

Video Transcript – Webinar: HIV Activists and Caretakers

Video Begins

Visual Description: [00:00:00] *Video slide appears displaying white Arial text in front of a solid turquoise background. Text reads “VIDEO WEBINAR natural history dot edu, National Museum of Natural History”. The text is on the top of a Smithsonian text with a sunburst logo. Webinar begins, a woman with happy expressions introducing herself and presenters. The woman has white pale toned skin with light blond combed hair, wearing a sky blue blouse plus a red sweater over her.*[00:00:05]

Sabrina Sholts: If anyone wants to start trying out the Q&A box to let us know where you are joining from, I would be happy to start to welcome everyone as they enter. It is the nature of this format that you can see and hear our speakers but they cannot see and hear you. I think it would be really nice to know who is joining us and who is out there on the other. -- Otherside. Ok. From the University of Maryland department of epidemiology, Marcia. Leslie, New York City. Thanks, everyone. Thanks for sharing this. This is nice. Robert from the Bronx. Quite a range of diversity. Thank you, thank you. And welcome. more, more. Marilyn was in San Francisco when HIV started. Someone saying hello from Chicago. I used to live in Chicago. Wonderful. All right. We are going to get started. Thank you. Thank you, everyone, for joining us today, and hello. My name is Sabrina Sholts, and I am a Biological Anthropologist and the Curator for the exhibit: Outbreak Epidemics in a Connected World at the Smithsonian's National Museum of Natural History. I am not there right now, unfortunately, and have not been in a while. I'm joining you all today from my home in Washington, D.C. On behalf of the museum, it's my pleasure to welcome you all again and to say thank you for joining this program HIV, Activists and Caretakers, the first program of three in the series. AIDS at the intersection of community, science, and policy. For more than two years the outbreak exhibit and associated programming has been educating the public about viruses that spillover to humans from animals, [00:01:00] about the pandemic threats of newly emerging diseases, and about the interconnectedness of human, animal, and environmental health as one health.

I would like to take a moment to say thank you to the many organizations that have supported the Outbreak Exhibit, including those that provided funding. When the Outbreak Exhibit reopens to the public, there will be updates on COVID-19 that situate among stories of other epidemic and pandemic diseases. HIV has been and will remain at the center of the exhibit. But despite all the people, perspectives, and experiences of the HIV pandemic that we've tried to represent, there are far more stories than we have seized to tell. That's why our programs, like this one, have been so important for expanding our ability [00:02:00] to bring more voices and faces into the conversation. Today we will hear from some really amazing activists and caretakers who have been working at the frontlines of the HIV pandemic for decades, some of them since the beginning of its global spread. We are really fortunate to be joined by them on World AIDS Day, as we all come together to raise awareness about the HIV pandemic and honor all the lives that have been lost. So how this will work speakers will be giving some short presentations, and afterwards they are going to answer a couple of questions for me. And then taking questions from you, the audience. Alright so, it seems some of you have found the Q&A box and can use it. But that is where we will be communicating throughout the program, we will be putting [00:03:00] links in there -- and other information as it comes up during the discussion and that is where you can submit your questions for our speakers. You will be speaking to them through me and I'll read them out. So if you take a moment to locate that box if you haven't done so already, it should be at the top or the bottom of your screen. You can type as many questions in there and we will do our best to answer as many of them as we can. We are also pleased to offer Captions. To turn on Closed Captions, click the CC button and then select show Subtitles. And you use the same menu if you need to turn Captions off. The CC button should be located at the bottom or top of your screen. Ok so now, let's get started. I would like to introduce our first speaker, Sasha Cuttler. Sasha you can turn on your video if you want. Sasha Cuttler RM, PhD, a nurse for 35 years. Sasha moved to San Francisco and worked at the AIDS unit at San Francisco General [00:04:00] Hospital featured in the documentary "5B". If you have not seen the "5B", I have to say you must truly. It's a fantastic film! Please check it out.

Among other roles, Sasha was a nurse on the AIDS home care team, a public health nurse for the clinics, and a nurse at Tuberculosis Control. Sasha visited the homes of San Francisco residents suspected of having scars in 2003 and volunteered again in 2020 for those infected with the Coronavirus that causes COVID-19. Sasha's PhD dissertation found that Tuberculosis patients treated by the public health department were less likely to die than patients at San Francisco's private hospitals. During the past four years, Sasha has acted to defend San Francisco from attempts to defund public health and to stop discriminatory health and human services regulations [00:05:00] that encourage healthcare workers to refuse care. Sasha provided testimony for a service employees international union court brief for the defense of the patient protection and Affordable Care Act, a.k.a Obamacare. Sasha is currently working for the San Francisco Department of Public Health's Nurse Advice Line. Inspired by activism, Sasha is the self-styled Corona Queen Nineteen. (Laughs) Thank you so much, Sasha, and please please, take it away. And you can unmute yourself.

Visual Description: [00:05:41] **Sasha's PowerPoint title slide appears with a solid black background and white Arial font text in front: Top text "Three viruses and a Mycobacterium: HIV, SARS, COVID-19 and Tuberculosis." Bottom text "December 1st World AIDS DAY 2020 Smithsonian's National Museum of Natural History by Sasha Cuttler RN PHD". In the upper right corner speaks Sasha placed in a tiny Zoom video square. Sasha, with olive skin tone, has on a red bandana over the head. Sasha is wearing an indigo t-shirt, reading glasses, and a necklace. Sasha has a black PowerPoint background in all slides. [00:07:00]**

Sasha Cuttler: That would be helpful. Alright. Ok. Hello, Smithsonian, and thank you, Sabrina. I feel I need to joke, make the obvious joke about the National Museum of Natural History being the host for this, because that is the place with dinosaurs, and as a 60-year-old nurse, I am happy to be old. One of the lessons I learned from this Epidemic, from the Outbreak of HIV that affected originally a lot of young people in San Francisco, is that aging is a very good thing. I will never forget when I was an AIDS home care nurse visiting Philip to give him an Intravenous Infusion that lasted four hours to treat his condition that he had, and it was on his birthday, and I said well, "Happy birthday", I

guess it's not really very happy. And he interrupted me and smiled at me and said "Sasha, a birthday is an accomplishment". [00:07:00] This slide is to show that I am going to be talking about my own experiences as well with these four different epidemics and how they relate. Next slide, please.

Visual Description: [00:07:05] *Two side by side photos of Sasha wearing medical clothing appears.*

Sasha Cuttler: Alright. Is the next slide now being shown? Oh dear. There we are.

Sabrina Sholts: I am not -- are you seeing it, Sasha? Do you see the next slide?

Sasha Cuttler: I do see it now.

Sabrina Sholts: Ok, I am not.

Sasha Cuttler: Alright. So, I started my nursing career with the emergence of HIV, and I worked a 12 hour night shift at San Francisco's General Hospital in their AIDS unit, as mentioned in the movie. [00:08:00] In the picture on the left, I'm preparing to join my colleagues for the pride parade. I think I look as unsure and exhausted as I often felt at that time. On the right, I am practicing the flatten the curve dance used in March of 2020 to lighten the atmosphere way back when COVID before sticking swabs of noses and throats of very brave Sanfransicans. These are the messages that I would like to tell you I have learned that I think would be helpful for all of us as we go through the current pandemic. One is that diagnoses do not define our humanity. Another is that both nurses and patients are resilient as well as being members of high-risk groups for disease. Nurses and patients demand and deserve respectful care, and nurses and patients benefit from improved staffing. Universal precautions reduce stigma. Safer devices and practices protect health care workers so that we can protect patients, [00:09:00] and finally, love and laughter could not be left at home.

Visual Description: [00:09:10] *Black and white photo on Sasha's slide was captured in the year 1988 at the Fifth Anniversary of the AIDS Unit celebration. Four people are standing pairs. One couple in the*

background and the second couple in the foreground. Everyone is dressed up in elegant party wear. [00:10:48]

Next slide, please. This picture was taken at the Fifth Anniversary of the AIDS Unit in 1988. It felt weird to celebrate at that time. Most of the nurses I worked with were gay and lesbian, and almost all of the patients I health care forward dead within a couple of years. One of my fellow nurses who passed a few years after I worked with him was a Leather Queen who drove a motorcycle, he had a dungeon in his basement, and he was the most kind and gentle person I worked with. I learned from him that men's masculinity does not have to be toxic. I also was fascinated to learn that he had participated in research that was instrumental in developing the Hepatitis B vaccine **[00:10:00]** that has now helped to virtually eliminate Hepatitis B as an occupational infection in hospitals. I have been vaccinated with that. I also worked with a lot of women, with butch and femme lesbians and the occasional, ever-elusive, heterosexual system under a woman.

One of the women I worked with contracted HIV from an intravenous line that had backed up. She went on to greatly reduce HIV and Hepatitis B and is currently volunteering today to help at a coronavirus testing site. Next slide.

Visual Description: **[00:10:48]** The slide displays a San Francisco map of Chinatown plus Downtown. The etched map is detailed, sharing dark grey lines and dots of resident data from people who died of tuberculosis. The map is colored a golden yellow and purple ombre effect with yellow on top and purple on bottom. **[00:12:51]**

I went on to work for Tuberculosis Control. This is a dot map of San Francisco from 1912. **[00:11:00]** In the upper right, you can see a concentration of dots in two places that represent Chinatown and downtown. Each of those dots is the residence of somebody who died from tuberculosis during that time. Not just having the disease, but they died from that. A century later, I learned that patients were continuing to have the highest rates of Tuberculosis -- some of the highest rates of Tuberculosis in the world, and they were living in those neighborhoods with a lot of immigrants, who are at risk of that, and a lot of people who are poor, and nonwhite people as well. So, it sounds familiar because this is the same story with HIV and now COVID-19 for those same neighborhoods. During the time that I was

in AIDS home care, I believed I was infected with tuberculosis because I had a positive skin test. And to this day, most health-care workers are given the reassuring news that they don't really have tuberculosis, they are simply exposed to tuberculosis if they have a positive test. In fact, it's not just exposed, but exposed and infected. One of the things I tried to do when I was at TB control giving an update to other people in the public health department was to say "Sasha Cuttler had a tuberculosis infection". Can you say that? All right. So, that was audience participation with Zoom.

Visual Description: [00:12:51] Text reads on top in white "**SEVERE ACUTE RESPIRATORY SYNDROME 2003.**" In the middle is a photo of a vietnamese women nurse. The photo of the nurse is a portrait of the women smiling with a short black bob cut at a hospital in Vietnam. Below more text continues "**NGUYEN THI MEN PEDIATRIC NURSE, HANCI, VIETNAM.**"[00:14:21]

Next slide, please. Here. Ok. In 2003, there was the outbreak of Sars, the first Sars, [00:13:00] the first Coronavirus to be a much larger problem than having a cold. This is a picture of one of the nurses, a pediatric nurse in Vietnam who survived, who was one of the very few health-care workers to become sick in the hospital. They were all isolated inside the hospital where they worked, and she was one of the very few to survive. I was very moved to read in the paper at the time that she had that experience. I was moved to volunteer to go and visit people in their homes when required, so that was my first experience of obtaining the nasal fribrial swab from patients. And it was at that time that I learned about the fear for myself and the importance of being able to see that for however much I was afraid, the patients were much more afraid, so I needed to respect that and try to help them through a very scary thing. None of the people I tested ended up coming back positive, but they were all quarantining, nonetheless.

Visual Description: [00:12:21] On the right of the slide, holds an image of Sasha wearing a mask and medical wear with a colleague in front of an ambulance. Next on the left of the image is an opaque purple graphic arch that has white text reading a quote. The text reads: "**The people we are testing are worried about their health, but they seem mostly scared that they may have infected their**

families. I love working as a public health nurse because I get to feel like I'm contributing to a small decrease of viral fear and fearful virus. And I'm really grateful I get to work with some incredibly dedicated nurses and EMTs and eligibility workers and disease control investigators and epidemiologists and doctors. We need all of us to control this pandemic.” [00:15:51]

Next slide, please. So when I tested the first few people for COVID-19, I was fortunate to volunteer with public health nurses and emergency medical technicians. That process had been set up by the health department with some ambulance companies, and we were available to go and do the tests in people's homes. We went in ambulances just in case. So my job was to get the test and leave but one instance, [00:15:00] I was asked to check on a family member who was confirmed positive to find out if I needed to find out how she was doing. The patient was protecting her family and public health by staying in her room. She, fortunately, had her own bathroom, so people were bringing food to her room, just as now people are experiencing throughout the world as they attempt to shelter-in-place. She was breathing hard and had a high fever, so we brought her to the emergency room. She did not seem to be afraid. Neither did the young EMTs, but I think it's possible that everybody was just trying to protect the other from being afraid. Next slide, please.

Visual Description: [00:15:51] In this slide an op-ed photo of Sasha wearing black glasses, a mask, and a purple plum tone shirt with a matching color beanie appears. The beanie has text that reads “UNIONS FOR ALL”. At the bottom of the op-ed reads a caption in tiny writing “Sasha Cutler is a nurse employed by the San Francisco Department of Public Health (Courtesy Photo)” Below that caption reads a quote from Sasha “We can't flatten the curve if we are sick”[00:16:54]

Alright, when the going gets tough, I tend to write op-ed's these days. This is a picture of myself and my workplace-- workplace as a telephone advice nurse. I wrote an op-ed at the beginning of April, and what I asked for at the time is that we needed to make sure that we don't flatten the curve at the expense of the health care workers who are providing that care. That is quite important because as of April, there were about 160 health-care workers in California alone

who had been infected, and now that number is up to 2,000, and 218 of them have died of COVID-19. So, we need to do better. I am doing everything I can about that. Next slide, please.

Visual Description: [00:16:56] **Sasha and Sasha's mother pose together in two side by side images that showcase energy and happy smiles. The two photos were taken in rooms with low pink and purple lights gleaming upon them in each photo. [00:17:46]**

Alright, this is a picture of my mother outlaw [00:17:00], who is now among the risk group of being old. She went with us to the drag king show, and she portrayed Willie Nelson, the outlaw country singer. Although she was too old to play the part of Willie Nelson, who is 87, his quote is important. He said "I think youngsters need to start thinking about the kind of world they are going to leave for me and Keith Richards".

Visual Description: [00:17:46] **On this slide has two side by side images of Sasha's father. The photo on the left includes a caucasian father who is bald, older, and has a grey scruffy short beard plus mustache. Sasha's father is lying under white hospital covers in a hospital bed, and Sasha is lying next to him. The image on the left includes Sasha's father through a protected glass door protecting them from the virus. In the photo, Sasha's father is wearing a mask, black sunglasses, a grey baseball hat, a white t-shirt with a yellow and black graphic on it. The two are communicating to each other face to face from Sasha's perspective. [00:18:43]**

Next slide, please. Not to be outdone, here is my father on the left when he was in the hospital pre-COVID and I could lie down and pose for a picture with him in bed. [00:18:00] Now, visiting him means visiting him through a glass door or, more recently, outside from 6 feet away. The other thing I wanted to say about this is that we need to be clear that old people are -- they are a high-risk group for this disease, so we have to be helping with that. To make sure that we don't leave people behind or think that because they are going to die -- because they are old they are going to die. They are going to die soon anyway is a recipe for disaster in the structure of our society.

Visual Description: [00:18:43] The setting of the photograph is during World AIDS Day 2019. Four colleagues and Sasha wear deep blue outfits and stand together smiling. Sasha poses on the far right with a deep blue dress, and a mini black purse. Sasha's hair is cut short and black. [00:19:42]

Next slide, please. Alright, this is from World AIDS Day in 2019. I was invited to -- well, I got myself invited, to be honest, [00:19:00] to appear at a screening of the documentary "Five B" in England for my colleagues, in Worcester and in Nottingham. And this one in Nottingham, at The Queen's Medical Center, without discussing it, we all wore blue for that presentation. I felt -- you may recognize that dress from the beginning of this presentation. Although I felt awkward to wear it -- wear it there at first, I realized I was appearing, after all, at the Queen's Medical Center. Thank you for your kind attention.

Visual Description: [00:19:42] Sasha's final slide is solid black with white text reading information about Giving Tuesday. On the top of the slide it reads: "Donations to support COVID 19 relief efforts are welcomed by: give2sf.org. Sasha closes the PowerPoint, and then appears full screen grinning from ear to ear. PowerPoint ends [00:20:14]

The next slide is to show that for my #GivingTuesday, I'm happy to give my honorarium to give2sf.org because they are providing support which is so needed to all of the measures we need to support our most affected communities in San Francisco and wherever we are in the world as we await this vaccine. Thank you.

Visual Description: [00:20:14] Transitioning onto the next presentation, Sasha and Sabrina comes on screen. Sabrina gives introductions and Sean Strub joins on at [00:21:47]

Sabrina Sholts: Thank you so much, Sasha. That was wonderful. I have to say, seeing your parents was lovely, and your daughter, Ida, is listening right now and says hi. So, great. We will now be hearing from Sean. So Sean Strub is our next speaker. Sean is the mayor of Milford, Pennsylvania, there you are Sean, and has been living with HIV for more than 35 years. He is the founder of POZ Magazine, the first openly HIV+ person to run for federal office [00:21:00] in the U.S. And the author

of "Body Counts: (this book, which I highly recommend) a Memoir of Politics, Sex, Aids and Survival," as well as two books on corporate social responsibility. Sean serves as the executive director of the Sero Project, a U.S. based national network of people living with HIV that is best known for its work combating HIV criminalization. Sean's short film "HIV is Not a Crime," introduced the problem of HIV criminalization to audiences and advocates around the world. Sean, thank you so much for being here today. You are unmuted. You are ready to go.

Visual Description: [00:21:46] Sean Strub comes on screen with a smile before he speaks. Sean is a White man with short grey wavy hair, and black glasses that have translucent frames surrounding the near the top of the forehead and translucent on the bottom resting on the cheeks. Mr. Strubs shirt is a dark solid navy sweater with a white collar work shirt folded neatly over the neck. Sean requests to share a slide, PowerPoint appears with white backgrounds throughout the presentation. On the title slide: Up on the left corner has the capitalized red text of the SERO logo, and the O has an emergency hospital symbol in the center. Descending in the bottom right center, the title slide reads, "Worlds Aids Day. December 1, 2020. Sean Strub. Early Epidemic History and the Contemporary PLHIV Network Movement." Sean is in the Zoom square in the upper right corner. [00:22:44]

Sean Strub: Thank you very much. This is a real honor to be invited to do this today and participate with the other panelists. I am going to speak first to give a little bit of a context [00:22:00] for when the first cases were discovered in the early 1980's, particularly context within the gay community. And then talk about the advocacy that preceded what most people think of when they think of AIDS activism in the 1980's. Most people think of the spectacular street demonstrations of act up. But there is an important chapter I will speak about things that are happening today. And then I want to speak specifically to the role of networks of HIV working with each other and working today. So now I will share my screen. Is the slide up?

Visual Description: [00:23:51] A black and white photograph appears on the screen of two men facing the camera. The man on the right is a White police officer, who is putting his hand on the right shoulder of the other man, who is a young adult, with white skin, and has long wavy hair. The young man has his

eyes closed and the image is slightly blurred, making it look like he is pulling away from the policeman. A crowd of other people and police officers can be seen in the background.[00:24:49]

Ok. Alright. So, in the queer movement, that emerged out of the 1960s and broad cultural-ship [00:23:00] sexual revolution. It was originally a sexual liberation movement that offered all sorts of people to free themselves sexually. In the 1970s, it began to morph into more of a political reform movement focusing on laws and municipal ordinances. Some of that was in reaction to police violence against gay people as we became more visible as we came out of the closet in the 60s and 70s. Then, as we had more places to gather in bars and elsewhere, we're being harassed and attacked. So the political movement began at the community-based neighborhood level in San Francisco, and the village in New York and sort of Gay-Borhoods. And consequently, the first victories we had, the first sort of political victories, were the passage of municipal nondiscrimination ordinances in a number of cities across the country in places like St. Paul, Minnesota, and Dade County - very famously so Dady County. And as we became more visible in the 1970s and began to have quite a first blush of success, we had the first Gay Rights Bill introduced congress in 1974 by Bella Abzug and Ed Koch; the American Psychological Society declassified homosexuality as a mental disorder in 1973 -- but as we became more visible and started to have these successes, there was a real push back.

Visual Description: [00:24:49] Another black and white photo appears of Anita Bryant, the beauty queen and spokesperson for the Florida Orange Juice Industry. Behind her has two posters of her program called "SAVE OUR CHILDREN." The posters are block lettered. Anita has white skin tone, big, short, wavy combed hair that is dark in the image. [00:25:30]

And the critical moment was when Anita Bryant, the beauty queen and spokesperson for the Florida Orange Juice Industry, began a campaign to overturn the Dade county non-discrimination ordinance. She called it "Save Our Children." And it was focused on homosexuals as a threat to people. [00:25:00] This was important because, to most people, up until about 40 or 50 years ago, there was a long list of biblical sins, fornication, adultery, homosexuality, but

Anita Bryant in 1977 really changed the public's focus to an individual who was a threat to your family

Visual Description: [00:25:30] A sign of someone holding a red sign with white painted text that reads "GAYS RECRUIT CHILDREN". The person holding the sign has a red shirt on while protesting the sign up high in front of the face.[00:25:31]

So in 1977, we had the campaign "GAYS RECRUIT CHILDREN.

Visual Description: [00:25:32] Next two key slides flash by slowly. First image is a Black and white photo displaying Harvey Milk. Harvey is a White man with an oval shaped face, short dark hair and a big grin on his smile with teeth showing. Harvey is dressed in a tie and suit that has a detachable graphic button on the right side. His tie is blowing in the wind and has a stripe pattern. [00:25:37]
Transitioning quickly, The next slide includes an old front page newspaper tabloid that reads text descending down "HEADLINE: MOSCONE, MILK SHOT TO DEATH. BODY: GUNFIRE AT CITY HALL -- EX SUPERVISOR WHITE HELD/ SAN FRANCISCO EXAMINER."

1978, Harvey Milk was assassinated. In 1977 the The Moral Majority was founded by Jerry Falwell. In 1980, Ronald Reagan was elected. A couple weeks after Reagan was elected, we had the ramrod shootings in New York where a mentally ill person went into a popular gay bar and shot and killed a number of people.

Visual Description: [00:25:39] A navy blue background sign with a white square reads a header with black text "RARE CANCER SEEN IN 41 HOMOSEXUALS" Below the line, black text reads "OUTBREAK OCCURS AMONG MEN IN NEW YORK AND CALIFORNIA -- 8 INSIDE 2 YEARS".[00:27:06]

By the time the first HIV cases were detected, the gay rights movement was under siege. We had a target on our back. It was unclear whether the gay-rights political movement was going to go anywhere. It was really a nascent movement at the time. It was not clear if it was a temporary aberration or really going somewhere. And then the epidemic hit. And in the emerging -- so, what we think of as

AIDS activism in the early 1980s was largely an outgrowth of the gay community activism. The first organizational institutional response in the community was from some of the gay-rights organization, but not all of them. Some of them distanced themselves from this and felt this was a real threat to the political reforms we were receiving. The last thing they wanted to talk about was what we were doing sexually. '

Visual Description: [00:27:06] A color image appears of people in the KKK (Ku Klux Klan) robe uniforms. Uniforms are pure white cotton robes, red stripes on cuffs, and a white pointed hood with eye holes. Each person has a symbol of the "Blood Drop Cross" on the right side of the robes. The symbol is a white cross centered in a red circle. The cross part has a drop of blood graphic in the center. One person on the right is turning his head to the right holding a white sign reading "AIDS IS GODS CURE FOR ALL FAGGOTS" The sign has painted black words except for "FAGGOT" which is red and quoted. [00:27:12]

So early on, by 1982 -- oh yeah, this was another lovely one. We weren't really popular then. Still aren't.

Visual Description: [00:27:12] A black and white image of a man photographed from the chest up. He is wearing a light color short sleeve t-shirt with Arial Black text reading "AIDS POSTER BOY". He is also wearing a big bow tie around the neck. The white man's fore-head is wrapped by a folded bandana fashioned like a headband and tied on the back of the hair. The man's hair is combed and cut short. His mouth is pursed, smiling, and facing toward the camera along with his right hand raised up a peace sign. He is standing outside a government building on the left and two men on the right of the image that is faded in the background [00:30:42]

By 1982, in San Francisco and New York, with AIDS who were going public. I don't know if this is Dan Turner or Bobby Campbell, I'm not sure, from San Francisco. There was Michael Callan and Richard Berkowitz and others, a number of people, not a lot, they didn't really know each other, there was not a national movement around people with AIDS. But there were people starting to emerge people with AIDS and starting to get together with each other. Usually finding each other themselves rather through organizations. Then through organizations,

because there really weren't any organizations at that point. And the first people started taking on the gay establishment, right? That was sort of speaking about AIDS and for them. Because initially when the first people were diagnosed they were so close [00:28:00] to death there wasn't really any activism around that. But then people were getting sick and living for a longer time and starting to speak for themselves. The initial activism was -- a lot of it was focused around confidentiality and privacy issues. New York state passed the first statutes in that protection. A gay man working with the doctor in New York made that happen. This early activism was a really big part of transitioning the concept of a person with AIDS from somebody literally on their deathbed to somebody who had a voice and was an activist. In the first -- or one of the very first national meetings about the epidemic, it was 1982, in Houston. It was mostly doctors. There were a handful of people with AIDS there. They were at the back of the room. They were not at the dais. They were not the speakers. There was a nurse there named Helen. She was a nurse in San Francisco. She told me a few years ago that she was so upset by some of what she saw -- there were lots of people with wonderful presentations, but some of the doctors were joking about making reservations to fly to Stockholm, joking about who would get the Nobel prize. This bothered her because there were not people with AIDS speaking. A few years later was The Fifth Annual National Gay and Lesbian Health Conference in Denver. She got on the phone with people around the country and urged them to come to Denver, and about a dozen guys with AIDS were in Denver, and they met each other, they gathered. They called themselves The People with AIDS Caucus. And they [00:30:00] gathered in a hotel room, and they wrote a manifesto called the Denver Principles, which outlines a series of rights and responsibilities for people with AIDS, caregivers, health care providers, and others. This document began by taking control of the language, saying we reject the label victim, which implies passivity and defeat. We are people. People with AIDS. So, the popular use of people's first language today in contemporary times was pioneered by the AIDS movement. It was actually first used in the 1930s by people with Leprosy.

Visual Description: [00:30:42] A colored image of eleven men advocates for the AIDS movement. The group of men are in a living room with red curtains to the left, and a red tall lamp pole in the back behind

the men. Each man has a shirt on and the front in center one is shirtless with glasses. Each of the men are bunched together with arms around each other surrounding a table. [00:30:50]

The group that met -- this is the group of people that wrote this first document. They are all gone now except for Richard Berkowitz

Visual Description: **[00:30:50]** A faded black and white photo of the same eleven men stand in a row on a stage with a long banner sign reading "FIGHTING FOR OUR LIVES". The banner is a dark color and the text is in block letters painted in a lighter tone. The background is darkened and the men are lightened on top and darkened waist down. **[00:32:23]**

The Denver Principles, they then took the podium at the conference and read the manifesto. Contemporaneous media coverage says they got a standing ovation for 15 minutes. People had tears in their eyes because they sensed there was something historic, something important that happened at that moment. And indeed, this document was sort of the Magna Carta Declaration of Independence and constitution all rolled up into one, not just for people with HIV, but for all people that share a health condition that defines them to society, that is highly stigmatized. The Denver Principles were cited in the Ottawa declaration, the world health organizations Ottawa Declaration, the U.N. involvement with people with HIV and AIDS, and has really become a foundation document for self-empowerment for people in health care. The ideas were not original. They were largely a codification **[00:32:00]** of The Women's Health Care Movement ideals. The personal is political. They also reflect practices that are common in tribal, nonindustrialized societies and communities in dealing with addressing health situations. But what came out of that was a self-empowerment movement that was really extraordinary in the U.S.

Visual Description: **[00:32:24]** A group of 7 advocates (5 men, 2 women) wearing professional work outfits in a black and white photograph.

Visual Description: **[00:32:33]**

An article from The AIDS Coalition reads in multiple columns:
**TITLE: CHEERY 'LIVING ROOM' HELPS AIDS VICTIMS COPE BY
ANNE-MARIE SCHIRO N.Y. TIMES NEWS SERVICE**

[COLUMN ONE]

"NEW YORK -- IT'S A PLEASANT LITTLE ROOM THAT LOOKS OUT ON A TRANQUIL GARDEN IN THE WEST VILLAGE, A PLACE WHERE PEOPLE WITH AIDS CAN GATHER FOR FOOD, CONVERSATION, RELAXATION AND SHARING OF INFORMATION. CALLED THE LIVING ROOM, ITS RUN BY THE PEOPLE WITH AIDS COALITION, WHICH IS OPERATED FOR AND BY PEOPLE WITH AIDS. AND THAT'S WHAT MAKES IT SPECIAL. "THERE ARE OTHER GROUPS FOR PEOPLE WITH AIDS, BUT THIS IS THE ONLY GROUP OF PEOPLE WITH AIDS DOING SOMETHING FOR THEMSELVES," SAID MICHAEL HIRSCH, DIRECTOR OF THE COALITION, AND ITS ONLY PAID EMPLOYEE. HE AND A FEW VOLUNTEERS ARE THE ONLY ONES OF THE 20 OR SO ACTIVE MEMBERS WHO DO NOT HAVE ACQUIRED IMMUNE DEFICIENCY SYNDROME OR AIDS-RELATED COMPLEX. "THE PEOPLE WITH AIDS WANT TO TALK ABOUT IT," SAID HIRSCH. "TO TELL EACH OTHER WHAT IT WAS LIKE TO TELL OUR PARENTS, WHAT IT WAS LIKE TO GO THROUGH CHEMOTHERAPY, TO SHARE THE PAIN. WE NEEDED A PLACE WHERE THEY COULD GO HANGOUT, SOME PLACE

[COLUMN TWO]

--IT HAS A FIREPLACE, A TELEVISION SET AND A VCR, A STEREO, SHELVES OF BOOKS AND WINDOWS THAT LOOK OUT ON THE GARDENS OF ST. JOHN'S EPISCOPAL CHURCH. IT ALSO SERVES MEALS ON SUNDAY, MONDAY, AND THURSDAYS AFTERNOONS--75 TO 100 MEALS A WEEK-- AND SHOWS COMEDY FILMS SATURDAY AFTERNOONS. BRUNCH IS SUPPLIED ON SUNDAYS BY DONALD SACKS. A SOHO CATERER. A VEGETARIAN MEAL IS BROUGHT IN EVERY MEAL BY DAVID FISCH, AN UPSTATE CHEF. ON THURSDAYS THE FRANCISCAN FRIARS OF ST. FRANCIS OF ASSISI CHURCH PROVIDE A MEAL -- USUALLY HOT SOUP AND A MEAT OR FISH SALAD. THE FRIARS ARE PLANNING A TRADITIONAL HOLIDAY FEAST FOR CHRISTMAS DAY AT THE LIVING ROOM, AS THEY DID FOR THANKSGIVING. LATE ON RECENT THURSDAY AFTERNOON, HALF A DOZEN MEN HAD DROPPED IN TO HAVE SOME CURRIED CHICKEN SALAD, PASS THE TIME AND SHARE THEIR FEELINGS ABOUT THE LIVING ROOM. HERE ARE SOME OF THEIR COMMENTS "THIS IS A THERAPY WITHOUT THE THERAPIST. I FEEL I BELONG. THEY DON'T ALL SIT AROUND TALKING ABOUT THEIR ILLNESSES, BUT BITS OF INFORMATION ARE HELPFUL." "WERE BUILDING A SUPPORT GROUP HERE. IF WE MISS SOMEONE, WE CAN GO HELP HIM OUT AND MAYBE --

[00:32:57]

A The National Organization of People with AIDS, people with AIDS organizing things like the living room in New York, which was the first place I went to and really connected with a group of other people with HIV. It was just a drop in place run by the people with AIDS coalition. There was a real power in getting us together with each other. It also led to the creation of networks all around the country.

[COLUMN THREE]

--SOMEONE WILL HELP US HELP SOMEDAY." "INSTEAD AROUND THE HOUSE AND HAVE ENOUGH STRENGTH HAVE TO PULL MYSELF UP BECAUSE I KNOW I HAVE VOLUNTEERS RAID \$7,000 THEIR TIME AND SERVICES LIVING ROOM A REALTY. A SEARCH FOR A LOCATION FOX SIX MONTHS WHEN S. TELEPHONED THE EPSICO NEW YORK, THE REV. PAUL WHO OFFERED THE USE OF RECTORS OFFICE AND ST. JOHN'S CHURCH. THE ROOM TWO FLOORS OF TINY BRICK IN THE CHURCHES COURTYARD. O'HARE, A PROFESSIONAL OFFERED HIS SERVICES TO THE DINGY LOWER FLOOR A COMFORTABLE LOUNGE. THE FLOOR SERVES AS THE COOKING OFFICE. O'HARE MANAGED CURTAINS AND UPHOLSTERY AND CARPETING DONATED KITCHEN UTENSILS, DISHES OF THE LABOR. THE SOFA, CHAIRS,,, DINING TABLE, STEREO AND TELEVISION PURCHASED

Visual Description: [00:32:57] Placed on a family album, four black and white faded photographs in a grid are present. Text in the photo album read

on the right in gold italicized text, “A FAMILY ALBUM FROM THE PEOPLE WITH AIDS COALITION BY DAVID SUMMERS”. Below that is a much smaller size text. Each photograph has pairs of people or a group with captions written underneath in smaller text. Photo one in the upper left shares two men conversing in a faded tone. Image to the upper right of the grid, shares two faded toned men facing their eyes into the distance with the heads turned right. Left bottom corner image of the grid shares a faded photo of a couple, a man on the left and a woman on the right both dressed for colder weather. Finally the bottom right photo is faded with a figure hunched into a fetal position and hands plus arms are crossed over the knees. [00:33:50]

The New York people with AIDS coalition was one I was very involved with, but there were networks in cities large and small across the country. I'm a native Iowan and there was a little network of people in Waterloo, one in Dubuque. Mostly, it was 2, 3, 4, 5 people in those communities, but early on, there were frequently people who had moved back to their home communities from coastal communities where they lived. Those networks and people with AIDS working with each other and led to the creation of the buyer's clubs, the community-based clinical trial networks, all sorts of things, the invention of safer sex, which was, of course, enormous

Visual Description: [00:33:50] In the colored image on the slide we have Michael Callan (on left) and Michael Hirsch on (right) Jane Rosett (middle). Together the three are standing in a row holding a purple banner that only reads part of “PEO” for the group. Michael Callan, smiling, has tan white skin, short black hair, and a short unbuttoned shirt over a graphic t shirt plus white cargo pants. Jean Rosett hair is styled into a curly afro, she is white with a tan, and peaking over the sign smiling. Michael Hirsch, smiling, is white with a tan and bald, he is wearing circular translucent glasses and a white t-shirt including yellow gloves, he is the one holding the end of the banner. Behind them is a large crowd holding purple balloons. The scenery has a lot of trees towards the far back. [00:33:57]

This is Michael Hirsch from the people with AIDS Coalition, and Michael Callan. -- Michael Cowan -- Jane Rosett in the middle.

Visual Description: [00:33:58] In the foreground, three men, arms around each other, are dressed up in a colored darkened photograph. The three are standing together from the waist up. On the right, Dr. Joseph Sonnaband in a dark unbuttoned suit and white shirt with cuffs. Sonnaband is a white man with a white and grey mustache beard combo and dark hair. He is smiling with lips pursed. In the middle is Michael Cowan who is wearing a buttoned down long sleeve shirt, short brown hair with a very light fringe cut for the bangs hairstyle. Mr. Cowan is also white. On the left is Richard Berkowitz who has short black hair, a black mustache, and is white. Berkowitz is wearing a solid black top with a lightly checkered black and white suit over the top. In the middle ground behind the three is a bouquet of yellow and white flowers appearing above the heads. The background casts a dark background surrounding them. [00:34:32]

This is Dr. Joseph Sonnabend both with patients Michael Cowan and Richard Berkowitz. He introduced them to each other. He was treating them and he believed that people with AIDS needed to be organizing and speaking for themselves, not waiting for others to address this issue, or waiting for the government. It was very conscious that the establishment was prepared to let people die. So they introduced these two and they became -- so he introduced these two, and they became a remarkable team for advocacy. One thing they did was write this booklet,

Visual Description: [00:34:32]
A faded white document, with black text typed on a stapled booklet appears. Top heading aligned to the center reads: "MEDICAL AND SCIENTIFIC CONSULTANT: JOSEPH SONNABEND, M.D. CHAIRMAN, SCIENTIFIC COMMITTEE, AIDS MEDICAL FOUNDATION" Bottom right text aligned to the right reads: "HOW TO HAVE SEX IN A EPIDEMIC: ONE APPROACH" [00:36:31]

"How to Have Sex in an Epidemic: One Approach." It really focused on how to prevent the transmission of whatever this was. At that point, we knew it was something infectious, probably a virus, and they spelled out all sorts of ways people could have sex without putting

themselves at risk. That at the time was actually in opposition to some of the dominant messages from the emerging AIDS organizations which were more about fewer partners. So, this was the early movement that I described as kind of a do-it-yourself movement. People with AIDS focused on empowering each other and creating what we needed ourselves, whether it was media, clinical trials, research, prevention strategies, social support and networks that had a collective political base. That grew dramatically in the early to mid-1980s. At the same time, more and more people were dying, and the anger in the community was growing. It was palpable. The events that triggered moving it to another level was in 1986 when The Hardwick Supreme Court decision came down that gay people did not have the right [00:36:00] to privacy in their own homes. That's on spontaneous demonstrations all across the country, similar to what we have seen in the occupying and Black Lives Matter's movements. People coming into the street. That was in 1986. In march of 1987 when Larry Kramer made a speech in New York that launched Act Up, it was prime. People wanted to do something.

Visual Description: [00:36:31] A white background with a graphic cartoon line drawing from an artist name, Keith Haring. The illustration is of a penis cartoon character with hands, feet, and a happy face. On the right hand, the cartoon is giving a thumbs up and the left hand is waving a condom. Bubble size read text says "SAFE SEX" over the cartoon character. [00:36:40]

With Act Up, -- this is part of the prevention strategies created by people with AIDS. In this case, Keith Haring did a whole series around this.

Visual Description: [00:36:40] An image with young Sean Strub getting arrested in an Act Up protest in front The White House. In the foreground, Sean, who is a white man with black short hair, is smiling with pursed lips, wearing a suit, a black tie, and a corsage on the suit. Wearing glasses, Sean is looking straight at the camera. Sean is approached in the photo by an officer wearing a police uniform and a helmet. The policeman is holding a gun on his waist, wearing yellow gloves, and reading a piece of paper to Sean. In the middle ground are several officers wearing the same uniform. The background shows a long white bus with big windows in

front of trees on the road during the middle of the protest.

[00:36:46]

This was getting arrested in 1987 in front of The White House.

Visual Description: **[00:36:45]** Another slide with an image of a large protest. Several people holding a dark banner and block shaped text reading "ACT UP FOR A CURE" painted white. The crowd of people are soldering several signs with phrases supporting the Aids movement. The photograph has buildings and trees in the far background. **[00:38:38]**

Then we have acted up, which started in the spring of 1987 and really got going by that fall. Amped up was not so much like this first part of the movement, -- Act Up was not so much like this first part of the movement, focused on people with AIDS, it was focused externally, the white house, the government, congress, pharmaceuticals, research institutions, trying to get them to do what they should have been doing all along. Act Up -- I was very involved with them and it saved my life, but in retrospect, there is another aspect to it that needs to be recognized and understood, particularly when we are looking at the history of the epidemic. To a large extent, especially in the early years, in the very beginning, act ups were overwhelmingly male and white. And it was really when there was sort of a critical mass of gay men who realized the government was going to let them die -- they had never experienced that sense of neglect or indifference from the government before. They had not imagined it. Lots of other communities, black and brown people, women, were quite accustomed to the government **[00:38:00]** interfering with their health care and neglecting them. But gay white men of relative privilege were angry. So there was an expression of anger, but also of privilege. Almost a tantrum, like the anger of privilege. Of course, act up grew over the years and became more diverse and merged with the arts, design, and research elsewhere.

Visual Description: **[00:38:38]** A slide with three posters appears from the Act Up protest. Starting from the left, poster 1: pink and green with the words that are see-through, and the background is green. In the middle ground is a pink triangle. A black thick line across the middle holding the movement "ACT UP". On top it reads in white

block letters “DON'T BE SILENT” on the bottom it reads black “FOR YOUR LIFE AIDS COALITION TO UNLEASH POWER 222-989-1114”. The center poster is red in the background, white font on the heading and bottom reading “DONT TREAD ON ME”, in the median of the middle poster is a thick black strip with a pink triangle in the median. The last poster on the right is a gray poster with a font that has a chalk style. The chalk font reads “NYC LOVES KEITH HARING “ACT UP” FIGHT BACK FIGHT AIDS”. [00:38:40]

Visual Description: [00:38:40] In the foreground, a colored image of an African American man, crouched down in a grassy field. The man has dark skin and is wearing a blue outfit with a brown fedora. His face is focused with a stern look. The man has short black hair. In the photo the man is crouched behind a head stone cardboard cut out that reads “DEAD FROM DRUG PROFITEERS”. Surrounding him are cardboard cut out 7 headstones . In the far back of the photograph is a building and crowd of people.[00:38:53]

Lets see what I got next here. Here are some more Act Up stuff that we did.

Act Up became increasingly focused on the drug development process and expediting treatments, having them move through the system faster

Visual Description: [00:38:53] A colored image appears of Jesse Helms' home. Architecturally, the house is a colonial home. The home is surrounded by trees on a grass yard. As an act of protest, members of ACT UP group designed a gigantic yellow condom that engulfed the Alexandria home. On the side of the condom that is visible in the photo, shows text that reads “A CONDOM TO STOP UNSAFE POLITICS. HELMS IS DEADLIER THAN THE VIRUS”.[00:38:17]

And then of course there were spectacular demonstrations like the gigantic condom over Jesse Helms [00:39:00] -- that was a senator, very racist, homophobic, a misogynistic senator from North Carolina, over his two-story home in Virginia. This guy put a condom over it that

said “PROTECT YOURSELF FROM UNSAFE POLITICS, JESSE HELMS MORE DANGEROUS THAN THE VIRUS”.

Visual Description: [00:39:18] A moving GIF photo appears of the group of men who participated in the protest appears. The group is of 7 people sitting on a parked moving truck. Each of them are cheering with excitement plus wearing t-shirts, long pants, and sneakers.
[00:39:18]

This was a group of us on the right.

Visual Description: [00:39:23] A photo of an electric road sign in orange digital font reads “WARNING HIV OUTBREAK”. The sign is staked in the ground on a field.[00:40:16]

So, Act Up, of course, was successful at expediting treatments. By the mid-1990s, we had treatments coming out and that changed all sorts of things. One of the things that changed was it really led to the erosion of support for networks of people with HIV, these coalitions, body positives, all these organizations out of the country. Many believed we would treat our way out of the epidemic. We had also lost many, many people, early activists. I see Sabrina, which must mean I'm almost out of time. Is that right? (Sean Laughs) In terms of activism from the community, we went into a bit of a lull in the 1990s and early 2000s. One of the consequences of that,

Visual Description: [00:40:16] A colored image of a crowd of advocates for Act Up. The crowd is on the streets in a city close together protesting. Several people are holding signs with activism text reading “HIV IS NOT A CRIME CRIMINALIZATION IT IS.” In the middle of each sign is an illustration of handcuffs. A similar activism sign is in front of the crowd of protesters but as a banner. The text of the font on the signs are yellow, the sign background is black, and handcuffs are orange. [00:40:51]

as we saw an increase of things like HIV criminalization, inappropriate use of a person's HIV status in a criminal prosecution resulting in people being sentenced to prison for decades for behaviors that did not put anyone at risk, let alone harm anyone. We began to see a resurgence in the growth of networks of people with HIV about 15

years ago. Today, that is a phenomenally vibrant and honestly, quite exciting

Visual Description: [00:40:51] A white slide with text on the heading “GROWING PLHIV MOVEMENT TODAAY”. Several network logos appear. [00:41:12]

arena of advocacy. The project I run, the U.S. Piwa Caucus, [00:41:00] is the network of networks in the U.S. Positively Trans, The Working Positive Coalition, and The Positive Women's Network.

Visual Description: [00:41:12] A white slide with black text appears of a quote from Michael Callan, an AIDS activist, read out loud by Sean Strub, the presenter. [00:41:38]

So, Michael Callan, who was an early activist and influential with my thinking used to say “There is a special magic in the room when it's just people with AIDS talking to other people with AIDS”. This is about the community and the power of us working with each other, speaking to each other, supporting each other.

Visual Description: [00:41:38] Another white background with black text read by Sean Strub appears.[00:41:48]

My last thought is a message that comes out of the movement of networks, which is, “To reduce stigma, stop focusing on trying to educate the stigmatized her's and instead focus on empowering the stigmatized. -- Stigmatizes, and instead focuses on empowering the stigmatized.

Visual Description: [00:41:48] Sean's final slide appears with the SERO project logo in the upper left corner. The middle of the slide displays Sean's email: Sean dot Strub at SeroProjects dot com. (Sean.Strub@SeroProject.com). Underneath the email is the website to SERO Project www dot sero project .com backslash (www.seroproject.com/). [00:41:52] (SLIDE SHOW ENDS) Sabrina Sholtz appears enthusiastically smiling.

Sabrina Sholtz: Thank you, Sean. That was fantastic. Only to say that I hope we have a lot of time for questions because [00:42:00] I could listen all day to

what you all are saying. We are going to move on to Cecilia. So, you can turn off your video and I see that Cecilia is there. Hello, hello. So, Cecilia Chung is nationally recognized as an advocate for human rights, social justice, human equity, and LGBT equality. She was the former chair of the San Francisco Human Rights Commission and is currently serving on the health commission. Cecilia has been working tirelessly on the local, national and international levels to improve access to treatment for transgender people and people living with HIV, and to erase stigma and discrimination through education, policy, advocacy, and visibility. Cecilia, thank you so much for joining us. I will let you take it away.

Visual Description: [00:42:55] Cecilia Chung appears in a home office setting. She has long, slightly darkened hair. Cecilia appears excited to be in the presentation, and is wearing a purple shirt. Cecilia begins to introduce herself. [00:44:53]

Cecilia Chung: Thank you for having me and good afternoon, everyone. I don't know how to follow, actually, after the two eloquent speakers, Sasha and Sean before me, but I will try to do my best. Instead of telling more of the history of the -- how Transgender people were involved in the beginning, I would like to really pivot to talk about how the movement has shifted. Like Sean says about building a network of people with HIV and finding a way where we are able to launch, like Transgender people network of folks living with HIV since 2015. I want to also share a little bit of the discoveries since then. I do this -- let me do this. I hope I am doing it right. [00:44:00] (READS QUIETLY)
Oh, I don't know how to do this part.

Sabrina Sholts: OK, Cecilia, let's try unsharing and then sharing again.

Cecilia Chung: Let me try again.

Visual Description: [00:44:12] (POWERPOINT OPENS)

Sabrina Sholts: You are sharing. You can play your slideshow.

Cecilia Chung: Is it working?

- Sabrina Sholts: Yes, although I think this might be your last slide.
- Cecilia Chung: Ok, let's see how I get to the beginning.
- Visual Description:** [00:44:32] (POWERPOINT SLIDES FLASH BY)
[00:44:53] A white slide appears. In the corner black text appears "WORLD AIDS DAY DECEMBER 1ST 2020. SMITHSONIAN NATIONAL MUSEUM OF NATURAL HISTORY. AIDS AT THE INTERSECTION OF COMMUNITY, SCIENCE, AND POLICY." In the center a giant "T" text in red has "TRANS" on the tail of the "T" and "POSITIVELY" on the top of the "T". Below the top of the right side of the "T" the logo has a little red plus sign. Next, on the right of the logo reads "LIVES AT THE INTERSECTION: TRANS PEOPLE OF COLOR LIVING WITH HIV." by "CECLIA CHUNG (PRONOUNS: SHE/HER) SENIOR DIRECTOR OF STRATEGIC INITIATIVES AND EVALUATION" In the right corner it reads in red text "Transgender Law Center , Making Aesthetic Lives Possible." [00:45:00]
- Ok, so this is the beginning. So, as I mentioned, my name is Cecilia Chung. I work for the Transgender Law Center, and I really want to take this opportunity again to thank the Smithsonian for inviting me to speak about transgender people of color living with HIV.
- Visual Description:** [00:44:53] A slide with Ceclia in the upper right corner Zoom box comes on. Text appears (FIRST HEADING): "TRANSGENDER LAW CENTER. (PARAGRAPH ONE) THE TRANSGENDER LAW CENTER (TLC) IS THE LARGEST NATIONAL TRANS-LED ORGANIZATION ADVOCATING SELF-DETERMINATION FOR ALL PEOPLE. TLC EMPLOYS A VARIETY OF COMMUNITY-DRIVEN STRATEGIES TO KEEP TRANSGENDER AND GENDER NONCONFORMING PEOPLE ALIVE, THRIVING, AND FIGHTING FOR LIBERATION. (SECOND HEADING) POSITIVELY TRANS (SECOND PARAGRAPH) POSITIVELY TRANS IS A CONTINUOUS RED PROJECT THAT SEEKS TO PROMOTE THE RESILIENCE OF TRANS PEOPLE MOST IMPACTED BY OR LIVING WITH HIV/AIDS, PARTICULARLY TRANS WOMEN OF COLOR, THROUGH: (BULLET POINTS BEGIN) BULLET ONE: RESEARCH BULLET TWO: STORIES: (BULLET THREE) LEADERSHIP

DEVELOPMENT (BULLET FOUR) POLICY ADVOCACY.
Transgender Law Center logo is down below in the left corner throughout all her slides. [00:45:58]

A little bit about Transgender Law Center. It's the largest national trans rights organization advocating self-determination for all people, and it employs a variety of community-driven strategies to keep transgender and nonconforming people alive and thriving and ready for liberations. The project I am going to touch on today is Positively Trans, a constituent led project that seeks to promote the resilience of trans people most impacted by or living with HIV and AIDS, particularly trans women of color, through research, stories, leadership, development, and policy advocacy. **[00:46:00]**

Visual Description: **[00:46:00]** White slide with a photograph appears as the header. Some people in the photo are wearing the organization "Positively Trans" t shirts to show support. Below bullet points begin: **(BULLET ONE): TRANSGENDER AND GENDER NONCONFORMING PEOPLE LIVING WITH HIV ARE: (BULLET TWO) CAPABLE OF FORMING OUR OWN NETWORK (BULLET THREE) TELLING OUR OWN STORIES AND DEVELOPING OUR OWN STRATEGIES IN ADDRESSING THE INQUEITIES, STIGMA, AND DISCRIMINATION THAT DRIVE THE HIGH RATES OF HIV AND POOR HEALTH OUTCOMES IN OUR COMMUNITY.[00:46:28]**

As Sean mentioned earlier about the Denver Principles, here are some of the operating principles that Positively Trans is guided by. That transgender and gender-nonconforming people are capable of forming our own network, telling our own stories, developing our own strategies and addressing the en-equity stigma discrimination in our community that drives the high rates of HIV and the poor health outcomes in our community. What we have done since 2015 is developed needs assessment by the community for the community. What I am about to share with you are some of the data we gathered from South Florida, New Orleans, and Detroit in the needs assessment -- and the needs assessment we did in 2018.

Visual Description: **[00:46:55]** A list of quotes in light orange rectangle text boxes appear.

(QUOTE ONE) "WE ARE PARTNERS YOU CANNOT DO YOUR JOBS WITHOUT ME AND YOU'RE NOT DOING ME A FAVOR. I SHOULD LEAVE THE CLINIC FEELING LIKE I PLAYED A PART IN MY WELLNESS AND I ALSO TAUGHT YOU SOMETHING" -- NEW ORLEANS PARTICIPANT.

(QUOTE TWO) ALL PROVIDERS NEED TO BE TAUGHT THAT YOU DON'T HAVE TO BE SUPER FEMININE IF YOU ARE TRANS, ITS WHO YOU ARE INSIDE, ITS NOT ONLY AN APPEARANCE, SO IF I AM A WOMAN THEN TREAT ME LIKE ONE, NO MATTER WHAT I LOOK LIKE." -- SOUTH FLORIDA PARTICIPANT.

(QUOTE THREE) I LIKE THE FACT THAT SCIENCE IS THERE FOR U=U, BUT IT PUTS ALL OF THE RESPONSIBILITY ON THOSE WHO ARE ALREADY MARGINALIZED"-DETROIT PARTICIPANT.

(QUOTE FOUR) I FEEL LIKE THE HEALTHCARE PROVIDERS ARE OBSESSED WITH MY PRIVATE PARTS. THEY ALWAYS INSIST ON EXAMINING IN DETAIL, EVEN IF IT'S THE FIRST TIME I AM SEEING THAT PROVIDER. THEY HAVE NO IDEA HOW MUCH IT RE-TRAUMATIZED ME TO HAVE MY PARTS LOOKED AT SO CLOSELY BEFORE THEY EVEN TRY TO GET TO KNOW ME."--NEW ORLEANS PARTICIPANT.

(QUOTE FIVE) WE NEED A RELATIONSHIP WITH A DOCTOR THAT WE CAN TRUST, WHO TAKES THE SHAME AWAY OF DEALING WITH OUR GENITALS, INCLUDING TALKING ABOUT STDs, AND MAKES COMING TO CLINIC FUN." DETROIT PARTICIPANT.

[00:48:29]

Before I share the actual numbers, I want to share some [00:47:00] quotes with you. I'm not going to go over all of them, but I think it is important to look at how stigma impacts people's lives, especially for Transgender people living with HIV. I feel like health care providers are obsessed with my private parts. They always insist on examining them in detail even if it is the first time I'm seeing that provider.

They have no idea how much it re-traumatizing need me to have my parts looked at so closely before they even try to get to know me. Another one I like to share is there is a campaign going on right now to really advocate for HIV treatment for people living with HIV, and the belief is that once we can get to a viral load -- and undetectable viral load, [00:48:00] we will not be able to transmit HIV. However, that is

not something that can be obtained by everyone. From a Detroit participant, "I feel like the fact that the science is there puts all the responsibility on those who are already marginalized."

Visual Description: [00:48:29] A slide with a pie chart titled in red text "NOLA DEMOGRAPHICS: RACE & ETHNICITY" black text "NOLA N=56". Underneath the title is the pie chart in yellow and orange colors. 92% is yellow for African American. 8% is orange for Hispanic. Labeled below the pie chart are the keys to know the percentages of the populations.[00:48:46]

We have three sites. The first one I share here is New Orleans, Louisiana, and this is the makeup of the demographics of the race and ethnic city -- ethnicity for New Orleans.

Visual Description: [00:48:29] Transitioning to a similar slide, a pie chart appears. Titled in red text " SOUTH FLORIDA DEMOGRAPHICS: RACE & ETHNICITY". The second heading title below in black text reads "SOUTH FLORIDA N=51." Underneath the title starts the pie chart. 63% orange Hispanic. 26% yellow African American. 2% white in green. 9% brown color for others. Below the chart is the key for each percentage and the.[00:48:49]

This is for South Florida.

Visual Description: [00:48:49] Transitioning to another similar slide, a pie chart appears. Title in red text "DETROIT DEMOGRAPHICS: RACE & ETHNICITY" Below also reads "DETROIT N=46". Underneath the title starts the pie. Orange 14% hispanic. Yellow 77% African American. Green 9% white.[00:48:51]

This is for Detroit.

Visual Description: [00:48:51] A slide with orange toned graphs appears for New Orleans, Detroit, and South Florida with various percentages regarding Gender Identity.[00:49:52]

We also get information about gender identity. As you can see, [00:049:00] trans people living with HIV are quite diverse as well in New Orleans. In our sample, 71% are trans-female. 23% identify as male. Of trans experience. In Detroit and South Florida, we are able to

also gather data from trans men living with HIV, which we knew very little of until this day.

Visual Description: [00:49:52] A similar slide with orange toned percentage graphs appear about Incarceration History for transgender stigma.
[00:49:32]

Here is some of how stigma plays out in Transgender people's lives, especially how Transgender people living with HIV have been impacted by some of the structural violence and institutional violence. In New Orleans, when we look at the history of incarcerations, 69% of our respondents of trans people living with HIV had reported [00:50:00] a history of jail or prison. In Detroit, it's 44%. You see two different bars for South Florida. That's because we are able to collect data from both the African-American community as well as trans LatinX. For Trans-LatinX, 65% have a history of incarceration.

Visual Description: [00:50:32] A similar slide of graphs with orange tones share information about Experience of Discrimination. The states of New Orleans, South Florida, and Detroit are placed in a table across the screen. Inside each table square are the graphs with percentages.[00:51:14]

For black trans people, it's 67%. In terms of discrimination, I am not going to go into the details of the bars, but the most prevalent complaint from respondents is either about employment discrimination due to HIV status or employment discrimination due to being Transgender. Here you can really see -- I will just call it a double whammy, that HIV itself already carries a stigma. For people living as Transgender or who come out as Transgender, that's another set of stigma we have to deal with from today.

Visual Description: [00:51:14] A slide of a graph with orange tones appears sharing information about Family Rejection in New Orleans. Six categories are presented on the slide
“EVER SENT TO FAITH LEADER TO CURE T/GNC (18%)”
“EVER SENT TO THERAPY OR COUNSELING TO CURE T/GNC”(16%)
“EVER LEFT OUT OF FAMILY GATHERINGS” (19%)
“BIRTH FAMILY EVER CUT OFF FAMILY CONTACT” (24%)

"LESS THAN 18 YEARS WHEN KICKED OUT" (64%)
"EVER KICKED OUT OF THEIR FAMILY HOME" (30%)
[00:51:40]

One of the things I think we often take for granted is our relationship with the family. That is not the case for Transgender people. In New Orleans, 64% of Transgender people living with HIV have reported that they have been kicked out by their family before they turned 18.

Visual Description: [00:51:40] A slide of a graph with orange tones appears sharing information about Family Rejection in South Florida.
Two population focuses are AFRICAN AMERICAN
(black slash) YELLOW and HISPANIC (black slash) ORANGE
"EVER SENT TO FAITH LEADER TO CURE T/GNC"
(50% yellow) (47% orange)
"EVER SENT TO THERAPY OR COUNSELING TO CURE T/GNC"
(50% yellow)(19% orange)
"EVER LEFT OUT OF FAMILY GATHERINGS"
(67% yellow) (57% orange)
"BIRTH FAMILY EVER CUT OFF FAMILY CONTACT"
(83% yellow) (44% orange)
"LESS THAN 18 YEARS WHEN KICKED OUT"
(80% yellow) (80% orange)
"EVER KICKED OUT OF THEIR FAMILY HOME"
(83% yellow) (31% orange)
[00:51:53]

The same kind of data was shared by respondents in Florida, and here, you can see that they have been kicked out, 80% of them have been kicked out before they turn 18.

Visual Description: [00:51:53] A slide of a graph with orange tones appears sharing information about Family Rejection in Detroit.
"EVER SENT TO FAITH LEADER TO CURE T/GNC" (22%)
"EVER SENT TO THERAPY OR COUNSELING TO CURE T/GNC" (15%)
"EVER LEFT OUT OF FAMILY GATHERINGS" (53%)
"BIRTH FAMILY EVER CUT OFF FAMILY CONTACT" (49%)
"LESS THAN 18 YEARS WHEN KICKED OUT" (82%)
"EVER KICKED OUT OF THEIR FAMILY HOME" (42%)

[00:52:47]

In Detroit, it's 82%. So, these are those shared experiences that Transgender people living with HIV **[00:52:00]** have a lot of them don't have the family support necessary for them to thrive. As we continue to seek treatment, we want to make sure we can address the social isolations. I am not here to share that study, but there are other studies that have been done that show that when people have their family accepting them, the risk of these issues is reduced quite significantly. If you google the family acceptance project, this data will show up.

Visual Description: **[00:52:47]** A slide with the title “EXPERIENCE OF VIOLENCE” appears in red. Below is another set of graphs colored in an orange tone. Categories read with percentages
“EVER FORCED TO HAVE...” (29.70%)
“BY PARTNER HURT...” (12.30%)
“BY PARTNER HURT...” (10.30%)
“PRIMARY PARTNER HURT...” (15.50%)
“PRIMARY PARTNER...” (8.40%)
“HARASSED OR...” (18.60%)
“PHYSICALLY ATTACKED...” (33.90%)
“PHYSICALLY ATTACKED BY...” (19.00%)
[00:53:31]

In terms of violence, that is something we just -- we are in December now, and we just commemorated **[00:053:00]** Transgender Day of Remembrance on November 20. This is something that is quite common, commonly faced by Transgender people as well. As you can see, 48% of Transgender people living with HIV have experienced being harassed on the streets, and also, 33% have reported being physically attacked.

Visual Description: **[00:53:31]** A black video screen appears on the slide with a white play button. **[00:54:53]**

As I mentioned earlier, this is really a project for Transgender people living with HIV by Transgender people living with HIV, and we are capable of telling our own stories. The powerful part about this is, when we tell our own stories, we are not just sharing with you what

happened to us, but it really puts [00:54:00] us in the light of the society, that we are human as well, and by humanizing our stories, making that connection, we are hoping that more people will understand why -- more people will understand why it is important to accept us. We are not asking people to approve everything we do, but we hope people can recognize and acknowledge that we do exist and that we deserve respect just like everybody else. I want to share with you here a video made by a steering committee member. Her video was one of the more touching ones and it has gotten a lot of acknowledgment, and I have enjoyed that as well.

Visual Description:

[00:54:54] (VIDEO BEGINS)

Title appears in white typewriter text

"A MESSAGE TO ETHAN". Title fades out.

(♪ MUSIC PLAYS ♪)

[00:54:58] A colored image of New York City's Times Square fades in. The image captures a Times Square green street sign with white font with "TIMES SQ" pointing to the left and "W 46 ST" to the right. Behind the sign are advertisements on big screens and a MAMA Mia moving truck.

(A SPEAKING VOICE BEGINS)

[00:55:00]

Before relocating to New York City, all I knew was drugs,

A colored image of a vaccine syringe shot fades in.

The shot is laying on a white paper towel.

sex, partying, and debt.

A group of three women at a darkened bar.

A light up red neon sign transitions quickly reading "SEX".

A colored gray image of a single rose droops over dead.

[00:55:07]

A set of four color photos fly by of a woman whose name is Octavia in different city settings. Octavia has bleach blonde straight long hair with full bangs. Octavia is African American.

[00:55:27]

You see, in the south, there were not many advancement opportunities for people like myself. It was hard to live my truth as Octavia.

Another colored image of a surrange shot flashes by.

I had to roof or -- I had to resort to survival sex to maintain a roof over my head and to begin my transition.

[00:55:37] A portrait color photo of Octavia appears.

I could not access quality, competent health care, employment opportunities, or the basic necessities afforded to everyone else.

[00:55:43] Five green and tan vintage suitcases stacked together only showing the handles.

Therefore, I packed five suitcases **[00:55:48] A color photo of a rural setting fades in. The image lays out a train track and a large AMTRACK train through a field.**

and purchased a one-way ticket to New York City,

[00:55:52] A poster from NYU college. The poster reads “WOMAN THROWING SHADE: A TALK ON COLORISM. TUESDAY 3/10 (VERTICAL BAR) 7 DASH 9 PM (VERTICAL BAR) E AND L AUDITORIUM. where I began to live my truth unapologetically for the first time.

[00:55:55] A color poster that reads “BLACK AND TRANS WOMAN, ECHOES OF OUR LEGACY.”

I was no longer afraid of what others thought of me
Image of a board room around a long table. Eleven people are sitting around in rolling chairs.
because their opinions are not mine to carry.

[00:56:04] Portrait selfie of Octavia smiling with lips pursed.

I will no longer be held hostage by society should, could, and would have because I decide who I am.

A destruction of a building in the background. Trash debri sits on the foreground plus middle ground abandoned and thrown across the landscape.

It took losing everything I held near and dear in order to gain

[00:56:16] A color photo of a family smiles together in bed. Three heads lay together smiling. A caucasian husband on the left with a beard and mustache. He is turning to his son on his right who is in the middle. The son in the middle is smiling. Octavia on the right smiling facing the camera and head tilt towards her son. Octavia is wearing a ring.

everything which has now made my life worthwhile.

[00:56:22] Two colored selfie photos of Octavia's husband with son together appear. All show with happy emotions.

My greatest accomplishment in life was becoming your mother. I left everything behind that was near and dear to me in order to get to where I am today.

[00:56:37] Octavia in front of a photoshopped poster says "JUNE 26 SAVE THE DATE, 11TH ANNUAL TRANS DAY OF ACTION."

Octavia's face is open wide yelling and her arm is in the air.

I never knew I could become an activist, advocate,

Three memorabilia photos flash by Octavia, including a fourth photo of her diplomas from university.

mother, star, and wife.

[00:56:47] A silent video of her son dancing appears in slow motion. Eight photos after the video of her son flash by of him with family and individually.

You are loved beyond measure. In this life, you will experience the isms of society. However, you will have been enlightened on what it is to meet people where they are. You will be able to understand what you can hold and what to release. You are gifted, smart, talented, and have what you need to be the catalyst for change. My gift to you is the knowledge of acceptance and the ability to become an agent of change. You, my child, are the greatest gift bestowed upon me.

- : [00:57:45] Black screen with white text appears.
"CREATED BY OCTAVIA Y LEWIS DOT MPA.

Credits begin descending down aligned in the center of the screen. EDITED BY STORY CENTER
“SEX IMAGE” BY Joao Pedro Perassolo
“SYRINGE AND POWDER” Image by Dimitris Kaleogeropoylos
“PILLS AND POWDER” by Adam Mulligan
“CLUB GRAFFITI” By Duncu C.
“GIRL CRAWLING ON A BAR” By GHOGUMA FILM
“BROADWAY” By Aurelien Guichard
“POD” By A.S. Canaan
“SUITCASES” By Vanessa IMAN
“TRAIN” By Chris Gaziano
“DEMOLITION” By Darius Norvilas
“PANELIST FLIER” By NYU
[00:57:44]
(VIDEO ENDS)

Visual Description: White slide appears with red text “FOR MORE INFORMATION, VISIT: PositivelyTrans dot org.”

Cecilia Chung: So, I think I am near my time. If you would like to find out more about positively trans, just go to this URL, PositivelyTrans dot org, and I believe the Smithsonian [00:058:00] will share this on their website as well. Thank you for letting me share all of this information with you. I will turn this back to you.

Visual Description: [00:058:05] A white slide is displayed. Appears is a graphic on the upper left with a question mark on its side face down and a white animated figure laying on the curve. On the center right, a cursive styled text reads “THANK YOU”.

**Cecilia Chung turns off her PowerPoint,
she appears for a second.
Sabrina Sholts video comes on, smiling.**

Sabrina Sholts: Thank you, Cecilia. Thank you so much. Sean, Sasha, and Cecilia come back. I would love to see all of you, because now we get to the fun part, to start having conversations and answering questions. While our audience continues to formulate their questions, quite a few are already coming through, I would like to ask one for all of you. With all the experiences you have had with the HIV pandemic and the stories,

and all the work you have done, here we are in another pandemic. Is there anything in particular that you think about your experiences [00:059:00] and what you have done and what you have been through that could help people coping with COVID-19 today? I don't know if we want to go in order of speakers or if anyone wants to jump in. Let's start with that. May I call on you first?

Visual Description: [00:059:22] Sean, Sasha, Cecilia converse back and forth with Sabrina. Screens come on in Zoom's speaker mode.

Sean Strub: I will just observe that so much of the community response around COVID has arisen out of the community of people who worked on AIDS. We know something about pandemics. We know something about diseases we don't know a lot about that are stigmatized and a government being lackadaisical or dangerous. That is something I have observed. I haven't seen it reported much. In one particular area, the growing call for criminalization of people with COVID [01:00:00] who put others at risk, which is a really bad idea and terrible public health policy, the work on criminalization that Cecilia, Sarah, and other organizations have done, the positive women's network, HIV justice worldwide, have created a group of activists who are informed around this issue that have sort of been there and are ready to step in and help educate parliamentarians and avoid some really bad legislation that's making the pandemic worse.

Cecilia Chung: [01:00:40] I would like to piggyback on what Sean mentioned. It's also an observation. Interestingly, I think one of the reasons HIV became such an impactful pandemic at the time was the denial we saw from the government. Sadly, we are seeing some of the same kind of responses in the early part of the COVID pandemic. I don't think it's an accident that we see the escalations of the pandemic and the spread of it. Unfortunately, Sean mentioned, what we turned to were very punitive strategies. From a public health perspective, I think Sasha can also tell you that punishing people has never worked before. I don't know that it's going to work now. What it shows is a lack of faith in people making the right decisions for themselves. I think what we really need to do is share accurate information and let people make their own decisions.

Yes, some people will choose to deal with the pandemic very differently, but it takes two to tango. I think we need to be able to respect both choices. Sometimes, it's not the choices we would like to see them make, but that is always the reality. Following them and arresting them is not going to end this pandemic.

[01:02:32]

Sabrina Sholts:

Sasha would you like to add to that?

[01:02:34]

Sasha Cuttler:

One of the things I have learned is that it is important to have accurate information without misinformation and it's really important to listen to people and their concerns. I am really thrilled that there are now three vaccines in the pipeline and another one coming, because it really makes a difference when you are working with people to be able to tell them that there is some hope that there is a light at the end of the tunnel, that it's not an oncoming train. Sadly, with the experience of HIV, we don't have a vaccine. For tuberculosis, there is not an effective vaccine either, and yet, with public health measures, if the world really wants to, we can eliminate that disease. I like to give people the good news about this as well as validating the fact that particular groups continue to be wrongly blamed for their own illness.

That's an American tradition, sadly, and when we need to fight back against it. Nobody deserves to get sick. So yes, I think there is a lot to learn and study from this, but I think we need to give people hope.

Sabrina Sholts:

[01:04:04] Yeah. Thank you.

[01:04:07]

Sean Strub:

I think we are also seeing the failure to provide health care to people in this country is just a way of obscuring what is essentially a eugenics policy. We put parts of society at greater risk, and then when they get sick, we blame them. This is fundamentally wrong, and I think covid is bringing more people around to understanding that, and it makes me

hopeful that we will be able to get universal health care in the U.S.
Knew I -- in the U.S.

[01:04:47]

Cecilia Chung:

My wishes that people can stop partisan politics, stop fighting, and look at the facts as they present themselves. The states that have sound public health policies are still very impacted by the pandemic, but at least not as impacted as states that continue to deny that this is a crisis.

[01:05:20]

Sabrina Sholts:

We have a question here actually about the vaccines for COVID-19 that I think is relevant to the conversation about HIV we just had. How do you respond to people who express doubts about the COVID-19 vaccines? I think this was directed to you, Sean. I think it came at the time when you were speaking.

[01:05:43]

Sean Strub:

You know In general--

[01:05:45]

Sabrina Sholts:

I don't mean that -- Sean
Oh sorry Sasha!

(LAUGHS WITH SEAN)

[01:05:57]

Sean Strub:

In general I think Sasha was talking about vaccines, but the mistrust we have in society around various kinds of things, including vaccines, a lot of it is driven by the lack of equity and who gets to be healthy in this country. Who gets health care?

[01:06:20]

Sabrina Sholts:

Does anyone else have any comments on vaccine hesitancy or doubts?

[01:06:28]

Sasha Cuttler:

I think it is a very important thing that we have to address and we need to do it sensitively. There was a lot of suspicions, particularly from black patients, when I was working with HIV-AIDS, and I --

because of my own ignorance, I thought the Syphilis trials were a long time ago, and it wasn't until later that I learned that the history of how black people have been targeted for terrible, terrible research, unethical, before, during, and after that, so, we need to respect that and speak with people. I have to speak to people every day on the phone to support them, and they tell people, you should not be using bleach inside your body as a disinfectant. Those that have heard the president of the united states talk about that say oh, that's just him, but the reality is, there are people other than Donald Trump who are selling Facebook bleach as a remedy, and people are desperate and afraid. We need to address people's fears with the understanding that some communities, as we have discussed, are targeted with misinformation, and we need to listen and validate their concerns and work with them individually and as a group, and we need to make sure we are doing that in Spanish in particular in the bay area, because almost half of our cases of COVID-19 are affecting this community, and they are the invisible people in the English-speaking world. We need to do better to listen to and honor the needs of the LatinX.

[01:08:40]

Sabrina Sholts:

We have a follow-up question here. It's related. And I will remind everyone in our audience, please keep typing your questions. This is for anyone. What do you think about the preventative vaccine set that has been developed against HIV? Should all healthy people or at risk -- at risk communities take it?

[01:09:13]

Cecilia Chung:

I didn't know we had a vaccine. I know we have Preexposure Prophylaxis.

[01:09:26]

Sabrina Sholts:

Yeah, I think that's what this is referring to.

[01:09:28]

Cecilia Chung:

That's something that somebody has to make that decision for themselves. It's effective for folks who are still sexually active, who want to make sure that whatever they do, they protect themselves from getting exposed to the virus. My research shows that it's take as directed. It is not a magic pill. It does have side effects and other

things that people have to weigh out for themselves. But it's not a vaccine, unfortunately.

[01:10:24]

Sean Strub:

I think it's important to also understand that preexposure prophylaxis gives a strategy, and HIV prevention strategy to receptive partners who cannot get their partners to use a condom. Receptive partners do not -- do not use condoms, they negotiate the use of condoms, and that can be difficult. So this gives them a way to protect themselves from HIV. There is a wide range and how people use it. Not everyone is sexual all the time or in a consistent way, so that also requires an education, but it is exceptionally effective at preventing people from acquiring HIV if they are using preexposure prophylaxis.

[01:11:16]

Sabrina Sholts:

I am actually getting a note from our crew that there is a preventative vaccine in the research phase, very early.

[01:11:24]

Sean Strub:

There are a lot of them.

[01:11:25]

Sabrina Shotls:

Yes. Still very early?

Sean Strub:

There has been an enormous amount of vaccine research. Not to -- an enormous amount of vaccine research. Not to sound cynical, but the vaccine has been just around the corner since 1992. These things take a really long time. That's why the fast development of the covid vaccine is so extraordinary.

[01:11:53]

Sabrina Sholts:

Well ok-- we have now that actually switches over about stigma, which I think is really important, and its directly to Sasha from Ida but I think anyone can jump in. From Ida: "Sasha you did a lot to fight the stigma with AIDS and LBGTQ people. Can you talk about the stigma with COVID? What are the challenges people with positive diagnoses face? How do you identify at risk people- how do you encourage self-care without promoting that stigma?"

[01:12:35]

Sasha Cuttler: Well, I think the important thing is that people have reliable, factual information about how they can best protect themselves, and at the hint of punishment or finger wagging, you are going to lose people. Cecilia aptly pointed out that punishment -- and in Sean's work is well with incarcerated populations, it will not work. That has certainly been my experience with individual patients. The vast majority of people out there do not want to be sick, and they don't want to make anybody else sick. Regardless of their politics, regardless of their understanding of things, anything that can be done to help them with that should be done without stigma. The other thing that's important is that when you hear stories about individual responsibility in terms of wearing a mask and that sort of thing, people realize that people have only -- if you are poor, for example, you are not going to be able to do things as well. I speak to people on the phone who are -- who have symptoms and are -- and/or are positive themselves and I say, does anyone else need to have a test in your household? I find out that somebody else is not there because they are out there looking for work. When they explain that they are working despite having symptoms, it's heartbreaking and sad. It's not because they are bad people. It's because they are at risk of starving to death staying in their room. And we have seen through activism that people can stand up for themselves as being beautiful, wonderful people regardless of what group you are in, whether you are in a risk group or not.

[01:15:00]You have resilience, and there are things we can do to help. public health works. Stigma is not just a reaction of something like you, that scary or gross.

-- Ew, that is scary or gross. It's being actively promoted to make people afraid of each other and isolated. So everything we can do to show love, have a sense of humor, and talk about how much you appreciate people from this particular group can be helpful with stigma. If I have a patient who is withdrawn and feels bad about something and I ask them a question like where did you go to high school and they say -- they mentioned this high school -- I can say that's a good one. If they say it's terrible, I say no, I'm so sorry. But have some common language.

People have either gone to high school or they haven't. If you speak to people and tell them that because people are infectious with this without symptoms and you have people who are infectious with

symptoms, I tell people there are only two groups of people you need to avoid, those with symptoms and those who don't have symptoms. We have a little laugh about it and then we move onto the fact that people are going to have friends with it and they need to figure out a way to move on. That's my answer.

[01:16:44]

Sabrina Sholts:

It's a good one. It's so important. We are already running over time, unfortunately. There are far more questions than we can get to right now. We all benefit so much from your experiences and wisdom. If there is anything else very quickly that anyone of you would like to add before we wrap up here, that you would like to share with the audience, please feel free.

[01:17:21]

Cecilia Chung:

I say a lot that HIV is no longer a death sentence. Neither is COVID. Just because somebody tested positive, that is not a death sentence. We should stop treating it like one. Like Sasha said, find some common language. The goal here is to get people care as early as possible. So everyone can have a healthy, good quality of life.

[01:17:58]

Sean Strub:

I would just urge people who are interested in this work to follow up with the website positively trans and the positive women's network and U.S. Plwa Caucus. There are all sorts of opportunities to get engaged, get information. There are fascinating conversations. One thing about the community of networks of people living with HIV, they are profoundly welcoming to anybody who wants to help. And they are not competitive. We are really mutually supportive across the board. It's a very personally satisfying arena for me to work and because it is filled with so many generous people. And we are doing a lot of work without very much money.

[01:19:02]

Sabrina Sholts:

Sasha, any final words? You are muted.

[01:19:13]

Sasha Cuttler:

Mr. Potato head says wear a mask!

(SABRINA LAUGHS)

[01:19:18]

Sabrina Sholts:

Yes! Thank you. That's a perfect way to end this conversation. So grateful, again, to all of you for joining us and being part of this. This has been a really, really special way to spend this World AIDS Day. I want to thank our audience, thank you all out there for being part of this, and for your questions. We hope you will join us tomorrow. We are going to continue this series and hear about advances in HIV treatment and detection from two physician-scientists with first-hand experiences of the HIV pandemic. From National Cancer Institute and from Georgetown University. You can register for that webinar on the NMNH events page that we shared in the Q&A box. And please take the survey that will pop up when you leave the Zoom webinar. It helps us continue to improve our programs and bring these conversations to the general public. With that, everyone, be well, stay safe, stay healthy. And look at Sasha's shirt. Take care, everyone. Goodbye.

[01:20:48]

Cecilia Chung:

I want that shirt, Sasha.

Visual Description: (VIDEO FADES AWAY)[01:20:53]

(VIDEO ENDS AND BEGINNING SLIDE APPEARS)

Video slide appears displaying white text in front of a solid turquoise background. Text reads “VIDEO WEBINAR natural history dot edu, National Museum of Natural History”.

The text is on the top of a Smithsonian text with a sunburst logo.

Thank you, everybody for coming. It has been a pleasure.

[Return to the web page for this video, “HIV Activists and Caretakers.”](#)