

Robert (Bob) Higginson: ... pulling the strings of insurance agencies and insurance programs. You know, even in the field I'm in, we're still having to fight with insurance companies to get medicines for patients, prior authorizations, all that kind of thing, it's just become more of a business-focused atmosphere for medicine than what it was thirty years ago when I first started. But I guess it's just unfortunately the change in our society over time... [**Videographer:** We're rolling! **BH:** Oh, okay. Okay. **LB:** Rolling? Oh great!]

Laura Browder: Bob, can you just start out by stating your full name and the date? Just so we can keep track of everything?

BH: Sure. My proper name is Robert Higginson. And today is September 1st, 2017. But I go by Bob. I prefer Bob.

LB: Okay, perfect. So, Bob, can you tell me something about where and how you grew up? Your childhood? Your family?

BH: Sure! I grew up in a small town outside of Pittsburgh, called Kittanning. It's right along the Allegheny River which goes on to Pittsburgh. I lived there from the time I was about four years old until I graduated from high school. The town hasn't changed a whole lot in that time. In fact it's gotten smaller. Unfortunately, it's not a very progressive atmosphere. But again that's... I grew up in western Pennsylvania. Steelers fan!

LB: What brought you here to Richmond?

BH: I came here for work. I did all my education in Pennsylvania. Undergraduate I went to University of Pittsburgh. And then for physician's assistant training I went to Penn State. And whenever I graduated from P.A. training in 1982 I decided I wanted to move a little bit further south than what I had been before and ended up coming to Richmond—not planning on staying in Richmond for an extended period of time. But I've been here for over thirty years, so apparently this is kind of where I'm supposed to be.

LB: This is it.

BH: Yes!

LB: So you came here for a job at MCV?

BH: No, originally I came for a job... I was working at the federal prison in Petersburg. When I first got out of school, when I graduated in 1982, the physician's assistant acknowledgement in the community wasn't very good so it was kind of hard getting a job in the beginning. So my

very first job I had, especially just getting out of school, was at a state prison in Georgia. I stayed there for a little bit and then went back to western Pennsylvania and worked in a private practice for a while. And then realized I really wanted to come move a little bit farther south. So I took a job at the federal prison in Petersburg as a physician's assistant there. And was there for four and a half years then—before taking my current position at VCU.

LB: So how did you first hear about HIV and AIDS? Can you tell me about that?

BH: There was a nurse working at the prison. I started working at the prison in 1985. I was in P.A. school from 1980 to 1982. At that time they just... there really wasn't any knowledge about HIV so in my training I didn't have any formal training in terms of HIV. I took the job at the federal prison in Petersburg and the HIV antibody test became available in 1985. We started testing some of the inmates, down at Petersburg for HIV. There were a fair number of the patients who we found to be HIV positive. And so that was how I got involved in the HIV epidemic at that point in time... realizing that I didn't have any real training on HIV.

At that point in time, the clinic at VCU functioned on Friday mornings. They had a clinic every Friday morning. The prison was obviously open 7 days a week, 24 hours a day. We did rotating shifts. So sometimes, whenever I would have a Friday off, I'd come up to the clinic at VCU and spend some time with them to kind of have an idea of how to treat and how to deal with people who are HIV-infected. And at that time there were no medicines. So it was more testing the individuals, informing them of the results, and initiating the process for, unfortunately, the expectation of what was going to happen.

LB: You know what I remember? ('Cause I graduated college in 1982.) I remember first hearing about HIV and AIDS and no one seemed to know what it was. Can you talk a little bit about when you first encountered HIV? How were people talking about it? What were people in your medical community *thinking* about it? And how did you get so interested in it?

BH: I think for me probably what happened was, since they didn't have any formal training when I was in school (because there wasn't HIV at that point in time), I remember in one of my infectious disease classes, one of the professors saying, "There's a new disease that was recognized that has just been identified in California." They weren't really sure what was causing it or anything like that. But that was all we knew and that was in 1981, when the first cases were being diagnosed. When we first started testing inmates in Petersburg, some of them were much more knowledgeable in terms of what it meant than any of the staff was, because at least they had friends on the street that had been diagnosed and so they kind of knew what to expect.

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BH (cont'd): As a staff none of us had really been trained. So when we started testing the guys and coming up positive—obviously it was a very emotional diagnosis from the patient's perspective. We kind of had to learn how to inform the patients, help them understand what was happening in their body, and what we needed to do. At that time we didn't really understand how it was transmitted exactly, what precautions to be taken. It was a very anxious time at that point. Also once we started testing we started hearing stories about individuals who were kinda shoved in a hospital room and no one really paid attention to them. The nursing staff would gown up head to toe; you couldn't see who was there. Once you started seeing those things on the news, then obviously from the inmates' perspective... the medical care in the prison system isn't always quite what you would consider in the community and so an awful lot of the inmates were concerned in terms of what was going to be offered to them. But again in 1985, '86, there wasn't anything to really offer. There weren't any medicines. The first medicines weren't available till 1989 with ACT.

6:50

Right about the time I was leaving the prison was whenever the medicines first became available. So in the beginning we were testing the inmates and having to find who was infected and who wasn't, and if nothing else assisting with their knowledge in terms of what was happening. Which is when I realized that my knowledge is very, very limited. I started coming up to the clinic at VCU to find out what they were doing so we could hopefully provide comparable education to the inmates as what was being provided in the community at that point in time.

LB: So what kinds of things would you tell them? How would you tell an inmate at that time (or any patient) that he was infected with a disease that was very little understood, had never really been studied, and for which, at that point, there was no treatment?

BH: Right. And the expectation was—it was a death sentence. For some of the inmates it was figuring out how much longer they were going to be incarcerated, whether it was likely that they were going to be able to get out and go home... also the big issue too was making sure that no one else knew what their status was at the prison because obviously they could be treated differently by the other inmates and by the staff there. But also not putting them in a situation where they could potentially transmit the virus to somebody else. There's always (in some respect) the public perception that there's no drug use, there's no sexual activity, there's none of those kinds of things that occur in the prison, but obviously there is. And so we had to make sure that the inmates who were infected were not engaging in any activity or at least hopefully limiting whatever activity they were engaging in so that they didn't increase their risk of transmitting to somebody else.

9:07

At that point in time at the federal system the inmates were being tested when they came into the prison and they had to be tested before they went home. But anybody that was there could volunteer to be tested, and so an awful lot of the inmates were asking to be tested. Well once

they were they knew they'd been engaging in an activity and were concerned in terms of what their status was. The inmates that we were testing before they went home, if they tested positive, then they were required to inform the people that they were going home to that they could potentially transmit the virus to them. There was an awful lot of educating with the inmates in terms of what we knew at that point in time. And granted what we knew at that point in time has turned out to kind of be true—in terms of the activities that put somebody at risk for transmitting HIV. And so, I happened to educate the inmates. But, at that point in time, there weren't any treatments, so it was kind of dealing with the emotional aspect of: Were they getting out of prison? Were they gonna end up dying in prison? How were they gonna be treated both when they were incarcerated and how were they gonna be treated when they got out? Assisting them in finding out, once they got out, where they could go to get care. Granted at that point in time there weren't any medicines available but at least we could hook 'em up with somebody so they could hopefully continue medical care in some respect, knowing that unfortunately for some of the inmates, that weren't going back to a larger city, their option for medical care was going to be extremely limited at that point in time.

LB: I'm also interested... I remember when I was interviewing female vets, I interviewed a doctor who talked about how even though it was illegal to have sex in theory, in Iraq, she still kept a basket of condoms in her clinic. Did you distribute condoms at all in the prison? Given that (I'm assuming) it's illegal to have sex? Right? [Bob nodding in agreement] How did you work around that?

BH: We couldn't provide condoms in the federal system. Even today there are very few institutions, whether it's a state institution or a city institution, where they provide condoms to the inmates. In the federal system, the only way they could get condoms in the federal prisons would be if Congress gave permission for that and I don't think anyone's going to hold their breath for that to happen. The inmates can get other restricted items into prison (drugs, alcohol, things like that) so there's always ways of sneaking condoms in. I frequently have guys who would ask for rubber gloves. So... if some rubber gloves disappeared, they disappeared. You kind of help to educate in terms of... if they couldn't get the same kind of items on the street in prison—what could you have access to in the prison that could help you if you're going to engage in an activity... that will hopefully decrease the risk of transmitting diseases.

LB: That makes a lot of sense.

BH: Yeah, so you had to be creative sometimes.

LB: After you left the prison, what happened then?

BH: I was working at the prison and... how am I going to word this? We had to keep a record of all the inmates that were testing positive for HIV. And the only people that had access that information was the medical staff and the warden of the prison. Then one day the warden of the prison decided that he thought it was permissible for any of the staff members who wanted to see that list, that they would have access to that list and all they'd do was just sign a piece of paper saying they looked at the list. Whenever we found out that was his intention, I went to my supervisor at the prison and told him what we had heard and he said it was the warden's discretion; he could do that. There wasn't anything we could do about it.

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Well, one of the physicians I used to work with in Petersburg had advanced and he was in the central office in Washington D.C. And so I called him to let him know what our warden's intentions were and he said that was against policy. So he sent out a letter to all the institutions stating what was permissible and what was not permissible with that information.

[interview paused because videographer is picking up "rattling" sounds from outside]

13:38

BH: So I contacted the person who was at the central office and they sent out a letter to all the wardens and the warden found out that I was the one who had initiated everything. I had won "Employee of the Quarter," "Employee of the Year" at the prison the year before and all the sudden everything changed. And I started to realize that was probably a good time for me to look for something else.

At that time I was already doing the Friday clinics on occasion with the people at VCU. And it was "destined in the stars," (or however you want to put it). The program at VCU had gone from being a half-a-day-a-week clinic to two-half-days-a-week-clinic. The population was growing and they realized they had to expand their clinic. And so they were going to have their own separate clinic that was gonna be a five-day-a-week-clinic. They were looking to obviously then have to expand their staff. VCU has a nurse practitioner program there, and so originally they were looking for a nurse practitioner to join their clinic staff and be there five days a week, but they had difficulty locating a nurse practitioner that was either interested in working in the clinic, or had some background or training in it. Then one time I went up on a Friday and they asked if I'd be interested in joining the clinic and it was perfect timing for me at that point in time. That's how I made the transition.

The clinic where I work at at VCU officially opened as a five-day-a-week-clinic in 1990 and I started working there February the 1st of 1990. It was open for a month before I started working. That was how I made the transition from the prison and up to the clinic at VCU. But I still do some work at the clinic. I'm a contractor with the prison in Petersburg. So I go down and I help with their clinic they do for inmates that are known to be HIV positive. And also I go down and do an educational program for the general population, for anyone who wants to learn about HIV.

They have a drug treatment program at the federal prison in Petersburg and it's one of the required things they have to take. So some of the people that I have there are people that are required to take the class for the program that I'm doing. But also some of the guys, especially the ones that are going to be going home soon, that have been incarcerated for ten or twenty years... The world is very different now than what it was when they came in, so they're learning some information that will prevent them from becoming infected once they get home. And also for the guys that knew they were infected, hopefully help educate them so they can better understand what's happening so they can prevent themselves from getting sick from this disease.

LB: Well that partly addresses what was going to be my next question. Which is—what kinds of changes have you seen in the prison system, since you first started working there to now, in the way HIV is dealt with?

BH: Now that we have medications, the inmates at the federal prison in Petersburg... and also I treat inmates in the State Department of Corrections, in the city jails, and the county jails. So I kind of see the whole spectrum of the inmates in the different settings. With the medications that are currently available, all those medicines are available to the inmates also. When they're in the state system or the federal system they have access to medications. Obviously, the goal is to get them on medications, get their infection under control, and realizing that for the inmates that are incarcerated, they do a much better job of taking their medicines every day, taking care of themselves medically and I think part of that's because they're in a more structured environment when they're incarcerated; they have access to medical care.

When they get out though, then things obviously will change. An awful lot of the inmates I take care of, when they come out of prison, they come back to the Richmond area. If they come back to the Richmond area, then I continue following them, once they come back. So it's nice continuation, continuity, care in that respect. They didn't have to change providers, they just stay with me. If they're going someplace else, in the state or someplace else in the nation then we try and connect them with a clinic that they can get their care. But obviously once they get out there's a lot more temptations. There are a lot more of the things that can go on in their life.

I have inmates I've been taking care of that I took care of when they were incarcerated. They've been out about five, ten, fifteen years and they still come and see me, they're still doing well. They're not becoming re-incarcerated. So hopefully in that respect we're helping to prevent recidivism and hopefully helping them to live a more productive life. And those do just as well. I mean, they're taking their medications, they're doing well, they're very productive members of society. They're working. They're taking care of their families, things like that. In the prison setting itself, just like in the community at large, there's not the same level of stigmatism for people who are HIV-infected. There still is. The general public has more information in terms of HIV and now that we're treating individuals, people don't look sick. So even if you look back at

the epidemic twenty or thirty years ago, when people had HIV or had AIDS, they looked sick, you know, a concentration camp kind of look to them. But now that people are on medicines and looking healthy, you can't tell from looking that some of them are HIV-infected. But I think along those same lines then, the public doesn't realize that there are still people out there that are infected, like in the past.

Unfortunately, the Richmond area has a significant issue with HIV. And we're still getting a lot of people that are becoming infected—either because they don't realize they're engaging in an activity that puts them at risk, or they're under the impression that they don't need to worry about HIV so why take the precautions, because it's not a problem in society anymore.

LB: That leads me to my next question. What are the changes that you've seen over time in HIV positive patients, in how they got infected, and how they understand and deal with their condition?

BH: I think in general people are more educated now than what they were before. But unfortunately, we still get a lot of people who have very limited information about HIV. Right now, most new people who we identify who are becoming infected are young adults. As I tell them, "I've been working at the clinic at least 30 years. We've known about HIV for longer than you've been alive." And so we have people in their late teens and early twenties who are becoming infected. They learn about HIV in school, or on TV, or whatever.

But for those of us who've been dealing with it for a long period of time, when the disease was first identified in the 1980s, there was a lot of public information about it. As I tell individuals, "If you watched the Emmy's or the Oscar's or any of the award shows, everyone wore red ribbons." HIV was the disease where... even if people didn't talk about it, they'd heard about it. Or there was some kind of visual clue that it was still out there. Now no one wears red ribbons. The only time anyone wears a red ribbon is at an HIV AIDS event of some kind. But you don't hear about it on the news like you did in the past. You don't see it at the award shows. Or anything like that.

In general I think our society at large, feels it's a disease that occurs somewhere else other than the United States. [*unclear, maybe: I've done research on*] the previous presidential administrations, they were talking about the epidemic of HIV especially in Africa and everything we're doing in Africa. I think because people don't look sick anymore, people are living well, everyone thinks we've conquered the problem in this country. It's a problem occurring outside of this country. It's occurring somewhere else. And we've done a very good job of treating people who are HIV-infected so people aren't getting sick. But you don't see the people that look sick. I think unfortunately it's kind of a double-edged sword: we've done an excellent job of treating people that are HIV-infected, but since people aren't dying of HIV and we're not seeing people

who are HIV-infected, we're not seeing people that look sick. The community thinks, "Well, it's not a problem anymore." And so, people aren't taking the precautions.

22:28

Also, everyone in this room is no longer in their 20s anymore. But if you think about whenever you were in your 20s—bad things always happen to somebody else. They don't happen to you at that age. You're not supposed to get sick in your 20s. You're not supposed to get a disease in your 20s. They don't take the precautions, because it's going to happen to somebody else. It's not going to happen to them. So they become infected and then it's... it changes everything.

LB: And how does it change everything for them?

BH: We've done an excellent job in terms of treating individuals. But most teenage, most twenty-year-olds don't take medicines. If it's a female patient, she's accustomed to taking medicine for birth control pills. But most men, teenage young adult men don't take medicines for anything on a daily basis. So you have to train them or teach them that if you want to stay healthy, you have to take something every day. It's not a choice. You have to take something every day.

When we first started treating people with this disease back in 1989, 1990, we weren't treating very effectively because we didn't know how to treat. In the beginning of the epidemic we treated people with one medicine at a time. It was only since 1996, 1997 that we realized in order to really treat the infection, effectively, it took a combination of three medicines every day. So we've been treating with three medicines every day for twenty years. So we've done a much better job of treating the infection.

In the beginning, people were taking ten to twenty pills a day to treat the disease. Now there are multiple pills on the market that are one pill once a day. It's very easy to take the medicine, but you have to take it every day. Since you're treating something alive inside the body, if the person doesn't take the pills every day and they skip pills periodically—the virus is starting to change and adapt—those medicines no longer work. And the virus becomes resistant to the medicines, which means we have to put them on something else, which is gonna be more complicated than a one pill once a day. So you have to work with the patients in terms of taking one pill once a day.

In fact there was an individual I saw yesterday... Whenever we first met he was nineteen years old. I put him on medication. He came to see me one time after going on medicine and then he disappeared for three years. He showed back up a month ago. In addition to restarting him on his HIV medications, he also had to be treated for syphilis, which means in the years I didn't see him he obviously was engaging in activity that put him at risk for getting other infections, potentially transmitting this virus to somebody else. He's twenty three years old right now. For the rest of his life he's going to take a medication for the foreseeable future until we come up with a cure

for this disease. And so he's going to take medicines for the rest of his life and hopefully it will just be one pill once a day, but obviously then he has to change his sexual behaviors.

25:13

At the clinic at VCU I follow several hundred patients. Every month some of my patients are getting treated for syphilis. In fact I have two patients coming in this morning to get their first bicellular injections... because they're in a relationship... the one became infected with syphilis... so they both need to be treated.... They're both in their thirties.

LB: So, it sounds as though syphilis is making a big comeback as well, along with AIDS?

BH: Yes. For the twenty-some years I've worked at the clinic at VCU, unfortunately the Richmond area consistently ranks in the top ten for the instance of syphilis, gonorrhea, chlamydia, per population... for the country.

LB: Why do you think? How do you explain that? And I'll ask you the follow-up question as well, which is: HIV? But it sounds like it's all the same thing?

BH: Right. I think part of it has to do with the fact that the city of Richmond is, in general, fairly conservative in terms of what you can talk about and what you can do and speak about in public. With my position where I work at VCU, there have been occasions I've gone out to some of the schools and talked in the school settings. It hasn't been recently. But say—five, ten years ago. And we're kind of informed, that when you talk in schools, the only thing you really talk about in terms of sexual activity is abstinence (in a big group). If they come and talk to you in person, you can talk more openly. But if you're talking in a group, all you can talk about is abstinence. Well... if all you're talking about is abstinence, then you're not educating individuals in terms of—if abstinence isn't your option—what can you do if you're gonna engage in sexual activity and protect yourself and protect your partner? If we aren't educating the youth of this community of what they can do to help protect themselves... It doesn't just help protect them against HIV, but syphilis, gonorrhea, chlamydia, unplanned pregnancies, all other kinds of diseases and problems. If you don't talk openly in those situations.

Then in the Richmond area I find that the issue also has to do with all the minority individuals. In our society at large there is a little bit of distrust sometimes between the medical profession and some of the minorities, especially for some things that happened in the past in this country. And so an awful lot of times they get their education in the churches. Well, if you're going to talk about HIV, it's very difficult to talk about HIV very honestly and openly in the church because some of the things you're going to talk about (sexual activity, HIV, drug use, those kinds of things) don't usually fit into what normally is discussed in a church setting.

There are often organizations in the city that are really trying to make an effort right now to get into the minority communities, and the white communities, and all different communities, to try and educate the youth in this country. Because the only way we can get this disease, and other sexually contracted diseases, under control is by educating.

28:04

LB: I'm still a little baffled though, because those abstinence-only sex education rules are in effect all over the country.

BH: Yes.

LB: Right? There are cities with large minority populations with distrust of the medical community for good reason, historically. Right? All over the country. Why Richmond? What is it that's so special about Richmond? Because you and I could probably between us name 50 pretty similar cities. So what is it about us?

BH: I think part of what happens with HIV is, Richmond is only a two hour drive to D.C.. Historically, D.C. has always had one of the highest rates of HIV of any other city in the country. For a long period of time it was the number one city in the country for instances of HIV per population. And a fair number of my patients drive back and forth to D.C. on a regular basis. If you're going up to D.C. for recreational activities, then sometimes you bring back things that you didn't go up with. Also Richmond has a fairly large drug problem. Baltimore, which is just on the other side of D.C., has the highest rate of IV drug use of any other city in the country. And then we're right on 95, so it's very easy to get to those cities. So I think part of it is the fact of the location of Richmond. We have a very small city population per se compared to D.C. and Baltimore, but I think because of the transportation back and forth and those kinds of things, I think it just unfortunately, some of the things you'd see more commonly in a larger city also occurs in the Richmond area then too.

LB: So how has the opioid epidemic affected HIV here in Richmond? And the work that you do?

BH: I think part of what's happening with the opioid epidemic... it's been going on for a longer period of time than I think our society wanted to acknowledge. From my perception, I think part of the reason why we're hearing so much about it now is the opioid epidemic has gone more from the inner cities to the suburbs. When it gets into the suburbs, it's now affecting a different population, a different community. I think that's part of the reason why we're hearing more about it. Unfortunately, with the opioid epidemic that's occurring right now in this country, it's not just popping pills, it's injecting. And so, I think, unfortunately we're going to see an increase in incidences of HIV from individuals who in the past as a society we wouldn't consider at increased risk for HIV, but because they're now become part of the opioid epidemic, and they're

injecting drugs, or they're engaging in activities when they're high that increases their risk, or they're engaging in activities to get money for their drugs, I think we're going to unfortunately start to see an increase in the incidence of other sexually transmitted diseases, in particular HIV.

31:09

LB: So what have some of your biggest challenges been over the years? Because you've been doing this work now for over 30 years. What have been some of the biggest challenges you've faced? And how have those challenges changed over time?

BH: In the beginning of the epidemic, the challenges were keeping people healthy. As I've said sometimes when I've done other talks. When I first started working at the clinic, on average, I'd have two or three patients die every month. We didn't have medicines and so at that point in time my responsibility was not just to keep people healthy but to try and help prepare them as best you could emotionally and physically for the probability that they were going to die in the very near future. Now, I have two or three patients die every year from their HIV. So instead of two or three every month, it's two or three every year—and those are the ones that aren't taking their medicines. My patients that die now die of things everyone else dies of—heart disease, cancer, car accidents, other things. My focus right now with my patients isn't preparing them for death. It's preparing them to live and to make healthier choices. Not just in taking their medications, but eating better, smoking, sexual activity, all the other things that you talk about in terms of leading a healthier life. And the expectation is you're going to die of something completely unrelated to your HIV.

In the beginning of the epidemic, when people were, unfortunately, dying in a very short period of time, I didn't care what someone's cholesterol was. I didn't care how much somebody weighed. You could eat anything you wanted to because you weren't going to die of heart disease. It wasn't...

Now I need to talk to people about getting their weight under control, exercising, following a diet, doing those things that we need to be doing. So in that respect it's changed. But in a sense, the epidemic has changed dramatically too in terms of the people who are getting infected. Now over fifty percent of my patients are over the age of fifty. We're talking about lifestyle issues, end-of-life-issues, but related to the fact that you're now over fifty and you're not going to live forever. The other patients are in their 20s. And a 20-year-old or 25-year-old is very different than a 55-year-old. So you're talking about different aspects of life, different things that are going on, in terms of the younger individuals, in terms of drug use, sexual activity, those kinds of issues, making the healthier choices, helping them to take their medications. An awful lot of them aren't gainfully employed or if they are gainfully employed, they don't have insurance. So dealing with access to medications, what programs are available through the state and federal government in terms of helping them to get their medicines, making sure they complete their paperwork so they don't end up running out of their medicines because they didn't do their

paperwork, and had to do the things they need to do. And so in that way it's changed dramatically.

LB: I'm curious about the insurance piece, especially for people who are either young and don't have insurance or people who are a bit off the grid and don't have insurance. How do you deal with that? Particularly in this new climate?

34:37

BH: It's made things much more challenging in some respect. There is a program that became available through the federal government called Ryan White Funding. Ryan White was a hemophiliac that died of AIDS decades ago. The federal government gives money to the state's health departments. And then the state health departments then purchase medicines for people who are HIV infected. In the state of Virginia if you're single and make less than, I think it's like, \$48,000 a year, and don't have insurance, you can get your medicine. The state health department also will assist individuals with getting insurance through the Affordable Care Act. It's much more fiscally responsible from the health department's perspective. They could purchase insurance for patients. For what they would normally spend on medicines for individuals they can get insurance for three or four or five people and so we're able to provide medical care then for those individuals.

For the patients, once they get insurance, they've got more options in terms of where they're getting their medical care, where they're getting their medicines. If they're getting their medicines through the health department program, then they get their medicines from the health department. The health departments have this program that if I give a patient a prescription, they go to the health department, get their medicines filled at the health department. But once they have insurance they can go to CVS, Walgreen's, whatever. So that's much more convenient. You can potentially walk to your pharmacy as opposed to driving someplace else and then for an awful lot of patients, they didn't want to go to the local health department to get their medicines because people would know why they were going to the health department, or they knew someone who worked at the health department. So sometimes individuals would go drive to a different county to get their medicines because they didn't want to go to their place that was closer to them. But now again they can go to their local pharmacies or they can get their medicines from a mail order pharmacy. And they get their medicines through the mail. They don't have to go anywhere to get their medicines. It definitely makes things much easier.

Also once the patient has insurance through the Affordable Care Act, then they can get other healthcare needs met. Because if they're getting their healthcare needs met through the health department's program, it only deals with their HIV. Whereas if they have insurance, then they can get their other healthcare needs met. From my perspective, the Affordable Care Act has greatly improved the access to medical care for an awful lot of our patients. Obviously with the current political climate, we're not quite sure what's gonna happen. Our concern is if the

Affordable Care Act goes away or doesn't get replaced by something similar, then all those individuals who were getting their medical care through their programs with the assistance of the health department, they're all going to go back on the health department's ADAP program, AIDS Drug Assistance Program, which means they have to go back to local pharmacies that they're not getting any medical care for anything outside of their HIV for that program. It's definitely going to limit what their resources are and what their options are.

LB: What did a lot of your patients do before the Affordable Care Act?

BH: They got their medications through the health department program.

LB: Okay.

BH: Before the Affordable Care Act, over a third of my patients didn't have any insurance at all. I mean—*over a third*. And so those are the individuals that got their medicines through the health department program. With VCU having a financial screening process, those individuals were essentially provided medical care, and provided the lab work and everything at no charge at all to them. It was just kind of being absorbed by the VCU system. And then they were getting their medications through the health department's program. VCU's pharmacy does participate with that program so they individually could get their medicines through the pharmacy at VCU. So they could come and see me and then get their medicines at the pharmacy at the same... which was convenient in that respect but they don't come and see me every month. So they'd have to make a trip downtown every month to pick up their medicines, because that was the only way they could get their medications. And then again if they needed to get any other medical care it had to be through the VCU system, through their financial screening 'cause they couldn't go anywhere else. So they ended up getting sick and then going to one of the local community hospitals, they didn't have no insurance, which means: they get a bill. Just walking into the emergency room you're not gonna get out without a couple-hundred-dollar bill.

LB: If you're lucky. If you're supremely lucky.

BH: If you're lucky, right. Yeah. So now with the Affordable Care Act they have insurance that helps cover that. Now we still have the right amount of funding in our clinic. There are funds available for individuals whether they have insurance or not under those programs. But it definitely does then give people access because without that they don't get medical care and if you don't get medical care... Not only for the patient's perspective, but we've learned over the years that if you treat the patient, get their viral load under control, get their viral load undetectable, then their likelihood to transmit the infection to somebody else drops down dramatically. So we're not only just treating an individual, we're also helping to prevent

additional infections in the community by treating the patients. In the long run we're doing good to kind of help keep the community at large healthier.

LB: What do you see as the biggest obstacles to providing treatment here in Richmond?

39:38

BH: I think the biggest barriers right now are—Number One—getting the patients tested. There are an awful lot of places in the city for being tested. Richmond Health Department, there are other agencies in the program that will provide the testing for free. Number One: Getting individuals to get tested. Having people to change their behaviors so that they don't become infected. There's still, unfortunately, not just in Richmond but in the community at large, there's a big drop off for the number of people, when they know they're infected with HIV and then those ones that access care. So just because someone becomes aware of their HIV infection doesn't mean they're gonna get care. Like I mentioned the gentleman earlier, he came and saw me but then he's been out of care for a couple years. And unfortunately, we see that a lot; Someone will be in care for a period of time and then something happens—whether it's family issues, financial issues, substance abuse issues. For those of us that have more of a middle-class upbringing, you would expect if someone becomes HIV positive, that'd become their number one concern in their lives. Well, for an awful lot of occasions that's not it. It's: Where ya gonna sleep tonight? Where ya gonna get your food? Are you in a safe environment? HIV sometimes isn't even in the top five for what their concerns are on a day-to-day basis.

LB: So how do you deal with that challenge?

BH: Fortunately, at the clinic where I work we have social workers, and case managers, and nursing staff. We can all kind of work as a team, realizing one person cannot solve all the problems for one individual. Takes many people to work with that. And try and make sure they're aware of what access they have. And you get them in to the proper things, whether it's psychiatric care...

Some of the agencies in town, they can provide assistance if someone's in an abusive relationship. RVHA and other programs like that if somebody's having substance abuse or mental health problems. But just because those agencies are available doesn't mean the patients are gonna access it. And realizing that for an awful lot of patients, it's multiple times that individual needs to have those problems addressed. You can get somebody who's doing well for a long period of time but then all it takes is one thing to happen. You know, someone who's been gainfully employed and doing well and then something happens and then they can lose their job. Well then, everything, everything in their life changes. All their priorities change.

LB: Yeah, I was talking to Dr. Kenneth Haft, who's a pulmonologist in town. He was telling me that he sees tons of twenty year olds in the ICU every week because of HIV, because of that spiral down that you're talking about.

42:48

BH: Right. Right. And unfortunately, in those situations they're not getting any medical care and so it isn't 'til they get really, really sick. And then, unfortunately, those individuals then end up being hospitalized for pneumonia or something related to their HIV—you know, things that are preventable. In my view, they're very easily preventable. But from the patient's perspective, it's just not as preventable.

Kind of along the same lines, I'm taking over a patient who lives in Williamsburg. He's in his thirties. He can probably bench press 400 lbs. A friend of his started having some medical problems and instead of him taking care of himself, he started taking care of his friend. He stopped taking his medicines. I didn't see him for a good six months. I caught him periodically. He never returned my phone calls. He ended up in the hospital with pneumocystis pneumonia, which was preventable. Easily preventable.

LB: Given that, and given the kind of slippery slope that you're talking about—that once someone gets infected, they can get derailed so easily from their course of treatment. What are some of the biggest challenges for you in preventing HIV in Richmond, a city with an extraordinarily high rate?

BH: I think unfortunately it comes back to... Number One... We have to educate individuals. I think because people don't see people that are sick, they don't realize the risk they're putting themselves in. So Number One: People have to become educated and realize that the education has to change their behaviors. We're not telling people, "Be abstinent." That's not realistic for most individuals. But if you're gonna engage in activity that puts you and your partner at risk, then you need to protect yourself. Use condoms, those types of things. Also frequently in that age population there's a connection between sexual activity and substance use—whether its legal substances or illegal substances.

Whenever they get out of prison I talk to them about the fact that—you go into a bar at ten o'clock, you look around at the people in the bar, no one looks that attractive. No one has left, no one has come in. It's now two o'clock in the morning. Everyone looks *so* much better at two o'clock in the morning! They didn't change. Your perception has changed. So, if you're engaging in activities that changes your perception—then you're much more likely to engage in activity that is gonna put you at risk of getting something that you weren't necessarily planning on being exposed to.

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How can we educate people not just in terms of how its transmitted, but—how do you need to change your behavior to decrease your risk of becoming infected?

I think still, in our society, an awful lot of taboo subjects, people don't talk about. As I've told people before and as I've been doing this—there are questions I ask my patients that I would never ask a friend. And I expect the patient to answer me accurately and correctly. But I would never have that conversation with a friend.

45:31

LB: I've always wondered about that. Do you feel that your patients, by and large, answer you accurately and correctly?

BH: I think sometimes in the beginning—no. Because... it's just like anybody else. I wouldn't. But I think, after you develop a relationship with them, you can. And I think sometimes, too, some of the patients will. There have been times where the very first time I've met someone I've asked them a question, and I get a lot more information than I was anticipating. So sometimes, yeah, I will. But you kind of have to realize that you kind of have to take what they're telling you with kind of a grain of salt. Part of my expectation is that no matter what they tell me in terms of what their risk is, I have to educate them about all the possibilities. I just don't have to educate them with what they're telling me—but I have to tell them everything.

Sometimes, I know that, especially with some of the male patients who I'm a little questionable in terms of what their sexual activity may be, when I talk about activities, with them, without their male partner... they sometimes get offended. But we still need to talk about that. I just have them use the information that I provide to everybody. Everyone gets the same question. Just like if a male patient talks to me about some urinary issues, the one thing we always talk about is who you've had sex with, what kind of sexual activity occurred, and what the possibilities may be. You need to cover all your bases, no matter what the patient may be telling you is going on. And do it in such a way that you're not offending the patient in the process.

LB: That must be very tricky. Especially in a conservative city where, as you were saying earlier, many of your patients grow up and live in environments where (**BH:** ... some behaviors aren't acceptable) some behaviors are not acceptable.

BH: But I think sometimes too when you approach it in that respect, then if there is something going on, then hopefully they'd feel more comfortable at a later time maybe bringing up something that they maybe wouldn't have brought up before—because I've already broken the ice.

An awful lot of times, when one of my patients is being seen somewhere else, and if they bring a female friend with them... If it's a male patient and they bring a female friend, the automatic

assumption from the other provider is that this is not a plutonic relationship. When an awful lot of times with male patients, especially a male patient that's gay, one of their best friends is a female. It's just a friend! You don't need to make assumptions in terms of what kind of relationship that person is having with each other. And so you need to kind of make the assumption that everyone potentially could be having sex with anybody.

LB: So how has your understanding of HIV changed over the course of the 30+ years that you...

48:22

BH: Oh, it's changed dramatically!

LB: Tell me more!

BH: It's changed dramatically. Just in terms of, from my perspective, feeling more comfortable talking to patients in terms of what's going on in their life, not just in terms of sexual things, but other things too in terms of substance use, work relationships, just kind of what's happening in their lives. For an awful lot of my patients they're doing well. And an awful lot of times what we're talking about isn't really related to the disease as such, but it's related to their life. But realizing that their disease affects their life and their life affects their disease.

I have one patient I've been following for twenty-seven years I just saw him recently. When I met him for the very first time and he was extremely anxious about the whole situation and I made the comment to him, I said, "There will come a point in time where this is not the overriding issue in your life. You'll go on with your life and things will be fine."

And whenever I saw him the other day, he brought that back up to me and he said, "I never thought that would be, but," he says, "Now other than taking my pill every day, I don't think about this anymore. I just don't." He has his own business in town. He travels internationally with his work. Other than taking his pills every day and coming to see me periodically, it does not affect his life. And that's good, I mean that's what I want!

As I tell patients (for instance for medicines), "I want your medicine to be something you take every day but it's not the focus of your day. The medicine works around your life. You don't work your life around your medicine. You don't work your life around your disease. You take your medicines every day. You make changes in your behavior. So you don't potentially transmit this disease to somebody else or you don't pick up anything else." But as I mentioned earlier, I still treat people on a regular basis for syphilis—so sometimes it gets through, sometimes not! If anything, ironically the people who are better educated, they're college educated, they're gainfully employed, are the ones that I treat more frequently for syphilis.

LB: How do you explain that?

BH: I'm not sure if it's the fact that they know what they need to be doing but they don't really think that it's an issue. I don't know... if someone who, I don't want to say "less educated," but someone maybe who has less medical resources, less access to education, less accesses to resources in general—would be a little more protective of themselves. Where individuals who are well educated, who have an awful lot of resources... Well, if something happens, they'll take care of it. You know: "We can fix this. It's not a big deal." But obviously, it's not quite what we want to be doing. It's better to prevent these kinds of infections than to have to keep treating individuals.

51:21

LB: So what have been some of your biggest turning points over these three plus decades? What are some moments that stand out to you? Where you could say things changed before and after?

BH: I think one of the major things, in terms of what we talked about earlier, are in terms of medications. In the beginning, we were treating with just one drug at a time. Then we realized that if we treated with three drugs at a time, then people did much better. And so we went from a disease of terminal illness to a chronic illness. As I tell people with hypertension or diabetes, "We don't cure someone with hypertension. We don't cure someone with diabetes. You take your medicines every day. You make changes in your behavior. And you live a normal life." Same thing with HIV. "You take your medicine every day. You make some changes in your behavior. But you live a normal life." I think '96, '97—the last twenty years, that's been a big change.

Before that I think – in an awful lot of ways when we found out that Magic Johnson was HIV-infected, it became a disease that people could relate to in a different aspect. And so I do think it's important when someone who, has a national, international, kind of recognition, does something in terms of the field of HIV. It kind of brings it back and people start talking about it again. When Magic Johnson came out and told everyone he was HIV infected, and that was in the early 90s, and then when we had the three drug therapy in 1997 and for the last twenty years, every once in a while, it will make the news. There's an international AIDS conference that occurs every two years. So whenever that's going on, you hear about it in the news a little bit.

But I think unfortunately our society in general has become a little apathetic about the whole disease in general. It's no longer "The Disease of the Day." It's no longer the topic of things. In some ways that can be good that it's not something someone's talking about and fearing like they were twenty, thirty years ago. But I think also, unfortunately, people aren't aware that it's out there. And people aren't taking necessary precautions. Even in the medical field I still occasionally get patients who when they tell their other provider they're HIV positive—everything changes. I remember one female patient I've been taking care of for over twenty years, when they found out she was HIV positive, she went to her gynecologist. Her perception

of his concept of her was—I don't take care of those kind of patients. You're not one of those individuals. You're not at risk. And so she didn't get tested. I think there's still the perception, not just in the general population, but in the medical population, that it's still us and them. People still get treated differently.

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Whenever one of my patients tells another provider they're HIV positive, the whole conversation changes from that point on. Unfortunately, some of the patients then learn very quickly: "We just don't tell them." But I try enforcing them, or empower them, to be able to tell somebody else. Because it does make a difference. If the other provider knows you're HIV positive, it may be something they might be looking for they wouldn't look for ordinarily. Or help to educate you in terms of things—that it's important for everyone who's providing you care to know what you're taking, what's wrong with you and also what medicines you're taking. Because then unfortunately what happens is they don't tell them they're HIV positive. They don't tell them what medicines they're on. If the other provider prescribes you a medication, there potentially could be a drug interaction with the medicines I'm prescribing you, which could be very dangerous. It's for the patient's best interest to tell the other providers #1: They're infected... But just as importantly, what medicines they're taking. Because there are drug interactions that occur, that either can decrease the effectiveness of your HIV medications and cause problems with your HIV—or it could interfere with how the other medicines work on your body, which could cause toxicities or other health issues.

LB: So, it sounds like it's a really strange kind of double bind, where on the one hand HIV has become normalized to the extent that people forget about it, but on the other hand there is still, in the back of even healthcare providers' minds, a kind of stigma. So it must be a very strange universe that your patients inhabit.

BH: Right. They kind of learn on an individual basis how to maneuver through that world... to their best interest.

LB: And what kind of strategies do you see for that?

BH: Sometimes they'll only come and see me. And as I tell my patients, "I would not come and see me for diabetes. Please don't expect me to be your diabetic provider. I can take care of your HIV and I can take care of some other things," but then it doesn't always become in the patient's best interest. And then sometimes they'll let their problems progress further than what they need to because they haven't addressed those problems. It makes it difficult for the patient sometimes. If they told their dentist and their dentist interacted inappropriately—well then, they're not gonna go back to see the dentist. Well you're gonna have the same problems everyone else has. You need to see the dentist every six months. There are things you need to do to take care of yourself. You need to take care of your whole person. We're not just taking care of your HIV, we have to

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take care of the whole body. We need to look at this holistically. So you need to take care of other health issues just like people that aren't HIV-infected. Also what happens on the same lines is, if they do see another provider and they have a problem, an awful lot of times the provider says, "Well it's related to HIV, go talk to your HIV provider." No it's not related to your HIV! It's related to other things that occur because of who you are and your other health problems. You can't blame everything on your HIV.

LB: That's interesting too. That's very interesting. If you could say one thing to the general public about HIV what would it be?

57:25

BH: I think the major thing is—it is preventable. But even though it's preventable and we have much fewer people getting infected now, there's still thirty to forty thousand Americans that become infected every year. Every year. Which means someone's getting infected every ten to fifteen minutes. Right now we can't cure the disease but we can prevent the disease. And as I tell patients and tell other individuals, "There's only one person who's going to protect you in this world. And that's you. And so if you don't take steps to protect yourself, and consequences occur, you can't blame somebody else for what happened." I think the major thing is, it is a preventable disease. Try and make changes in your behavior. No one's expecting you to be a monk and not interact with other people. But you can live a normal, healthy life, whether you're infected or you're not infected, and protect yourself, and protect the rest of the community.

LB: Good. Is there anything I didn't ask you that you'd like to talk about? Or that you think I should ask other people? Again Bob, you're my guinea pig.

BH: Okay. [long pause, Bob thinking] I think kind of along the lines of what we were talking—what as a society do we need to be doing differently to help educate the youth of this world? The patients I take care of in their fifties, most of them became infected before we knew about HIV. But those in their twenties and thirties, we've known about HIV. So obviously we're doing something incorrectly. Because those individuals are still becoming infected. What can we do to make this something that as a society we can talk about more openly and more freely without being judgmental.

I'll try and make sure I say this properly... I think as a society, unfortunately, not all the people but a significant number of the people and a majority of the people who are HIV infected are considered at the peripheral of society. An awful lot of times, that demeans their value in our community and so they are dispensable. What do we need to do as a society that would equal more value in everybody's life, [such] that some people weren't more valuable or more important because of either who they are, where their position is or their family is... You hear about bullying in high schools and colleges and the kids that commit suicide, or those kinds of things, because they're being mistreated by people that ideally should be, if not friends, at least

their community. But what are we doing as a society that we're not valuing everybody? And really doing our best to try and help everyone become the best person they can be? Under whatever the circumstances may be.

1:01:44

When I worked at the prison, some of the inmates I talked to, we talked about their lifestyle. And I'm thinking: if I was born into your environment—would I be any different than who you are? I was fortunate enough that I grew up in a middle-class neighborhood in a middle-class family. There were some things that I never really questioned. But if I was born into a different family, a different environment... A friend of mine, she adopted a baby, and the girl is now in her twenties. But she went back to visit her family just recently, her birth family. They live in a trailer. They're on welfare. She's gone to college. She's well-educated. If you look at someone's environment... If we do something to people's environment, then we can make that person so much... Not that they're more important, but they could be much more productive and be able to accomplish more, if we just did a little bit more to kind of help people. I guess that's my soap box for the time.

LB: It's a good soap box. It sounds like one of the things that you're really stressing is that HIV is almost our societal "canary in the coal mine."

BH: Yeah, that's a good way of putting it. Yeah. It kind of brings up the values of our society, and maybe what we could do differently to try and not just improve the lives of people that are infected, but hopefully in the process improve our community at large.

LB: That makes a lot of sense. Thank you so much, Bob.

BH: Oh! You're very welcome. This was good! I liked this. And you're very easy to talk to.

LB: Thank you.

BH: But you've been doing this for a long time in other fields so I'm sure you've gotten comfortable with making other people comfortable.

LB: Well, I just enjoy it a lot. I feel like I learn a lot every time I talk to someone. But thank you, you've been a great first interview.

BH: Oh, okay, well thank you. And thank you very much! [to videographer] Hopefully everything was okay from your perspective.

[video skips time]

BH: And no one knows.

LB: That's the thing that's stunning. Right? That is *still* so taboo. It's so routine and so taboo at the same time. And that seems very complicated.

BH: And then for the patient, I mean, I have patients who purposefully come in and see me at 7:30 in the morning, first patient of the day, get in, get out, no one sees them.

LB: Yeah. I could see that. I could absolutely see that. Rodney was telling me about someone he sees who lives across the street from the only clinic in Church Hill that provides AIDS treatment and will not cross the street. So he's dying because he's choosing not to get treated.

1:04:01

BH: I have people who drive from Charlottesville. There's a clinic in Charlottesville and they come down here because they don't want anyone to see them.

LB: That's super interesting... Well thank you, Bob. I think I'm gonna go and find Rodney because I think he's next.

BH: I think Rodney's next. Thank you!