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| TPWKY |  | This is Exactly Right. |
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| Erin Welsh |  | Hi, I'm Erin Welsh. |
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| Erin Allmann Updyke |  | And I'm Erin Allmann Updyke. |
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| Erin Welsh |  | And this is This Podcast Will Kill You. |
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| Erin Allmann Updyke |  | Before we start off, we first want to ask you to make sure that if you're not subscribed that you do so now because this is our last episode of the season and we don't want you to miss next season's premiere or all the super fun bonus episodes that we're gonna have in the interim. |
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| Erin Welsh |  | The subject of this week's episode is HIV and AIDS and we were fortunate enough to interview three individuals who shared their experiences with us. |
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| Frank Iamelli |  | Well my name is Frank and my last name is Iamelli, I'm 65, a gay man, I live outside of Boston. I was about 27 I guess or 28 when we first started to hear about it. I remember distinctly walking to work one morning and this woman I work with, she had been reading the newspaper and she said something about, 'Hey have you heard about this gay plague that's going on, this gay cancer?' And I had never heard of it before. You know, we started hearing that, 'Well this one's not well and this one's not well' and it just sort of mushroomed from there. So within I would say about a year and a half to two years of reading about it in the paper, it had hit Boston like crazy. |
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|  |  | So I think in times of crisis your true self really comes into being and I had always thought of myself as kind of a really nurturing kind of a guy and it was just my first instinct, was when people around me that I loved and cared for were getting sick, there was nothing that was gonna keep me away from helping them. And you also have to keep in mind there was a fair number of people, I won't say all of them, whose families had abandoned them. We were their only family and so we took care of them, we cleaned them, we fed them, you know we socialized with them, we tried to keep them in good spirits and all of that. And basically just be with them through the end. I can't tell you how many people I've sat and held their hand until they died. It wasn't easy for me but I knew I was doing the right thing for them. |
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|  |  | But the bigger thing is in retrospect, when I was growing up, once I started making friends, we had a really large circle of friends and a very, very strong gay community at the time and I remember thinking in the late 70s, early 80s, I had such a wonderful group of friends that I thought this is gonna be wonderful, we're all gonna grow old together, we're all taking care of each other as we get older. And they're all gone. That whole family that you created is just gone. I've got like maybe, I don't know, four or five friends left from that time period and I cherish them but the larger community... It's just weird to realize that everybody that you loved is gone. I even lost my partner to AIDS, too. And honestly that's one of the reasons that I'm doing this today is if we don't tell our stories about what happened, who will? |
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| Hillel Wasserman |  | My name is Hillel Wasserman, I live in Los Angeles, California and at present time I work in the motion picture business. At the time that I first learned about HIV I was about, I guess, I was in my late 20s. We started to hear these whispers about this weird gay cancer that was going around which, you know, a lot of us discounted because come on, cancer isn't a communicable disease, how can you transfer cancer from one person to another? It must just be a way for the repressive society that we were living in to kind of quash the gay liberation, revolution, whatever we were doing. And so we easily discounted but it was getting harder and harder to overlook. Guys were getting together for funerals more often than we were getting together for brunch and people were showing up at the gym that looked like walking skeletons. |
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|  |  | It very much became a reality for me when I woke up one morning and I saw four purple spots on my legs. I jumped in my car and I ran to my doctor and I marched into his office and I pulled down my pants with my legs shaking and I pointed at them and I said, 'Look,' I said, 'I've got the spots, they're KS. I'm gonna die right?' He took a long breath and he said to me finally, 'Hillel,' he said, 'What you have on your legs are bruises!' But it had really kind of gotten to be enough for me because every time I had a cold that lasts an extra week, I'm running to the doctor, every time I got out of the shower and did a quick check on me and saw something new growing on me, I'm running to the doctor. And every time we had the exact same conversation. |
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|  |  | And so he said to me, 'Hillel,' he said, 'I'm happy to give you the AIDS test but you have to be prepared for results you may not like.' And I said, 'You know what?' I said, 'I'm a UCLA graduate, I am good at taking tests. Give me the AIDS test.' And so there I was, sitting in my beautiful office when I get a phone call from the doctor after the seven days to tell me that the test results came back and they were positive. Then he started to talk to me about statistics, about the odds, right, about getting my affairs in order which is doctor code for 'get ready to die'. And as I sat there and listened to that, all I could think of was oh my god, how am I ever going to tell my parents? And that was it, I mean I controlled that information very, very tightly until I couldn't anymore. |
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|  |  | In 1995, eight years after taking that test, finally, finally the rain started to fall. I developed HIV-related Non-Hodgkin's lymphoma which is lymphatic cancer. And there I was, I wasn't quite 40 years old, I was 39, I'd never been in love, I'd never been to Israel, I'd never done so many of the things that I'd hoped and wished I'd do and... And yet, well, you march. You know? That was 23 almost years ago and still here. How does he do it? You know. What is the magic formula, the secret weapon that I posses? Well, it's drugs. (laughs) Not the kind that we took back in the day, oh no, no, no. No these are HIV drugs. So when I ask myself or people ask me how HIV has affected my everyday life, I mean seriously, how can it not? At one point I was taking medicine six times in a day. Seriously, who takes that much medicine normally? No one does! Sick people take medicine! But as I've grown fond of saying, I may have HIV but it doesn't have me. |
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| Brryan Jackson |  | My name is Brryan Jackson and I'm from St. Louis, Missouri. I am a motivational speaker and life coach. What else is there to say about me? I'm cool and I think one of the most important things because we're talking about this on the podcast is I'm HIV positive. My story is a little bit different about how people contract HIV. When I was 11 months old, my father who is a phlebotomist at a hospital decided to steal HIV-tainted blood and come over to the hospital that I was staying at, I was admitted for my asthma attack. And he got my mother out of the room and then he started injecting me with the HIV virus hoping I would die off and he wouldn't have to pay child support. So not only was it HIV but it was also incompatible blood and so my vital signs started going out of whack, I was screaming and crying, no one could figure out what was going on with me. They transferred me to another hospital 24 hours later, I was stabilized and everything was okay. |
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|  |  | Then in 1996 I went from being this playful, happy, energetic 5-year-old to this bloated, feverish, sick kid. In matter of months my body began to break down and doctors started testing me for numerous diseases, even rare ones that only exist in other countries. In conclusion they came to say, 'You know, I know he's not at risk for HIV but let's test him for HIV.' The results came back and I was diagnosed with full-blown AIDS, given five months to live. My T cell count was at 0, they put me on 23 oral medications, 3 IV antibiotics, and 3 injections daily. The majority of those were not available for children at the time. But three months passed, five months passed, and as I stand before you today, wasn't supposed to see my 6th birthday but come next month I will be celebrating my 27th birthday. |
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|  |  | Well a lot of people in my family were very receptive towards it, they wanted to get educated and they wanted to be a part of my life but on the social atmosphere, I was left out of birthday parties, social events, my older sister who had a different father, her father decided to take out of her life because he didn't want to be associated with the HIV family, she was even left out of birthday parties and social events. I lost a lot of friends, I couldn't play sports and stuff growing up even though I'm a very athletic person. I did find my calling in cheerleading though and I am a state champion. |
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|  |  | Even after I came clean with my story and said, 'Hey, I don't care about what you guys think, like this is who I am, HIV doesn't define me.' And I started showing people that I was lobbying in Washington, D.C. some of the ignorance went away but still the ignorance is still consistent. But it's 2018, you know we have great medications that can help people live long and healthy lives and be undetectable. Most people can have a 0% chance of passing on the virus but a lot of people, that stigma is still alive and real to where people don't wanna go and get tested or when people contract the virus they automatically think, 'I'm screwed. I'm going to die.' And that's not the truth. Like people who are living with HIV can lead successful lives and people who hang out with HIV positive people who are probably always gonna remain HIV negative. |
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| TPWKY |  | (This Podcast Will Kill You intro theme) |
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| Erin Allmann Updyke |  | (sighs) |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Wow. |
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| Erin Welsh |  | Wow. Those stories were so incredibly touching. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Thank you again to Frank, to Hillel, and to Brryan for sitting down with us to tell us those stories. |
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| Erin Allmann Updyke |  | Yeah. And for being willing to share your stories with our listeners. |
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| Erin Welsh |  | And next week, listeners, we are going to be releasing a bonus episode in which Frank, Hillel, and Brryan will be telling more of their stories in detail and we want you guys to tune into that because it's going to be absolutely incredible, so please keep an ear out for that. |
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| Erin Allmann Updyke |  | Yeah. All right. |
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| Erin Welsh |  | This week we don't have a quarantini for you. |
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| Erin Allmann Updyke |  | No. (laughs) |
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| Erin Welsh |  | Nope. But what we will advise you to do, which is what we're doing, is just make yourself a drink, whatever you have. |
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| Erin Allmann Updyke |  | Make yourself a drink. Yeah. |
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| Erin Welsh |  | And sit back and get ready to learn. |
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| Erin Allmann Updyke |  | Yeah I was thinking about it before we started recording this and you know how, if you listen to This American Life, sometimes it's like you're laughing and it's a funny one and sometimes you're like, 'Wow, gosh, that was really interesting, I learned a lot,' and then sometimes you just cry? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Like the whole episode you're just bawling? |
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| Erin Welsh |  | Ours is that one. |
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| Erin Allmann Updyke |  | Welcome to This Podcast Will Kill You: This American Life edition. (laughs) |
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| Erin Welsh |  | The crying episode. |
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| Erin Allmann Updyke |  | Not really but kind of. |
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| Erin Welsh |  | Well it's a very serious topic, not that all the ones we've discussed haven't been serious topics but because this is so recent, it really dows hit a nerve and there are a lot of very serious issues that we're gonna discuss in it. So. |
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| Erin Allmann Updyke |  | All right. Business is out of the way. |
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| Erin Welsh |  | All right. Biology time. |
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| Erin Allmann Updyke |  | All right. |
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| TPWKY |  | (transition theme) |
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| Erin Allmann Updyke |  | So it's 1980, October, Los Angeles. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | You're a physician. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | A 33 year old man comes to your hospital complaining of a fever for about two months. His liver enzymes are elevated which is not good and his white blood cell count is pretty low. |
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| Erin Welsh |  | And a fever for two months. |
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| Erin Allmann Updyke |  | Two months! It's a pretty long time. He's also infected, as it turns out, with cytomegalovirus which is a pretty common virus that generally doesn't cause any problems unless a person is immunocompromised. You run a whole bunch of tests and you diagnose him with pneumonia caused by a fungus called Pneumocystis carinii. |
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| Erin Welsh |  | Weird. |
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| Erin Allmann Updyke |  | It's really not common, especially not in otherwise healthy young people. You also diagnose him with oral candidiasis which is another fungal infection, this time of the mouth instead of the lungs. Unfortunately his condition deteriorates despite attempts to treat with antifungals and the patient dies in May of 1981. Cut back to April, 1981. Another patient presents to your hospital in LA with strikingly similar symptoms, then you find out that in January and February or 1981 at another hospital, two other men presented with the same cluster of symptoms and in April at yet another hospital, the same. So that's a total of five otherwise healthy young men, aged 29-36, who are diagnosed with fungal pneumonia and fungal infections of the mouth as well. |
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| Erin Welsh |  | A cluster. |
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| Erin Allmann Updyke |  | A cluster. This is not normal. |
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| Erin Welsh |  | No. |
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| Erin Allmann Updyke |  | But in 1982, the CDC had received reports of a cluster of 19 cases of PCP, that's Pneumocystis carinii pneumonia, not the drug. (laughs) |
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| Erin Welsh |  | Not the drug, mm-hmm. |
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| Erin Allmann Updyke |  | And something else called Kaposi sarcoma which is a viral-induced cancer. Kaposi sarcoma leaves these characteristic purple lesions on your skin and before this time, pretty much only ever affected much older men or severely immunocompromised people and generally was a very slow, progressive disease. |
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| Erin Welsh |  | And it wasn't even known at that time that it was caused by a virus. |
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| Erin Allmann Updyke |  | Right, yeah. Of these 19 patients, 11 of them died. |
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| Erin Welsh |  | Whoa. |
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| Erin Allmann Updyke |  | At first these case reports were almost exclusively popping up in gay men, however they quickly started seeing similar cases in patients with hemophilia, in intravenous drug users, in infants. And so something was clearly happening and at the time physicians and public health professionals had no idea what it was, but we do now. What was happening is that each of these men and women and children were suffering from what we now know of as AIDS, acquired immunodeficiency syndrome, which we now know means they were infected with HIV, human immunodeficiency virus. |
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| Erin Welsh |  | Yep. That's how it begins in the U.S. |
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| Erin Allmann Updyke |  | So. This is how it begins. So what is HIV? HIV is a retrovirus, the first actual retrovirus that we're gonna talk about on this show. So we're gonna do a quick Virology 101 course. Okay? |
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| Erin Welsh |  | All right, come on, it's been several years. Let's do it. |
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| Erin Allmann Updyke |  | Great, all right. It's time then, you need a refresher. (laughs) |
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| Erin Welsh |  | Yeah I need a refresher for sure. (laughs) |
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| Erin Allmann Updyke |  | All right, so the other RNA viruses that we've talked about on this show like influenza and yellow fever, when they get into your cells, they basically hijack your cell's machinery and force your cells to start making protein. Normally, RNA codes for protein. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | So these RNA viruses basically tell your cells, 'Get busy making more of me!' And your cells are like, 'Oh okay, whatever, you're so smart and scary!' Okay? |
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| Erin Welsh |  | (laughs) |
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| Erin Allmann Updyke |  | But retroviruses do something a little bit different. Retroviruses which are also RNA viruses get into your cells and they bring along an enzyme of their own called reverse transcriptase. And that enzyme makes copies of their RNA but not just regular copies, it actually makes DNA copies. And so now this viral DNA is in your cells and can just swoop its way straight into your DNA. |
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| Erin Welsh |  | So it's a sneakier tactic. |
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| Erin Allmann Updyke |  | Exactly. And so it literally fits this viral DNA into your genome and that makes it a lot harder for your cells to target and it basically means that whenever your cells replicate, they'll replicate not only your DNA but this viral DNA as well. |
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| Erin Welsh |  | Which is like a background replication. |
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| Erin Allmann Updyke |  | Exactly, yes. And then eventually those copies of viral DNA will do what DNA normally does and that is make an RNA copy, make some protein, and then get to work making more viruses. And HIV is really good, once more viruses are made, at spreading from cell to cell. It has a bunch of crazy mechanisms that are too complicated for our Virology 101 course. |
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| Erin Welsh |  | Okay, great. |
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| Erin Allmann Updyke |  | So we'll just say that it basically has several different ways that it can perpetuate itself and selectively spread to more and more cells. So that's HIV 101. |
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| Erin Welsh |  | All right. |
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| Erin Allmann Updyke |  | Okay. So there are two main subtypes of HIV, HIV-1 and HIV-2. |
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| Erin Welsh |  | All right. |
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| Erin Allmann Updyke |  | HIV-1 is what the overwhelming majority of people are infected with and it's the more virulent strain. |
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| Erin Welsh |  | Okay, that's the pandemic strain. |
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| Erin Allmann Updyke |  | Exactly, right. HIV-2 is pretty much confined to West Africa. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | But within these two strains, there's considerable genetic variability. And if you remember all the way back to leprosy- |
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| Erin Welsh |  | I think I can remember that far back, yeah. |
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| Erin Allmann Updyke |  | Which was our slowest-producing pathogen. |
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| Erin Welsh |  | Yeah. 13 days? |
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| Erin Allmann Updyke |  | Exactly. Well HIV makes 100 billion copies of itself everyday. |
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| Erin Welsh |  | What? |
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| Erin Allmann Updyke |  | I know! |
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| Erin Welsh |  | Hold on. |
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| Erin Allmann Updyke |  | I feel like I should've double checked that number because it's really overwhelming. |
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| Erin Welsh |  | 100 billion. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | With a 'b'. |
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| Erin Allmann Updyke |  | Everyday. |
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| Erin Welsh |  | Everyday. |
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| Erin Allmann Updyke |  | Every dang day. And because it's an RNA virus and a retrovirus at that, it has a super high mutation rate so it's constantly replicating and it's constantly changing and so it's really hard for our immune system to target and it mutates a lot faster than our drug development can keep up with. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | Okay, so. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | How does this actually end up causing what we know of as AIDS? That's the real question. |
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| Erin Welsh |  | Yeah, tell me about it. |
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| Erin Allmann Updyke |  | So HIV is spread via extremely close contact with a few bodily fluids. Blood, semen, vaginal secretions, that sort of thing. So I'll just say it in case anyone listening doesn't know, which I assume all of our listeners do know, you can't get it by kissing, touching, high-fiving, shaking hands, hugging, none of that. It's really extremely intimate contact, sex, sharing of needles, blood products, things like that. |
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| Erin Welsh |  | Mm-hmm. |
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| Erin Allmann Updyke |  | So when HIV enters your body, it's not just infecting any random cells. It infects several different immune cells. You've probably heard of CD4 counts in relation to HIV. |
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| Erin Welsh |  | Yes. |
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| Erin Allmann Updyke |  | Well, CD4 cells are a type of T cell which is a lymphocyte or a white blood cell. CD4 T cells are also called helper T cells, so their job in your body normally is to help activate other white blood cells to promote an immune response. They also make something called cytokines which we've talked a bit before about on this show. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | But basically those are proteins that help in your immune response. So CD4 T cells are basically helper cells that are activating your immune response. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | And one thing that they do that's really important is activate another type of cell called your B cells which are the cells that make antibodies. |
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| Erin Welsh |  | So it seems like a lot hinges on CD4 numbers. |
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| Erin Allmann Updyke |  | Exactly. So when people talk about their CD4 cell counts, they're literally talking about how many CD4 T cells they have left in their body that haven't been destroyed. But the mechanism of CD4 T cell destruction in HIV is actually unclear at this point, even to this day. |
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| Erin Welsh |  | Really? |
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| Erin Allmann Updyke |  | Yeah. I think that's so fascinating. So I would've assumed that like malaria, for example, when malaria parasites replicate in your red blood cells, they burst out and destroy your red blood cells in the process. Well that's not what happens in HIV. When HIV replicates in your CD4 T cells, it actually buds out. I tried really hard to think of an analogy for that but I couldn't come up with one. |
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| Erin Welsh |  | Wait, let me think of one for a second cause I know that there's one. |
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| Erin Allmann Updyke |  | The best I came up with was it's like if you're making meatballs and the whole bowl of meat is your CD4 cell and you take one meatball out at a time, like that's your HIV? (laughs) |
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| Erin Welsh |  | Okay, okay. |
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| Erin Allmann Updyke |  | It's not great, I feel like we could do better. |
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| Erin Welsh |  | No I definitely, I feel like... Maybe it's just that I've seen a YouTube video with this animation. |
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| Erin Allmann Updyke |  | With them budding off, right? |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | With like little viral particles budding off, they take a piece of that plasma membrane with them, so that's again making them harder to see in your body because they're covered in your own lymphocyte tissue. |
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| Erin Welsh |  | Right, so they hide out. |
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| Erin Allmann Updyke |  | Exactly, yeah. But at the end of the day what happens is you have depletion of these T cells, your body's no longer making cytokines or other proteins, you can't make antibodies as effectively because you're not activating B cells. So usually what happens when you get infected with HIV is this replication happens really quickly. Within 10 days the patient usually has really high viremia, so tons of viruses in their bloodstream. And at first this is gonna activate a massive immune response. So- |
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| Erin Welsh |  | And just to clarify, this is a person who has been infected HIV, we're not talking about AIDS quite yet. |
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| Erin Allmann Updyke |  | Right, we'll get to exactly what happens with AIDS, exactly. So when you get infected with HIV at first, HIV is gonna replicate in your body, you'll have a massive immune response and a large proportion of those virally-infection cells will be actually destroyed, which is great. So during this time you'll have a primary HIV infection. You might have a fever, you might feel like you have the flu, but mostly this is a transient illness, you might not even have any symptoms at all. Your body is doing what your body is supposed to do when you get an infection and it fights it off. So usually by about 28 days after exposure to HIV, your body has controlled or suppressed the initial infection and viremia is reduced drastically. The problem is it doesn't eliminate it. This virus, like we've said, is really hard for your body to detect and so you end up with the latent stage of HIV. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | So it's hanging out, it's quietly, slowly replicating and eventually, albeit slowly, it will deplete your CD4 T cells making it impossible for your immune system to fight off opportunistic infection. This can take anywhere from 3-20 years. |
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| Erin Welsh |  | Wow. |
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| Erin Allmann Updyke |  | But on average about 50% of people who are infected with HIV and are untreated will progress to AIDS within 10 years. |
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| Erin Welsh |  | 10 years. |
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| Erin Allmann Updyke |  | Yeah. So the incubation period for HIV itself, the virus, is only about 7-10 days but the incubation period for AIDS is about 10 years. And one thing that's really important is that the infectivity of HIV really depends on your viremia. So you're far, far more infectious at that early stage, say within the first month of infection, because your viral load is insanely high. Whereas after that for a number of years you're actually not very infectious. And then again when you reach the AIDS stage, your viremia increases again and you become extremely infectious. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | So there are four recognized stages of an HIV infection, all of which are classified by measuring your CD4 T cell count and then also looking for specific symptoms or opportunistic infections associated with AIDS. And that is the ultimate stage of HIV infection. So that's what those doctors were seeing all the way back in the 80s and at the time they had no idea about everything that had been happening in that patient's body for years prior to their presentation with AIDS. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | So. Tell me how all of this happened, Erin. |
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| Erin Welsh |  | Oh, okay, yeah. |
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| Erin Allmann Updyke |  | So how did we end up with this global pandemic? |
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| TPWKY |  | (transition theme) |
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| Erin Welsh |  | I'm gonna try to answer that. The history of HIV and AIDS is a big one and I'm dividing the history of this modern plague into four acts à la This American Life. |
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| Erin Allmann Updyke |  | Right? I said so. (laughs) |
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| Erin Welsh |  | From its earliest beginnings in Central Africa to its eruption in the U.S. in the 80s and 90s, then to the failures of the government, and then the heroic actions of advocacy groups and finally to the development of effective treatments and the emotional fallout of the pandemic. Let's start. |
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| Erin Welsh |  | Act I: Origin. 1908-1982. Let's take a trip in space and time back to Central Africa in the early 1900s, to a lush rainforest filled with the sounds of exotic birds and a chorus of insects. In this rainforest stood a hunter. He was there to check on the snares he had so carefully laid a few days earlier, and look, in one of the snares was a chimpanzee. The hunter quickly and efficiently killed the chimp, but in the process of butchering the chimp, the hunter sliced his own hand and some of the chimp's blood flowed into the fresh wound. Unbeknownst to the hunter, the blood from the chimp, the blood that had just entered the cut on his hand, contained the virus that would later become the human immunodeficiency virus, HIV. |
|  |  |  |
|  |  | The hunter hauled his kill back home and continued his day to day life. Over the next few years the virus continued to integrate itself into the hunter's DNA and more viral particles were produced. But it wasn't for years that he felt any effects of the virus and by the time he did, he had transmitted the virus to at least one other person. This bloody encounter between the hunter and the chimpanzee he killed is the true ground zero of the AIDS pandemic. We have no way of knowing exactly who this hunter was or exactly when or where it happened but we have a pretty good guess, which is around 1908 in Central Africa. |
|  |  |  |
| Erin Allmann Updyke |  | I think that that's a lot earlier than most people think. |
|  |  |  |
| Erin Welsh |  | Definitely. |
|  |  |  |
| Erin Allmann Updyke |  | So I think that that's an important thing. Like 1908, that's a really long time ago. |
|  |  |  |
| Erin Welsh |  | Yeah. Highlight that, double underline it. |
|  |  |  |
| Erin Allmann Updyke |  | Double underline. And it was from most likely a hunter hunting bushmeat who caught a chimpanzee. |
|  |  |  |
| Erin Welsh |  | Yes. |
|  |  |  |
| Erin Allmann Updyke |  | Not anything else you might have in mind. |
|  |  |  |
| Erin Welsh |  | Right. |
|  |  |  |
| Erin Allmann Updyke |  | Not you, but like the royal 'you'. |
|  |  |  |
| Erin Welsh |  | Yeah. The virus moved beyond this hunter, eventually making its way to a city where it continued to be transmitted through sexual contact, through reuse of dirty needles, or some other route. And that's when it became HIV-1, the pandemic strain of the virus. And slowly, with one person infecting one or two others and those people infecting one or two more in turn, the virus's distribution grew until it had spread across the globe. Later testing of stored blood samples helped to flesh out a timeline for the spread of HIV. |
|  |  |  |
| Erin Allmann Updyke |  | Ooh. |
|  |  |  |
| Erin Welsh |  | I'm gonna give you a brief rundown of this timeline to bring us up to speed to the early days of the AIDS pandemic in the U.S. |
|  |  |  |
| Erin Allmann Updyke |  | Awesome. Great. |
|  |  |  |
| Erin Welsh |  | Okay. Scientists guess that HIV was circulating in Kinshasa which is the capital of the DRC, Democratic Republic of the Congo, by the early 1920s. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. Circulating. |
|  |  |  |
| Erin Welsh |  | Circulating. |
|  |  |  |
| Erin Allmann Updyke |  | In that big city. |
|  |  |  |
| Erin Welsh |  | In the population, yes. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | And the first molecular evidence of HIV infection comes from 1959 in a man from the DRC. The virus then probably arrives in Haiti which became later a big hotspot in 1966. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | And it probably arrived first in the U.S. in 1968 though it could've been almost 10 years earlier. |
|  |  |  |
| Erin Allmann Updyke |  | Wow! |
|  |  |  |
| Erin Welsh |  | So the first AIDS-related death in the U.S. was in 1969 and that was confirmed by later blood testing and for that to be the case, that person had to have been infected, who was a young man, had to be infected much earlier, years earlier. So it's kind of a shaky ground there but i would say 1968 is at the latest estimate of when the virus arrived in the U.S. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. In the U.S. populations. |
|  |  |  |
| Erin Welsh |  | Later testing of blood samples shows HIV infection in a Norwegian sailor and his family and a Danish physician in the mid to late 1970s. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | All of whom died of AIDS-related illnesses. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | By this time the virus had firmly established itself in major cities in the U.S., in particular those that would later be identified as the epicenters of the AIDS crisis: New York City, San Francisco, LA. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | In April 1980, San Francisco resident Ken Horne goes to his doctor complaining of dark purple spots on his skin which his doctor diagnoses as Kaposi sarcoma. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | And as we learned earlier, a super rare cancer and he's not of the right demographic or the typical demographic. |
|  |  |  |
| Erin Allmann Updyke |  | No. Not at all. It's like men over the age of 66. |
|  |  |  |
| Erin Welsh |  | Yeah and of Mediterranean or Ashkenazi background. |
|  |  |  |
| Erin Allmann Updyke |  | Oh I didn't know that part that's interesting. |
|  |  |  |
| Erin Welsh |  | And his doctor doesn't know what to make of the diagnosis or of the unusual blood test results which show almost no functional immune system. Something was making Ken Horne very sick but he didn't know what. So yeah, as we heard earlier there were a bunch of these other cases and doctors were baffled. Why were these men in otherwise good health struggling to beat these normally harmless infections and losing? It would be many years and thousands more cases before there would be an answer. By the end of 1980, 55 men had been diagnosed with some infection later recognized as characteristic of AIDS. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Doctors were beginning to notice a pattern, something was destroying gay men's immune systems, leaving them open to opportunistic infection. Early 1981, the CDC is alerted to the pandemic for the first time by Sandra Ford, a lab tech at the CDC who works to fill prescriptions and notices an unusual increase for a drug used to treat a rare pneumonia. |
|  |  |  |
| Erin Allmann Updyke |  | I found our Friends of STEM crossover. |
|  |  |  |
| Erin Welsh |  | There we go, Sandy Ford. |
|  |  |  |
| Erin Allmann Updyke |  | Sandy Ford! |
|  |  |  |
| Erin Welsh |  | By May, rumors of a mysterious disease attacking and killing gay men are rampant throughout parts of the country. The first article in the world - in the world - about the disease is published on May 18th in The New York Native, which is a gay newspaper, titled 'Disease Rumors Largely Unfounded'. Turns out they were founded, but... |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Yeah. So anyway, shortly after that the morbidity and mortality weekly report describing that cluster of five cases that Erin talked about in the biology section appears. |
|  |  |  |
| Erin Allmann Updyke |  | Right, yeah. |
|  |  |  |
| Erin Welsh |  | And a task force is formed at the CDC. Their immediate goal is to identify what is causing this epidemic. So far this disease has seemed to primarily hit gay males in cities with large gay communities. The scientists think, 'Okay, we're dealing with a common exposure or an infectious agent.' |
|  |  |  |
| Erin Allmann Updyke |  | Yes. |
|  |  |  |
| Erin Welsh |  | Poppers, or nitrile inhalants, was a contender in the noninfectious origin camp while a sexually transmitted virus new to humans was proposed by epidemiologist and task force member Don Francis as the cause. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Criminally understaffed and suffering from sweeping budget cuts, the CDC task force set about trying to isolate a common thread that would reveal the origin of this epidemic. For those physicians and epidemiologists who were seeing the suffering and devastation caused by AIDS firsthand, there was no time for a leisurely comprehensive case control study. The house was already on fire. But to so many others, AIDS was an opportunity to get an article published in Science, to patent a test for the disease, or a shot at a Nobel Prize. The CDC task force set out to conduct some shoe-leather epidemiology, which if you remember from the cholera episode includes interviews with people suffering from the disease and physicians who had treated them. |
|  |  |  |
| Erin Allmann Updyke |  | Mm-hmm. And all of their friends and family and close contacts. |
|  |  |  |
| Erin Welsh |  | Mm-hmm, exactly. |
|  |  |  |
| Erin Allmann Updyke |  | Especially if you think that it might be something that's transmitted sexually. |
|  |  |  |
| Erin Welsh |  | Right. |
|  |  |  |
| Erin Allmann Updyke |  | Then that's really important to trace contacts. |
|  |  |  |
| Erin Welsh |  | Exactly. And two things emerged from these early interviews. One is that heterosexual intravenous drug users were also becoming sick with the disease. The other is that several of the gay men who were among the earliest recognized cases seemed to be linked to one another by their sexual history. Both of these things pointed to an infectious disease transmitted by blood or bodily fluids, not an environmental exposure. I wasn't going to talk much about the infamous patient zero but I feel like I need to just to clear up a few things. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | First of all, did you know that the term 'patient zero' comes from the AIDS crisis in the U.S.? |
|  |  |  |
| Erin Allmann Updyke |  | No! I didn't know that at all! |
|  |  |  |
| Erin Welsh |  | Yeah. If you've read anything about the early days of the AIDS epidemic, it's likely that you've stumbled upon the name Gaëtan Dugas or at least his description: a handsome, charming, gay flight attendant from Montreal, a frequenter of gay bath houses in the cities he visited. And in popular history, responsible for the AIDS epidemic in the U.S. In the early days of the CDC task force, epidemiologists took note of interviewees' social network, friends, sexual contacts, etc. Gaëtan had registered on the CDC's radar because he popped up on a few of the networks they had mapped and because he had been interviewed and provided a sizeable list of past contacts himself. His circle on the network map of sexual contacts was labeled 'Patient O' as in the letter 'O' for 'Outside of California' as someone who did not live in the study site. |
|  |  |  |
| Erin Allmann Updyke |  | Huh. |
|  |  |  |
| Erin Welsh |  | This was later misread and the term 'patient zero' became popularized in And The Band Played On, which was the incredible journalistic work by Randy Shilts published in 1987. |
|  |  |  |
| Erin Allmann Updyke |  | Dude! |
|  |  |  |
| Erin Welsh |  | Yup. |
|  |  |  |
| Erin Allmann Updyke |  | That is so interesting. |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | So they just meant this is a patient that is outside of California that is interacting with these patient circles and now we use the term 'patient zero' all the time. |
|  |  |  |
| Erin Welsh |  | He was absolutely... Well yeah, so not only that in terms of the origin of the phrase 'patient zero' but he was demonized in this book. |
|  |  |  |
| Erin Allmann Updyke |  | Oh, yeah. |
|  |  |  |
| Erin Welsh |  | I mean he was basically portrayed as a sociopath. |
|  |  |  |
| Erin Allmann Updyke |  | Like he was doing it on purpose or something? |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Oh god. |
|  |  |  |
| Erin Welsh |  | Oh, absolutely. I don't know anything about the validity of any of the claims that he went against public health advice or whatever but regardless of that, later genetic analyses would exonerate him as the U.S. patient zero. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | The virus had been in the U.S., as we've learned, in New York and California long before Gaëtan was sexually active. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Unfortunately he would never know that the blame heaped on him was unfairly done, he died of AIDS in 1984. |
|  |  |  |
| Erin Allmann Updyke |  | Oh no. Oh, poor baby. |
|  |  |  |
| Erin Welsh |  | I just wanted to clear that up. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Okay. |
|  |  |  |
| Erin Allmann Updyke |  | That's also a really interesting way that we have a term now. |
|  |  |  |
| Erin Welsh |  | Right. |
|  |  |  |
| Erin Allmann Updyke |  | Patient zero. |
|  |  |  |
| Erin Welsh |  | On a misreading. |
|  |  |  |
| Erin Allmann Updyke |  | On a misreading and then a further victimization. Wow. That is so interesting. |
|  |  |  |
| Erin Welsh |  | Yeah. I really wanted to include that. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah! |
|  |  |  |
| Erin Welsh |  | Okay, moving back to the timeline here. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, let's. |
|  |  |  |
| Erin Welsh |  | It was clear to many of those studying it that this was an infectious agent transmitted by the exchange of bodily fluids. But where were the front page headlines? Where was the funding requested by the CDC task force months earlier? Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Who was the president at this time? |
|  |  |  |
| Erin Welsh |  | Reagan. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | Mm-hmm. |
|  |  |  |
| Erin Allmann Updyke |  | (laughs) Just want to- |
|  |  |  |
| Erin Welsh |  | Oh no, we'll get there. We'll get there. |
|  |  |  |
| Erin Allmann Updyke |  | Just wanted to remind myself. |
|  |  |  |
| Erin Welsh |  | Yeah. By the end of 1981, 121 people in the U.S. had died from the disease with hundreds more infected, likely thousands. And yet among public health officials, among politicians, among those whose very job it is to protect the health and wellbeing of the people they served, all there was was deadly silence. Compare this silence and lack of funding to the outbreak of Legionnaires' disease in 1976, which killed 29 and infected 182 people, mostly straight male veterans. |
|  |  |  |
| Erin Allmann Updyke |  | I was just gonna say you have to say who it killed: old white men. |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Straight, white, old men. (laughs) |
|  |  |  |
| Erin Welsh |  | The funding records show that the life of a gay man with AIDS was worth 1/10 of the life of a straight Legionnaire to those making funding decisions. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Because Legionnaires was not a marginalized group, not a group that was repeatedly told they were sick. Homosexuality as a diagnosis, as a pathological diagnosis was not removed from the Diagnostic and Statistical Manual used by the American Psychological Association until 1973. |
|  |  |  |
| Erin Allmann Updyke |  | I'm gonna throw up. |
|  |  |  |
| Erin Welsh |  | At which point it was replaced by quote, "sexual orientation disturbance". |
|  |  |  |
| Erin Allmann Updyke |  | Well they just removed transgender very recently from the DSM-5 or 4 or something? |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah it's disgusting. |
|  |  |  |
| Erin Welsh |  | (sighs) Yeah. I mean so this means that if you were not heterosexual, you could be diagnosed by a medical professional as being sick. |
|  |  |  |
| Erin Allmann Updyke |  | Right. |
|  |  |  |
| Erin Welsh |  | This and the general discrimination by so many others led to the complete failure to provide adequate funding and resources quickly enough to slow down this building epidemic. In the early years of the AIDS crisis, the disease was referred to as alternatively gay cancer, gay pneumonia, or GRID for gay-related immune deficiency. This labeling of AIDS as unique to gay men had profound consequences. First, as Susan Sontag points out in her essay 'AIDS and its metaphors', people seek meaning in disease and want to find out 'why me'? |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god, I know. |
|  |  |  |
| Erin Welsh |  | This labeling allowed people to answer, 'Because you're gay.' |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | Or, 'Because I'm gay.' |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | Which perpetuated feelings of shame and guilt. |
|  |  |  |
| Erin Allmann Updyke |  | And also is just factually untrue. |
|  |  |  |
| Erin Welsh |  | Completely untrue. |
|  |  |  |
| Erin Allmann Updyke |  | So that sucks for people who are infected who are not gay or, you know... |
|  |  |  |
| Erin Welsh |  | I mean this is a form of victim-blaming that we're still not past today. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | It also allowed homophobic, bigoted people to look at this as justified, as divine punishment for what they viewed as immoral behavior. Many of these bigots, by the way, were politicians who would later actively lobby against funding for AIDS research. Jesse Helms, I'm looking at you, you piece of human garbage. I have chills. |
|  |  |  |
| Erin Allmann Updyke |  | You're rage chilling, you're rage inhaling right now. (laughs) |
|  |  |  |
| Erin Welsh |  | (laughs) Yeah, I am. Welcome to the past three weeks of my life. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Finally these labels made silence acceptable. After all, this was a disease hitting only a small group of people, it would probably burn itself out quickly. What's the point of throwing money away? That's not what I believe, that's what the politicians believed, allow me to clear that up. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Yeah. Some however refused to be silent. In January of 1982, Larry Kramer, who was the author of the play 'The Normal Heart' which was just a few years ago turned into an HBO movie. |
|  |  |  |
| Erin Allmann Updyke |  | With that really beautiful man. |
|  |  |  |
| Erin Welsh |  | Fantastic, you need to see it, it's... Oh my god. I cried a lot. So Larry Kramer along with Paul Popham formed the Gay Men's Health Crisis in New York City, GMHC, to raise money for AIDS awareness and research. The GMHC stepped in where no other public health organization had even attempted. This group of men, mostly gay, set up a crisis counseling hotline, raised awareness, recruited social workers, and provided legal aid and other forms of assistance to gay men and their friends and family. |
|  |  |  |
| Erin Allmann Updyke |  | Remind me what year this is. |
|  |  |  |
| Erin Welsh |  | 1982 |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | Cause we're in early years still. |
|  |  |  |
| Erin Allmann Updyke |  | Early years, yeah. No one knows what's causing AIDS. |
|  |  |  |
| Erin Welsh |  | Not at all. Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | Later their mission would extend to anyone affected by AIDS. The GMHC would continue to play a big role in HIV and AIDS advocacy throughout present day and their early, organized approach to raising awareness and providing support set and example that many other organizations would later follow. In its first year, several internal debates raged at GMHC, one of them over whether or not to tell gay men to change their sexual behavior which mirrored a debate among public health officials over the closing of gay bath houses. It was becoming clear that this disease, whatever it was, was sexually transmitted. Telling gay men to stop having sex or at least stop having unprotected sex, even if that message was delivered by another gay man, hearkened back to a pre-Stonewall time when gay people were even more shunned than they were in the 80s. It was viewed by many as finger wagging, moralistic B.S. that served to only shame people and stall gay liberation which had gained so much momentum since the 60s. |
|  |  |  |
|  |  | Larry Kramer was on the losing side of this argument. He wanted to tell people to stop having sex and this disagreement along with others would lead to his departure from the group. The discussion at the public health level was the forced closure of bath houses which was supported by some epidemiologists on the CDC task force but was obviously illegal. Plus the owners of the bathhouses didn't wanna lose profit and have their institutions labeled as centers of disease. Whether or not bath house closure or telling gay men to stop having unprotected sex was well intentioned, these suggestions were placing the burden of disease prevention not on the medical research community but on the people who may become infected or already are infected. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | And that's just not the way to do things. |
|  |  |  |
| Erin Allmann Updyke |  | No that's not the way we do public health. Or not the way we should do public health, rather. |
|  |  |  |
| Erin Welsh |  | Right. Shortly after the creation of the GMHC, AIDS gets its first mention in the Wall Street Journal February 1982. Buried deep beyond the first page was the headline, quote, "New Often Fatal Illness in Homosexuals Turns Up in Women, Heterosexual Males". If you read between the lines, that headline reads, 'You know, we've known about this disease killing gay people for a while, but now that it's also killing straight people, we care enough to tell you about it.' |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | And this exemplifies how mainstream news outlets framed HIV and AIDS well into the 90s and 2000s. 1982 saw no slowing of AIDS diagnoses, instead epidemiologists and doctors were using the word 'exponential' to describe its growth. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. I was looking at a lot of numbers and well through the 90s it was terrifying, just how much not only diagnoses but deaths were increasing. |
|  |  |  |
| Erin Welsh |  | Yes. Oh absolutely. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Whatever was causing this disease, it had been spreading silently for years and the worst was clearly yet to come. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | By the end of 1982, the disease's name had been officially changed from GRID to AIDS, though GRID would continue to be used well into the 90s. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Yeah. And the estimated number of people with AIDS in the U.S. was around 900. The last year, that number would be in the triple digits. |
|  |  |  |
| Erin Allmann Updyke |  | In 1982. |
|  |  |  |
| Erin Welsh |  | 1982 |
|  |  |  |
| Erin Allmann Updyke |  | Wow. And already in 1982 it was 900. |
|  |  |  |
| Erin Welsh |  | Already. I know we're at the beginning of the history here, I'm sorry. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my gosh! |
|  |  |  |
| Erin Welsh |  | It's a long one and it's- |
|  |  |  |
| Erin Allmann Updyke |  | Buckle up for three more hours. (laughs) |
|  |  |  |
| Erin Welsh |  | It is so important, I wanted to tell all parts of it. |
|  |  |  |
| Erin Allmann Updyke |  | Good. |
|  |  |  |
| Erin Welsh |  | Act II: Explosion. 1983-1987. 1983 would later be viewed as a turning point of AIDS research and AIDS awareness but don't expect any great advancements or justice yet. The before is just that AIDS wasn't recognized as a problem by the general public while the after was that it was suddenly making the news and popping up on scientists' radar as the hottest new thing to research. |
|  |  |  |
| Erin Allmann Updyke |  | Oh god, don't we all know about that. You get funding for like a day and then your funding is taken away. |
|  |  |  |
| Erin Welsh |  | Uh huh. |
|  |  |  |
| Erin Allmann Updyke |  | That's what the next new thing is. |
|  |  |  |
| Erin Welsh |  | Yeah. By the time that the National Cancer Institute announced in April of 1983 that it was committed to finding the cause of the disease, 1295 Americans had contracted AIDS and 492 had died. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Add in the extremely long latent period of the virus, which was still undiscovered at this point, and the estimates of current and future infections ran into the tens and hundreds of thousands. Contributing to the recognition of AIDS as a public health problem were reports of people with AIDS who seemed to have gotten it from a blood transfusion, people who tended to not belong to marginalized groups. Suddenly to many Americans this became a 'it could happen to you' disease and a reason to care. |
|  |  |  |
| Erin Allmann Updyke |  | God. |
|  |  |  |
| Erin Welsh |  | Yeah, it's really- |
|  |  |  |
| Erin Allmann Updyke |  | Humans, man. |
|  |  |  |
| Erin Welsh |  | Horrible. The CDC had been wary of blood transfusion cases for several years and their fears were confirmed. Bringing their reports to the heads of the blood banks, the CDC was met with scorn and resistance. The chances of developing AIDS from infected blood banks was, according to one official, "less than one in a million". |
|  |  |  |
| Erin Allmann Updyke |  | Oh my gosh. It's over 90%. |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | So the infectivity of HIV from what we'll call maybe standard routes of transmission, sexual contact, intravenous drug use, or needle sticks, is extremely low, like well under 1%, usually per contact it's only about 0.3%. But with blood transfusions it's over 90%. Like I can't believe that people would be like, 'Don't worry about it, it's fine.' |
|  |  |  |
| Erin Welsh |  | Uh huh, uh huh. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Well I think that that one in a million was referring to the number of units that were infected with HIV or whatever they... Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Bags of blood they think? But that's a crazy- |
|  |  |  |
| Erin Welsh |  | Still, still. It was an incredible underestimate. |
|  |  |  |
| Erin Allmann Updyke |  | Because they had no idea what they were dealing with at that time so to just throw a number out there is so incredibly... What's the word? |
|  |  |  |
| Erin Welsh |  | Well let's find the motivation. Screening was too expensive. |
|  |  |  |
| Erin Allmann Updyke |  | Well and what were they gonna screen for? |
|  |  |  |
| Erin Welsh |  | Well actually there wasn't a test for the disease itself but there still was a test for hepatitis B, for screenings of hepatitis B and it was found I think that those who had AIDS or were diagnosed with AIDS, 88% of them also had hepatitis B. So it was one way to do it. |
|  |  |  |
| Erin Allmann Updyke |  | That makes sense. |
|  |  |  |
| Erin Welsh |  | Yeah it was a proxy. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. Interesting, okay. So still. |
|  |  |  |
| Erin Welsh |  | And so a very small minority did screen. |
|  |  |  |
| Erin Allmann Updyke |  | Okay. |
|  |  |  |
| Erin Welsh |  | But so many didn't. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | And so many just waited until the cost of being sued by infected transfusion recipients outweighed the cost of testing. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Money, money, money. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | And about that causative agent thing. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Let's get to that. |
|  |  |  |
| Erin Allmann Updyke |  | Let's talk about it. |
|  |  |  |
| Erin Welsh |  | It's 1983, where do we stand? |
|  |  |  |
| Erin Allmann Updyke |  | Where do we? |
|  |  |  |
| Erin Welsh |  | Well, let me fill you in. Are you ready for your daily dose of toxic masculinity? |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. (singing) We need it every episode. Can we have a toxic masculinity jingle? Toxic masculinity time! |
|  |  |  |
| Erin Welsh |  | (laughs) Love it. I hate it but actually yeah. Love your jingle, hate toxic masculinity. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Okay. Well here it comes in the form of old Bob Gallo, former researcher for the National Cancer Institute. Still alive, by the way. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. Gallo! |
|  |  |  |
| Erin Welsh |  | Maybe he'll listen. |
|  |  |  |
| Erin Allmann Updyke |  | You listening? |
|  |  |  |
| Erin Welsh |  | When Gallo first heard about AIDS and in particular the high rate of Kaposi sarcoma, he immediately thought retrovirus. He happened to be right and he would go to great lengths to show this. Although the vast majority of what I've talked about so far has taken place in the U.S. that does not mean that AIDS wasn't being diagnosed or researched across the world, because it was. And one of those places is France where a team of researchers had in May 1983 published their discovery of a virus they called LAV. Bob Gallo had read the article. Heck, Bob Gallo had reviewed the article. |
|  |  |  |
| Erin Allmann Updyke |  | (gasps) |
|  |  |  |
| Erin Welsh |  | (laughs) |
|  |  |  |
| Erin Allmann Updyke |  | Heck. |
|  |  |  |
| Erin Welsh |  | And now Gallo was paralyzed with fear that he would get no credit for the discovery. He made angry, threatening calls to Don Francis at the CDC pledging to withhold funds and refusing to send any specimens or antibodies because he feared that the CDC was collaborating with this French team behind his back. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | All this while people were dying and this narcissism slowed research considerably. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Rumors began circulating, probably started by Gallo himself, that the French specimens were contaminated and that the true virus could only come from Gallo's lab. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god, I hate this person. |
|  |  |  |
| Erin Welsh |  | Oh yeah. So even though there was a likely candidate for the virus that caused AIDS, testing or development of antivirals wouldn't start for another year when Gallo would announce that he had discovered the cause of AIDS, a virus he called HTLV-III. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. I hate people who just care about themselves and their own... How are you gonna research cancer and diseases and this and not care about human lives? |
|  |  |  |
| Erin Welsh |  | Well he's doing research for himself. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, clearly! |
|  |  |  |
| Erin Welsh |  | He's not doing research for the people that the research should be done for. |
|  |  |  |
| Erin Allmann Updyke |  | No, not at all! |
|  |  |  |
| Erin Welsh |  | Yeah. It's a messed up system and messed up people. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah dude. |
|  |  |  |
| Erin Welsh |  | So when Gallo finally got his discovery papers safely published, he included images of his virus which looked oddly enough exactly like the French LAV. But the real revelation and scandal wouldn't come until 1985. |
|  |  |  |
| Erin Allmann Updyke |  | What? |
|  |  |  |
| Erin Welsh |  | At a press conference came the announcement that tests had revealed that when comparing Gallo's HTLV-III and the French LAV, they were shown to be less than 1% different. |
|  |  |  |
| Erin Allmann Updyke |  | (gasps) He stole their samples? |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god! |
|  |  |  |
| Erin Welsh |  | Yeah. Basically Gallo had simple re-isolated the LAV, the French virus that the French team had sent him from previous samples over a year before. |
|  |  |  |
| Erin Allmann Updyke |  | Okay so not only is he a horrible person who cares only about himself but he's not even fast and good at science. |
|  |  |  |
| Erin Welsh |  | No. |
|  |  |  |
| Erin Allmann Updyke |  | Cause it takes him forever. Are you serious? |
|  |  |  |
| Erin Welsh |  | I'm 100% serious. |
|  |  |  |
| Erin Allmann Updyke |  | That's infuriating. |
|  |  |  |
| Erin Welsh |  | Whether this was an intentional theft by Gallo or just an accidental contamination remains unclear. |
|  |  |  |
| Erin Allmann Updyke |  | B.S. bro. Now way. No but. |
|  |  |  |
| Erin Welsh |  | I know, oh I know. I know deep in my heart of hearts. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, mm-hmm. |
|  |  |  |
| Erin Welsh |  | A 1991 federal inquiry did find Gallo guilty of misconduct during this research. |
|  |  |  |
| Erin Allmann Updyke |  | Misconduct, what does that get you? Absolutely nothing. Except a lot of hate on This Podcast Will Kill You. |
|  |  |  |
| Erin Welsh |  | (laughs) There is a little bit of justice, wait for it. The relationship between the French and U.S. research teams had soured and tensions continued to build with a legal dispute over a patent for an antibody test. |
|  |  |  |
| Erin Allmann Updyke |  | I hate these people. |
|  |  |  |
| Erin Welsh |  | I know. It got so bad that in 1985 the U.S. president, Reagan, and the French president, Jacques Chirac, had to settle this in person. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | The result? Gallo and the French researchers would share co-discoverer credit and the virus would be called HIV, which is how it got its name. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | This ugly chapter in AIDS research would cost Gallo the Nobel Prize in 2008 which was granted not to him but to the French discoverers of the viral cause of AIDS. |
|  |  |  |
| Erin Allmann Updyke |  | I don't want either of them to get it to be honest, they both annoyed me. |
|  |  |  |
| Erin Welsh |  | Yeah well whatever. And while all this posturing and shameless self-promotion was going on, people were dying by the thousands. Although the mid 1980s saw increased awareness of AIDS in news reports, this wasn't accompanied by increased compassion or treatment, quite the opposite. Violence toward gay men increased enormously and fear took hold. Hospitals refused to treat AIDS patients, morgues refused to handle the bodies of those who had succumbed to AIDS, schools refused to admit children who were HIV positive. And the availability of an antibody test, while hugely valuable for an individual who could now keep an eye out for their own wellbeing and also for public health officials to try to get an idea of the number of people that were HIV positive. But on the other side of things, this test brought with it the fear that huge screening campaigns would be forced upon the populations that had been hardest hit by AIDS. |
|  |  |  |
| Erin Allmann Updyke |  | Right and it's not like they're offering anything. Like okay, you know you're positive, no what? Nothing. |
|  |  |  |
| Erin Welsh |  | Now we can give you drugs for free to treat it? No, there was nothing. |
|  |  |  |
| Erin Allmann Updyke |  | No. Yeah. |
|  |  |  |
| Erin Welsh |  | Countries were closely their borders to those who tested HIV positive, including the U.S. |
|  |  |  |
| Erin Allmann Updyke |  | Really?! I didn't know that. Oh my god. |
|  |  |  |
| Erin Welsh |  | Oh yeah. So yeah, so there was a test, there was no treatment. |
|  |  |  |
| Erin Allmann Updyke |  | Right. |
|  |  |  |
| Erin Welsh |  | When in 1985 Rock Hudson announced to the world that he was suffering from AIDS, finally, infuriatingly finally, the world paid attention. |
|  |  |  |
| Erin Allmann Updyke |  | Who's Rock Hudson? |
|  |  |  |
| Erin Welsh |  | He's a movie star. |
|  |  |  |
| Erin Allmann Updyke |  | Oh. |
|  |  |  |
| Erin Welsh |  | Yeah so all of a sudden there were articles in The New York Times, in Newsweek, all of a sudden people cared. Rock Hudson was handsome, and all-American movie star, good friends with Ronald and Nancy Reagan. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Yeah, eye roll. And I do feel really bad of course that he died of AIDS, he eventually did die of AIDS in 1985, it just is such a shame that it took a famous person for people to care about it. |
|  |  |  |
| Erin Allmann Updyke |  | It took that. Mm-hmm. It so often does, I mean, still to this day. |
|  |  |  |
| Erin Welsh |  | I know, I know. And where was the president in all of this? What was he doing about the disease that was killing thousands of U.S. citizens? Reagan would first publicly say the word 'AIDS' in 1985. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | And that was only in response to a reporter's question. It would be another two years before Reagan would deliver his first speech on the AIDS epidemic. |
|  |  |  |
| Erin Allmann Updyke |  | Are you serious? |
|  |  |  |
| Erin Welsh |  | 1987 |
|  |  |  |
| Erin Allmann Updyke |  | 87? |
|  |  |  |
| Erin Welsh |  | He had been president for seven years at this point. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah, that's disgusting. The entirety of the AIDS epidemic to that point was during his presidency. |
|  |  |  |
| Erin Welsh |  | Yes. At the time of his speech, which did not mention gay men as one of the hardest hit groups, 36,058 Americans had been diagnosed with AIDS and 20,849 had died. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Those numbers don't include the global figures which by now were climbing into the hundreds of thousands. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| TPWKY |  | (transition theme) |
|  |  |  |
| Erin Welsh |  | Act III: Outrage. |
|  |  |  |
| Erin Allmann Updyke |  | I'm already feeling that so, my god. |
|  |  |  |
| Erin Welsh |  | 1987-1996. The year was 1987. The AIDS crisis in the U.S. was in its seventh year. Scientists had identified the virus that caused the disease and even developed a test to determine the infection status. But with 500,000 cases of AIDS worldwide and still no reliable, effective treatment, the diagnosis of AIDS was basically a death sentence. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Years of delays in starting research on the disease and providing adequate funding in isolating its cause had a cascading effect on the development, testing, and approval of treatment to manage or cure the disease. The timeline for a pharmaceutical drug to be approved by the FDA is on average 10 years. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah that's still true. |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Still true today. |
|  |  |  |
| Erin Welsh |  | Yeah, that's current numbers, yeah. |
|  |  |  |
| Erin Allmann Updyke |  | Oh yeah. |
|  |  |  |
| Erin Welsh |  | That's an incredibly long time for people who are dying within a year of diagnosis. The later this process started, the more people died without ever receiving treatment. It's not exaggerating to say that tens or hundreds of thousands of lives were lost due to the apathy with which the U.S. government responded to the AIDS crisis in its early years. And people saw this and they would not stand for it. In March 1987, Larry Kramer, remember him from GMHC? |
|  |  |  |
| Erin Allmann Updyke |  | I do. |
|  |  |  |
| Erin Welsh |  | Gay Men's Health Crisis? Helped to found ACT UP, an advocacy group focused on improving the lives of people with AIDS by direct actions aimed at changing policy, affecting the medical research pipeline, and helping to get treatment to those in need. ACT UP, by the way, stands for AIDS Coalition to Unleash Power. The actions of ACT UP are the subject of the 2012 documentary How To Survive a Plague and the 2016 book of the same name. If you haven't seen or read it, go do that immediately. If you have seen or read it, go do it again. |
|  |  |  |
| Erin Allmann Updyke |  | (laughs) We'll wait. |
|  |  |  |
| Erin Welsh |  | Yeah. You really should. By 1987, one drug had been approved to treat AIDS, AZT in the U.S. |
|  |  |  |
| Erin Allmann Updyke |  | Yep. |
|  |  |  |
| Erin Welsh |  | Developed initially as an anti-cancer drug- |
|  |  |  |
| Erin Allmann Updyke |  | I didn't know that. So that explains how they were able to get it on the market faster than they would have if it had already been developed. |
|  |  |  |
| Erin Welsh |  | Yep. Yeah. And so yeah it had gone through clinical trials in 1985 to treat AIDS and shown some promise although many patients experienced strong negative reactions like anemia. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah it was gnarly. |
|  |  |  |
| Erin Welsh |  | Uncontrollable, yeah. When FDA approval went through in March of 1987, the pharmaceutical company that held the single patent on the drug, Burroughs Wellcome, announced that it would charge $10,000 a year for the treatment. A price well out of reach for many people with AIDS. |
|  |  |  |
| Erin Allmann Updyke |  | Not just many, like literally everyone. |
|  |  |  |
| Erin Welsh |  | Uh huh. |
|  |  |  |
| Erin Allmann Updyke |  | That's absurd. |
|  |  |  |
| Erin Welsh |  | Yeah. |
|  |  |  |
| Erin Allmann Updyke |  | I hate money. |
|  |  |  |
| Erin Welsh |  | I hate people. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. I hate people and money. People and money together. Like if you took the money away from the people, then would be too much... Okay, continue. |
|  |  |  |
| Erin Welsh |  | (laughs) This announcement inspired one of the earliest actions of ACT UP, a demonstration on Wall Street to protest this criminally high cost of AZT. Though it would take a couple of years and many more demonstrations, ACT Up would finally get Burroughs Wellcome to reduce that price to $8000. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Yeah. But still, that's amazing to me. That this advocacy group actually made a change, made an impact on a pharmaceutical company. |
|  |  |  |
| Erin Allmann Updyke |  | I know but that's still just so infuriating that they can just charge whatever the hell they want. |
|  |  |  |
| Erin Welsh |  | I know. Well we've got glass half full, glass half empty. |
|  |  |  |
| Erin Allmann Updyke |  | There we go, we need both sides. |
|  |  |  |
| Erin Welsh |  | Yin and yang, that's why we do this together. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah it is. When one of us is up, the other one is all the way in the hole. (laughs) So true. |
|  |  |  |
| Erin Welsh |  | (laughs) But even when AZT was more easily accessible, many people with AIDS couldn't take it, as I mentioned. So what other drugs were being researched? What else was out there? |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Not very much, it turns out. |
|  |  |  |
| Erin Allmann Updyke |  | Oh no. Oh no. |
|  |  |  |
| Erin Welsh |  | So a lot of the U.S. research efforts seemed to be focused on honing AZT without developing new drugs. |
|  |  |  |
| Erin Allmann Updyke |  | Interesting. |
|  |  |  |
| Erin Welsh |  | Well it was money-making, right? That's where the incentives were. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | But there were some drugs in their early infancy. ACT UP members read the latest medical journals to do their own research on the status of new drugs to treat HIV or AIDS, educating themselves, reading textbooks about pharmacology, immunology, virology. In the words of Derek Hodel who's one of the ACT UP members, quote: "In the absence of adequate healthcare, we have learned to become our own clinicians, researchers, lobbyists, drug smugglers, pharmacists. We have our own libraries, newspapers, drugstores, and laboratories." And that's exactly what they did. |
|  |  |  |
| Erin Allmann Updyke |  | Dude, this is why, I'm sorry to get off topic for a second but I'm feeling the outrage so I just need to. |
|  |  |  |
| Erin Welsh |  | Yeah. We're in Act III: Outrage, yeah. |
|  |  |  |
| Erin Allmann Updyke |  | I feel like this is such a beautiful example of why it is so important that we have diverse people in diverse roles because then you wouldn't end up in this situation in the first place. If it wasn't all old white men in politics, research, medicine, everything at this point in time, I don't think you would've seen the same situation. You know what I mean? Like it's just because if everyone in your office, in your lab is the same, then you all have the same viewpoint, then no one is going, 'Hey but what about this thing? What about this new drug? Or what about looking at it from this perspective?' Anyways. |
|  |  |  |
| Erin Welsh |  | Yeah, multidisciplinary is such a word that's thrown around but it actually can really make a big impact in terms of thinking, reframing things in a way that you wouldn't have thought of earlier. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. Well and just having like intersectional workplaces where you have multiple literal people of different colors and different creeds and different genders and everything, you know? |
|  |  |  |
| Erin Welsh |  | And that's very true. The problem though that still remains is the fact that the money is all held primarily and the policies are all held primarily by old rich white men with an agenda that is only self-serving. |
|  |  |  |
| Erin Allmann Updyke |  | Exactly. Yeah. Yep, exactly. Totally. |
|  |  |  |
| Erin Welsh |  | So yeah. |
|  |  |  |
| Erin Allmann Updyke |  | 100% on board with hating that. (laughs) |
|  |  |  |
| Erin Welsh |  | I mean we could go on forever talking about the injustice. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | Yep. Okay so yeah, the members of ACT UP affected real measurable change in the turnaround time for experimental HIV or AIDS drugs. |
|  |  |  |
| Erin Allmann Updyke |  | That's awesome. |
|  |  |  |
| Erin Welsh |  | They made it like, let's get it to the market faster, let's get these experiments done faster. They also brought about the early though long, long overdue approval of drugs used to treat AIDS-related opportunistic infections in terms of preventative for pneumonia. |
|  |  |  |
| Erin Allmann Updyke |  | Oh! That's great. |
|  |  |  |
| Erin Welsh |  | The development of educational materials about AIDS for people with AIDS and their advocates, so a lot of distribution of materials and compiling it into packets that were accessible, that could be read by people without a PhD in biophysics and molecular genetics and crap like that. |
|  |  |  |
| Erin Allmann Updyke |  | Right. So that the research is actually reaching the people that need what they're... Yeah. |
|  |  |  |
| Erin Welsh |  | Yeah, yeah. It bridged the gap from primary research to communication so amazingly, it was really so inspiring to me. |
|  |  |  |
| Erin Allmann Updyke |  | SciComm at its finest. |
|  |  |  |
| Erin Welsh |  | Yeah. Their demonstrations were unignorable, shutting down the FDA for a day during one awesome protest. In another, some members chained themselves to a balcony at the New York Stock Exchange. |
|  |  |  |
| Erin Allmann Updyke |  | Whoa. |
|  |  |  |
| Erin Welsh |  | My personal favorite is when TAG, Treatment Action Group, which had split off from ACT UP put a giant inflatable condom over North Carolina Republican Senator Jesse Helms' house. |
|  |  |  |
| Erin Allmann Updyke |  | What?! |
|  |  |  |
| Erin Welsh |  | Yep. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Helms was one of the politicians actively campaigning on the Senate floor against federal funding for AIDS-related research or treatment on the basis of moral outrage. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god, I hate him. How did they get an inflatable condom that big? |
|  |  |  |
| Erin Welsh |  | Well there's an entire story that actually... Peter Staley tells the story in a blog, I can't remember the exact website. |
|  |  |  |
| Erin Allmann Updyke |  | Oh man. |
|  |  |  |
| Erin Welsh |  | But he tells the story, it's in the documentary. |
|  |  |  |
| Erin Allmann Updyke |  | We'll link to it. We'll find it. |
|  |  |  |
| Erin Welsh |  | Oh my god, it's so great. |
|  |  |  |
| Erin Allmann Updyke |  | Cause that sounds amazing. |
|  |  |  |
| Erin Welsh |  | Yeah, yeah. So Jesse Helms was an enormous piece of- |
|  |  |  |
| Erin Allmann Updyke |  | Garbage? (laughs) |
|  |  |  |
| Erin Welsh |  | Yeah. On the condom was written, quote: "A condom to stop unsafe politics. Helms is deadlier than a virus." |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god, I love that. |
|  |  |  |
| Erin Welsh |  | And I don't think they got in trouble for it, which is the best part. |
|  |  |  |
| Erin Allmann Updyke |  | (laughs) |
|  |  |  |
| Erin Welsh |  | I think they got like a parking ticket or something. |
|  |  |  |
| Erin Allmann Updyke |  | Oh that's so funny. |
|  |  |  |
| Erin Welsh |  | Makes me so happy. Perhaps the most recognizable demonstration or the one that you may have heard of from the late 80s was the second national march on Washington for lesbian and gay rights, an event which marked the first national media coverage of ACT UP and which revealed the AIDS quilt. 3.5 tons, 1900 squares at the time, it's since grown, with each square representing someone who had died of AIDS. This march was attended by an estimated 750,000 people. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | Way more than attended Trump's inauguration, by the way. |
|  |  |  |
| Erin Allmann Updyke |  | (laughs) There's like seven people there, so. |
|  |  |  |
| Erin Welsh |  | So it could be as many as three times more. |
|  |  |  |
| Erin Allmann Updyke |  | Oh my god. |
|  |  |  |
| Erin Welsh |  | Than attended Trump's inauguration. (laughs) Throughout the late 80s and early 90s, ACT UP chapters started in cities across the U.S. and continued to educate, demonstrate, and advocate. Meanwhile the number of people with AIDS around the world was steeply climbing. By 1991, it was at an estimated 10 million. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | 10 million. |
|  |  |  |
| Erin Allmann Updyke |  | 10 million people with AIDS, not just with HIV. |
|  |  |  |
| Erin Welsh |  | Mm-hmm. |
|  |  |  |
| Erin Allmann Updyke |  | Wow. |
|  |  |  |
| Erin Welsh |  | And an estimated 100,000 people in the U.S. had died from AIDS since the start of the epidemic by 1991. 11 years. Oh my god. It is during these years that we see the highest death tolls in the U.S. |
|  |  |  |
| Erin Allmann Updyke |  | Yeah. |
|  |  |  |
| Erin Welsh |  | With 15,000; 20,000; 25,000 dead each year in the early 90s. |
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| Erin Allmann Updyke |  | Yeah. I saw some numbers estimated even higher than that, like in the 30,000 and 40,000. |
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| Erin Welsh |  | Yeah, 30,000 and 40,000 were around '94-'95, '96. Yeah. |
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| Erin Allmann Updyke |  | Jesus. |
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| Erin Welsh |  | New experimental antivirals came onto the scene, sometimes cooked up at home, sometimes brought into the country. Buyer's clubs are all over providing people with experimental drugs, which is they didn't offer a cure, maybe offered hope. Real measurable qualified hope didn't come until 1995, the year the first protease inhibitors were approved. People with AIDS who seemed to be nearing the end of their days rebounded after taking these drugs. |
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| Erin Allmann Updyke |  | Wow. |
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| Erin Welsh |  | Doctors called it the Lazarus effect. It was very dramatic. |
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| Erin Allmann Updyke |  | Wow. |
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| Erin Welsh |  | Within two years, death rates in the U.S. and in much of Europe plummeted but this miracle cure would come too late for so, so many people. For over 300,000 dead in the U.S., for the million dead worldwide. The members of ACT UP number in the thousands but I wanna mention the names of just some of those who were instrumental in the fight to improve the lives of people with AIDS through ACT UP: David Barr, Spencer Cox, David France, Jim Aygo, Garance Franke-Ruta, Larry Kramer, Iris Long, Mark Harrington, Bob Rafsky, Peter Staley. These people are heroes. |
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| TPWKY |  | (transition theme) |
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| Erin Welsh |  | ACT IV: Persistence. 1997-2000. The first few years in gay communities after the release of protease inhibitors have been compared to coming up from the trenches only to realize the world had no idea you were even fighting a war. Entire neighborhoods in San Francisco and New York City were empty. People had watched as hundreds of their friends died, it wasn't uncommon to attend one or more funerals a week. These were young men and so many of them died. PTSD and survivor's guilt were prevalent among those who had escaped the epidemic, but 'escape' isn't really an appropriate word. There was no escape from the experience and it would stay with them forever, as we heard in our firsthand account. There was no parade, no march, no rally to signify the end of the AIDS crisis in the U.S. Slowly AIDS treatment centers closed their doors, demonstrations became more infrequent. Although an HIV positive result no longer carried the death sentence it had before protease inhibitors, AIDS diagnoses continued to climb worldwide and in regions where treatment is completely unaffordable. In 1997, the worldwide death count is 6.4 million and current cases 20 million. |
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| Erin Allmann Updyke |  | Wow. |
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| Erin Welsh |  | Before getting into current status of HIV and AIDS today, I wanna say one more thing. At the end of each episode we usually ask the question how scared do you need to be of x disease? |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | But researching the history of HIV and AIDS made me realize that that's not the question we should have been asking all along. |
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| Erin Allmann Updyke |  | Yeah. |
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| Erin Welsh |  | Instead we should be asking what should scare you about this disease. For smallpox I would've said that it was historical accounts of intentional infection or the future threat of biowarfare. |
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| Erin Allmann Updyke |  | Yep. |
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| Erin Welsh |  | For leprosy, it's the mistreatment of people with leprosy. In every case the answer has something to do with the failings of humanity and the story of AIDS is no different. There are towering villains in this story, the people that you would have thought you could have trusted to do something about the disease. The thing that we should be most scared about in terms of HIV and AIDS is not the disease itself but the response or lack of response of the government and public health agencies to this crisis. The discrimination and disregard for this disease because in the U.S. it happened to pop up in a marginalized and long ostracized group of people. For every villain in this story though, there is a hero or several heroes, those brave men and women who took it upon themselves to organize, mobilize, and affect change. And while the history of AIDS is full of heartbreak and injustice, these heroes should give you hope and a belief that some people will have the courage to fight and prevail. |
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| TPWKY |  | (transition theme) |
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| Erin Welsh |  | And with that, handing it off to you. (laughs) |
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| Erin Allmann Updyke |  | How on earth am I supposed to follow that? |
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| Erin Welsh |  | Uh, god. |
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| Erin Allmann Updyke |  | That was beautifully written, Erin. |
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| Erin Welsh |  | Oh thanks. That was the first thing I wrote, actually. The end. |
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| Erin Allmann Updyke |  | You have little cries in your eyes. |
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| Erin Welsh |  | I do have little cries in my eyes. Oh my god I just... Ugh. Okay, so. |
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| Erin Allmann Updyke |  | So, what's happening today? |
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| Erin Welsh |  | What's happening, I wanna know about it. |
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| Erin Allmann Updyke |  | (laughs) Well I could sit here and hit you with number after number, which is what I did to myself while I was researching this. |
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| Erin Welsh |  | (laughs) Yeah. |
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| Erin Allmann Updyke |  | I was like, table, table, infections, deaths, deaths, deaths. |
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| Erin Welsh |  | Yeah it kind of detaches you from the reality of things. |
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| Erin Allmann Updyke |  | It does, it does. So I really appreciate what you said because it's very true and yeah, sometimes there's too many numbers when I'm just staring at them to deal with. So here's what I wanna say. HIV/AIDS is still a huge problem today. It's not a problem of the past. Like tens of thousands of people in the U.S. are diagnosed with HIV and with AIDS every year and thousands are still dying from it in the U.S. |
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| Erin Welsh |  | Oh my gosh. |
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| Erin Allmann Updyke |  | But what I think is the most important thing to realize is that this risk still to this day is not homogenous and if you thought that we learned from how marginalized groups were treated at the start of the HIV/AIDS epidemic, you're very much mistaken. Because while advocacy groups did a lot to raise awareness and it's true that HIV/AIDS research is very well funded in comparison to many other very inadequately funded diseases, and while CDC and WHO say things on their website like rates of HIV infections are decreasing and AIDS deaths are decreasing, it's not happening across the board. By far the largest population at risk and getting diagnosed with HIV every year in the U.S. are gay African-American men, followed by gay Hispanic and Latino men. And for years while the number of new diagnoses in others groups, especially in white gay men were declining, they've been increasing in African-American men and Latino men. And just finally over the last year or two have these numbers seemed to have stabilized. |
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| Erin Welsh |  | Stabilized. |
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| Erin Allmann Updyke |  | Exactly, they're not decreasing by any rate. African-Americans, men and women, represent only 12% of the U.S. population but accounted for 44% of HIV diagnoses last year. |
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| Erin Welsh |  | Oh my god. |
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| Erin Allmann Updyke |  | And to make it even worse, cause why not- |
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| Erin Welsh |  | Oh yeah. |
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| Erin Allmann Updyke |  | The most neglected group that has the worst outcomes are transgender women. In the U.S. transgender women are diagnosed with HIV at rates three times higher than the general population. |
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| Erin Welsh |  | Wow. |
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| Erin Allmann Updyke |  | And a meta analysis in 2013 that we'll link to estimated that infection prevalence in transgender women worldwide was 17% and in high income countries, including the United States, 22%. |
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| Erin Welsh |  | What? |
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| Erin Allmann Updyke |  | Yeah, that's ridiculous. |
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| Erin Welsh |  | 22%. |
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| Erin Allmann Updyke |  | It's ridiculous, it's unacceptable, and there's essentially no research being done on how to stop this from happening in these communities. |
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| Erin Welsh |  | I mean we haven't learned anything. |
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| Erin Allmann Updyke |  | Yeah. And no we've talked a lot today about HIV/AIDS in the U.S. but this is by no means a disease of the U.S., this is a global pandemic. The WHO currently estimates that there are over 36 million people globally living with HIV. |
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| Erin Welsh |  | Wow. |
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| Erin Allmann Updyke |  | Including 2 million children and there were almost 2 million new cases diagnosed last year. |
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| Erin Welsh |  | 2 million new cases. |
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| Erin Allmann Updyke |  | And remember that these new cases don't necessarily represent new infections, they just mean that people are finally coming and seeking treatment or getting tested. |
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| Erin Welsh |  | And so those are HIV prevalence, okay. |
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| Erin Allmann Updyke |  | Those are HIV cases, right. The saddest statistic is that only around 50% of adults and 43% of children that currently live with HIV are actually receiving any sort of antiretroviral therapy. |
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| Erin Welsh |  | Like why is that number 50%? Why is that number not 100%? Is it because accessibility is... |
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| Erin Allmann Updyke |  | Yeah, I think it's lack of access- |
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| Erin Welsh |  | Lack of access means oftentimes not just logistics but actual financial. |
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| Erin Allmann Updyke |  | Right, yes, definitely. Definitely financials. And the WHO also estimates that only about 70% of people living with HIV or 70% of people who are HIV positive actually know their status. And even today, it's 2018 now, 1 in 3 people that present with HIV for the first time are presenting with advanced disease, which means they're not getting tested early, they don't know that they're infected until the disease has already progressed to either AIDS or stage 2 or something like that. |
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| Erin Welsh |  | Wow. And the thing about getting tested which I didn't talk much about but the term 'diseased' is so interesting and if part of the fear of getting tested, and it's a completely legitimate fear, is that even if you get an HIV positive result, even though that's no longer the death sentence that it used to be, you are automatically lumped into this diseased category. |
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| Erin Allmann Updyke |  | Right. Yeah and if you are- |
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| Erin Welsh |  | Even if you have no symptoms or seem perfectly healthy. |
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| Erin Allmann Updyke |  | And if you are part of an already marginalized group, you just then further marginalize and potentially are ostracized by that. |
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| Erin Welsh |  | Right. Yeah. |
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| Erin Allmann Updyke |  | And yeah, it's horrible. And even though, I mean, with treatment you can effectively reduce the risk of transmission to other people to very small. And treatment is not perfect by any means, drug resistance is very real and treatment has serious side effects and complications, but it does greatly prolong your life expectancy and decreases the risk of progressing to AIDS if you are HIV positive. So I mean, yeah. It sucks that there's such a huge stigma associated with it where they might be many people out there who don't get tested because they don't wanna know. |
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| Erin Welsh |  | What's so frustrating is that public health officials or government officials complain about this lack of people testing themselves but they're the ones who created the stigma. They're the ones who created these conditions in which being tested is not a desirable thing to do. It's so frustrating. |
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| Erin Allmann Updyke |  | Right. Yep. |
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| Erin Welsh |  | So is there anything- |
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| Erin Allmann Updyke |  | To do? (laughs) |
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| Erin Welsh |  | Is there any silver, not silver lining, but is there any sort of... Like what about PrEP? |
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| Erin Allmann Updyke |  | Yeah so let's talk about PrEP. So PrEP is pre-exposure prophylaxis which is when seronegative people, so HIV negative people, are taking retrovirals to prevent infection with HIV. The good news is it's very effective. |
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| Erin Welsh |  | Awesome. |
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| Erin Allmann Updyke |  | This has actually been around for at least 10 years, trials started in 2005 was the earliest that I saw. It wasn't licensed oral use of PrEP, the trade name I think is TRUVADA or something, wasn't licensed in the U.S. until 2012 but it's been around since long before that. |
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| Erin Welsh |  | Okay. |
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| Erin Allmann Updyke |  | And it's really effective. Dozens and dozens of clinical trials and cohort studies have shown that the use of these oral antiretrovirals can reduce risk of infection by around 90%, that's more effective than condom use, condoms are about 85% effective when used correctly. |
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| Erin Welsh |  | Wow! |
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| Erin Allmann Updyke |  | Yeah. So that's great. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | There is also a gel that is an antiretroviral gel that is used, I don't think that it's licensed that I know of - someone can correct me if I'm wrong - in the U.S. but it is used in a lot of other countries, that you can use either before or sometime during I think, I would assume before sexual intercourse. And that is an antiretroviral gel not a spermicidal gel and that's also very effective. So it's not something that you have to take all the time. |
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| Erin Welsh |  | Uh huh. Very cool. |
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| Erin Allmann Updyke |  | Yeah and so I wanna point out that there have been a lot of criticisms of this drug, PrEp because people claim that since it can prevent HIV infection it will then lead to an increase in the rates of other STDs because people are no longer using condoms, essentially. And to that I just wanna say: f(beep)k you. |
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| Erin Welsh |  | (laughs) |
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| Erin Allmann Updyke |  | Like that's the same B.S. argument that people try to use to say that women shouldn't have access to birth control options. Any option that is available that can prevent the spread of a disease as gnarly and devastating as HIV should be available to people who could benefit from it. |
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| Erin Welsh |  | Yup. |
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| Erin Allmann Updyke |  | Should people practice safe sex in general, da-da-da-da-da? Of course! Yeah, that would be great. But also they should use PrEP if they can benefit from it, I mean... Ugh, I was reading that and it's so demeaning, it's insulting to assume that humans aren't capable of making our own decisions about our own healthcare and what is best for us. It's just plain wrong. |
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| Erin Welsh |  | We're looking at you, conservatives! Get out of our bedrooms. |
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| Erin Allmann Updyke |  | I also wanna point out that this is a very expensive drug. I was looking for coupons for it, it's like $1600 for 30 tablets, so that's for a one month supply. |
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| Erin Welsh |  | (gasps) What? |
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| Erin Allmann Updyke |  | It is covered by most health insurance. |
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| Erin Welsh |  | That's awesome! |
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| Erin Allmann Updyke |  | Yes, I didn't know that and it seems like it is. It's not covered under Medicaid or Medicare or any other government insurance policies. |
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| Erin Welsh |  | No government insurance... Oh my god. |
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| Erin Allmann Updyke |  | Which means guess what? The most vulnerable sections of our populations- |
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| Erin Welsh |  | Don't have access. |
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| Erin Allmann Updyke |  | Exactly, yet again. |
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| Erin Welsh |  | Cool, cool. Thumbs up, government. |
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| Erin Allmann Updyke |  | Thumbs up. We give you something good then we take it back. So it's not surprising to know that these are the same populations that we see having the highest rates of HIV and AIDS. |
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| Erin Welsh |  | Right. |
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| Erin Allmann Updyke |  | So honestly, because of all this I feel like we don't even have time to talk about the research that is being done on HIV. |
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| Erin Welsh |  | Sorry. |
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| Erin Allmann Updyke |  | Sorry. There is a ton, everything from better rapid diagnostic tools, more effective antiretroviral therapies, and of course a vaccine. |
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| Erin Welsh |  | That'd be awesome. |
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| Erin Allmann Updyke |  | It would be great. There are tons of different strategies that people are exploring and I'm sure there's a podcast episode out there somewhere about all of these different options and maybe we can find it and link to it. But just to end it off with some numbers cause I didn't do a lot of numbers. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | In total, from the beginning of the epidemic in 1981 or 1980 until 2016, there have been an estimated 1,232,346 people diagnosed with AIDS in the U.S. |
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| Erin Welsh |  | Wow. |
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| Erin Allmann Updyke |  | Cumulatively 692,789 people have died since the beginning of the epidemic. |
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| Erin Welsh |  | In the U.S. |
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| Erin Allmann Updyke |  | In the U.S., yes. |
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| Erin Welsh |  | Oh my god. |
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| Erin Allmann Updyke |  | Millions and millions more worldwide. And that is the state of HIV today. |
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| Erin Welsh |  | Well I'd say that's a pretty sorry state. |
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| Erin Allmann Updyke |  | Yep, I'd agree. |
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| Erin Welsh |  | Okay well there you have it. The biology, history, and current status of HIV and AIDS in the world. |
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| Erin Allmann Updyke |  | Thanks for sticking with us. |
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| Erin Welsh |  | Thank you so much for listening. |
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| Erin Allmann Updyke |  | We really, really appreciate it. |
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| Erin Welsh |  | Yeah. |
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| Erin Allmann Updyke |  | I hope that you guys feel that you learned something new. I know I definitely did, I didn't know a lot about this history, so. |
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| Erin Welsh |  | Yeah. And again, thank you so, so much to the providers of our firsthand accounts. |
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| Erin Allmann Updyke |  | Brryan, Hillel, and Frank, we really, really appreciate it, it was wonderful talking to you. And listeners, hold your breath for next week because you're gonna get to hear more of these stories. So should we talk about what our sources were? |
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| Erin Welsh |  | Let's do it. I have a few books here. The first is 'The Chimp and the River' by David Quammen, and 'The Band Played On' by Randy Shilts. 'How to Survive a Plague' by David France, I mentioned. And the final book I'll mention is called 'AIDS and its Metaphors' and it's really more of an essay by Susan Sontag. |
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| Erin Allmann Updyke |  | Cool. I've got honestly too many things to cite here, so we will post... Just because they're too long to read. |
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| Erin Welsh |  | Yeah. You can find all of these books and articles on a Google Doc list that we have a link to on our Podbean website. |
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| Erin Allmann Updyke |  | Yeah and we'll also make sure that that's posted on Facebook so if you're interested in getting a list of everything that we've ever cited from all of our episodes, that'll be there. |
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| TPWKY |  | (transition theme) |
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| Erin Welsh |  | As always, thanks for listening. |
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| Erin Allmann Updyke |  | Yeah thank you so much, we really like it. |
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| Erin Welsh |  | And thanks to Bloodmobile for providing the music in this episode. And finally, wash your hands. |
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| Erin Allmann Updyke |  | Ya filthy animals. And be kind. |
|  |  |  |
| Erin Welsh |  | I like that. |