and it can also reduce the rate of transmission, okay. They also say on the CDC website that because the long term complications are essentially minimal to nonexistent with HSV compared to other STIs that we do screen for like chlamydia and gonorrhea and syphilis. They also really highlight in their FAQ section that part of their reasoning, part of their rationale is that telling people their HSV status does nothing to change their sexual practices or at least we don't have evidence that it will change their sexual practices.

Erin Welsh

Okay.

Erin Allmann Updyke

I really don't like that.

Erin Welsh

There are lots of problems with this I feel.

Erin Allmann Updyke

There are. And I think that the biggest, the most legitimate reason and the one that USPSTF cites in their guidelines is just because our screening tests are so cruddy. What's the point of a screening test that has a 50% false positive rate?

Erin Welsh

Right. I mean and I think the fact that the CDC brings up the aspect of stigma associated with this is good because it's like okay, we're acknowledging that there's a huge problem with stigma but at the same time it's saying there's this problem but we can't do anything about it.

Erin Allmann Updyke

Right, yeah.

Erin Welsh

So it's not actually changing the conversation about why the stigma exists and also the fact that this is still a public health issue that can be affected or impacted some way by screening.

Erin Allmann Updyke

Yeah.

Erin Welsh

I don't like it, I don't think.

Erin Allmann Updyke

I don't either, I think. So I guess that leads us to the question of is there any hope in terms of vaccines etc? You wanna talk about that?

Erin Welsh

Yeah, I do wanna know that. So there's a chickenpox vaccine.

Erin Allmann Updyke

There is.

Erin Welsh

And that can hide out in your nerves.

Erin Allmann Updyke

It does.

Erin Welsh

So why don't we have a herpes vaccine?

Erin Allmann Updyke

Yeah, good question. One paper that I read that was pretty dense but i really enjoyed their last closing line, and I quote: "HSV is assuredly wiler than we are clever."

Erin Welsh

Okay.

Erin Allmann Updyke

Yeah, we still don't have a vaccine. There have been a few that have made it all the way through phase 3 trials but then in those phase 3 trials have been found to just really not be effective. We just still don't have a good handle on the immune response to HSV and how exactly to best make a vaccine. So there are certainly a lot of groups working on it, there's still a lot of interest in both prophylactic, so preventative vaccines, but also therapeutic vaccines, especially not just in the US but in low and middle income countries because there is a lot of association between HSV infection and increasing the risk of HIV transmission. So in a lot of places where HIV is a very, very high burden, people are like, 'Well if we target HSV, could we then also reduce HIV?' So there's definitely a lot of groups working on it but we're not there yet.

Erin Welsh

Okay.

Erin Allmann Updyke

So with that in mind we've talked a lot about stigma in general in this episode. We wanted to talk with someone who is a bit of an expert not just on herpes and the stigma associated with herpes but on sexually transmitted infections in general who wrote an entire book about these bugs, their science, their history, and their stigma. This was a really exciting interview for us, you guys.

Erin Welsh

It was such a great interview, we had such a good time.

Erin Allmann Updyke

We did. We were honored and thrilled to get to speak with this next guest, we had such a fun conversation, we can't wait for you all to hear her thoughts about herpes, about other STIs, how to have the talk with kids, why it's so important that we talk about sex, the role of doctors and providers in creating a sex positive environment, it's really fun. So without further ado, may we present Dr. Ina Park.

Ina Park

I'm Dr. Ina Park, I am an Associate Professor at the University of California San Francisco School of Medicine, a Medical Consultant to the Center for Disease Control and Prevention in the Division of STD Prevention, and the Medical Director of the California Prevention Training Center.

Erin Welsh

Awesome.

Erin Allmann Updyke

Amazing. So we wanted to start off my asking you about your upcoming book 'Strange Bedfellows' which is due to be released next February. First of all we absolutely both loved the book so much, we're just laughing out loud, it's phenomenal.

Erin Welsh

Oh my gosh, we laughed so hard we spit out our quarantinis.

Erin Allmann Updyke

Sure did.

Ina Park

(laughs)

Erin Allmann Updyke

It's so accessible and hilarious but it's also so informative. So can you tell our listeners what 'Strange Bedfellows' is about and what inspired you to write it?

Ina Park

Sure. So 'Strange Bedfellows' really is a love letter to my field which is sexually transmitted infection and HIV prevention research. And it takes stories and history and in depth interviews with scientists and humor and sort of weaves them all together and each chapter tackles a different concept or a different infection and traces the history that's relevant to it as well as some of the cutting edge research and the current thinking. But throughout I think it wears its theory really lightly and humor I feel like I tried to use throughout and real stories that I think people can connect with.

Erin Welsh

Well you did such a great job with it, I kept reading it going oh my gosh, I need to tell every person I know about this book.

Ina Park

Well feel free, Erin.

Erin Welsh

(laughs) And we're starting here.

Erin Allmann Updyke

Yeah. So I think we've both had friends tell us about their STI diagnoses and how their doctor kind of just handed them a prescription and then shooed them out the door leaving not a lot of time for discussion or questions. So how much do you think that providers' attitudes about sex and sexually transmitted infections contributes to the stigma that we see in the general population?

Ina Park

I think it can strongly contribute and I think part of the issue that we talked about is our larger sort of societal discomfort, that translates to providers unless you're practicing that skill of talking about sex. If you're not used to talking about it, you feel awkward and then the patient senses that you feel awkward so then they feel awkward. And so I do think that it can contribute. And so I have an editorial coming out in a couple of days where my colleague and I talk about how providers really if they don't feel comfortable doing it, they need to figure out some other way to assess sort of sexual behavior and what's going on either through some sort of computer or tablet-based assessment or paper-based assessment cause if they don't feel comfortable asking those questions the they're not gonna be able to counsel effectively. And so I absolutely think it contributes.

But that being said I know that some physicians and other healthcare providers are never gonna get there, I acknowledge that, they're just never gonna get there. So that's why I feel like if people are able to put systems in place to make sure that that information is collected somehow, especially people's gender identity as well as their sexual preferences and their sexual behavior, I think that will help at least set up to have enough information to counsel effectively.

Erin Welsh

Yeah. And so from your experience as a primary care provider, how do you walk that super fine line between talking with the people that you treat about the risks of these infections or the risks of certain sexual behaviors while also encouraging the sex positive or healthy sexual attitudes? Basically how do you strike that balance between where knowledge becomes empowering without causing fear or shame?

Ina Park

Right. So I do think it's a very fine line and you tow the line and sometimes you swing back and forth from one side to the other. I think my take on it is that I generally am very sex positive in terms of the fact that I normalize having sex, that you should have sex, if you wanna have sex with multiple partners it's fine. What I try to do is take a harm reduction approach and say listen, STIs are gonna happen to everybody, so normalize, and then also an acceptance piece of it that STIs are sort of the cost of doing business in the sexual marketplace. Even if you use condoms 100% of the time for penetrative sex you can still catch particularly the viral STIs, you can still catch those.

And so I think normalizing, acceptance, and then if people sort of ask questions I am truthful about what the consequences can be of having multiple partners in a short period of time for example which certainly could increase the risk of STIs and HIV but I don't discourage people from expressing themselves sexually however they want to. I don't think it's effective because people are gonna have the drive and the urge to have sex and making them feel guilty and ashamed about it just prevents them from actually coming in and seeking the services they need. Some people might disagree with me, they might say we should take a little bit more of a truthful and factual and not scare tactics but you know what I mean, a little bit more of a hard line on it. And I just don't feel that way.

Erin Allmann Updyke

Yeah, yeah. So what are some of the ways that we as individuals can work towards reducing the shame and stigma surrounding STIs, what's your advice for us?

Ina Park

So two things. I think those folks that are parents I think should probably begin having discussions with kids early as soon as they start bringing up the topic and normalizing sex and normalizing the fact that STIs are a consequence of sex that are gonna happen to everybody. So that's a piece with young people. The other thing is I think being open with friends and colleagues about getting STI tested or if you actually have an STI, telling a friend. I think the more people that know other people who've been dealing with an STI I think the more other people realize that this is a consequence of having sex, it's not something that only happens to other people. Do you know what I mean?

I also think that we should change our language on how we discuss STIs because I'll tell you I was at a hotel, at a conference and I was in line and someone asks me what I do for a living and then of course it always ends up becoming a longer conversation as soon as I tell them. But this woman in line was telling me, 'Oh yeah, I just started dating again cause I broke up and I got my STI test and I was clean.' And a lot of patients use this terminology of 'I'm clean' and that would imply that if you had an STI that you would be dirty, right, that's the opposite of clean. So changing our language around how we talk about STIs I think would definitely help.

And then I also think with herpes in particular, I would like to change our language and call it something like HSV positive instead of having herpes because most of the time people who have HSV do not have actual clinical herpes and yet if you talk about yourself as saying 'I have herpes' really you don't, you have a virus, you may or may not actually express it and you may not have symptoms at all, most people don't, right, recognizable symptoms. So I think framing it as calling it HSV positive just the way we say HIV positive instead of having AIDS because most people with HIV don't have AIDS. I think changing our language would certainly help.

I think with the advent of social media, I think there always were sex positive people out there but now I feel like young people can actually more easily find examples of people who are sex positive out there and that is something that I didn't have growing up. And I also think that there is a lot more visibility for sex positivity. So I think we haven't gone backwards but we still have a long way to go, let's put it that way.

TPWKY

(transition theme)

Erin Welsh: Thank you so much Dr. Park, that was so wonderful, we really appreciate you taking the time out of your day to chat with us.

Erin Allmann Updyke: It was such a fun conversation. Ugh, I love it.

Erin Welsh: And you guys should go and preorder 'Strange Bedfellows' by Ina Park as soon as possible and let me just tell you, you will not be disappointed.

Erin Allmann Updyke: Oh it's so good.

Erin Welsh: Okay. So sources?

Erin Allmann Updyke: Yes.

Erin Welsh: Okay. A few of the books I already mentioned, 'Make Love Not War' by David Allyn. And then there's 'No Magic Bullet: A Social History of Venereal Disease in the US', that's by Allan Brandt. And the also of course I used 'Strange Bedfellows' by Dr. Park, wonderful. And then I wanna shout out a couple of articles that were super helpful. So one is by Hutfield from 1966 called 'History of herpes genitalis' and another one is Wertheim et al 2014, 'Evolutionary origins of human herpes simplex viruses 1 and 2'. And then another great article that I found was actually on slate.com by L. V. Anderson titled 'How herpes became a sexual boogeyman' and that is an incredible read and has all of the sources linked. So that was very helpful.

Erin Allmann Updyke: Awesome. We will post all of our sources for this episode and every single episode on our website [thispodcastwillkillyou.com](http://thispodcastwillkillyou.com), you can learn lots more about the biology, the specifics of vaccine development, encephalitis, neonatal infections, there's a lot there. Yeah.

Erin Welsh: Great. Thanks again so much to our wonderful guests Courtney Brame and Ina Park, we really appreciate you taking the time to chat with us and we just had the best time talking with you. We wish the conversations would never end!

Erin Allmann Updyke: I know, it was so fun. Thank you again so much. And thank you to Bloodmobile for providing the music for this episode and all of our episodes.

Erin Welsh: And thank you to you, listeners for listening. We love you, we appreciate you, and we hope that you enjoyed this episode.

Erin Allmann Updyke: We hope so.

Erin Welsh: All right well with that, wash your hands.

Erin Allmann Updyke: You filthy animals!