

NC Crossroads

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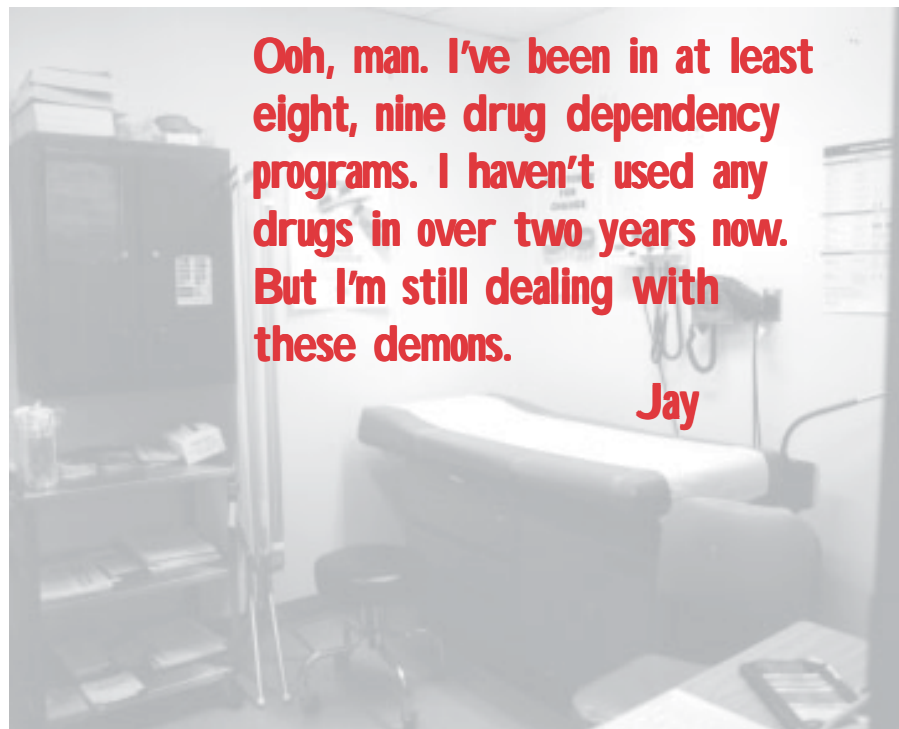
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WHOLE LIVES: Reflections on Living with HIV

“I’ve been through a whole lot. I’ve been in and out of jails, I’ve been in and out of hospitals, I’ve been through a lot of hurting and a lot of pain. What good does all this do me when I see other people out there suffering, and I got all this vital information, and not telling anyone about it?”

Johnnie Robinson



For the last year, Johnnie Robinson and four other HIV-positive men—clients of the Durham County Health Department’s Early Intervention Clinic—have shared stories of their lives in oral history interviews and group life review sessions as part of the Durham HIV Life Review Project. Jennifer Sosensky, a social worker at the clinic, conceived of the project to provide opportunities for people with HIV to create a lasting record of their lives in a culture that often devalues or misunderstands their experiences.

Jennifer began by identifying eight potential participants, both men and women, black and white. Some who had expressed initial interest found the logistics of the group meetings hard to manage—such as transportation and time conflicts. Some seemed reluctant to address the personal material the interviews raised. Others feared that the public dimensions of the project might compromise their privacy or that of their families. Ultimately, five men elected to join the oral history project. Three of them agreed to work also with photographer Abigail Blosser to create a visual autobiography of their lives.

The five men who did participate had all reached a point of acceptance of their HIV status and felt comfortable talking openly about their lives. Yet participation still posed tremendous challenges: all had to balance the interviews, group meetings and photography sessions with more pressing demands, such as childcare, doctor’s appointments, and the health emergencies of loved ones. Over the course of the project, the participants—like many with HIV—contended with multiple health problems, including heart disease, diabetes, and high blood pressure. In January, one participant was diagnosed with inoperable lung cancer, and another awaits biopsy results on a tumor. Four participants changed housing situations within the last six months; one of them is now back in prison.

To date, the project has generated more than 25 hours of taped oral narratives. We could only select a handful of stories for inclusion in this publication, and space limitations required us to tighten the narratives considerably. We tried to respect individual narrative styles, but in some instances, we re-sequenced material within a single narrative to provide clarity or context for the story. The participants helped determine which themes this publication should explore and also reviewed the final excerpts.

These narratives may seem to impose a kind of false order and seamlessness to the tellers’ lives. Yet the purpose of life review is to engage individuals in storytelling in order to give form and meaning to the past. The men who participated in this project recognize that everything in their lives is not always okay. At the same time, they see meaning in the experience of having HIV. While they may or may not be typical, they acknowledge that for them HIV, though unwanted, has brought gifts. They hope their stories will make a difference to kids and adults grappling with tough issues like drugs and sexuality. All of us hope that the narratives allow listeners and readers to encounter individuals living with HIV as whole people, with a diverse range of goals, fears, and life experiences.

Andre

My name is Andre. And I was born in September of 1967 in a rural North Carolina community. I come from a family of teachers—my parents, my aunts, uncles, great aunts—just a whole family worth of teachers. I was the oldest of five children and my parents brought me up in the Baptist Church. Discipline was important to my family from as early as I can remember. We were always taught to be very mannerable and respectful of others, of our elders.

I grew up in a very protected environment. And being that we were from a small town, I didn't get to experience a lot of the things people from larger cities experienced, until I got to college. I went to North Carolina A & T. That's when I was first introduced to people who did drugs. I personally never experimented with drugs and I never had a desire. And I thank God that drugs and alcohol were never part of my life. For me, I count that as a blessing.

But during my college years, I was gradually coming to know myself. I had suppressed some feelings or emotions I had all my life, emotions of being homosexual. I did not come out to anybody, my family, friends or anyone, until my senior year in college. When I finally did admit it to myself, I still didn't come completely out to everyone at that time. Being brought up in a religious environment, it was kind of hard for me to deal with being gay.

Over time, I gradually accepted who I was and I learned to live with it. But there were times when I would have brief encounters with other men, which I believe is how I contracted HIV, through unprotected sex.

I've been living with the virus since 1991. And for me, everything has been like a learning experience. Sometimes I look at the HIV that I do have and I come to realize that God has a purpose for all of us. I feel that there are ways that God can use me to help others to learn about themselves, to keep from getting the virus.

I really still do admire my father a lot. He's a deacon of a church, he's father of five, now a grandfather of five, he's just accomplished so much. And I always wanted to be just like my daddy and follow in his footsteps. He owned his own house by age twenty-eight. It's fully paid for now. And so I went to school, and I tried to do my best to excel in everything. After I finished, I got a pretty decent job, but I wasn't quite on the road that I wanted to be on. And when I got hit with HIV, that detoured my plans a little bit. I planned on working until I was maybe sixty, sixty-five years old, retiring in style, putting aside money and everything. And HIV, when I got hit with that, I worked as long as I could until the symptoms started becoming overwhelming, and I just had to stop. So stopping work for me was the biggest change that HIV has had on my life.



Jay

You know what separates your lifestyle and mine is choices. You made some good choices in your life. My choices was kind of screwed up. It's all about choices.

I remember the day that I dropped out. Like I said, by hanging with these negative people, I guess demons got off in me. I became cold to everybody. I looked at my mother like it was no big thing. I just couldn't help it; I was out of control. She had set up interviews with psychiatrists and all this, because this was like an overnight change. Here's a guy that could have gotten an academic scholarship. And I'm just throwing this away.

I walked away from school as if it didn't matter. And I moved to New York, and for two years straight, all I did was run in the street, hustle, shoot dope, stick up. Whatever it took to get a dollar, that's what I was doing. Until one day, it dawned on me. I went back to see my brother. And my mother wouldn't allow me around him. She said I was a bad influence. And when I started seeing my family, the way they looked at me, as if they were looking at a total stranger. You know? I moved back to Stamford, I enrolled back in school. But as soon as I graduated, I'm right back at the same thing. Ever since then—I'm talking from 1966 up until the present day—I still have those demons pulling at me. Because of those things I allowed myself to become involved with when I was a kid.



I've been in and out of institutions. Ooh, man. I've been in at least eight, nine drug dependency programs. I haven't used any drugs in over two

years now. But I'm still dealing with these demons.

My wife, my kids, my grandbabies—they're a very big part of my life. They won't let me slide. I might slip, I might get a beer, and then when I look at my kids and my wife, I can see the fear in their face. It's like I've got to walk the straight and narrow and try to be the person that I know my wife and my kids expect. But deep down inside of me, it's a struggle.

So basically that's my story. Everyday I live with fear. Not for myself, because I've done mine. I had a lot—there was a lot places you could turn to during those times. They had the Boy's Club, they had the camps, they had the neighbors. But now you have none of that. And it scares me to think that kids growing up in this environment with nobody out there to help them—so many of them falling through the cracks. I just pray to God that somebody intervenes and helps those kids to get what they really need. Especially mine. Like I said, I can talk to them 'til I'm blue in the face. But I've learned through experience that it doesn't always work.

Center for Disease Control National AIDS Hotline 1-800-342-2437

North Carolina STD/HIV Control Branch

1-919-733-7301

Or contact your local chapter of the American Red Cross.

Willis

I just wanted to keep it to myself, but at the same time, one morning I woke up and, you know, here it is. Hey, you got AIDS. You're dying. I said to myself, well, you know, you're not even giving yourself a chance. You're not even fighting back at this thing. So I called the AIDS Hotline that day, talked to them about it. . . .

At first my father didn't want to believe it. He had watched a show on TV about HIV in Africa one time, and he had seen how these people were just dying so bad and so rapidly. It scared him to death. And so when I told them, it really hit my dad hard. He didn't want me in the house with them, he didn't want me to use the same utensils, like food, glasses, plates, he just didn't want me near. He didn't want my mom near; we'd get in arguments, he'd accuse me of coming to kill them, because I was around them and had it. That I didn't care about them, you know, and things like that. Which used to bother me. But now, that was just another challenge I had to face. I had to get my dad educated, and my mother too.

So I got some pamphlets and some information from the AIDS Hotline, and I had it sent to my mom and dad's house. And my mother got it, and my mom actually started reading it. So I guess when she started letting him know how the virus really was and how it was transmitted, he kind of opened up and he eventually hugged my neck and told me that he

was sorry, that he didn't know, but he wasn't taking any chances. That he was sorry that I was in this situation and everything, and that he would support me. And they did come to Duke to see the doctor with me one day. At that point, they wanted to come up and see what the doctors actually had to say. I guess that was the real turning point in my life. Because, with my previous story, you know how abusive and how things was in my family, with the alcoholism from my father. For the first time, he was showing some kind of care. I hated that it had to actually be something to bring our family together, but I was enjoying it at the same time. You know?

1990—that's when I found out. When I first accepted it, it was probably 1993, 1994. It took me until I woke up that morning and looked at the ceiling and said hey, you got to do something about this. You can't just lay here like it's not there.

WHAT IS HIV?

HIV means Human Immunodeficiency Virus. HIV is the virus that causes AIDS (Acquired Immunodeficiency Syndrome). HIV damages the body's ability to fight off diseases. This damage leaves the body open to attack by infections and cancers that are not usually a threat to people who do not have HIV. There is no cure for HIV. Once someone is infected with HIV, they are infected for life and can infect others. People who have HIV can be infected for years before they get sick. However, symptoms or infections that range from mild to severe gradually develop and progress to AIDS.

HOW IS HIV TRANSMITTED?

You could be at risk if you have sex or use drugs.

You are at risk for getting HIV if you ever get blood, semen or vaginal fluids of an infected person inside your body.

HIV is transmitted by:

- * having vaginal, anal or oral sex, especially without a latex condom/rubber; or by
- * sharing needles while injecting drugs, including steroids.
- * A woman can give the virus to her unborn child before or during birth, and sometimes through breast milk.

YOU CAN'T GET HIV FROM CASUAL CONTACT.

HIV is not spread through the air, by insects, food or casual contact.

You cannot get HIV from:

- * handshakes, hugging, or casual kissing;
- * sneezing, coughing or spitting;
- * dishes, utensils or food handled by a person with HIV;
- * bathtubs, sinks or toilet seats used by a person with HIV; or
- * mosquitoes and other insects.

Information taken from: "What Everyone Should Know about AIDS," a flyer published by the North Carolina Department of Health and Human Services HIV/STD Control Branch.

Johnnie Robinson

When I learned first that I tested HIV-positive, my response was that this was the end of me. And I'm the type person that takes the bad with the good. I knew I had it before the test even came back, because prior to that, I was in a shooting gallery where three of the guys were already dead from AIDS, and they were active with me shooting drugs at this particular time. Not that I used the needle behind them, but you would get so high, you don't know who's needle was you using—yours or somebody else's. And you'd lay it down to go to the bathroom, somebody would use it, then you'd take their shot with you. And another reason I knew I had it was because I was very active sexually.

What did I know or think about HIV prior to learning about my condition? Well, I thought it was something that was very, very bad to have, that it would kill you, and that upon getting HIV, and getting the AIDS, you were automatically dead. In other words, I thought it was a death sentence. But I guess I was a little ignorant on that part, because I found out that you can live a productive life, you know, if you do the right things that you're supposed to do and take care of yourself. I found that out.

This may sound strange—in some way, having HIV may have very well saved my life. Because I had no intention of stopping until I got sick. What I'm trying to say is, this HIV maybe prolonged my life further than the way I was going, because I was a time bomb ready to explode any time. I was shooting so much cocaine that I would pass out on the floor for hours and wouldn't even know where I was. I would get one shoe off, and when I'd wake up the next morning, the other shoe would still be on; I don't remember anything.

It was twenty-seven years I did solid drugs. Twenty-seven straight years up to the time I quit two and a half years ago. In twenty-seven years I could have been a master carpenter, one of the greatest chefs that ever lived, a preacher.



This is where I'm at in my life at this particular point. I like talking about the disease, like talking about the drug addiction. I want to spread the news, because I know it will help. It can help somebody else. Where they maybe won't have to come to the point that I came to, and can spare them some pain. And that's what I feel that God wants me to do. He doesn't want me to sit down on this!

I asked God to keep me around to see my small children graduate from high school and college. If it wasn't for the HIV, I don't think I would be here now. Matter of fact, I know I would be gone.

Lawrence Ridgle

HIV for me? I was detected in 1984. And I don't see why half of Durham isn't HIV. Because there was a lot of people that I knew that was active with each other. Not only sharing needles, but they're telling me that you can get it from sharing cotton, sharing cookers, sharing other paraphernalia. And I know we've all done that.

I've had a lot of friends that's died. I've had a lot of friends that's been awful sick. They lose weight, lose their hair. Some of them went blind. And I'm talking about people that was very close to me in our little circle.

If I had to speak to a bunch of youngsters or somebody who was going to venture on this same journey that I've been on, I wouldn't tell them not to do

it. Because it's been my experience, every time somebody tells me, "Don't do this," or "You can't do this," this is exactly what I want to try. So I wouldn't tell them, "Don't do it." But I would like to tell them about all of the pitfalls that could happen to them if they did it. Whether it be HIV, some policeman shooting you down, OD-ing with drugs. Those are pitfalls out there for you if you take that drug route.

I've always known that there was a God, but for a long time, I didn't think he cared nothing about me. HIV has made me really look at myself. It made me realize that something other than myself has kept me here. For what, I don't know yet. But I know it has put me closer with God. And it made me be more thankful for all the little things that I used to didn't even see. Like people trying to help me.



I wish I didn't have it, but by having it, it ain't did me no worse in life than what I did to myself. At least today, I can look at myself and say, "I ain't did nobody wrong today." Today, I got people in my life who care about me and prove it in more than one way. And they do it just because it's me. Four or five years ago, I couldn't feel things like that. Some people say, "Man, you're a crybaby now." I couldn't cry five years ago! I didn't hurt; I didn't have no feelings for nobody else but the drugs. But today I do have feelings for people, because I don't play con games no more. I don't steal. I don't rob no more. And today I can look at a police officer and feel good that he can't touch me.

Did it take all of this to make me become human? Or to feel human?





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Audiotapes and selected photographs will be on deposit at the Southern Oral History Program, Wilson Library, University of North Carolina at Chapel Hill.

Number of AIDS cases in NC through 9/30/99*

White	33%
Black	64
Hispanic	2
American Indian	1

Method of Transmission

Men who have sex with men	36 %
Injecting drug use	23
Heterosexual contact	14
Men who have sex with men and inject drugs	5
Receipt of blood, tissue	2
Hemophilia/coagulation disorder	1
Not reported/other	18

Age of People with AIDS

Under 5	1 %
5-12	0
13-19	1
20-29	19
30-39	46
40-49	25
Over 49	9

**The numbers above do not reflect the total number of people who have tested positive for HIV in North Carolina, only cases that have progressed to the point in the HIV disease where they are diagnosed with AIDS. Statistics from the NC HIV/AIDS Control Branch of the Department of Health and Human Services.*

NC CROSSROADS is a publication of the North Carolina Humanities Council (NCHC). Serving North Carolina for more than 25 years, NCHC is a non-profit foundation and state-based affiliate of the National Endowment for the Humanities. NCHC's mission is to support public programs that address fundamental questions about who we as human beings are and how we can live together in the world we share.

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