FINAL Transcript Jason Cianciotto July 27, 2022 Hello, I'm Vanessa Corwin

And I'm Kathleen Kaan

VC: The World Health Organization has declared monkeypox a global health emergency, and New York City is the epicenter of this disease in the US. To help clear up misconceptions and provide guidance to affected populations, with us today is Jason Cianciotto, Vice President of Communications and Public Policy for the Gay Men's Health Crisis. Welcome, Jason. Thank you so much for joining us today. Let's get right to it. For those who may not be familiar with Gay Men's Health Crisis, or GMHC, tell our listeners about your organization.

JC: Thank you, Vanessa and Kathleen, for having me. GMHC was founded in 1982 as Gay Men's Health Crisis, the world's first HIV and AIDS services organization. So, when it comes to viruses that disproportionately affect the gay, bisexual, men who have sex with men, transgender, and gender non binary communities, we've been here before. And we think it's not only important but critical to our mission and history to be public and visible on monkeypox.

KK: It seems like a little bit like déjà vu with the news right away saying that monkeypox is affecting more gay and bisexual community. Can you first tell us what monkeypox is and how it's transmitted?

JC: I sure can. I should give the caveat that I am not a doctor or epidemiologist but like everybody, though it's part of my job, I've been learning as we go along. And that's one of the reasons why right away when this first hit at the end of May, early June, GMHC created a web page at gmhc.org/monkeypox that includes all kinds of links to authoritative sources, public health agencies, the CDC and so on that people can read so I do encourage people to go there and learn more. What I do know based on all of that information is that monkeypox is part of the orthopox virus family. It's very similar to smallpox and it can be transmitted via close, skin-to-skin contact with someone who has an active pustule, a pox on their body where fluid can then be transferred to another person's body that can lead to infection. I also know that there are instances where monkeypox can be transmitted via large respiratory droplets. It's more rare than skin-to-skin contact but if you, for example, are being intimate with someone even fully clothed, if you're kissing them very close to their face, it is possible to contract monkeypox that way. Science is still out on whether monkeypox can be transmitted similar to a sexually transmitted infection, meaning can the virus transmit or infect someone via semen or vaginal fluids? We don't know that yet so we don't refer to monkeypox as a sexually transmitted infection. It's just that close, intimate skin-to-skin contact is very effective for transmission and that also often occurs during sex. Now, one of the challenges of monkeypox is that it has a very long incubation period and its symptoms initially, before the pox break out, can look like the flu – fever, chills, swollen lymph nodes. So it's possible if your physicians are not better educated and on the lookout for someone to go to a doctor or urgent care or ER with those symptoms, and they diagnose with Covid, or the flu, and that challenge is really further strengthened by the fact that the only way currently to test for monkeypox is to swab one of those poxes with a fluid and send that to a lab and so in that way a monkeypox test is more of a confirmatory test for someone who is showing active symptoms than it is like Covid where we can take a nasal swab when we start to feel sick and do at-home tests to see it.

VC: Is it also possible to get it from contact, as far as you know, is it possible to get it from contacting like sheets or towels that an infected person has used?

JC: Yes, thank you for pointing me in that direction. It definitely can be. Again, that fluid from a pox touches a fabric, a sheet, a towel, even a surface, it can then be transmitted to someone else.

KK: I still question why the government is saying that this is a gay disease, for lack of anything else, since it's not transmitted necessarily through sex. Do you feel stigmatized, going back to the AIDS crisis, when everybody else thought, no big deal, it's not my problem, but it's everybody's problem?

JC: Well, you know, that is one of the million-dollar questions, Kathleen, so I appreciate you raising that because there's nothing positive about the outbreak of a virus. But one of the things that at least gives me hope about the present and future challenges is the way that government agencies have talked about monkeypox in a non-stigmatizing way. I think that I've consistently seen, and I monitor, on a daily basis, government saying things like "monkeypox can and does affect everyone," but this particular outbreak has started among gay, bisexual, and men who have sex with men. But I think, Kathleen, that your question raises the difference between intent and perception. So, our government's intent is to be scientifically accurate and to direct messaging and resources, and we can get to the whole just abysmal failure of vaccine rollout. But still, it is a fundamental tenet of I think fighting a disease outbreak, a virus outbreak to understand who's being affected and to direct resources and attention to that, because the goal of course, is to, if you think about it, build a barrier of vaccination and outreach and public education around those most affected. They use a term called ring vaccination, when someone is identified as being affected with monkeypox, to ask who they've had direct contact with in a way that could transmit it and then like those folks are a ring around somebody and contact them and vaccinate them prophylactically even if they're not showing any symptoms.

VC: So, it's like contact tracing, what they did in the early days of Covid.

JC: Correct. And they still do with HIV. We live in an era when social media is the prime source of news for people, and we've learned from assessment of how social media can play a role in disinformation, particularly around the 2020 election that they use algorithms that will reinforce the information that people like and say they are interested in so that means that it can often promote misinformation, or click bait headlines. That very much could communicate to people "oh, this is a gay disease." Or, "this isn't affecting me, so I don't need to worry about or be concerned about it." But scientifically, and certainly since this virus has been identified and then tracked in Africa since the 1950s, it is not quote unquote a gay disease or primarily affecting part of that community in Africa and no one calls monkeypox an African disease. So, we're playing a balancing game of trying to support the right kind of public health outreach and messaging, while also understanding that sadly not only can people misinterpret what that means, but there are actors, even at the highest levels of state and Federal government who would actively prey upon that misunderstanding to harm people.

KK: I totally agree with you, there are so many misconceptions. And I listen to this all the time, and some people are saying HIV patients are not at greater risk, and then the next day you hear the opposite. Can you provide insight on that?

VC: Yeah, are HIV patients at greater risk than others to get this?

JC: Well again, the answer to that is, it depends. There is something called being undetectable where an individual who is living with HIV is on the right kind of antiviral medication, stays connected with their healthcare team and their physician for monitoring, and it's very possible in a short period of time after someone is diagnosed, for the number of copies in their blood, of the virus to reduce to such a small amount that it seems like the virus is virtually undetectable in their body. And all of the vast peer-reviewed research so far has shown that people who are undetectable, is incapable for HIV to be transmitted from them to someone else via sexual contact. And when that virus is under control it also means that it's not wreaking havoc on their immune system or harming them in other ways, though of course taking medications can have side effects and

long-term effects. So, for the subset of people living with HIV who are undetectable, engage well with their healthcare team and are not facing what we call comorbidities, in other words, other illnesses, long term illnesses or syndromes like heart disease or obesity, diabetes, we have no reason right now to believe that people living with HIV are at either higher risk of becoming infected just because they have HIV or at higher risk of a more severe monkeypox outbreak. Now with that said, you can have someone who is not engaged in medical care, may not be able to consistently take their medication and then they can have a lower immune system, be immunocompromised, and then be both at higher risk for infection and at higher risk for a more serious, perhaps life-threatening case.

VC: We are aware that at least for now there is a limited supply of the vaccine. Is this a multi-dose vaccine?

JC: Yes, the manufacturer of the vaccine does recommend multi-dose, with a second dose in around 28 days post the first and it does report, and this is for a vaccine called Jynneos, and there is another monkeypox vaccine that isn't currently being used because it has a much harder side effect profile, that after a two-dose administration it's about 85% effective. Now we've learned similar things around the Covid vaccine, right, like multiple doses while it's not going to prevent 100% from getting it. If you were to contract it it could prevent a more severe outbreak. Now what New York City is doing is only supporting first doses right now because the vaccine is in such limited supply and there's such high demand, we're continually calling on the Federal government, certainly the CDC to release more vaccine from the stockpiles so that everyone can get the full course that's needed.

VC: So, is there a priority in terms of who are the best candidates to receive this vaccine at this time?

JC: Yes. So currently in New York City the only people who are eligible for the vaccine are people who identify as gay, bisexual, or other men who have sex with men who are over the age of 18 and who have multiple sexual partners in a week period whom they do not have a good amount of information about that person's history, their monkeypox status, whether they've been vaccinated and so on. And that limitation is based upon the science of who is currently but not limited to being affected and the fact that there is such a limited amount of vaccine available.

KK: The Federal government has announced that they are going to name a White House coordinator for the monkeypox virus. Do you think that's going to be helpful?

JC: That's a good question. Having that person be a primary spokesperson on the news networks and hopefully filtering through to various social media via video clips and things like that will be able to help address a lot of the questions that we're hearing from the community. Lack of answers cause fear and anxiety. Let me give you an example. There have been in social media, particularly on Tik Tok, people who have been infected sharing their experiences and sharing what excruciatingly horrific pain because this particular outbreak of monkeypox, it seems that the pox, or lesions occur at the place of contact and from what I've read, in about 20% of people, that can lead to pox, for example, inside their rectum or inside their mouth and that therefore, doing the basic things of life, eating and then what naturally happens after eating can be horrifically painful and in fact people have been hospitalized not because monkeypox in and of itself is life threatening, but because they need such strong pain management. Now that leads us to another problem that has happened similar to the vaccination which is that there is also a medication that has been approved for many years in the United States for treatment of the symptoms of smallpox similar to Paxolovid for Covid. But in the US, it only has an experimental status for prescription for people who have monkeypox. And this past Friday the Federal government has made it slightly easier for someone to get access to that medication, it still requires up to three or four hours of paperwork to be completed (VC: wow). Yeah, it's terrible how much of a barrier that is and it

requires going to a physician who is willing and able and has the time to support having that patient be part of a Federal investigational study. Among the other challenges, and this relates to our fears of where this virus will go. Those forms, to my knowledge, are only available in English (KK English). Yeah, and if you think about the diversity of language, and even for people who have conversational or business fluency in English, that's entirely different than the kind of language that is on multi-page Federal investigational study forms. And what physician right now is able to or has people who speak multiple languages or translation services for someone to complete it. One of the things GMHC has been advocating for is for the FDA to move t-poxx from experimental to emergency use authorization, EUA which people may have heard of before, related to, of course, the Covid vaccine

VC: I know that we touched on this earlier, but what are some symptoms of monkeypox that people should be on the lookout for?

JC: This is an important question to one of the main points we've been getting across which is that people need to care for themselves and each other, right? And part of caring for oneself and others is recognizing, like we did with Covid that if you're sick, if you develop symptoms like a fever, swollen lymph nodes, lethargy, a rash that is anywhere on your body, particularly in the genital area, around your mouth, on your hands, to not go out and to seek medical attention. And for people who don't have a primary care physician that they can just pick up the phone and talk to, all of the city's public health clinics are ready and available to support someone who may have been exposed or has symptoms if they are concerned are related to monkeypox or has a rash. They are equipped to provide a test all at no cost. Now at some point after those initial symptoms a rash will develop, a kind of standard pox. It might look first like an ingrown hair or a purple but then eventually it will become what is referred to as a pustule which is really just a packet filled with pus. And pain may develop as a result. And that's when someone is most in a sense contagious because it is the fluid in those pustules that can transmit the virus. We talked about, and I think it bears mention again, the tremendous pain that these pustules can cause, the uncomfortableness, particularly if they are in the mucous membranes of the body. And really, it is not until the pox or pustules have scabbed over and that scab has fallen off and new, healthy skin has replaced it that someone is no longer contagious. Because of that healing process, that could take two or three or more weeks.

KK: You know, you're giving us so much great information. What are you telling people about going to the gyms and saunas, do you feel a fear there?

JC: I know that there is anxiety among a wide swath of the population about monkeypox, particularly as the government pays more attention to it, as the media pays more attention to it. We now have confirmed cases, I know of at least two, children have tested positive (KK: Yes). A growing but small number of women who have tested positive. And frankly, I expect that is only going to increase. I think that it's important for people who are among the high-risk group to take a close hard look at what they can do to limit their risk, right? So based on the data we have so far, going to your gym for a workout down the street is likely not going to have any risk at all, or very little risk. But going to a sauna that particularly caters to men who have sex with men where there may be some kind of intimate contact happening, well, that's another story. I have to share how much we love the CDC's director of HIV and STI disease prevention, Dr. Demetre Daskalakis who is a former GMHC board member. He has been putting out a series of videos where they talk about things that people who are sexually active can do for harm reduction to reduce their risk, because we learned from the HIV epidemic that telling people they shouldn't have sex at all, or they should somehow be ashamed of who they are and who they're intimate with doesn't work. Rather, we need to equip people with the information and tools they can use to mitigate their risk. For example, if you're going to go to a party on Fire Island, where there's going to be lots of people dancing around, maybe you should wear a shirt. Maybe even a long-sleeved shirt. If you're going to

have sex there are things that you can do like using a condom, though because we're talking about fluid from a pox transmission it's possible for that fluid to get on the outside of a condom first. You can get into the devil and the details but it's still better... they can use their imagination on other things they can do at a distance where you can still enjoy being with someone without having the direct skin-to-skin contact. It's just about basic protection against any STI. So, if you're going to be down real close to someone's genitals, well, that's a great opportunity to see where you're going first. And if there is a rash or something there to take a step back and ask questions. And ask your partner "Hey, have you felt this way, have you been vaccinated? What do you know about monkeypox?" And if you can't ask those questions, or if the answers to those questions are incomplete, or don't make you feel safe and secure then maybe it's time to take a step back until the vaccine is more readily available. Just be careful.

VC: How is the GMHC reaching out to educate people? I know on your website. You have lots of great resources.

JC: Thank you. Again, folks can go to gmhc.org/monkeypox to see a curated list of information about monkeypox vaccine availability in the New York City metro area, also news articles including podcasts like this, we'll put it up there, a link and a curated list of scientific journal or science based articles—we don't usually have journal articles, because those are really hard to read for most people including me—and also we've been very public and visible across all kinds of media having these similar conversations to get this information out there, non-stigmatizing, public education, access to vaccines, access to the t-poxx treatment. We need to make sure that the vaccine is put out in a way that is readily available to everyone who needs it. This is an area where New York City really needs to improve, because the past couple of times, the way you could get a vaccine was to go on line at 6PM and sign up. And if you get to the site, and you can't get there because it's so busy, you keep going back and going back. Okay, well, who has the capacity and ability to do that? Certainly not people who are working at 6PM. And who may be more likely to be working at 6PM or evening? That's right, the populations that are disproportionately affected by other illnesses. Who doesn't have access to a phone, a smartphone or a computer or the Internet, that can't go on line at 6:00 and keep going back and back and back until they get an appointment? Again, these are these low-income communities that are already ravaged by so many structural determinants of health. That's the term for someone who looks like me, white, college educated person with employment and access to healthcare provided by the employer. The folks who don't have that privilege that I have, which I own are at much greater risk and we need to make sure that they get it. So. one of the other things that we've been doing is working with the city to help make vaccination appointments for our clients. Since the majority of our clients are low-income people of color and men who have sex with men and other high-risk populations.

KK: You know, Vanessa said something when we were talking before you got on that there are all these vaccines in—where did you say it was—Denmark?

VC: Oh yes, I heard a news report recently that said that the US has a really large number of vaccines stockpiled in a cold warehouse in Denmark and they will have to make efforts to ship these to the States and put them in appropriate warehouses because apparently the vaccine has to be kept chilled at a certain temperature.

KK: I think it's the same thing with the Covid vaccine.

JC: It is, you're right. Yes, the manufacturer of Jynneos, the monkeypox vaccine, is in Denmark and had been holding on to I think over a million doses that had been bought and paid for by the United States government because the government has long been stockpiling smallpox vaccine and treatment in case of bioterrorism with smallpox which is much more deadly. I should say that no one that we know of in this current

outbreak in Europe or in the United States has died from monkeypox. My understanding of why they were waiting there was some FDA bureaucratic approval, proving that the manufacturer's facility met certain requirements for manufacturing and storage before it could be sent over, and look, I love that our government wants to protect us. That's a key role of government, make sure that the food we're eating or the medications that we're taking don't harm us. But when that process gets in the way of responding to a public health outbreak that really is a great problem. In fact, I also heard that the manufacturer said, "Well, we're holding on to all these but there are other parts of the world that really need it. So, we need you to release some of those doses to go to England and other places, "which the US did which is good but only further highlights the insanity, honestly, of existing doses not getting into the arms of people as quickly as possible. Kathleen, your point about the Covid vaccine needing to be chilled, it brings in this whole... we've been here before. You know, there was a system developed that did not exist before of distributing vaccines to places where people can more readily go to get them, right, such as your pharmacist or your physician, keeping those virus doses at the right temperature while they're being transmitted or being stored at local locations, creating a variety of systems that can be used to make an appointment both online and by phone. And one of the things that makes that happen with Covid was that it was declared a public health emergency at the Federal and State level and funds were released to support local and state governments doing this. And that's why we're also calling upon CDC and New York State to declare the outbreak of monkeypox a public health emergency so that these resources can flow more readily to where they're needed.

KK: The World Health Organization has already done that.

JC: It has. And I think that can open the window to other places not allowing politics, especially as elections come up, to prevent the right decisions related to an outbreak of a virus like this.

VC: So, Jason, is there anything that you'd like to add that we haven't covered?

JC: I think that it's important for people who aren't members of the gay, bisexual, men who have sex with men and trans communities to not dismiss or scroll past stories about monkeypox and think that it's not something they have to pay attention to, because at the molecular level where a virus can be transmitted, your sexual orientation or gender identity is not an indicator of whether or not you could contract it. Now that also means that people should be aware of their relative risk. Right? So right now, if you're not a gay or bisexual man who has multiple sexual encounters in a week's period of time, chances are your risk is really, really low and next to nothing. But society, for example, still promotes invisibility of bisexual people. But when you look at demographics, a far greater proportion of the population identifies as bisexual or has a sexual history of having sex with both men and women than the gay and lesbian and trans populations put together. So it serves that people need to be aware, educated and make smart choices and that our government needs to get these vaccines out because right now that limitation is exclusive of other people who may be invisible to science, or the media, or the news, for any number of reasons who either are already transmitting the virus to each other and simply don't know it or are not aware that they should because they don't see themselves as like the image of a muscly guy in a disco, bouncing around, things like that, and this is the tough stuff about public health and I really appreciate you both making this an issue on your podcast and inviting me and GMHC to be here, because the right public health strategy includes going to the places where people go to get information, not just throwing up a website and hoping that people hear about it and go to it, and I hope this is helpful to the community that you reach as well.

VC: This is enormously helpful, excellent information. And then once again if people have questions how can they reach out to GMHC?

JC: I urge everyone to go to GMHC.org/monkeypox and take a look there. I do want to emphasize that GMHC is not a direct healthcare provider so we do not provide vaccines directly, and the best way, and only

way for most people to get a vaccine is to monitor when the New York City Department of Health receives its next batch. I have heard that the next distribution from the CDC will be over 700,000 vaccinations. Now that's not for New York City alone, that's nationwide of which a portion will go. And that reminds me, there is one important fact that I really need to get out there which is even though New York City has received about 13 ½% of the vaccines distributed nationwide, which may sound like a lot, it has consistently carried over 30% of the number of known—in fact monkeypox infections in the nation. New York City needs a fair and equitable distribution so it really is critical that these vaccines get here into people's arms.

KK: Jason, thank you so much. This has been so interesting, educational, and it's going to help a lot of people out there.

VC: Since this interview, which took place on July 27, 2022, New York City and New York State have both declared a "monkeypox state of emergency" joining California and Illinois. Additionally, Robert Fenton has been named White House Coordinator for monkeypox.

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