Talking ’Bout Their Generation

Young, positive and proud: The new faces of AIDS activism send you back to school

September 1, 1998 By Kevin O'Leary

Being HIV positive is hard enough. But being HIV positive and young, when everyone around you seems to be taking life lightly and looking eagerly toward the future, is perhaps even harder. In May, POZ *invited eight young HIV positive activists from around the country to sit down and discuss their fears, needs and hopes.* POZ *Senior Editor Kevin O’Leary moderated*.]

Bill Barnes, 21, special assistant to San Francisco Mayor Willie Brown. HIV positive for five years.

Brett VanBenschoten, 25, project assistant with Health Initiatives for Youth in San Francisco. HIV positive for eight years.

J.J.*, 19, peer educator and consumer advocate from Fort Lauderdale, Florida. Mother of two. HIV positive for two years.

John*, 24, adolescent counselor from Philadelphia. HIV positive for eight years.

Raymond*, 19, educator with CHIRPY (the Chicago HIV Reduction Project for Youth). Originally from the Caribbean. Tested HIV positive in February.

Scott Brynildsen, 21, peer coordinator with Seattle HIV positive group. HIV positive for more than a year.

Shay Barnette, 25, special events and outreach coordinator for HIFY (Health Initiatives for Youth) in San Francisco. HIV positive for five years.

Tina*, 24, peer educator from the Bronx. HIV positive for eight years.

*Note: The participants marked with an * requested that their real names not be used. They said that they were not yet out as HIV positive to their families, coworkers or friends.*

Kevin: I know Bill was going to ACT UP meetings at age 13. To what extent were the rest of you aware of HIV as you were growing up?

Brett: I knew about HIV before I even knew I was queer.

John: Before I had HIV, I had heard nothing about it. At the age of 15, I caught a sexually transmitted disease (STD). I heard about the Philadelphia Department of Health giving free STD testing, so oneday after school I decided to go. I gave them my name because I didn't know any better. When the guy called me back, he told me to pull down my pants. He pulled back the elastic of my tighty-whiteys and said,"You have crabs." Then he asked if I wanted an HIV test. "Oh, sure."Here I am, 15 years old, and he does not take the time out to explain what HIV is.

So they drew the blood and told me to come back in two weeks. I never went back because I didn't see the importance. So, about a month later, *they came to my house*. Three o'clock, broad daylight.They buzzed our apartment. I lived on the third floor, so I looked out the window and I see this big, yellow truck. I mean it was like cheese-bus yellow, and on the side of the truck it says, "Philadelphia Department of Health" in big, blue letters. First thing that came to my mind is "Death is coming to get me!" I went downstairs to let the guyin. He asked me my name and I told him. "Do you recall taking an HIV test, John?" I nodded. So he told me I tested positive for the HIV virus. I'm like, "All right." No questions, nothing. He asked me, "Do you want me to tell your parent or guardian?" and I said sure. So my grandmother, who was about 67, comes downstairs and he tells her. I received no pre- or post-test counseling. He didn't give me any resources. My grandmother told me that if I took some pills it would go away.

Raymond: I went to get tested when I got checked for crabs, too. I knew what HIV was, but people in the Caribbean don't speak of it. They don't want to know about AIDS.

They don't want to know about homosexuality. They say, "The tourists bring those things to our country and they take it home with them." But when I found out I was HIV positive, I didn't take it like a death sentence. My sister was crying and crying. My brother told me that if he found out he was HIV positive he would go out and have sex with a lot of girls. Crazy stuff.

Bill: I tested and they were like, "OK, you're going to die now, so go off and live your life." It was well-meaning middle-aged people with master's degrees who wanted to make sure that I didn't miss out on my life. I always wanted to go to school to be a filmmaker or TV anchorman. But in reality, I graduated high school not expecting to live another four years. I haven't been on any meds yet, and it's been five and a half years so it's like, "Oh, you all lied to me."

But you know, there's a benefit to being a young person with HIV. It helps me get entrée to jobs that I'd probably need a college degree to get otherwise. But I think I'd be taken more seriously if I had a college degree. I don't want to blame HIV for anything that's happening in my life, but it did throw me off the track to success that I was on.

Shay: When I found out, I thought I was just a faggoty-ass kid with a faggoty-ass disease. I thought I was going to die in like a year or two. But I'm 25 now, and since I'm here, I have to deal with things in my past. I was raped in jail by seven guys; two of them were positive. I was always pushing the memories back because what was the point of dealing with it if I was going to die soon anyway?

J.J.: People say, "At least you found out in 1996 when HIV was more open." But this was my first

year in college and I found out through my second pregnancy. I had been taking Depo-Provera [a birth-control treatment]; I didn't know I was pregnant. So by the time I was eight months pregnant, they were telling me I was gonna have a deformed baby with one leg and all types of crazy things. I was in hell. The prenatal care people had also said it was mandatory that I take this HIV test. I'm like, "OK." I had an HIV test with my first child, so I'm thinking everything's fine and dandy. So I went back for an ultrasound again; forgot about the test. This lady put me in a room right next to the waiting room, and she said I needed to sit down for this. I'm thinking I have chlamydia. She looks at the chart and says, "You got HIV." I said, "What?" Then she's all, "You heard me, you got HIV." "What the hell you mean I got HIV?" So I went up on her and I threw all the shit off her desk. I tore down the whole place, and she was telling me to calm down. So I said what I had to say to her and she said she understood. "You understand? What the hell you understand?" And she was like "I see this all the time." And I was like, "You see it but you don't feel it!" She goes, "So how do you feel?" I was like "I feel you better get the fuck outta my way, lady." I stormed out of her office and the hospital. It was on a main road. This truck was coming and I got ready to just walk right in front of it, I swear to God. But the lady from the clinic ran out and she was like, "Oh, wait a minute! You forgot your meds." It was some iron because I was anemic. So the lady was like, "Come inside," and she talked to me some more about what I should do.

Scott: Before I tested, I read up on the symptoms in the library. "Check, check." I figured there was only one way to find out, so I went to get tested. They said to come back in a week. I spent most of my nights writing letters to my family or calling and saying, "Hey, I'm testing, and I don't think the outcome is going to be very good." And Mom said, "Oh don't worry, just come back with good news." So a week later I went in and said, "I'm positive, right?" and the counselor's like, "Yes." I said, "OK, what now?" And she goes, "Let's take a moment to reflect."

[Laughter]

"I've been reflecting all week," I said. "I make a funhouse look stupid." She gave me a booklet. I opened it, and it says "Welcome to the world of AIDS." Like it's some fun forest or something.

My family asked what they could do for me. I said I wanted them to educate themselves. I don't want to feel like I have to diagram everything like *Win, Lose or Draw* when I talk about a CD4 count. So, my mom has now surpassed my knowledge by reading every book in the library and advocating for everything.

Kevin: Your mom rocks. Those of you from the big cities, do you find that your experience with disclosure has been better than your rural counterparts?

Bill: The discrimination is still there. If I'm out at a bar trying to pick somebody up, people ask, "Are you clean?" What does that mean? And I chose to put my status out there so I have to take the ramifications of it, but some days it's a little disconcerting to be on the muni [bus] and have somebody say, "Aren't you the AIDS boy on the cover of *The Bay Area Reporter*?"

Brett: I went through an AIDS poster-boy routine to guard against discrimination. Hell, I'd meet a total stranger and the third sentence out of my mouth was "I have HIV."

Bill: I would just have all sorts of drama and think it was like a major sin if I had unprotected sex with someone who was HIV negative. I don't feel that way about having sex with someone who's positive. It's cool that you can date someone and have a normal sex life like it was before AIDS, but the medical issues make it kind of sketchy. I certainly learned my lesson because, in having unprotected sex with someone who's positive, I got a really nasty STD.

The other weird thing about dating someone with HIV, it's like, "Who's going to die first?" My boyfriend and I have conversations about who will take care of the other one. I have an ex who, while we were dating, was undetectable with 600 T-cells. A couple of months after we broke up he plunged off the charts and had AIDS.

My point is that if I date someone who's HIV negative, then it's only my issue, and I can work through that. When HIV is our issue, it gets a whole lot more complicated.

Kevin: I see we're now talking about the L-word. You're all so damn cute that they must be banging down your door. Do you have a preference of positive or negative?

John: I've never dated anyone who was HIV positive to my knowledge. It would make my life a lot easier. I still wouldn't have unprotected sex though, because I have this thing about me being at 600 and my partner being at 150. If he brought my T-cells down, I would feel some kind of way about that. It'd be good, too, because then I wouldn't have to hide my medication. If I felt ill, I wouldn't have to lie and say, "I'm coming down with this cold." I've only told one of the people who I was with -- my last boyfriend. I told him that I was HIV positive but I lied about the process. Oh, this lie was magnificent! One day I went to the doctor and they drew blood. They gave me a Snoopy Band-Aid that I liked, so I kept it on. So he asked me about it later. I thought real quick and said, "Oh, I just got tested for HIV." Mind you, I had been HIV positive for seven years.

[Laughter]

We had this big old discussion where I asked, "If I come up HIV positive, would you be there for me?" And it took him by surprise, but he said, "Yeah, I would." So I said, "OK, I'm going back for my results in a week." Since I work for a medical facility, it was very convenient for me to go to work, then come home and say, "Well, you know I went to the testing site and I got my results. I'm positive." So he got tested. He came back negative. We had already been in a relationship for about two months and he probably thought he loved me, so therefore he felt as though he couldn't leave me in my crisis. So I played on it and we stayed together for a whole year after that. He didn't like to use condoms and I kept saying we needed to but he was all "I *love* you." So I was in a sticky place. We did it twice without condoms and then my conscience kicked in and I just couldn't do it anymore. I would not be able to sleep at night if I gave him HIV.

Tina: I did what you did. It was horrible. I told my boyfriend that I wanted to get tested and he went with me. I cried and cried. Same thing as you. I worked in the place where I took him, and they played along with me. I cried hysterically, but it was out of fear, because I thought, "This guy is going to kick my ass when he finds out." After I found out, he was open with me. He said he was scared but that he was going to try it out.

John: Like a shoe.

Tina: Then three months later with no warning, no nothing, he just left. It hurt like hell. I was alone for five years. It's really hard for me to tell anybody that I am positive because I just don't think I could go through it again. I can't. It took a long time to get back my self-esteem. To actually look at myself like a woman and think someone would want me, you understand? It just drains you.

Brett: What you guys were joking about is what I went through. I'm positive because I was in love. It was more important for me to be close to somebody than care about what might happen to me. What's worse is, I have an ex who is HIV positive now because he thought the same thing I did. I carry that on my conscience now.

Bill: For me, sex wasn't the thing, it was the intimacy and wanting somebody to love. I should say quickly that I got HIV from somebody my age. In high school, I would never fuck around with kids with a condom; I would only use a condom with older folks. I had been educated through ACT UP and that's what you were supposed to do. It never occurred to me that this 15 year old who I was in love with could possibly have HIV.

Shay: The year before I got tested, I had slept with seven people. I had the chance to talk to two of them later. A girl and a guy, both positive. I won't say I felt like a murderer, but I changed two people's lives.

The relationship I'm in now -- he's negative, but he works in the field. We're totally honest with each other. I feel lucky 'cause I'm with a person who will be there for me.

J.J.: I had someone who loved me and accepted me, but he just recently passed away. He did not die of AIDS. He was killed. I miss being with someone. Not only the sex -- but having someone by my side. And I've been rejected so many times because I don't feel comfortable unless I tell the person that I am positive. I'd like to hide, but I can't.

Brett: Yup. I cannot imagine *not* telling somebody I'm positive. I'm single now and it's by choice, *POZ* readers. One of the reasons why I'm positive ties into wanting to be with somebody. That never went away -- having HIV just kind of complicates it more. But I won't date outside my status anymore. My last relationship was with somebody who was negative, and no, we did not always have safe sex. When he got tested, I was just as scared waiting for his results as I was for mine.

Scott: I used to have this funny theory that people mature with age, but that was shot to shit way back when. I've lived more than the 30 year olds I know. For a while I wanted somebody older, but then it turns out you're just a trophy. And I don't want somebody my age because there's not many people at the same maturity level. I don't want to sit there and talk to him about Beavis and Butthead or his rad skateboard.

Bill: What I've learned in the AIDS community is that there are a lot of people who talk the talk but they don't walk the walk. And people can say they understand how I feel or they're working on my behalf, but OK, let's look under that and see what you're actually doing. Sometimes I get hit when

I ask people questions like: “You say you’re doing this work for young people with HIV, and how many are actually on your staff? And why is that? And why do you take money in my name when you don’t hire people like me?”

Brett: I don’t want anybody saving me.

Bill: And I don’t want to be president of NOW just because I have friends who are women.

Tina: I get pissed off when people say to me, “If you do not disclose, you cannot be a good educator.” Kiss my ass. I’m the best educator that my site has. And I bust my ass to get the resources to everybody out there. But my weakness is disclosure. Growing up in the ghetto, you do not trust. I have always been a leader. I was a leader of those gangs. That’s not hard for me to do. Trusting is. I’m not going to trust someone with my status because they say they should have my confidence.

And you can’t judge me because I don’t disclose and you do. If you think your life story is going to help someone, that’s fine. Nobody needs to know mine. It won’t stop anyone from catching HIV, because they’ll say, “Well, that happened to you. That ain’t gonna happen to me.” I will say that I am proud of every person who has the heart to get up there and say that they are HIV positive because that takes a lot of courage. But not everybody has to.

Kevin: Let’s talk about care, services and medications.

Tina: I’ve never taken medication.

Shay: You go, girl. Me neither.

Tina: But I still find out as much as I can and I talk to other youth. I hear all these different things about side effects -- it scares me half to death.

J.J.: Especially that rash.

Bill: Buffalo hump.

Brett: Can I just say that protease inhibitors are not God’s gift to positoids? In eight years, I’ve been on and off meds a couple of times. The first set made me unable to go out in public. You know, one end or the other.

Currently I’m on two medications plus a couple of prophylactics. I’ve got an undetectable viral load and the T-cells have been holding steady for over a year. So I’ve got no problem with the *concept* of medications -- it’s the taking them. I’ve always got to have a backpack. I’ve always got to have my pill container with me. I could leave it at home, but I’m sorry, I’m 25 years old, I don’t always know that I’m going to be sleeping at my house.

John: Right.

Brett: It's frustrating to feel like it's in your face every day.

Bill: Not to bring up old memories, but everybody I knew who was on AZT monotherapy is dead. I don't know a lot about meds, but I know that once you get resistant to one of the classes of drugs, you're pretty fucked. So I want to wait until there are as many drugs available as possible before I start. People want to force folks on meds, especially young people. And at some point, you have to accept about HIV that there is no answer. Most of the time, people die with this thing. I don't want to say people who are taking meds are in denial, but do meds prolong people's lives in a quality way?

Shay: I took AZT and 3TC for a year and a half of my life. I went from being this vibrant, energized young man to being some couch-motherfucking-potato. I felt like shit. I don't want to go through that. I'm 25, I have a life. I don't need to be running home to take the medicine in my fridge -- right at 12 o'clock not 12:05 -- and then have nine, ten bottles I have to choose from at night.

Tina: Not too long ago my viral load went sky-high and my self-confidence was going lower and lower. They were trying to talk me into taking medication. I refused it. If I'm already stressed out, the medicine's going to stress me out more. I'm gonna have to make sure that I remember that I have to take these pills at a certain time every day, otherwise I might get immune to the shit. I work and I have a big responsibility taking care of someone right now.

Raymond: I could not keep the Viracept down. If my body kept throwing it up, how can it be good for my body?

John: I must speak up for medication. My first protease inhibitor was Crixivan. It was like a miracle worker for me because I had lived four years without any T-cells at all. I had dementia, flat warts, thrush so bad you could scrape it and it looked like yogurt. I never tried AZT because a friend told me, "Don't take that stuff -- it'll kill you." I tried d4T by itself and it just didn't work. Then my wonderful doctor said to try this new protease inhibitor. It just seemed like I was doing the worst out of my whole clinic, so I was the first person on my site to try the protease inhibitor. In a five-month period my T-cells went from zero to 400, so I'm like, this is it. I was really dedicated to the regimen -- I broke my neck to be in the house, I carried it with me and it was excellent.

But then every magazine had a picture of Crixivan in it and that was a problem for me. All of my pills said Crixivan on them and I felt like if I lost a pill, everyone would know! So I wanted to change my medications.

Most people have not been as lucky as me. But I'm worn out on meds. I need a breather so I can live normally.

Brett: My teeth turned yellow because I've been taking Septra as prophylaxis for pneumonia for years. I found through my own research that antibiotics over a long term yellow your teeth. I want to look good but it's that or get pneumonia. I've learned to live with yellow teeth.

J.J.: I don't want to take them until I'm at a point of needing to. In October I was almost at that

point. I went to jail -- bam -- the state took my kids. But God was beside me. The charges got dropped and I got my kids back. So I can't get stressed now because that's what'll make my viral load shoot up.

Bill: You can get on all these drugs, but at the end of the day HIV will still progress in your body to some degree. No one's come out with a drug today and said, "If you take this, HIV will leave your body and you will go off, like, skateboarding.

Brett: They're certainly implying it.

Bill: They're sure as hell are, and that pisses me off.

Kevin: What message would you like to leave our readers with?

Brett: Don't ever underestimate us. I will be around for a while -- get used to it.

Scott: Yeah, I've got quite a mouth on me, so I think they're gonna hear from me. We have HIV but that's only one of the fires in our stomachs.

John: After eight years of this, I have finally gotten to the point where I feel like I'm living a normal life. I hardly ever think about being HIV positive, and before this I thought if I ever got to that point I would be in denial. But I can live with it. It's like having asthma. [*Laughs*] When people ask, "You have HIV, how do you feel?" I say, "I feel the same as you feel."

Raymond: For me the most important thing is hope.

J.J.: I don't know what to say but "Be smart, get educated, get tested."

John: J.J. was the only motivator!

Brett: Is there anybody we avoided stinging tonight?

Bill: Bill Clinton and Donna Shalala.

Group: [dismissively] Naaaaah.

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