

TPWKY	This is Exactly Right.
	(This Podcast Will Kill You intro theme)
Erin Welsh	Hi and welcome to This Podcast Will Kill You, the bonus episode. I'm Erin Welsh.
Erin Allmann Updyke	And I'm Erin Allmann Updyke. First of all, holy crap (chuckles).
Erin Welsh	Holy crap.
Erin Allmann Updyke	Hi to all you literal thousands of new listeners.
Erin Welsh	It's insane.
Erin Allmann Updyke	We are completely overwhelmed with the response and with the love from all of you. Thank you, thank you, thank you.
Erin Welsh	Thank you.
Erin Allmann Updyke	Thank you for listening, and for rating and reviewing us on iTunes.
Erin Welsh	And also for engaging with us on social media.
Erin Allmann Updyke	Yeah!
Erin Welsh	These last few days have been an absolute whirlwind in the best way. And we're very excited to have you all here.
Erin Allmann Updyke	Yeah (chuckles). So, this is our first bonus episode, which we're releasing while we work on gearing up for Season 2. If there are any diseases or epidemics that you would like to hear about in Season 2, let us know! You can find us at all of our usual places. On email we're thispodcastwillkillyou@gmail.com . Our Twitter, our Facebook, our Instagram, et cetera.
Erin Welsh	Yeah. Look us up.
Erin Allmann Updyke	Yeah.
Erin Welsh	Well, this week we will be sharing more of Frank, Hillel, and Brryan's stories which you heard a bit of at the beginning of last week's episode. So, if you haven't listened to Episode 12: HIV/AIDS Apathy Will Kill You, go and do that now. We'll wait. Just kidding we won't. Just go do it.
Erin Allmann Updyke	You press the pause button.
Erin Welsh	We'll still be here.
Erin Allmann Updyke	(laughs) Yeah, so when we interviewed these three men their stories were just so powerful and there was so much more that we wanted to be able to include in last week's episode but we couldn't fit it in.

Erin Welsh

So what we decided to do was to bring them to you in a special bonus episode. And consider this kind of like the director's cut of Episode 12. It's bigger and better. Honestly though, we are really excited and honored to be able to share these stories with you all. So let's get to the interview.

Erin Allmann Updyke

Yeah.

TPWKY

(transition theme)

Erin Allmann Updyke

We sat down with Frank and Hillel who are both gay men who lived through the HIV/AIDS crisis in the U.S. in the 1980s and 90s. So we asked them to tell us about where they were at the time, at the beginning of the AIDS epidemic and about what they remember about how it was perceived right at the beginning.

Frank Iamelli

Well, my name is Frank and my last name is Iamelli. I was living in Boston, just 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 worked 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 so we read the article together and I distinctly remember it saying that one of the signs of the 'gay cancer', at the time we were calling it, was a rash on your feet. So I immediately went and checked (chuckles) and everything was fine.

You know, when we first heard about it there was words... "We don't have to worry about it cause it's happening over there." You know? And then when it hit here, there didn't seem to be an immediate panic about it. That all changed within a very short amount of time when people started to get sick here, because they died pretty quickly when it happened. Because as far as I can remember there were no treatment protocols, there literally was an immediate sense of panic throughout the whole city. You would go to a bar or something on a Friday night and you'd meet with your group of friends and have a drink and all of a sudden the conversations got, "Hey, we haven't seen so-and-so in a couple of weeks, we have to check on him." Or, "I heard so-and-so was sick." And it was just a horrible, horrible panic that went on right at the beginning.

But then as more people started to get sick, it quickly organized, informally, into being caretakers for your friends that got sick, because in many instances people didn't have families, families cut them out of their lives, and the only families that they really had was their network of friends. So I wanna say within probably two, two and a half years of me first hearing about this, we were already attending to our friends that had come down with it... Originally it was called Kaposi's sarcoma was the big thing I think at the time. But we all sort of went into this state of mind that we need to help those that are sick and we need to try to be as cautious as we can be in taking care of them because we still didn't know that much about how you can catch it.

Hillel Wasserman

My name is Hillel Wasserman, I was in Los Angeles, California, and at present time I work in the motion picture business. At the time of the AIDS crisis I was here in what was in fact the epicenter of the epidemic. The first three cases were reported at the UCLA medical center, as a matter of fact. So we were very much in the center of that storm, living here in Los Angeles. At the time that I first learned about HIV, I was in my late 20s. We started to hear these whispers about this weird, gay cancer that was going around. I understand, this was now the mid-80s, to put a timeframe on it, and there was a whole stew of sexually transmitted diseases that were getting passed around, and they were getting progressively more and more exotic in the gay community.

I was just beginning to wade into that world myself and so that's what I was greeted with, sort of the fruits of the sexual revolution. And we started to hear first there was some kind of a strange amoeba that was going around, and guys were getting terribly sick with diarrhea and the like. There were other things like that, and the whispers of this 'gay cancer', which a lot of us discounted because, c'mon, 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 it was 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. I really was, it began to be kind of overwhelming. And then you started to see weird articles in the newspaper. And where it really hit home for me was when Rock Hudson began to die all over the front pages of the L.A. Times. You couldn't open up the paper without seeing another story about this man. Now, I don't know how many people really remember who Rock Hudson was, but he was probably the biggest movie star in the world. He was Hugh Jackman, he was Tom Cruise, he was Daniel Craig, he was all that rolled up into one, you know? Comedies and action movies and dramas and the like. And here was this man, this buff, handsome man that we all watched in collective horror as he shrunk before our very eyes.

Among my community and friends, the perception of this, well, it suddenly became a whole lot more serious, right. Like I said, this was something that we could no longer discount.

Erin Welsh

Since the federal government's response to the crisis was so woefully inadequate, activism played a huge role in creating real change. And so we asked Frank and Hillel whether they were personally active in any political groups at the time.

Frank Iamelli

You know honestly I wasn't because I would say a good five, six, seven year stretch after that, my life was working and taking care of everybody that was getting sick around me. There were periods of time throughout the 80s where I had a partner at the time, and he and I were caring for, at one time, probably seven or eight different people. Just one night with this one, one night with that one, one night with this one. And then when we weren't doing that, there were memorial services because people were dying in the night. And as angry as you would get from seeing this carnage, I just thought, for me, my energies were best spent in caring for those that I loved. And there was certainly plenty of people who had joined ACT UP, which was the AIDS activist group, and they were doing their job and I felt like I was doing mine in the trenches, kind of thing.

And I do want to say that something that is not really... I don't think it's really well-known, but the lesbian community was truly the unsung heroes of the whole AIDS crisis because they stepped up to the plate. I mean, this was a disease that relatively did not affect them at all, and my god, they just stepped up and they were in there taking care of people left and right and working in hospitals and volunteering and caring for their gay men friends. It was amazing.

Hillel Wasserman

At the time that I was diagnosed, as I had said, I was concerned for my job security because I was perfectly healthy, though I did have this virus running through my blood. So I really was not involved in any activist sort of groups, at least not in a public way. I gave money, because you could do that anonymously, but I didn't show up at HIV social groups because who knew who I was gonna run into there and what they might say to somebody and what that somebody might say to somebody else, it could cost me my job. So no, I wasn't.

But at a certain point, it was post-cancer, and I'm not that much of an egomaniac but I could not help but believe that there must be something in my experience that somehow could illuminate the lives of others, and that's when I decided that it was my turn to step up. And what I did is I sought out a speaker's program and there was one tiny little speaker's bureau, I should say the remnants of a speaker's bureau, it was being run by an organization called Being Alive Los Angeles. Look it up on the web, beingalivela.org.

Being Alive was founded now some 30 or more years ago by two HIV+ guys, remember this was the darkest days of the epidemic, and they founded this as a way for HIV+ men and women to come together and speak openly to one another of our fears and share the rumors we heard. Because our doctors were completely stumped. But here they formed an organization where people could speak in an authentic voice, cause we were living it everyday. I had given lots and lots of money to Being Alive, but finally it was my turn to put some skin in the game.

Erin Allmann Updyke

Effective treatment for people with HIV didn't really emerge until the mid-1990s with the introduction of antiretroviral therapy. All of a sudden, AIDS diagnosis was no longer the death sentence it once was for a lot of people.

Erin Welsh

Though Frank remained HIV- throughout the epidemic, he lost countless friends and his partner at the time. And Hillel had been diagnosed with HIV in 1987. We asked them both how things changed once these so-called 'miracle drugs' came onto the scene.

Frank lamelli

We're talking a good, at least 10 years or so I'm guessing from my memory of when we first heard about AIDS up to that point when those recombination therapies came into play. During those years it just seemed like every week there was some other drug or some other treatment that was coming into play. There was AIDS leukemia and then there was this and then there was that. So in retrospect, when those drugs, those therapies came out, we did not know at that time, obviously, what a game-changer it was going to be. To us it was just, "See how this one does," you know, that kind of thing. So it wasn't really that big a deal to us at the time.

Hillel Wasserman

Protease Inhibitor drugs had entered the scene and that changed everything. People were getting up off of deathbeds, returning to work, returning to life as productive citizens, there was real reason for hope again. And so the last thing people wanted to do was get up in front of a bunch of high school kids or junior high school kids or community college kids and talk about how miserable their lives were with HIV when in fact, they were starting to live good lives again. But that's what was most important, that's what made my participation so urgent was because you can't tell by looking. The joke is you walk into a gay bar, you can tell who the HIV+ guys are, they're the really buff, good-looking ones. Because we're taking care of ourselves, right? But we're walking around with this, and as I grew fond of telling my audiences, you really cannot tell by looking. And that's why I thought it was so important to carry that message out, to put a human face on what at that time was a terrifying, mysterious disease.

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(transition theme)

Erin Allmann Updyke

We also sat down and spoke with Bryyan Jackson, whose story you heard a little of last week. He was infected with HIV when he was only 11 months old after his father, a phlebotomist, intentionally injected him with HIV-infected blood in an attempt to avoid paying child support. Which is just the most unfathomably evil thing I can even think of.

Erin Welsh

Yeah.

Erin Allmann Updyke

And he is now, his father, is now serving a life sentence in prison for this act.

Erin Welsh

Yeah.

Bryan Jackson

My name is Bryan Jackson. When I was 11 months old, my father, who was a phlebotomist at a hospital, decided to steal HIV tainted blood and then injected me with the HIV virus hoping I would die off and he wouldn't have to pay child support. My father stayed in the picture for about a month longer, telling my mom, "Don't worry about looking me up for child support, this child's not gonna live long." She didn't think anything about that until 1996 when I went from being this playful, happy, energetic five year old to this sick kid. In a matter of months my body began to break down and doctors started testing me for numerous diseases, even rare ones in other countries. In conclusion they came to, "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, three IV antibiotics and three injections daily. The majority of those were not available for children at the time.

But three months passes, five months passed, and as I stand before you today, I wasn't supposed to see my 6th birthday, but come next month I will be celebrating my 27th birthday.

Erin Welsh

As we talked about last week, a diagnosis of HIV or AIDS carried with it a stigma and a feeling sometimes of impending doom, particularly during the height of the AIDS crisis through the mid-80s to the end of the 90s when treatment was hard to come by and ignorance of how the disease worked was rampant both in the scientific community and in the public.

Hillel and Bryan discussed with us the emotional toll that their diagnoses took on their lives.

Bryan Jackson

When I first became diagnosed with HIV, my body was just shutting down day by day. The muscles in my legs were breaking down, my bones were becoming brittle and achy, I was vomiting all the time. If it wasn't HIV or the opportunistic infections that were making me sick, it was the side effects of the medication. I also lost a little bit of my hearing because the doctors weren't monitoring the blood that I was on, and therefore I lost my hearing.

And then all these years of just battling this illness... Actually, another thing I'll speak about besides HIV is mental health. So, when I was 13 years old, I was really struggling with depression, I was left out of birthday parties... This was when bullying was really hard for me, I'd be getting jumped in the locker room... And at 13 I said, "You know what? I'm just gonna do everybody a favor and I'm gonna kill myself." And at age 13 I had three knives in front of me, I asked myself which one could cut deepest. And in my moment of desperation, this voice called me to my bible and I read this passage and it said, "Why are you downcast, my soul? Put your hope in God." And that word 'hope' stuck out to me.

And so this is about 2003, so I couldn't just go google 'what is hope', but I was really fascinated by the word 'hope' and I really wanted to find out what it is, and dial-up internet's not gonna cut it. So I'm reading books and I loved the encyclopedia before Wikipedia, and what I came to was that in life, you're gonna go through struggles no matter what but the consistency you need to have is hope and hope is vital. And so with that I started to realize that we have two choices when we have these 'oh crap' moments. Either to be a part of the problem or to be part of the solution. And I said, "You know what, I'm tired of being part of the problem, I wanna be part of the solution. I wanna live in victory, not victimhood."

And so a question I asked myself is if I believe that I have a purpose in life, what is my purpose? And I started asking myself that question that we all ask in that victim zone, is what can I get out of this? And I realized life isn't about what you can get, it's about what you can give. And then I started asking, what do I have to give? And I saw that I had a path and I had a story, and my story is now a story of hope. And I think the world is missing hope. So I wanted to start sharing that story of hope.

And so since the age of 13 I've been doing motivational speaking and traveled all around the world, to Haiti, Ecuador, Kenya, last year I was named Canada's Speaker of the Year. And so motivational speaking for me is my time to give back to people who have a struggle with something in their life, whether it's mental health, whether it's a disease, whether it's just a day-to-day life problem. And I just want to empower people that there is hope and that hope is vital and that regardless of your situation, you can do anything, and you can overcome it, and you can be the best person you are capable of being.

Hillel Wasserman

And so there I was, sitting in my beautiful office, then 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. And as I sat there listening to all of that, all I could think of was, "Oh my god. How am I ever going to tell my parents?" See, I was between my 30th and 31st birthday at that time, and I know to many people that seems impossibly old, but it is not. When you are between 30 and 31 your entire life is ahead of you, or at least it should be.

But there I was in my 30th and 31st birthday and the primary relationship I had in my life, for better or worse, was with my parents. I'm also the oldest of three kids, and I don't know if anyone out there is the oldest of their family, but I can tell you if you aren't, it is the oldest child that is the repository of all their parents' fondest hopes and dreams, right. We're the ones that re gonna change the world, we're gonna have grandchildren, we're going to shine in our lives and make them proud.

On that afternoon, that no longer was a possibility for me. And I'm no actor, when I walked into the house they clearly saw that something was wrong. I'm their eldest, no one knows me better. (chuckles) Or in this case, knows me the least. But that's when I had to sit them down and tell them that it was time to start planning my funeral. You know, (voice breaking) it's wrong for a parent to bury a child. It's out of the natural order of things. We're supposed to go to our parents' funerals, we're supposed to cause our parents' funerals, right? Ever since the day they gave me those car keys at 16 they have not slept a night, I guarantee you that.

(sighs) I remember my mother's eyes filled with tears and my father got this serious look on his face that he gets when he's thinking about something really important. And he looked me in the eye after a moment and he said, "Hillel," he said. "You are our son. And we love you unconditionally. And we will live to see you well." Which was an astonishing thing to hear in 1987. In 1987, what you heard at the end of that story was how that guy's parents threw him out, how they turned their back on their own sick child. How can you do that and call yourself a parent? But that's what was happening, it was real.

But that's not what I come from. Thank god I come from better people than that. And I sensed a moment, I sensed an opportunity here and I thought, okay, what can I ask for? Right, I can ask for anything I want now because I've got sympathy on my side. And I asked that my parents not tell my younger sister or brother. I was just afraid of having them be hurt by that news, you know? Like I said, I'm their older brother, I'm the one they look up to for reasons I still don't understand, and I just couldn't bear the thought of them worrying about me.

And that was an amazing thing to ask of my parents. I had no idea what an enormous demand that was. What a strain that put on their everyday lives. There was no one they could talk to about this except me and they were so afraid of upsetting my apple cart that they just didn't talk about it. I really isolated them so terribly and I feel (sigh), I feel so bad for that. But you know what? Life doesn't come with an instruction book, right. We make the best choices that we can given the information that we have and in my life, that takes the form of trying to spare the feelings of others.

I did what anybody else would do at that point. I put one foot in front of the other and I marched onward. Because here's what was weird. I had a perfectly intact immune system. I had 1200 T-Cells! I also had the HIV virus circulating through my body, who knew how long it would take before the damage started, but I was healthier than the doctor at that point! So like I said, I put one foot in front of the other and I marched. I walked into work everyday, I stabbed people in the back and I got promoted, I climbed over the dead bodies and I got promoted again! I quit the studio, they hired me back a year later at twice the salary, I quit again, started my own business. I did what any normal person does, right? I made contributions to my retirement fund, I bought a condominium with a 30-year fixed mortgage. Right? What dead man does that, you know?

So I did what just normal people do because that was all I could do.

Erin Allmann Updyke

At the end of each of our interviews, we asked Frank, Hillel, and Bryyan to share with our listeners some of the things they felt were most important about the AIDS crisis or what it's like to live with HIV today.

Bryyan Jackson

Even after I came clean with my story and said, "Hey, I don't care about what you guys think, 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 some of the ignorance is still consistent. And it's just mind-boggling to me that we live in 2018 now and there's still ignorance around HIV and AIDs, and just several years ago I was dating this girl and her father had the audacity to tell me, "You can't marry or date my daughter because you are killing her, and you're gonna be just like your father." And I'm like, "What? What do you mean?"

And what people don't know about me is that I have an open invitation for anybody who wants to come to the doctor with me. My health status is not hidden, I'm an open book, I've said ask questions, I've done the research, I've lived with it. But still people are ignorant, and also, I've had doctors who aren't well-educated about HIV, and they would just slip the prescription under the door and not even come in and take a look at me.

But it's 2018, we have great medications that can help people live a long and healthy life and be undetectable. Most people can have a 0% chance at 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. People who are living with HIV can lead successful lives and people who are not HIV+ people are probably always gonna remain HIV-.

Hillel Wasserman

There's a Jewish saying from the Talmud that saving the life of one person is like saving the world entire. And it's my hope that somebody listening today might change the way they think or they act toward the people who they meet in their lives who are living with HIV. And if you haven't met us, you will. If you haven't met us yet, you will, because the CDC estimates that there are 750,000 to 1.5 million people living with HIV, and fully a third of them don't even know it. Right here in America, and they don't know it because they're not getting tested. That is so key. Get tested! Share the results with your partner. Develop strategies if you have to to negotiate safer sexual practices. But get tested. That will feel like my life has been well-lived, like I have done my part to try and fix the world.

So giving me this platform to speak on this program is deeply touching and I truly thank you both.

Frank lamelli

Like I said, I really believe it's important to pass these stories down because let's face it, we're all getting older and someday I'm not gonna be here and life is just gonna go on and those stories are gonna be forgotten. And part of that is just life, it happens. But at the same time, this just still needs to be some record somewhere that there was a wonderfully alive, vibrant community of people that loved each other and cared about one another and supported each other when times were bad. And now all that's gone. 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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(transition theme)

Erin Welsh

Again, we wanna give a huge, huge thank you to Frank, Hillel, and Bryn for sharing their experiences with us. We feel so fortunate for their openness and willingness to talk about their lives and we hope that it made as much of an impact on you as it has on us, listeners. Thanks again.

Erin Allmann Updyke

Yeah. Thank you. And thank you for listening, everyone.

Erin Welsh

Until next time, wash your hands!

Erin Allmann Updyke

Ya filthy animals (chuckles).

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(TPWKY outro theme)