

Tammy Kremer:

Today, we are speaking with two guests about monkeypox. We've put an episode out on June 1st of this year with Dr. Ina Park at a very different stage of the spread of monkeypox. Since then, monkeypox has spread dramatically, and the US and World Health Organization have declared monkeypox a public health emergency. Today, we'll be hearing from Dr. Akanksha Vaidya about her work with the California Department of Public Health responding to the spread of monkeypox and from Stephan Ferris on his experience of contracting monkeypox and being a part of the San Francisco queer community. Welcome to Coming Together for Sexual Health, where we talk about enhancing sexual healthcare.

Dr. Ina Park:

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

Dr. Rosalyn Plotzker:

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:

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

Dr. Rosalyn Plotzker:

This is so, so, so preventable.

Tammy Kremer:

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.

Welcome, Stephan and Dr. Vaidya. Dr. Akanksha Vaidya is a clinical fellow trained in internal medicine and infectious diseases at the California Prevention Training Center. She completed her medical degree at Cornell University and her residency in internal medicine at Emory University. She came to UCSF in July 2022 for her infectious diseases fellowship. Her research and professional interests include improving health equity and access to care for people with STIs and HIV. Stephan Ferris is an openly queer activist lawyer who focuses on entertainment law with an emphasis on uplifting LGBTQ+ voices. Stephan is also the producer and cohost of the entertainment law podcast, Reading is Fundamental. Check it out. He volunteers with various Bay Area LGBTQI+ organizations and is on the board of directors for Bay Area Lawyers for Individual Freedom, a community of LGBTQI+ legal professionals.

So welcome, both of you. To start us off, I want to ask a silly question even though we'll be talking about some very serious and real issues. If you had a magic wand, either one that vibrates or not, and for those listeners who might not know what I'm talking about, google magic wand vibrators, what's the first thing you do to address monkeypox in our communities?

Stephan Ferris:

Thank you for having me here, Tammy. If I had a magic wand, I'm going to choose the vibrating kind. I would wave it and have vaccines, testing, and treatment for everyone right away without having to wait in eight-hour lines or filling out pages and pages of paperwork.

Dr. Akanksha Vaidya:

Thanks for that answer, Stephan. And thanks, Tammy, for having me here. I would agree with Stephan. First, definitely want the magic wand that vibrates. And then for what I would want for monkeypox, agree, we definitely want vaccines available for everyone who wants them. I think it's really hard to say no to people who want the vaccine just because we don't have enough. And then for testing, if we could have a home test so people could just test at home, I think that would be great, too.

Tammy Kremer:

I love both those answers, and I hope that we can somehow conjure this magic wand. But in the meantime, I guess we'll get back to reality and do our best here with what we have. So I look forward to hearing from both of you, and we're going to start with some questions for Stephan. So Stephan, I'd love to hear where you're from and what brought you to San Francisco?

Stephan Ferris:

Yeah, I'm originally from Las Vegas, Nevada. I was born and raised there. When I went to San Francisco, I moved here in 2005 when I was 18 to go to SF State. I originally wanted to do radio and television production, but I kind of went towards the law route and with UC Hastings to study entertainment and intellectual property law. And that's the focus of my practice right now. And lately, I've been kind of veering in the content production, kind of as you mentioned, with the Reading is Fundamental podcast, which me and my friend, she gets all [inaudible 00:04:15] and drag, and we talk about entertainment contracts and topics.

Tammy Kremer:

Nice. And how does your engagement in the queer community in San Francisco alongside the law expertise that you've described impact your understanding of monkeypox and monkeypox response?

Stephan Ferris:

Before I became an attorney, I also worked in adult entertainment as a performer. And a lot of the things going on with monkeypox kind of have parallels to HIV for me, in particular, stigma around messaging and outreach. I remember when I was in law school, the AIDS healthcare organization tried to pass a law called Prop 60, which tried to mandate condom usage in porn under the guise of save the poor porn performers from HIV. But when you really look down into the messaging around what they were saying, it took away performer autonomy. It had a lot of fear messaging around HIV. I mean, it was really stigmatizing.

And I see a lot of that kind of going on with monkeypox right now, especially in regards that this is, one, a gay man's disease. And two, even within kind of the queer community, that this is a sexually transmitted infection, I see a lot of [inaudible 00:05:19] slut shaming, especially with the Dore Alley festival that just happened, saying if gay guys could just skip these parties and stop having sex, monkeypox would go away, not realizing that you can get it just by casual touch in a bar from hugging and stuff like that.

Tammy Kremer:

Yeah. I can see how the experience of seeing those laws and the community's previous experience with HIV/AIDS would impact the way that monkeypox is being received. And certainly there's been lots of discussion about stigma and ways to reduce stigma against the gay community, given that, like you said,

anybody can get monkeypox. It is not based on a person's identity, of course. Can you tell us about your experience of getting monkeypox?

Stephan Ferris:

Yeah, so I was one of the first 40 reported cases in San Francisco. I came into contact during a pride event, I think at a dance party. I found out through a contact that they had tested positive. So I reached out to my doctor at Kaiser to get the vaccine because I've heard that that was one of the requirements, was being in contact. This was before the kind of mass messaging went out from the pride parties that there was exposure there. So I think I kind of got to Kaiser early. They were able to get me a vaccine almost right away. My friends that tried to get a vaccine only a couple days later were put on wait list of over hundreds of people.

But I went and I got a vaccine on... This is the Friday before July 4th. That Saturday, I was really sick with flu symptoms, and I had been a little bit sick from the COVID booster so I kind of just chalked it up that it was a bad reaction. But on Sunday, I continued to be sick, and I started to notice a little cluster of red spots. And by Monday, the fever broke, and the spots had kind of spread to the rest of my body. I e-mailed my doctor at Kaiser, and he scheduled me to get a test, which wasn't immediately available. It took two days, but basically through my e-mail communication, he pretty much thought it was monkeypox. And about a week later, the test confirmed that. But by that time, the marks had kind of spread everywhere so it was really [inaudible 00:07:22] that it was monkeypox.

Tammy Kremer:

And so it sounds like you started to have the flu-like symptoms about a week plus or minus since the party where you believe you contracted it. Is that right?

Stephan Ferris:

Yeah. That sounds about right.

Tammy Kremer:

What was your experience in that first week of having symptoms before the full diagnosis was clear? And what was your level of pain, discomfort, and all of that?

Stephan Ferris:

Yeah, I guess it kind of came in waves. The flu symptoms were really bad, and then those went away. And there was kind of maybe about a week where there was a ramp up of the pox symptoms. And the pox symptoms probably were in full force within five days of the flu symptoms. I had them on my genitals, all over my butt, made it extremely painful to go to the restroom. I felt like you were kind of pushing glass through skin. And I called Kaiser. Kaiser was like, "Take some ibuprofen. That's all we could really say for you." And I kept on calling back. I had some friends who were able to get TPOXX who had the same kind symptoms that I had, either they had problems swallowing food or going to the bathroom because it was on those areas. And Kaiser kind of just dug their heels in the ground and said, "TPOXX is very hard to get. We're not going to prescribe it to you. We'll give you opiates if you want. And we'll give you a dermatologist recommendation if you're worried about scarring."

Tammy Kremer:

Yeah, very limited treatment options and also frustrating that sounds like TPOXX was going to people that were experiencing similar symptoms and to not be able to have that support. You mentioned earlier when we were speaking before this interview about trying to access that dermatological care. Can you speak about that experience a little bit?

Stephan Ferris:

Yeah. So you're right. Kaiser did say the TPOXX was in short supply, and it was going to be rationed out, but it did seem kind of weird how they distributed it. It seemed my symptoms were kind of the same as other people. So they did say to go to the dermatology department. I scheduled an appointment maybe about three weeks in. And at that point, I had gone down the city clinic, again, to try to get TPOXX there because I heard it was easier to get it than Kaiser. And their nurse practitioner evaluated me and said it was okay to leave quarantine and that pretty much all the external sores had scabbed over and had fresh skin and had healed. So I took that information. I'm like, great, I'm going to go to Kaiser dermatology, see my dermatologist and get this taken care of. They initially scheduled me in person and then canceled it saying that I still had active monkeypox.

So I messaged infectious disease, and I'm like, "Hey, can you clear my record? I got seen by a nurse practitioner. They said I'm good to go." They sent me a message that I think it was, quote-unquote, "Your monkeypox has been resolved." So I took that, and I scheduled another appointment to go in, and they accepted my in-person. And I made it all the way pretty much to the doctor's door. And he showed up head to toe, scrubs, gloves, and a face shield and basically refused to see me because he still felt I was contagious even when I showed him the internal message from Kaiser that said that my monkeypox had been resolved.

Tammy Kremer:

What was that like for you?

Stephan Ferris:

It was super frustrating. I mean, their kind of approach was, "We're not going to treat you for anything. We're just going to help you deal with the scars." And then even at that point, they wouldn't assist with that. I'm in recovery for substance use so I really didn't want to touch opiates at all. And on top of that, when I was speaking to the nurse practitioner at Kaiser, they said, "We could give you opiates, but if you have them on your butt, they're going to make you constipated. This is only going to make the pain worse. It's not going to make it go away." So it really seemed that there was no treatment options other than wait and see if they scar and then kind of dealing with the stigma around monkeypox and kind of the other healthcare professionals not really knowing how to deal with patients there. I think I went to the French Campus, and two floors underneath, you have medical professionals actively testing people for monkeypox, and they're able to deal with patients in a safe way. So you would think that this is disease that affects your skin. A dermatologist would be able to figure out how to see patients in a safe way.

Tammy Kremer:

Yeah. I think this is actually a great time to bring Akanksha into the conversation because Akanksha, your work with the CDPH, the California Department of Public Health on the clinical team really involves education for providers, among other things. So I'd love to hear your perspective on what Stephan has shared.

Dr. Akanksha Vaidya:

Yeah. Thanks, Tammy, and thanks, Stephan, for sharing your experience. I'm sorry it was so frustrating. Wish I could say that's a one-off experience, but I feel like we have heard stories from other patients kind of going through similar frustrating experiences. So really, I think provider education is key. I also work at city clinic, so I feel like over there, there's a system. We're gowning up and wearing full PPE only when we're swabbing lesions. And even then, we're giving patients a heads up that, "Hey, this is what's going to happen. Our risk of transmission is still pretty much low, but we're just required to kind of wear this PPE just to be fully safe." So I think they have a system in place. They're really well aware of how this presents. I've seen a lot of cases at this point. But for providers who are not seeing these cases on a day-to-day basis, I think there's still a lot of education that needs to be done.

And it's not even just about TPOXX. I think another thing that we have learned is that there are other things that you can do to help with symptom management. So if it's taking time to get TPOXX or you're running short of supplies or you're not a provider for TPOXX and it's going to take time to get all of that set up, apart from opioids, which Stephan had mentioned, other things that you could consider are stool softeners. If someone's having rectal symptoms, make it easier for them to go to the bathroom. I was talking to a patient the other day who is started on TPOXX, and he's still having pretty severe symptoms. So one of the things that I was telling him is something that we call a sitz bath. So get a container, fill it up with warm water, and kind of soak the rectal area in it just to reduce some of the inflammation and make it a little bit more comfortable.

It's still definitely a very uncomfortable disease, very painful, from what I've been hearing. So I think anything that you can do to support patients through it is important. So I think definitely, I think overall, the work that the PTC actually is doing with education, I think, is huge as well. And then through CDPH, I think they're learning the need to educate more primary care providers, especially in rural areas that might not be seeing as many cases but will likely start seeing cases. And we just want to prevent patient experiences like what Stephan was describing.

Tammy Kremer:

Yeah. And can you speak a little bit more to the different aspects of your role with the California Department of Public Health?

Dr. Akanksha Vaidya:

Yeah. So in my role as a clinical STI fellow with the California Prevention Training Center and the CDPH, currently I've been working with CDPH's clinical team. They have a monkeypox response team that has a clinical team, epidemiological team, a team that deals with outbreaks. So I'm more on the clinical side where I've been following more severe cases and kind of seeing, what can we learn from these cases, or what could we do moving forward? And then I'm also involved in discussions regarding treatment and treatment provisions. So that's kind of been my role on the CDPH side. And I will also be working with more education and outreach, which I like doing and, as we were talking about, is very necessary.

Tammy Kremer:

Absolutely. And can you share a bit about your take on transmission? One thing that we're hearing about this virus is that it is transmitted in a variety of ways. If you could speak a little bit to what ways you think are the most dominant at this point and then also about the stages of monkeypox once contracted.

Dr. Akanksha Vaidya:

Yeah, for sure. So I think the most common way that it's spread is direct skin-to-skin contact with a lesion that somebody has. And usually it requires prolonged skin-to-skin contact. So we are seeing this transmitted through sex. And the reason for that is that sex does involve prolonged skin-to-skin contact. But like Stephan was mentioning, sex isn't the only way that this can be transmitted. Other ways that it can be transmitted are actually sometimes through inanimate object, so things like bedding or towel. So if somebody who has active monkeypox lesions has used a towel, then some of the fluid from those lesions can get onto the towel. And then if somebody else uses the same towel, they could potentially get monkeypox as well because that fluid could infect their skin. So that is another way.

And then we do know that oral secretions can have it, too, so things like kissing can also spread it or even non-sexual intimate contact, so cuddling or even sometimes massages. If somebody has active lesions, again, you're having skin-to-skin contacts, so this can spread it as well. With regards to kind of respiratory transmission, I feel like we get asked that a lot, especially in the era of COVID. What I think we know about that is that you need very prolonged face-to-face interaction, the kind that you'll have when you're living with someone. You're kind of in each other's space and each other's face for a long time, and that can be a risk factor for spread. But it's not going to spread from casual, short conversations outside or at work. So I think it's not as infectious as COVID and that, we know at this point.

And with regards to your second question about the stages, so there's what we call the classic stages because monkeypox actually has been around for years in endemic countries. So we know things about it from the data that we have from endemic countries. But in the current epidemic, it's kind of presenting a little differently. So I'll talk about both. So I would say, classically, people start having these flu-like symptoms first. So Stephan's presentation is actually pretty classic from what we know before. So you start having fever, flu-like symptoms, and then a day to three days after that, you start having this rash crop up. And the rash kind of goes through a few stages. So it'll first, sometimes it can start off as just a flat red patch, which we call a macule, and then it can start looking like a pimple, and then it can kind of form more of the fluid-filled vesicle stage, and then it can have puss. And then the last stage is when it scabs over. And then when we know that somebody has healed from it, the scab falls off, and there's a new layer of skin that's formed underneath.

So this is kind of what we know from the classic cases. But in the current outbreak, what we're seeing is that often, the fever and flu-like symptoms can be absent, and the first symptoms that people notice are the rash. And then sometimes, after the rash starts, they can get a fever. So this classic progression of first fever and then rash is not always followed in the current outbreak. And then another thing that we're seeing is that the rash can be in different stages, in different parts of the body. So that's, again, something that is new. And it makes it a little bit more tricky because the rash could be scabbing over in one part of the body but not in another part. So I think that's something that people just have to take into account when you're thinking about leaving isolation.

Tammy Kremer:

And one aspect of monkeypox that I'm hearing about, too, is the length of isolation and quarantine is significant even beyond COVID often in terms of what we were experiencing. Stephan, what was that like for you in terms of just the isolation, quarantine period?

Stephan Ferris:

Yeah. So I ended up quarantining for about 22 days. I'm fortunate enough that I live alone, so that helped a lot. I think what was the most difficult for me other than dealing with the actual symptoms of monkeypox was kind of worrying about my dog. Some of the information that I read was if you can let someone else watch your dog because your dog can get monkeypox and you don't want to give it to your dog. But then I was asking my doctor, I've been around my dog for a week already with monkeypox, if they can get it, is it safe to give it to someone? And they're actually like, "No, don't give your dog to someone because then your dog may give it to someone else." So even though I lived by myself, found that I was still wearing sweatpants and socks and covering all my skin up around the house just to make sure that my dog was okay.

Tammy Kremer:

Akanksha, do you have any thoughts on that in terms of pets?

Dr. Akanksha Vaidya:

Yeah. I mean, in general, it's hard. I feel like, again, I'm just talking about COVID because that's what we've been used to unfortunately for the past two years. But with COVID, the isolation periods are not that long. So I feel like it's really hard for people to isolate that long. And pets, I mean, that's the tough issue because we do know that animals can get it, and I think that's why it's tricky. With knowing that it can last so long, the CDC did kind of modify the guidelines a little bit to take into account the fact that it's not entirely practical for people to isolate for four weeks. So the newer guidelines are kind of saying that ideally you should still isolate until all the lesions are scabbed over and the scabs fall off. But in a practical situation, if you can't isolate, then definitely isolate while you're having fever and flu-like symptoms because you're probably very infectious at that point.

But if the fever and flu-like symptoms have resolved, then you should still cover up all the lesions, like Stephan was talking about, and also wear a mask when you're around other people because we do know, especially for face-to-face contact, it can spread that way. So I think still not ideal. I think it's still really hard for people, especially people who can't work from home. Unless their employer is okay with a doctor's letter saying this person can't come to work, it's a very difficult situation. But hopefully as we get more data, we could kind of move to a happy medium. But I think where things stand right now, that's kind of what we have in terms of isolation guidelines. So if you can't isolate, just cover up all the lesions and wear a mask.

Tammy Kremer:

Yeah, it really is a long time that I imagine, falls on people differently depending on their ability to quarantine, their home structure, work structure. And that kind of leads into another question that I would love to hear responses from both of you about, which is, essentially which communities and folks are you most concerned about during this outbreak? Stephan, if you want to speak to that from your involvement in the queer community, and, Akanksha, I know that the CDPH and others of course are closely monitoring demographic data that's being collected, I'd love to hear from you both about which communities are kind of at the top of your mind.

Stephan Ferris:

Well, I know that this isn't specifically an STI, I guess what comes to mind would be sex workers and people that have to interact through physical touch for their income. And then in addition to sex workers, just pretty much anyone that kind of works with the public, drag queens, touching people in crowds, bartenders, people cutting hair, people that don't have the privilege of staying home for three



to six weeks or however long it's going to be, that they can't just work from home and have an income that are going to really be affected by this.

Dr. Akanksha Vaidya:

I think if we look at the demographic data, it is primarily affecting gay men. But again, it's really hard to... I think the difficulty with messaging is that, on the one hand, we really want to help people who are at risk and target resources to the community that is at risk, but at the same time, the virus can affect anybody, and it can infect anybody. And so I think the messaging part is tricky, and I think it's really nice to have people like Stephan involved because I think the best thing that we can do in public health and in clinical medicine moving forward is learn from the community and be like, "Hey, what do you need? Who do you think is most at risk?" So I think it was great to hear from Stephan who he thought is most at risk, and I think target resources to that community. So I think right now, in terms of vaccination, I do think that we do need to kind of focus on that particular community. That's where the effort should be, but the messaging has to be done pretty sensitively.

Tammy Kremer:

And where do you think we are in terms of the scale of the monkeypox outbreak? It's kind of hard to look at the numbers, see them growing exponentially but also still being fairly small compared to what we saw with COVID, which is, again, just the most recent reference point. Can you give us a sense of how you think about the current level of transmission?

Dr. Akanksha Vaidya:

Like you said, if we purely look at the numbers, they are increasing. I think I just looked at the CDC dashboard today, and there are 30,000 cases globally, which I would say is a lot. I think we are a little warped with COVID just because COVID was so infectious. But I think, in a way, that should make us think of monkeypox as more of an opportunity to get on top of before it spreads to that level. So I think getting a handle on the sooner rather than later is the way I think about it. And I think we're at a place where we could potentially try to get a handle on it still because it's not become, again, like COVID, which is what we keep referencing to.

Tammy Kremer:

And from your perspective, Akanksha, what is needed to get ahead of it in that way at this point? What's that magic wand?

Dr. Akanksha Vaidya:

I know. I was just thinking back to the magic wand. I think it's everything that Stephan and I said, I think scaling up vaccines. I think things that have been nice that have happened, so testing is now more widely available. Previously, it was just at public health labs, but now there are commercial labs that can do testing. So testing is a lot faster, which is great, and the testing capacity has increased, which is great. But I think vaccines, I think definitely, we need to scale that up. I have a lot of patients who ask for the vaccine, but I have to go through the CDC guidelines, and I'm like, "You know what? You don't fall within the categories that could get the vaccine," but I wish I never had to do that for someone. So I think vaccines are going to be a major thing. And then home tests, I think, are kind of wishful thinking. I feel like we're a little further away from that just because the testing for this is a little different from, for example, COVID again. But again, I think if we had that, that would be great as well.



Tammy Kremer:

And clinically, I'm curious what your sense is on the severity of the courses of illness people are having. I've heard a really wide range of experiences from someone having one sore that they barely noticed to people being in just really excruciating pain. What's your sense of that range? You spoke a little bit earlier about different therapeutic options, if you could address that as well.

Dr. Akanksha Vaidya:

I agree there is a range, and I think a lot of that depends on where you have the rash and where you have the lesions. I think what we are seeing is that people who have the lesions more in the genital area and especially kind of in the rectal area, that's very, very painful. So I think we are seeing that. For people who kind of maybe just have it around the groin, just have a couple lesions here and there, that's pretty mild, I would say. I feel like they might not have severe symptoms. I think we don't have enough data to predict so far who's going to get the severe symptoms and who's not. But I will say that we have seen quite a few people with just severe pain. So I wouldn't call this a mild disease per se, which is, initially we were thinking that this would be a mild disease, but I definitely wouldn't call it a mild disease because the pain is pretty severe.

But again, there are some people who, fortunately for them, don't experience a level of pain. And I think it has to do with where the lesions are. It might also have to do with what other medical conditions they have. But I think it's a little early for us to kind of be able to predict who's going to have severe symptoms and who's not. For your second question with regard to treatment, I know we've been talking about TPOXX. So just a little bit of background, so TPOXX or tecovirimat is an antiviral, which was actually initially made for smallpox. But smallpox and monkeypox are pretty closely related, so we are using it for monkeypox. It's available through the CDC, but since it's been approved for smallpox, it's available only through this investigational drug protocol for monkeypox. So essentially what that means is that there's paperwork involved in getting it.

So there's paperwork to be set up as a TPOXX treatment provider. And then once you start giving it to a patient, you have to fill out certain paperwork as well so that the CDC can monitor how the patient's doing because this is still being given out on an investigational basis. They have tried to reduce the amount of paperwork to make it easier for providers because I think initially that was the one thing that providers were hesitant about to start being TPOXX providers. They were like, "There's too much paperwork. We don't have the capacity to do this." But now that they've produced the paperwork, hopefully it'll get a little easier. And hopefully, as we get more data, we can get rid of the paperwork. But I don't know when that'll happen.

Stephan Ferris:

Actually I have a question about that. So a lot of the messaging that I've heard, especially from Kaiser, is that, "We're unable to give TPOXX out because it's a limited supply," but it seems that based on what you just said that there isn't necessarily a limited supply. There's enough supply that the CDC has. It's just going through the paperwork. So is it true that there's limited supply in San Francisco, or are doctors just not wanting to do the work to get it?

Dr. Akanksha Vaidya:

I mean, I would say it's not something that's produced on a daily basis. And the whole TPOXX process is that the shipments are shipped out from the CDC based on need. So I would say it is still limited in that sense, in that it's kind of a limited stock that is shipped out to each local health jurisdiction. Within that,

I will say that I think we're more limited in vaccine supplies at this point than treatment. But I think people do worry that if we start treating everybody who is coming in with monkeypox, we won't have enough for the people who do present with very, very severe cases. So I agree, I think there still needs to be a lot more provider education. But from what I'm seeing, I think there is this worry that, "Hey, if we start handing this out to everybody, we're going to kind of run out of it," which is a possibility because, again, we are getting limited supplies from the CDC just because this is not a drug that's available everywhere. It's through the CDC.

Tammy Kremer:

And on that note, if we can talk about vaccines as well, certainly there's been a lot of talk about the limited access to vaccines at the moment. What is your take, Akanksha, on when vaccines might be more broadly available? I'm hearing lots about 2023. And I'd also love to hear from you, Stephan, just about your experience and those of your community members that you've spoken to about trying to access vaccines, too. So why don't we start with Akanksha and then Stephan can respond as well.

Dr. Akanksha Vaidya:

Yeah, I wish I could say when. I just know from our allocations right now, we're in what we're calling phase three allocations, which, again, the CDC is doing based on how many cases a state or local jurisdiction has had. And then they're also basing it on the need in terms of what kind of other cases we're seeing in that local health jurisdiction. So I will say, there is more vaccine now than there was before, but it's still not enough to the point that, usually, the main vaccine that we're using, which is called JYNNEOS, is a two-dose vaccine. And we've been delaying the second doses. Usually the second dose is supposed to be given a month after the first dose. So we're delaying that until the vaccine supplies increase and are prioritizing people who have immune compromising conditions to get the second dose rather than everybody else. So unfortunately, I'm not sure that I have a good date on when this will get better, but I am hoping with time that it will get better.

Stephan Ferris:

Yeah. From what I've seen, it seems to be the case that access is definitely improving. But in the early weeks, I remember that people were lining up for eight plus hours outside of the bathhouse in Berkeley to be able to get a vaccine. I know friends, and Palm Springs, there's a little access to the vaccine there. So the people that are at risk have to either lie about an exposure to be able to qualify for the vaccine or travel sometimes hundreds of miles to a different city to be able to get it. I know my sister tried getting access to the vaccine. And she's a person who has sex with men, and she wasn't able to get it even though she interacts with communities that have it and would be in cases where she would have contact people who are at risk. So I think the restrictions on it definitely need to be lifted, and there definitely needs to be a lot more availability of it.

Tammy Kremer:

Yeah. And I think those lines, in terms of representation, in the media and articles has been developing over the course of the summer. Those images of lines are really striking in terms of how much people want to take care of themselves and want to protect themselves and their communities, then that aspect of it being limited, being really hard to hold in the moment. But I am really glad to hear that it seems to be getting easier to access for those folks that do currently qualify based on the CDC's criteria. And on the aspect of the media representation, Stephan, I'd love to hear from you. How different or similar was your experience of monkeypox to how monkeypox is being talked about in the media?

Stephan Ferris:

I think in that regard with the media, most of it is reflected. I think a lot of the pain elements and the placement of the sores is kind of glazed over. And that may be because they are in sensitive areas, in the rectum, on the genitals, and the news doesn't necessarily want to post those pictures all over the place. And I'm not even sure. My anecdotal evidence is, for me, I'm thinking the area where I have the biggest cluster of sores is maybe the area of contact that I've had it. And I've seen men with sores on their mouth, sores on their penis, sores on rectum. And I'm assuming that was the type of contact I got it. But I don't know if that's necessarily backed up by science.

So yeah, I think the pain aspect is left out. And I think there's a lot of attention on testing and the vaccine but less attention on treatment. I had no idea what to do with the sores to help them. I didn't know if you had to keep them dry to help the pus go away and have them scab over or if it was better to keep them wet or different ways to treat them. And the most valuable information I learned was just kind of connecting with people over social media who were kind of positive themselves and going through the same experience and figuring out what worked and what didn't work for other people.

Tammy Kremer:

Akanksha, do you want to respond to any of that?

Dr. Akanksha Vaidya:

Yeah, for sure. I think two things that you mentioned, Stephan, that I totally agree with, I think the pain aspect has definitely been overlooked. Even from a provider standpoint, I think we definitely, when this started, we're thinking, "It's not smallpox, it's going to be mild," but the pain is not mild. So I think we definitely have to think about that. And then the second aspect, which, thanks for mentioning this, and I feel like it's nice for people who are seeing patients to know, is there are a lot of questions in, what do you do with the lesions? What is going to help them heal faster? I feel like we don't do a good job about talking to patients about all of that. And I think we can definitely do better. So I think, again, I go back to provider outreach. I think it's always easier to have materials handy.

So again, I feel like city clinics, since they're seeing a lot of cases, have handouts now. So if you're busy and don't have time, just hand that to a patient, and that has a good list of creams and lotions that you can use for the lesions to make it less itchy, to make it more tolerable. It tells you kind of how to cover the lesions. So I think that is one way to think about managing a busy clinic when you're seeing a lot of patients. And especially, I think sexual health clinics are kind of overloaded at this point. They're very busy. So I think having those things handy will be helpful. But I think it's also important, again, to message out to providers who might not be seeing so many of these cases and to definitely message about the pain and the aspect that you do need to tell patients more anticipatory guidance, I guess, is what you would call it about, what to expect, and other things that they could do at home to kind of take care of themselves.

Tammy Kremer:

I'd like to talk about stigma, something I'd love to hear from both of you about. It's come up already in our discussion. Stephan, if you could speak to stigma that you have experienced or witnessed around monkeypox.

Stephan Ferris:

Yeah. So in regards to stigma, I think from the general population, there's just stigma that this is a gay men's disease. And I think maybe that's why this hasn't been prioritized by certain health jurisdictions and departments. But this is a disease that can affect everyone. And in particular, again, even within the gay community, there's stigma that this is an STI, and there's a lot of judgment around sex. Just two weekends ago, we had Dore Alley, which is a huge kink fair. And there were a lot of people in the city pressuring the government, like, "Why aren't we shutting down this festival? It's only going to spread monkeypox. We just declared a state of emergency. Why are we allowing this fair to go on?" not realizing that places like Dore Alley, places like the bathhouse places that are sexually charged are probably the most important areas for outreach.

And I think we've kind of seen that with HIV. There's, in the '80s, this huge movement to close the bathhouses, but the bathhouses were the sites of HIV education and testing. And we're seeing that today. Steamworks in Berkeley is a site for vaccine access. At Dore Alley, and I've never even heard of this testing before, but if you wanted to get into a bar, there was the long line, or you could sign up for this new monkeypox test that swabbed your throat. When they collect the data and you got to go into the shorter line, and that was a new site to collect information and do outreach to the communities that are the most at risk. So instead of having this knee jerk reaction that this is an STI, this is a gay man's disease, and shut this down, I think we should know that it's predominantly affecting this community first but also be very aware that it could spread quickly to other communities.

Dr. Akanksha Vaidya:

I think Stephan put it so nicely. I'm like, what do I add? That was wonderful. But I think that brings me to the point that I wanted to make. I really feel like partnering with communities is so necessary. And I think we forget that. And we should learn from the HIV experience that we have. I think we really need to learn from history and see what was successful then and kind of use those tools, for public health professionals really partnering with the communities is key.

The fact that we have this data, I think it should be used to help the communities that are most in need and not to spread stigma. That is not the point. This is a virus that can affect anybody. For now, it appears to be in certain sexual networks, but it can spill over. And I think we need to take a handle of it before and give the resources and provide the resources to the community that is in need. And I loved how Stephan was mentioning that these places where people kind of meet and congregate are places where you can have a lot of education and outreach. So definitely, I agree with everything he said.

Tammy Kremer:

So Stephan, we've started talking about outreach to queer communities. Is there anything else that you can add about ways we can be reaching queer folks now?

Stephan Ferris:

Sure. As was mentioned earlier, I think it's important to partner with community organizations. I think this kind of wait and see approach by both the federal state and city governments has been very harmful at the expense of queer people, at the expense of BIPOC people, at the expense of marginalized communities. I know our communities aren't exactly trustful of government entities, but I know that hearing the information coming from a more reputable source within the community, such as a queer health organization or a queer activist group may have more impact than hearing something that's coming from Kaiser, which may be dictated by their corporate policies or something coming from the government, which may have a lot of red tape around it, which may not be as impactful and specific to my community's specific needs.

Tammy Kremer:

And are there any specific organizations that are coming to mind for you that you've been seeing taking actions around monkeypox?

Stephan Ferris:

Yeah. I mean, I love the city clinic. I went there to try to get access to TPOXX because I knew that they were doing a better job working with the community than Kaiser was. I know the San Francisco AIDS Foundation has been doing a great job. And I know that there has been groups of activists and community leaders from all aspects of life, drag queens event promoters, health professionals coming together in kind of more private WhatsApp chat groups to kind of figure out how to press the local government and the national government to act and have a sense of immediacy.

Tammy Kremer:

And Akanksha, what's it like at CDPH in terms of how you've heard people responding to the more community based efforts? What are some ways CDPH might be joining with those?

Dr. Akanksha Vaidya:

I think definitely having more partnerships is definitely necessary. It's interesting because I just recently started working in public health. And I'm like, behind the scenes, I'm like, "Man, there's so much work going on." But I feel like the way it's disseminated, people don't realize everything that's happening behind the scenes, and it's frustrating. So I will say that I think recently there was a webinar, which was organized with some LGBTQ community organizations. I just was listening in, and I thought it was a great start.

Tammy Kremer:

What's your take on what should be highest priority right now in terms of research and clinical advancement?

Dr. Akanksha Vaidya:

In terms of clinical research priorities, I think the main one that pops up into my mind is looking at treatment outcomes. We don't have great data on how tecovirimat really performs with monkeypox. I think anecdotally we're hearing from patients that once they start tecovirimat, their symptoms do improve. So anecdotally, it seems like it's working, but I think having hard data on that is going to be really important and really necessary. And it'll also hopefully help kind of remove this drug from the investigational status at some point just to increase access to the medication. And then I think the second piece is vaccination. I think, obviously, we do need to scale up vaccine production but also think about novel ways in which the vaccine can be administered. So if there are ways to use smaller amounts of the vaccine per person and if that is still pretty effective, then we could potentially vaccinate more people.

Tammy Kremer:

Stephan, I'm curious here from you. How is the vibe moving and changing in queer communities around monkeypox? How are events being impacted? And what's your take on just that kind of tone that people are experiencing now?

Stephan Ferris:

Yeah, I think the queer community is very adept at dealing with stigma, having dealt with it around HIV. In terms of dealing with monkeypox specifically, I think a lot of our community is taking a harm reduction approach with trying to have as little judgment as possible. There are some parties that have decided to cancel, that have decided that the risk to the guest and the staff working the party was too high, and they didn't feel comfortable having the party. But there's other people that have basically said, "What level of risk are you willing to take," and have sent out kind of charts that break down the risk. So I think kind of taking these approaches that are non-judgmental, that don't tell people that they shouldn't be doing something and just finding ways to meet people where they're at, you could take venues away and parties away, and it's not necessarily going to take the underlying behavior away, like having sex, touching people. These are all human things that are going to continue to happen, whether it's at a party or a bathhouse or in someone's home.

Tammy Kremer:

And is there anything else you want people to know about your experience with monkeypox? If you were speaking to someone who newly was diagnosed, what would you say to them?

Stephan Ferris:

I would say, lean into the community. The most valuable information I had was sharing what remedies worked and what didn't. There's very little data about what actually worked specifically with monkeypox, so a lot of this right now is trial by error. And I know it was super helpful for me, when I was home, I was just kind of [inaudible 00:43:50] looking at the sores, being like, "Are these ever going to go away? Will they ever heal up?" But it was nice to lean on other people that were kind of going through the same experience and to comfort each other and hear what worked for each other.

Tammy Kremer:

And, Akanksha, from your perspective working with providers, is there anything else that you would like providers to know? And can you speak to a provider who is right now just trying to gear up and learn what they need to learn in order to treat people with monkeypox?

Dr. Akanksha Vaidya:

Yeah. I mean, one thing that we haven't touched upon so far that I would like to message out to healthcare providers is, based on the data that we have from prior monkeypox outbreaks, healthcare transmission seems to be very, very, very low. I would never want anyone to have the experience that Stephan shared. And if you're wearing PPE, it's very, very low. So I think that would be one kind of piece of messaging that I really want to get out there. And then second, really, to listen to the patients. I think, in general, as providers, we're not that good about managing pain, I would say. With this disease, the pain can be really severe, so realize that and talk to your patients about that. And if you've not signed up to be a TPOXX provider, definitely sign up if your clinic has not because it is necessary, and people do seem to be benefiting from it.

Tammy Kremer:

Yeah. And we'll include links in the show notes to various resources for providers, so please take a look at those if you're listening to this and want more information. So this podcast is called Coming Together

for Sexual Health, and I like to ask guests, what's one thing you hope we can create by coming together for sexual health?

Stephan Ferris:

I would like folks to know kind of just what monkeypox is and help to demystify some of the misconceptions there are around it and some of the stigma there is around it. To someone that's newly positive, I would also add, be an advocate for yourself and don't just trust one organization's information. Call every day. Be on your doctor. Check with various organizations, to kind of just be your own best advocate because no one else is really going to do it for you.

Dr. Akanksha Vaidya:

Agree. I think reducing stigma, not just about monkeypox but all STIs, I think we do want to promote a sex positive atmosphere. And if this podcast could do that, I think that would be a huge accomplishment.

Tammy Kremer:

Absolutely. Well, thank you both so much for sharing those visions and for sharing about your own experience. Stephan, I really appreciate the bravery that that can take to do that. And Akanksha, thanks for all the work that you're doing, for enlightening us about the conversations happening kind of in the background of the public health world. And onwards and upwards.

Dr. Akanksha Vaidya:

Thanks, Tammy.

Stephan Ferris:

Yeah. Thanks for having us, Tammy.

Tammy Kremer:

Absolutely. 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 at ComingTogetherPod, and learn more about us and get in touch at ComingTogetherPod.com.

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