CONFRONTING THE STIGMA OF HIV

BREAKING THE SILENCE ABOUT TRAUMA AND PTSD

PEER NAVIGATORS TELL THEIR STORIES

CONVERSATIONS
Doctors, peer counselors, and advocates share their experiences of life with HIV
1  GUEST EDITOR’S NOTE
Troubled waters.

FEATURES

2  A clinical view
A trio of HIV specialists offer their takes on HIV—then, now, and in the future.

6  Guiding lights
Three peer navigators share their own personal stories to help others with HIV.

10  Piecing the puzzle together
Is there a solution to HIV ignorance and stigma?

15  Breaking the silence
The insidious effects of trauma and PTSD.

18  Simply Rob
Advocate and artist, a man of words uses them to spread truth.

ON THE COVER
GINA BROWN PHOTOGRAPHED
BY TERRY GASKINS

THIS PAGE
ROB VASSILARAKIS
© EVENT PHOTOGRAPHY GROUP

FOLLOW US
ON FACEBOOK AND ON TWITTER (@POSAware)

WE READ YOU
COMMENT ON OUR ARTICLES AT POSITIVELYAWARE.COM

© 2012. POSITIVELY AWARE (ISSN: 1523-2883) is published bi-monthly by Test Positive Aware Network (TPAN). 5537 N. Broadway St., Chicago, IL 60640. TPAN is an Illinois not-for-profit corporation, providing information and support to anyone concerned with HIV and AIDS issues. POSITIVELY AWARE is a registered trademark of TPAN. All rights reserved. Circulation: 100,000. For reprint permission, contact Sue Saltmarsh. Six issues mailed bulk rate for $30 donation; mailed free to those living with HIV or those unable to contribute.

A model, photographer, or author’s HIV status should not be assumed based on their appearance in POSITIVELY AWARE, association with TPAN, or contributions to this journal.

This special supplement of POSITIVELY AWARE is made possible through the exclusive support of BRISTOL-MYERS SQUIBB.

FOLLOW US
ON FACEBOOK AND ON TWITTER (@POSAware)

WE READ YOU
COMMENT ON OUR ARTICLES AT POSITIVELYAWARE.COM

© 2012. POSITIVELY AWARE (ISSN: 1523-2883) is published bi-monthly by Test Positive Aware Network (TPAN). 5537 N. Broadway St., Chicago, IL 60640. TPAN is an Illinois not-for-profit corporation, providing information and support to anyone concerned with HIV and AIDS issues. POSITIVELY AWARE is a registered trademark of TPAN. All rights reserved. Circulation: 100,000. For reprint permission, contact Sue Saltmarsh. Six issues mailed bulk rate for $30 donation; mailed free to those living with HIV or those unable to contribute.

A model, photographer, or author’s HIV status should not be assumed based on their appearance in POSITIVELY AWARE, association with TPAN, or contributions to this journal.

This special supplement of POSITIVELY AWARE is made possible through the exclusive support of BRISTOL-MYERS SQUIBB.
Troubled waters

OUR ARSENAL OF HIV PREVENTION AND TREATMENT tools is good enough to end the epidemic in the U.S. Anthony Fauci, Mr. HIV/AIDS of the federal government, has said as much. Secretary of State Hillary Clinton has said an “AIDS free generation” is not only possible, it is a priority. President Obama agrees: “We can end this epidemic,” he said last World AIDS Day.

There’s a doozy of a rub, though. Only 28% of HIV-positive people in the U.S. have met one of the requirements to end AIDS by anyone’s calculation—total viral suppression. Only 41% stay in care, let alone start treatment and stay there. Oh, and federal HIV/AIDS funding is going in the wrong direction to right this boat. President Obama gave us some long-awaited goals in the first-ever national HIV/AIDS strategy, but he neglected to put any money where his mouth was.

Empty rhetoric couldn’t get this far without apathy and indifference. Where I live is an example, from state AIDS directors who seem almost content with more than a decade of static infection rates, down to local clinics devoid of community outreach or involvement, and an AIDS service organization that exploits the most archaic notions of people with HIV rather than stamping out fear and judgment.

No wonder 34% of Americans still think HIV is transmitted via toilet seats, drinking glasses, and swimming pools, or that only 28% feel very comfortable eating food prepared by someone living with HIV/AIDS. Thirty years in, we’re still stuck in the mud of ignorance, fear, and judgment.

If it’s true that counting one’s blessings is an antidote to depression, the pages of this magazine are just the thing. It’s hard not to feel inspired by the triumphant stories of the peer navigators featured here, for example, and how they’ve chosen to invest their hard-won success in bringing others into care and treatment.

There’s also Rob Vassilarakis. He traveled a very different road to his HIV diagnosis than I did, yet my heart somehow recognizes the story he tells in his spoken word poetry, as if deep down we share a language of grief and shame, and survival and self-acceptance. Such is the power of honesty and art.

These personal stories highlight some critical, insidious challenges that have been blindly stepped over by policy leaders rather than looked at with full gaze. Structural barriers like poverty, discrimination, and violence lay down a path that, as research shows, can be a shortcut to addiction and HIV infection. Michael Mugavero takes on one consistently under-appreciated and overlooked element of the stories here and everywhere: trauma.

Over and over, the experiences of people living with HIV/AIDS—the original HIV experts, I dare say—show the way. A few who became outspoken activists share with us, alongside some equally passionate front-line providers and advocates, their reactions to the state of HIV/AIDS in the U.S. and ideas about the way forward. If they were steering our boat to the end of AIDS, we’d surely be heading double-time in the right direction.

Three clinicians, including the indefatigable pioneer of HIV specialists, Paul Volberding, have a conversation of sorts in these pages about their experience and perspective as care providers, from San Francisco to Minneapolis to Santa Fe. Theirs is an interesting story about geographical, historical, and resource differences that carries an echo of what the peer navigators and activists say about stigma, fear, and silence.

The antiquated notion that HIV/AIDS equals a horrible life of pills by the fistful followed by an inevitably painful death keeps people from even getting tested, let alone starting treatment and staying on it. This is at odds with what we know: early treatment preserves health; fully suppressive treatment can render the virus essentially uninfectious; and today’s medications are more like an occasionally bothersome houseguest than the ruthless intruder that is HIV. Somewhere along the way, Americans fell back into the sea of HIV ignorance, if they ever climbed out of it at all.

If I may quote the late, great Dorothy Parker, what fresh hell can this be? It is as preposterous today that people would die on wait lists for HIV medications (possible in 10 states) as it is that they would die of ignorance and shame, yet both threats are disturbingly real. How far we’ve come, how very far we have to go.

HEIDI NASS is an HIV-positive lawyer, treatment advocate, educator, and writer from Madison, Wisconsin. She serves on the U.S. Panel on Antiretroviral Guidelines for Adults and Adolescents and is a founding member of the AIDS Treatment Activists Coalition. She advocates nationally and internationally for the rights of people with HIV/AIDS.

These personal stories highlight some critical, insidious challenges that have been blindly stepped over by policy leaders rather than looked at with full gaze.
A trio of HIV specialists offer their take on HIV—then, now, and in the future

BY HEIDI M. NASS

HIV DOESN’T DISCRIMINATE GEOGRAPHICALLY ANY MORE THAN it does any other way, but the experiences of physicians who treat it can differ significantly depending on where their clinics are. To get some sense of the differences, as well as the commonalities, PA asked three doctors to share their thoughts and experiences, especially when it comes to stigma, fear, and denial.

**DR. BETSY BROWN** has specialized in HIV since 1996 and practices in Santa Fe, New Mexico at the Southwest CARE Center.

**DR. KEITH HENRY** leads the HIV Program at the Hennepin County Medical Center in Minneapolis, where he started the first AIDS clinic in Minnesota in 1986.

**DR. PAUL VOLBERDING** founded the nation’s first HIV program in San Francisco in 1981, and now practices at the VA and University of California, San Francisco.

**How would you describe your patient population?**

**BROWN:** We have many Hispanics and whites and a significant number of Native Americans, but only a smattering of African Americans. We are also seeing more Central American immigrants. Most of our patients are gay men, although we do have a number with IV drug use as their HIV risk factor. We do not see many women, but it feels as if that is increasing. Our clinic is funded by Ryan White and we have many patients who would not have insurance if not for their diagnosis. We also have patients who have jobs and good income.

**HENRY:** Initially, most of our patients were gay white men. Over the last three decades, I have seen a large shift toward more women (almost 30% of our population), more minorities (whites are less than 50%) and foreign-born people. We actively follow a large number of people (more than 350) from Africa.

**VOLBERDING:** I see patients primarily at the VA, predominantly men; about 25% are people of color. They are great people. Most are very adherent, but many suffer from the same set of challenges in any HIV clinic—smoking, alcohol, poverty. I also see a small number of patients at UCSF.

**Compared to when you started in HIV medicine, what is your sense of HIV/AIDS stigma now?**

**BROWN:** I have been working in HIV medicine since 1996. Stigma is still strong here, especially in the more rural areas. The fear of being seen at our clinic is often palpable. We still have patients coming to the clinic who have a tough time disclosing their status and we still answer questions regarding fear families have of someone with HIV living in their household. This includes white, educated families as well as poorer, ethnically diverse ones. People also blame the person who is infected, believing it was being gay or their behavior that caused it—using IV drugs, having multiple sex partners, etc.

**HENRY:** When I started the first AIDS clinic in Minnesota in 1986, the stigma was staggering. The key driving factors then were links with homosexuality and fear of AIDS. For the openly gay community in the Twin Cities, acceptance regarding HIV and homosexuality has generally improved markedly. For closeted gay or bisexual men, rural residents, many women, minority groups (such as African Americans and
Latinos), and foreign-born people (particularly those born in Africa), the experience of stigma remains severe.

**VOLBERDING:** I saw my first AIDS patient at San Francisco General Hospital on July 1, 1981. The very earliest patients had little support, but the gay community quickly mobilized, providing services that replaced the absence of “normal” families. There never was any real panic in San Francisco despite the explosion of cases and our deep ignorance of the cause. Our early epidemic was almost exclusively in young gay men and the political and social climate was very accepting of that large community. I did have patients, especially with extensive facial KS, say they felt ostracized even within the gay community—one said his only social life was movies at night so people wouldn’t notice him. I felt some stigma directed at me, such as in “jokes” about shaking my hand, and it often felt as though devoting my career to AIDS was a bit “dissed” in the academic community. As the epidemic has matured and settled into a chronic disease affecting a largely impoverished population, often with underlying mental health and substance use issues, much of that early positive energy has waned.

Does it seem to you that Americans have made slow progress with respect to tolerance and acceptance when it comes to attitudes about people with HIV/AIDS?

**BROWN:** I think the biggest issue right now is that HIV/AIDS has become an invisible disease. People aren’t hearing about people dying from AIDS, so they think the problem is gone.

**HENRY:** I think that as long as people get much of their information from popular sources such as *People* magazine, FOX News, and celebrity tweets, ignorance about important health matters will remain widespread. Despite widespread availability of the Internet with good sources of medical information, use of credible sources...
and learning how to filter out poor sources seem to be trending in the wrong direction.

**VOLBERDING:** I think this also goes with more acceptance of homosexuality, in general. Certain states excepted, many have learned more tolerance, which I think extends to more comfort about HIV.

**BROWN:** Also, younger people did not live during the height of the AIDS epidemic, so they don’t remember the deaths from it. They also aren’t learning about sex in a meaningful way, since sex education is really more about abstinence now.

**Do you see much stigma within the health care setting, including among medical providers?**

**BROWN:** Yes! A young female patient of mine was hospitalized with brain lesions appearing like toxoplasmosis on imaging studies. She had two brain biopsies that showed toxoplasmosis before they actually ran an HIV test! Another example is a gay male who had KS lesions biopsied and diagnosed before an HIV test was offered. Last week a nurse in a nursing home said he was worried about sores on an HIV-positive patient infecting someone else, even if they were scabbed over (no blood) and his viral load was undetectable.

**VOLBERDING:** I don’t think there’s really much [stigma] these days. We had some examples early in the epidemic—patients being “dumped” on San Francisco General Hospital, or nurses not changing wet sheets, but not anymore. I’ve been rather impressed that sexual histories are routine these days in house staff presentations.

**HENRY:** Ignorance and avoidance are still a problem, like not routinely testing for HIV or connecting clinical situations (for example, shingles, thrush, or very low lymphocyte counts) to it. There is also a growing stigma against immigrants, including HIV-positive immigrants, regarding access to the health care system. Immigrants are having more problems with immigration status, so they’re afraid to use health care even when needed.

**It’s been 30 years. What do you think it will take to get people up to speed about HIV/AIDS—transmission basics, the benefit of early treatment, understanding that treatment is prevention, etc.?**

**BROWN:** I wish I knew. I think the media could be more helpful. I think perhaps more characters with HIV, not just AIDS, in sitcoms, soap operas, and medical dramas, might help. We did a video locally regarding HIV and treatment, and why it’s better to know your status and that treatment is a lot easier now (also available in Spanish). [Go to www.youtube.com/watch?v=yPt_2s5Dp6U]. I have had many friends and family—educated and aware, I thought—tell me how much they learned from it. We have also put up beautiful murals in town and have other promotions for this testing program.

**VOLBERDING:** Maybe a new Surgeon General willing to take this on?

**For you, how big of a challenge are things like stigma, lack of information, and fear about being a person with HIV/AIDS, in helping your patients manage their health?**

**VOLBERDING:** I think this is going quite well, at least in San Francisco. I still hear of cases where a patient is in hiding with the diagnosis, but those seem rather rare.

**BROWN:** It is a challenge to help patients when they are afraid of being seen at the clinic and will not come for appointments. I have a patient who was so fearful, we made arrangements for him to go somewhere else for a checkup so he could avoid being seen at our facility. He had not come in for a visit in over a year. We have people who will drive four hours across the state for their lab work and appointments, so they can maintain their privacy. Also, we...
KEITH HENRY, MD
HENNEPIN COUNTY MEDICAL CENTER
Minneapolis, Minnesota

BROWN: I also have many patients who don’t trust conventional medicine. It takes extra time and reassurance that I am not just about them taking their HIV meds. After I spend time with them and work with their need to try alternatives first, I have been able to transition some to taking ART.

HENRY: I believe that key elements to running a good HIV clinic include the availability of a benefits counselor/insurance guru with the patient’s best interest at heart, peer navigators, outreach to the community, efforts to reach patients who have been lost to care, an in-house 340B pharmacy (a government-run drug discount program), case managers, social workers, safe sex and testing programs within the clinic, staff hired from the impacted communities, friendly secretaries and phone trees, sensitivity to diversity issues, and quality clinicians (many of whom are currently supported by the Ryan White Program and are not paid for or supported by standard insurance or billing mechanisms).

What do you think it will take to bridge the gap between the available tools of HIV management and the societal realities that make success difficult?

VOLBERDING: We need a concerted and continuing effort at diagnosis and facilitated entry to care. I think we know how to do that, but it will be expensive when many seem to think we should be reducing, not expanding, public programs in health care.

HENRY: Universal access to health care and the nurturing of user-friendly health care environments (sometimes called patient-friendly or medical home systems) are a good start to addressing key problems, including HIV care.

BROWN: I really believe a single-payer national health plan would go a long way toward addressing these issues—even though I don’t think it will happen.

What are the most effective approaches and tools you’ve found to help people get into care and stay there?

BROWN: The rapid testing we do is helpful in getting people engaged in care. If someone from our clinic has given them the results, there is a familiar face that person can see when they return for the confirmatory test results. That face-to-face contact is crucial. We try to link people to care when a positive test occurs in our testing program, but a few people do disappear for a while. We have a multidisciplinary team with providers, nurses, and case managers, and we really try to help the patient feel safe and welcome. Even though the meds are so much easier to take and people can live a more normal life span, I think my patients really like that I take the time to acknowledge the challenges they face. It helps them trust me more.

VOLBERDING: My own experience is that conveying the reality that HIV will kill in all cases unless it’s treated, and that treatment can allow a normal life, are the things I focus on in keeping patients engaged. It usually seems to work.

HENRY: The most important element is having a friendly and supportive team of good listeners so that every person coming into contact with the patient sends a positive message. One of my colleagues coined the term “stickiness” to describe the concept of us getting our patients to stick to clinic and get ongoing care. Any negative interaction with staff (even the billing office) that is interpreted the wrong (or unfortunately sometimes the right) way represents the weak link in the chain of care and can result in the patient leaving and not returning.

have them draw their labs here in case they know someone working in the local lab. We reassure patients all the time that we are very careful with their health information, but they are still afraid. We reassure them that we will not speak to them or engage with them away from the clinic, unless they acknowledge us first. We have our pharmacy send meds by mail, unlabeled. We send mail unlabeled. We have special doctor’s notes for missed work and school that are minimally identified. Even with these special efforts, we have patients who will stop coming for fear of being recognized.

I feel like we actually do a decent job once a patient is in care—we have a really high rate of undetectable virus in our patients. I focus on in keeping patients engaged. It usually seems to work.

The most important element is having a friendly and supportive team of good listeners so that every person coming into contact with the patient sends a positive message. One of my colleagues coined the term “stickiness” to describe the concept of us getting our patients to stick to clinic and get ongoing care. Any negative interaction with staff (even the billing office) that is interpreted the wrong (or unfortunately sometimes the right) way represents the weak link in the chain of care and can result in the patient leaving and not returning.

people can live a more normal life span, I think my patients really like that I take the time to acknowledge the challenges they face. It helps them trust me more.

VOLBERDING: My own experience is that conveying the reality that HIV will kill in all cases unless it’s treated, and that treatment can allow a normal life, are the things I focus on in keeping patients engaged. It usually seems to work.

HENRY: The most important element is having a friendly and supportive team of good listeners so that every person coming into contact with the patient sends a positive message. One of my colleagues coined the term “stickiness” to describe the concept of us getting our patients to stick to clinic and get ongoing care. Any negative interaction with staff (even the billing office) that is interpreted the wrong (or unfortunately sometimes the right) way represents the weak link in the chain of care and can result in the patient leaving and not returning.

people can live a more normal life span, I think my patients really like that I take the time to acknowledge the challenges they face. It helps them trust me more.

VOLBERDING: My own experience is that conveying the reality that HIV will kill in all cases unless it’s treated, and that treatment can allow a normal life, are the things I focus on in keeping patients engaged. It usually seems to work.

HENRY: The most important element is having a friendly and supportive team of good listeners so that every person coming into contact with the patient sends a positive message. One of my colleagues coined the term “stickiness” to describe the concept of us getting our patients to stick to clinic and get ongoing care. Any negative interaction with staff (even the billing office) that is interpreted the wrong (or unfortunately sometimes the right) way represents the weak link in the chain of care and can result in the patient leaving and not returning.

people can live a more normal life span, I think my patients really like that I take the time to acknowledge the challenges they face. It helps them trust me more.

VOLBERDING: My own experience is that conveying the reality that HIV will kill in all cases unless it’s treated, and that treatment can allow a normal life, are the things I focus on in keeping patients engaged. It usually seems to work.

HENRY: The most important element is having a friendly and supportive team of good listeners so that every person coming into contact with the patient sends a positive message. One of my colleagues coined the term “stickiness” to describe the concept of us getting our patients to stick to clinic and get ongoing care. Any negative interaction with staff (even the billing office) that is interpreted the wrong (or unfortunately sometimes the right) way represents the weak link in the chain of care and can result in the patient leaving and not returning.
GUIDING LIGHTS

Peer navigators help others after finding their own way

BY JEFF BERRY

JUAN MERCADO GREW UP IN HUMBOLDT PARK ON the West Side of Chicago. Juan’s father was involved with gangs and illegal activities and often in and out of jail. His mother had to work long hours to provide for both Juan and his older brother. As a result, Juan says, he was forced to grow up and be a man—fast.

“I never had a real childhood like others, and wasn’t allowed time to play, or just be a kid,” says Juan. “Due to my father’s gang affiliations, I was not allowed outside my house without a bodyguard, someone who could protect me, and [I had] a weapon concealed on me for emergencies.” Like many teens, he began to rebel in high school, and he started skipping school, experimenting with drugs, and hanging out with the wrong crowd. “I was becoming a younger version of my father, but without being in a gang. I got my first fake I.D. at the age of 17 and began going out to clubs and bars. I was reintroduced to alcohol around this time, and used it as a social lubricant to allow myself to socialize with people without having to have my guard up. I was looking for love or a father figure in all the wrong places.”

By the time Juan was 21, the partying and clubbing took its toll, and he was hospitalized due to a drug overdose. “This may have been a wake-up call for some, but for me it was just another night of fun. I did not take life seriously and just wanted to make up for not having the childhood I wanted. This continued until I got my HIV diagnosis on one of my several trips to a detox center and psychiatric ward due to alcohol, drugs, and depression.”

Today Juan works at Test Positive Network (publisher of POSITIVELY AWARE) in Chicago and is one of many peer navigators around the country whose job it is to assist and guide HIV-positive individuals by serving as buddy, mentor, coach, and advocate, and at the same time share his own personal story as a person who has already “been there.” The program Juan works on, Project IN-CARE, is for men who have sex with men (MSM) who have been recently diagnosed, or who’ve fallen out of care. It’s funded under the Positive Charge Initiative through AIDS United and in conjunction with AIDS Foundation of Chicago (AFC) and helps connect HIV-positive men of color to counseling, treatment, and peer-to-peer support.

“For many who are newly diagnosed and are dealing with stigma, fear of the unknown, disclosure, and false information, I like to reassure them that I can relate to what they are going through,” says Juan. “I tell them that being HIV-positive does not mean that life is over, and that I am living proof of this.” He tells them that education about the virus was useful for him, and that medication, taking care of his health, and living a healthier lifestyle keeps him undetectable. But what works for him may not work for them, and they need to see a doctor who specializes in HIV to find out what they should do to maintain their own good health.

Of course, it wasn’t always this way. Juan was tested for HIV in 2003, at the age of 23 during one of his stays in detox, because his partner at that time thought he might have an STI (Sexually Transmitted...
Infection) and suggested Juan get tested as well. The doctor asked Juan if he also wanted an HIV test, but the only people Juan knew who were being tested for the virus on a regular basis were sex workers he knew from the club and bar scene.

“My first reaction was no, I did not need one, and that I looked and felt healthy,” says Juan. “I never avoided being tested—in all honesty, I thought that it could not happen to me.”

When the HIV test came back positive, all Juan could focus on was that he was negative for STIs. When the nurse repeated that he had tested positive for HIV, he immediately went into denial and began to laugh, and told them they had made a mistake. “About five minutes into the conversation, I began to cry,” says Juan. “I was telling them that they were wrong and I was thinking how or if I was going to tell my family the bad news.”

When Juan did give his family the news, they informed him that they loved him regardless, and would get him the best care that was available. “I was fortunate to have my family’s support. Without their assistance and unconditional love, I probably would not have seen a doctor until I came to terms with being positive.” The actual visit was scary, he says, and he wasn’t sure what to expect. “It seemed as if the doctor was speaking a foreign language while she was talking about the virus, antibodies, T-cells, and viral load.”

Juan sees challenges in his own work similar to those he himself experienced, such as people who refuse services, are in denial, or may not believe they are HIV-positive. “Others may feel as if they don’t need to see a doctor, or as if their life is already over and that no one can help them.”

Honesty and trust are the main factors for Juan when it comes to building support with the participants. “It enables them to see that I am not just looking to enroll them in a program, but that I actually care for them, and will listen to what they have to say. I like to begin with getting to know the individual before we even discuss IN-CARE, and how they may benefit from working with a peer.”

Unfortunately there have been times when he’s come across an individual who he’d worked with for months, only to find they are no longer in care. “I’ve also worked with others who have unrealistic expectations, expect everything to be done for them, and do not gain the proper tools to advocate for themselves,” says Juan, “and become too dependent on the peers.”

“Today, after educating myself on the virus, attending trainings, and working in the field, I can honestly say that becoming positive was a blessing in disguise,” he says. If he had not found out he was HIV-positive, he probably would have been on the same destructive path, living life a day at a time, but with no goals, aspirations, or even dreams. “It has now been almost three years since my last drink or drug, and I have accomplished so much in that amount of time.”

Education is key, he says, and HIV is no longer a death sentence. Not only is knowledge important for people who are positive, but also for the ones who love them. “As a community we should advocate for our friends, family, and loved ones to know their status, and for those who are positive to get into care as soon as possible,” says Juan.

“Becoming positive was a wake-up call for me—it also forced me to care about my health, and grow up.”

**SABRINA**

Diagnosed HIV-positive in 1989 when she was 32, Sabrina Heard was pregnant at the time with her daughter, and was tested during a routine visit to the doctor. Sabrina, like Juan, also says she didn’t think she was at risk. “I was an active crack user, and I didn’t think about a whole lot except smoking crack.” When she found out she was positive, “I was pretty numb,” says Sabrina, “and with the limited kind of information I had, I didn’t internalize it as a death sentence [which it almost certainly was, in 1989]. I went into some kind of fantasy and stayed in denial for 11 years.”

She would sometimes use her diagnosis as a defense mechanism. “If someone was going to hurt me, I’d say, ‘I’m already dead.’ ”

Her children were placed into foster care after her life had deteriorated and she
became sick, and she was told she would have to go into treatment in order to get them back. “Before, I used not going into treatment as an excuse—who will take care of my kids? Now it was, ‘So what’s your excuse now?’”

While in treatment for her addiction Sabrina had a roommate who would talk with her about her HIV and vitamins that she took, and was very casual about it. “After talking to her, I was ready to start taking those steps to find out about HIV and be able to talk about it like she was talking about it—to not be so ashamed, so numb. I had never talked about it before that.”

Sabrina says she needed to go through all that in order to get to where she is today. “I guess I was meant to be a community health worker so I can share what I know and experienced. Working on the front line is therapeutic.”

Now a peer navigator at the Women’s Collective in Washington, D.C., Sabrina says her role is to meet people where they are. “I’ve been supportive of those newly diagnosed patients—they’re going to be devastated. I want to make sure they get the confirmatory test and get into care. A lot of times I share my story.

“Sometimes you can be so deep down in that hole that you can’t see the way out.”

She says one of the most frustrating parts of her work is retention. “Sometimes my clients are still active users,” she says. “I try to tell them, ‘I don’t care if you’re using or not,’ and let them know that I have a real interest in them staying healthy. The most important thing is not that they’re using, it’s that they take their medicines.”

A recurring issue that she sees in her clients is that they put aside the need to go to the doctor or do things for themselves, in order to take care of their children or grandchildren. “And housing comes up a lot—it’s not so important that I make it to the doctor when I don’t know where I’m going to sleep tonight.”

One approach that Sabrina has found to work best in her work is to start by finding out where someone is in terms of HIV knowledge or stigma, and how they view other people’s perception of them. “I do it one-on-one and find out what each person’s barrier is.”

So what does she think needs to happen to make testing, care, and treatment truly accessible for everyone? “I need someplace that’s open in the evening, not just 9–5. I need access to a confirmatory test and a doctor, a 24-hour access-to-care kind of thing.”

Oftentimes, people in emergency rooms and even in social services are not always sensitive to HIV, says Sabrina. “These are the kinds of things that keep people from coming back—the rude receptionist or insensitive case manager, or whatever.”

In the beginning she experienced stigma and denial very intensely. “Initially, I had a partner who was HIV-negative. I disclosed my status to him after we kissed. He didn’t even care, but I was so sensitive and afraid that it bothered me that he didn’t care. I couldn’t take it.”

Sabrina says she wasted a lot of time in her addiction, “I got off to a late start—wasted 15 years smoking crack, and 30 years drinking alcohol.”

“Some days I get discouraged and I talk with my children and say, ‘I’m tired,’ but I have to keep reminding myself this gift of life is precious and I’ve been entrusted with it so I have to take care of it. How dare I say I don’t want to take care of it? Each day I remind myself that it is a precious responsibility. I have to take care of it because it’s a gift.”

GINA

“G
there was a study (076) going on at the hospital that I was a good candidate for.” There were three things, the nurse told her, that would help her live a long life: Learn all she could about HIV; attend all PMC (primary medical care) appointments; and take all meds as prescribed. “I have lived by that advice for the last 18 years!”

Like Juan and Sabrina, Gina didn’t think she was at risk. “I never thought I was at risk because the messages back then were still geared towards gay men, and I didn’t know any women with HIV—boy, was I wrong!”

Gina saw a doctor within two weeks of her diagnosis, and she says that because she enrolled in the research study, her experience was a good one. “Stigma was my greatest barrier,” says Gina, “I was afraid of who would see me at the clinic, but I didn’t let it keep me from getting into and staying in care.

“I can honestly say my HIV infection is a direct result of my being introduced to sex at such a young age [Gina was molested from ages 5–7] and never receiving any therapy. Therapy would have allowed me the opportunity to see that I wasn’t a bad person and it was not my fault. Because of the molestation, I became sexually active at 13, I was very promiscuous, and I equated sex with love. I can remember always feeling empty and sex seemed to ease that feeling. I eventually got on drugs to escape the pain of the molestation and that’s when I contracted HIV.”

Gina says her stigma came from within. “I thought I knew how people would accept my diagnosis—I started journaling, and that helped a lot. I put so much pressure and stress on myself, but once I did come out, everybody embraced me and my experience so much more fully.

“Before HIV, I was a very self-centered person—it was all about me and I wasn’t afraid to say it,” says Gina about her earlier life. “Today I’m a giving, selfless, compassionate person; I care about the welfare of others. As an activist, I have to set a good example for those coming behind me.”

Today Gina is working at the New Orleans AIDS Task Force (NO/AIDS), and as a peer advocate she assists clients in not only navigating the Ryan White system of care, but also helping them see that they are not alone. “Before HIV, I was a very self-centered person—it was all about me and I wasn’t afraid to say it,” says Gina about her earlier life. “Today I’m a giving, selfless, compassionate person; I care about the welfare of others. As an activist, I have to set a good example for those coming behind me.”

Today Gina is working at the New Orleans AIDS Task Force (NO/AIDS), and as a peer advocate she assists clients in not only navigating the Ryan White system of care, but also helping them see that they are not alone. “For me, it has always been about giving hope to clients,” says Gina. “There’s a part of me that wishes I didn’t have it, especially when I have to disclose to a man I may like. If I tell him, how will he see me? Will he stay?

“Gina says she’d be lying if she said she was okay with having HIV. “There’s still a part of me that wishes I didn’t have it, especially when I have to disclose to a man I may like. If I tell him, how will he see me? Will he stay?

“Gina says she’d be lying if she said she was okay with having HIV. “There’s still a part of me that wishes I didn’t have it, especially when I have to disclose to a man I may like. If I tell him, how will he see me? Will he stay?”
PA asked a few activists, advocates, and medical providers for their take on the state of HIV/AIDS knowledge in the U.S. and the level of comfort Americans have with people who are living with HIV/AIDS. Here’s what they had to say about how these things connect to the fear, denial, and silence that keep people from getting tested, into care, and successfully maintained there. They also have some ideas about how to improve the general public’s knowledge and reduce stigma.

GINA BROWN
PEER NAVIGATOR, ADVOCATE, LONG-TERM HIV SURVIVOR
New Orleans, Louisiana

We will only make things better once we start addressing the specific issues that keep people out of care. HIV is not only a medical condition, but for a lot of people, it is more of a social problem—housing that’s safe and affordable, transportation, stigma, childcare, and food are more important than taking care of their HIV disease.

We won’t see a real decline in the number of new infections until we can educate the communities that are hardest hit: blacks and Latinos. The myths and rumors have to be addressed before real HIV education can begin. As someone who sees both sides, I can honestly say there is not enough education that is both culturally and gender specific.

NELSON VERGEL
ACTIVIST, FITNESS EXPERT, AUTHOR, LONG-TERM HIV SURVIVOR
Houston, Texas

No amount of money spent on billboards can educate others as well as what can be accomplished with our visibility. People can see that we are living well and have productive lives, and those who know us also learn about things we go through to stay healthy and navigate the system. We all need more HIV-positive role models to show their faces to the world. But I know doing this is virtually impossible for many people who would be discriminated against if the world knew their HIV status.

I’m very lucky—no one has judged me except my father, who still does not talk to me after 25 years. My life has been enriched ever since I came out of the HIV closet and started helping others through my work. People see me as a healthy man with HIV who has turned life around for the better, and they respect that.

We are survivors and warriors. Letting go of shame is the biggest challenge for many of us. Knowing that we deserve good health care and a healthy long life makes us stay on treatment and adhere to our medical care.
BETTE MENTZ-POWELL
DEAF COMMUNITY ADVOCATE,
HIV EDUCATOR
Madison, Wisconsin

HIV prevention information has passed the Deaf community by. HIV campaigns rarely reach us and, if they do, they are frequently distorted and not understood by the majority of Deaf people.

One Deaf woman told me she won’t get HIV because she “only has sex with Deaf men.” This belief is not uncommon in the Deaf community. For many Deaf individuals, HIV/AIDS remains a “hearing person’s disease.” No accurate statistics exist about the number of Deaf and hard-of-hearing people living with HIV/AIDS, the number getting tested, receiving treatment, etc.

There are higher rates of substance abuse in the deaf community. There are higher rates of sexual abuse for both boys and girls who are Deaf. There is a lack of sex education and accurate information related to sexual health, period. Deaf people struggle for equal access to medical and social services, employment, and education and are represented in every group at highest risk for HIV.

Culturally competent education efforts that respect Deaf culture and its use of American Sign Language are long overdue. I see little progress.
MATT SHARP
ACTIVIST, EDUCATOR, LONG-TERM HIV SURVIVOR
San Francisco, California

I live in the AIDS “bubble” of San Francisco and I work with AIDS educators and activists internationally. My partner is HIV-positive and my family and friends have known for years that I am positive and still, thankfully, healthy. I live in a world of openness and fulfillment because I made a choice to live proudly with HIV. I made that choice so hopefully others could see.

For me, then, it seems unfathomable that people are still so unaware of HIV/AIDS. Yet I know that AIDS ignorance, HIV stigma and hatred towards people who are “different” exists, especially in the right-wing quagmire that is so pervasive in this country. As people with HIV/AIDS, we should harken back to the early days of in-your-face activism and not settle for anything less than full acceptance in this world.

PAT KELLY
ACTIVIST, OUTREACH WORKER, LONG-TERM HIV SURVIVOR
Orangeburg, South Carolina

I am a first generation HIV/AIDS survivor, diagnosed in 1985. The current generation is ignorant beyond belief and sometimes I am mystified—it’s like the ’80s all over again. They won’t speak up, they won’t get tested, and if they find out they are positive, they won’t get in and stay in care for fear of someone finding out their status, so they die in silence.

We have done a terrible job of prevention and education—people are still being infected from a preventable disease and still dying in droves in the South. Homophobia, racism, and classism are reasons why we will not move to a level of understanding, compassion, and brotherly love, but this is the Bible Belt!

We did not get here by chance. Societal systems that are set up to fail helped get us here. People with their judgments, ignorance, and bias got us here. It is up to me and others like me to raise our voices for change. This is a human rights crisis and it involves us all.

I will fight and raise Cain until people are no longer afraid of me preparing their food, are no longer afraid of me caring for their child or being their neighbor because I have AIDS. I am here. I am not going anywhere but in your face if I need to, because I am a human being with a chronic disease who’s no different than the next person.

COMFORT LEVELS

In 2011, the percentage of people who said they would be very comfortable with someone HIV-positive who is a...

- FOOD PREPARER
  - 24%

- ROOMMATE
  - 30%

- TEACHER
  - 36%
It is encouraging to see that stigma is slowly dissipating, but sad to see how much persists. It is one of the worst aspects of this disease.

Stigma comes not only from outside, but also from within. Approximately half of the newly diagnosed people I see admit that they have thought about killing themselves because they are HIV-positive. When I ask, “Would you have thought about killing yourself if you had been diagnosed with diabetes?” they usually look at me with amazement and answer “No.” I tell them that HIV is a chronic disease, similar to diabetes.

At every stage of what should be a seamless referral-care-retention-treatment-adherence-success linkage, the system fails people with HIV. Obama’s national AIDS plan is failing. The illusion that better epidemic control can be achieved by efficiencies without new resources is a delusion.

U.S. HIV treatment coverage rates are a disgrace. New therapies developed and approved in the past decade, much safer and more durable than the first two generations of HIV therapy, are not reaching 64% of those who need them. Annual new HIV infection rates haven’t budged since 1990. Annual AIDS deaths have remained near the same level since around 1998.

Former Confederate states and some Tea Party-dominated ones have disgracefully long ADAP waiting lists, indicating the indifference of those states’ legislators, governors, and voters to the people living with HIV in their midst. Only small islands of relative homogeneity and affluence, like San Francisco, are even trying to achieve universal access and uptake. While the past year has seen great excitement about the preventive promise of earlier ART and treatment as prevention (TasP), this promise will remain unrealized until we have achieved treatment as treatment everywhere (TASTE).

In a 1987 speech on HIV/AIDS, Surgeon General C. Everett Koop said, “Our single best defense against this disease from the very beginning has been information and education, and it still is…..” Our policy leaders today have put the total focus on prevention, care, and treatment—a laudable focus that sorely lacks one important component: public awareness.

Until we improve public awareness, we will silently nurture the ignorance and stigma that has taken root in a generation for which AIDS has always been about someone other and older than themselves. The early “death sentence” years of AIDS are a part of history that almost half the population of the country under age 30 never experienced. They just can’t relate.

Dr. Koop also said, “…..we see more evidence every day that this disease is becoming the particular scourge of people who are young, black, and Hispanic. How tragic for them. And how tragic for America.” Tragically, in my state, one in three African American MSM are HIV-positive and in 2011 39% of people newly infected were under the age of 30.

In 30 years of the epidemic, we have failed to use the tools of information and education to confront, head-on, HIV/AIDS stigma and ignorance. I am outraged, even if today’s leaders are not.
**BETSY BROWN**  
**HIV SPECIALIST**  
Santa Fe, New Mexico

The number of people not engaged in care really saddens me but is not shocking. I feel it is a combination of factors, not the least of which is our dysfunctional health care system, where many people don’t have health insurance and many others don’t have access to care. Retaining people in care is also a challenge. Also, many clinicians don’t think of testing for HIV.

It doesn’t help that in this political environment, science is vilified and sex has become only about procreation and not the beautiful thing it can be. For so many people, especially people of color, being gay has as much a stigma as anything else.

Somehow we need to refocus on education and destigmatizing HIV in the religious communities. People aren’t hearing about people dying from AIDS so they think the problem is gone. Engaging the black and Hispanic churches might help in some communities. The Catholic Church and many of the African American churches hide these issues and blame the victims.

**PAUL VOLBERDING**  
**PIONEERING HIV SPECIALIST, RESEARCHER**  
San Francisco, California

HIV/AIDS is seldom in the news and has passed from the public’s mind. We invest almost nothing in educating the larger public about science and health in general and HIV, in particular. It’s not surprising there’s so much ignorance. Dangerous beliefs in the vaccination of children, as well as ongoing health risks like smoking and obesity, underscore our failure to inform our citizens. It is deeply discouraging.
LARRY’S CASE
Larry is a 43-year-old, successful accountant who has been living with HIV for the past 10 years. He has had a stably suppressed viral load since starting antiretroviral treatment seven years ago. He comes to the clinic for a routine care visit. Before his exam, I review his chart and am surprised to see his viral load is now 1,750 copies/mL. Larry is unshaven and seems distant when I greet him. He appears unsettled and fidgety, which is highly uncharacteristic.

WHAT IS PTSD?
PTSD is a severe anxiety disorder that can occur in people who have experienced major psychological distress, or trauma, as a result of a serious adverse life event. These events typically involve concern for serious injury or death, or a threat to physical safety. They invoke a response of horror, intense fear, and a sense of helplessness.

PTSD SYMPTOMS
A wide range of symptoms may be experienced among those with PTSD, classified into three groups (see sidebar):
- Re-experiencing the traumatic event (flashbacks)
- Avoidance and numbing
- Increased arousal and emotional volatility

These psychological, emotional, and physical symptoms are normal responses after experiencing a traumatic event. When symptoms last for longer than one month and interfere with social and/or occupational functioning, however, a diagnosis of PTSD is considered. Not everyone who experiences traumatic events will go on to develop PTSD, which occurs in roughly one out of five people following trauma. Symptoms are further classified as “acute” if present for less than three months, and “chronic” if they last longer than three months. PTSD is described as “with delayed onset” if symptoms begin six months or longer after the traumatic event occurs. This is less common, as most people diagnosed with PTSD experience symptom onset shortly after the traumatic event.

TRAUMA, PTSD, AND HIV
The lifetime occurrence of traumatic events is incredibly common among HIV-positive people—greater than 90% of individuals have experienced at least one in a range of events (see sidebar, page 17). The diagnosis of HIV itself may serve as a traumatic event. Other traumatic events include physical and sexual abuse, experienced by roughly 50% of people living with HIV, or other childhood and adult events involving the individual and/or family and loved ones, especially parents, children, and spouses or partners.
Common symptoms of post-traumatic stress disorder (PTSD)

RE-EXPERIENCING THE TRAUMATIC EVENT:

- Frequent and distressing memories of the event
- Frequent distressing dreams
- Feeling like the event is happening again (flashbacks)
- Psychological distress from cues that are reminders of the event
- Physical symptoms from cues that are reminders of the event: sweating, rapid heartbeat, nausea, rapid breathing

AVOIDANCE AND NUMBING:

- Efforts to avoid thoughts and feelings related to the event
- Efforts to avoid people, places, and activities related to the event
- Inability to remember important aspects of the event
- Decreased interest in significant activities
- Sense of detachment from others
- Emotional numbness—limited range of feelings
- Sense of limited future

INCREASED AROUSAL AND EMOTIONAL VOLATILITY:

- Insomnia—difficulty falling asleep or staying asleep
- Feeling irritable
- Angry outbursts
- Difficulty concentrating
- Never feeling at ease; always “on guard” (hypervigilance)
- Easily startled or feeling jumpy

In one larger study, the average number of different traumatic events experienced by people living with HIV was three, with some having experienced as many as 12 distinct types of events. Individuals who have experienced traumatic events are at increased risk of future traumatic events—commonly referred to as “re-victimization.”

Despite the high frequency of childhood physical and sexual abuse and other traumatic life events in their HIV-positive patients, most clinicians do not routinely screen for PTSD.

LARRY’S DIAGNOSIS

When I initially probe as to what’s going on, Larry gives a dismissive response and assures me everything is okay. Upon further questioning, he breaks down and explains that a new boss at work reminds him of an uncle who abused him as a child. He’s been feeling angry, agitated, and has had difficulty concentrating at work. He’s not sleeping well and is plagued by intrusive thoughts about the abuse he experienced as a child. He feels distant from his partner and out of touch with his emotions. Larry needs help.

EFFECTS OF TRAUMA AND STRESS ON HIV-POSITIVE PEOPLE

Traumatic life events have important implications for health behaviors and outcomes in people living with HIV. A number of studies have shown the damaging impact of PTSD on medication adherence, sexual risk behaviors, and HIV disease progression.1-4

A robust collection of literature has linked traumatic life events, even in the absence of PTSD, with a range of unhealthy behaviors and outcomes. It shows that people who experience a higher number of distinct traumatic life events are more likely to engage in unprotected sex, be non-adherent to their antiretroviral medications, go to an emergency room or become hospitalized, and report lower overall health and well being, with greater risk for HIV disease progression.1-4

When combined, the impact is even further exacerbated. Moreover, as observed in those with PTSD, difficulty in establishing trust and utilizing social support may interfere with care-seeking and management of mental illness and substance abuse.1

Perhaps less commonly discussed is the overlap between trauma, PTSD, mental illness, and substance abuse, which is extremely common and of concern on numerous levels. Namely, each of these conditions is linked to unhealthy behaviors and unfavorable outcomes on their own. When combined, the impact is even further exacerbated. Moreover, as observed in those with PTSD, difficulty in establishing trust and utilizing social support may interfere with care-seeking and management of mental illness and substance abuse.1

To date, studies have shown that these relationships are incredibly complex and that it is not easy to untangle the roles of trauma, PTSD, mental illness, and substance abuse in terms of how they interact and lead to negative health effects.1-4 Research has tried to better understand the relationships between these common co-occurring conditions. Do childhood traumatic events predispose someone to depression and substance abuse? Do past traumatic events and PTSD negatively impact health behaviors and outcomes by
way of increased risk for new stressful life events and re-victimization? Or is reoccurrence of trauma and PTSD perhaps due to a higher frequency of mental illness and substance abuse? While there may not be definitive answers, it is clear that these conditions commonly co-occur and when they do, their adverse impact on health and well being are increased.

DIAGNOSIS AND TREATMENT FOR TRAUMA AND PTSD
The first essential step for initiating trauma and PTSD treatment is identification. While this seems obvious, screening is not commonplace in most HIV clinical settings.

People living with HIV may not recognize that the symptoms they are experiencing relate to traumatic life events, or have knowledge of PTSD, or feel comfortable talking about trauma and related symptoms with their health care provider or loved ones. Although difficult, acknowledging past traumatic events, recognizing symptoms indicative of PTSD, and breaking the silence are vital steps towards seeking medical help.

Trauma and PTSD treatment has focused on intensive psychological and behavioral approaches, with a common theme of group-based support sessions and emphasis on coping skills. The focus is generally on developing and enhancing adaptive, or healthy, coping mechanisms like problem-solving, positive re-framing, and relaxation techniques, as well as stress management and sexual risk reduction skills. Common subjects addressed are things like intimacy, safety, and self-esteem, in the context of past trauma, re-victimization, and HIV.

Few interventions have been rigorously tested through randomized trials. There is a compelling need for more intervention research.

LARRY’S TREATMENT
Larry connected with a clinical psychologist, which was highly beneficial for his emotional, psychological, and physical health. They worked on coping skills to address his past trauma and PTSD symptoms. He got a new job, and was quite pleased and successful in his new work environment. His ART adherence improved and he regained virologic control. Aided by the steadfast support of his partner, Larry’s sense of distress, emotional detachment, and related PTSD symptoms abated over time, and he felt an improved sense of connection with his partner.

MAKING PROGRESS
Recognizing and treating co-occurring mental illness and/or substance abuse disorders are also essential to the successful management of trauma and PTSD. Enlisting the support of close friends and family, avoiding alcohol, drugs, and mal-adaptive coping strategies (such as denial and substance abuse), and challenging the sense of detachment and emotional numbness that accompany PTSD can make the initial steps to fostering a connection to a skilled health care provider easier. The provider can then assist with subsequent management and connection to treatment and support resources.

POST-TRAUMATIC GROWTH (PTG)
While decades of research have focused on PTSD in response to traumatic life events, only recently has the concept of post-traumatic growth (PTG) emerged in the context of HIV and other medical conditions like cancer and rheumatoid arthritis. PTG describes the positive behaviors that emerge following a diagnosis of HIV or related medical condition. It has been linked to stronger social support, adaptive coping strategies, and favorable indicators of mental and physical health.

Following trauma exposure, people experiencing PTG may have improved relationships, a greater appreciation of life, and a greater sense of spirituality and personal strength. Moreover, in HIV-positive people, PTG has been linked to lower levels of depression, alcohol use, and substance abuse. Future study of PTG may enhance our understanding and inform our treatment approaches for those experiencing PTSD.

SUMMARY
Traumatic life events and PTSD are incredibly common and widely under-recognized in people living with HIV/AIDS. An understanding of what constitutes trauma and an appreciation of symptoms of PTSD are essential first steps to successfully addressing them. Because trauma, PTSD, and co-occurring mental illness and substance abuse are so pervasive and so damaging across a range of self-care behaviors, risk behaviors, and HIV disease progression, it is imperative that knowledge and resources expand to properly identify and treat these conditions.

We must break the silence and recognize the insidious effects of PTSD on the lives of people living with HIV and their loved ones. Only with recognition and action can full emotional, psychological, and physical health and wellness be achieved by survivors of trauma.

FOR REFERENCES, GO TO POSITIVELYAWARE.COM

TRAUMATIC LIFE EVENTS COMMONLY EXPERIENCED AMONG PEOPLE LIVING WITH HIV
- Sexual abuse
- Physical abuse
- Childhood physical neglect
- Childhood emotional neglect
- Being placed in reform school, prison, or jail
- Parental alcohol or drug abuse
- Parental suicide or attempt
- Parental imprisonment
- Violence in the home
- Having a life-threatening illness unrelated to HIV
- Murder of a family member
- Death of a child
- Death of a spouse or partner
- Diagnosis of HIV infection

MICHAEL J. MUGAVERO, MD is an Associate Professor of Medicine at the University of Alabama at Birmingham (UAB), Associate Director of the UAB Center for AIDS Research (CFAR), and a practicing Infectious Diseases physician at the UAB 1917 HIV Clinic. He focuses on HIV health services research with particular emphasis on the influence of socio-behavioral and contextual factors related to HIV testing, engagement and retention in HIV medical care, antiretroviral medication adherence, and clinical outcomes.
When I was 17, I was disowned for being gay after my mother read some of my journal entries. I was forced to leave my mama’s-boy existence in the suburbs of Long Island. I fled to New York City with my newly found freedom and found work in night clubs like the Sound Factory, the Tunnel, and Roxy. I used sex as a way to cope and escape my troubles. I was lonely, missing home, and welcomed any and all kinds of sexual attention as a substitute for love.

I started using sex as a way to negotiate, to connect, to feel wanted and desired, to find acceptance, and as a means to an end. I was receiving a lot of attention, sometimes to the point where it would get overwhelming, but if people were willing to dish it out, I was more than happy to take it. I never knew that the time would come (like with my own family) when they would snatch it back and throw me away. It wasn’t love, but for the moment, I reveled in it.

“I had met an older gentleman who spent a lot of time mentoring me after I was thrown out of my mom’s house. He knew the circumstances of my life and understood that as green as I was, I might be easily led astray. He was more of a father to me than anyone else I’d known. He also had advanced AIDS. I knew other people who had died of AIDS, but this was the first time I saw someone, who seemed relatively healthy when I met him, deteriorate over three years and die. I watched him go from healthy to dementia, tubes everywhere, diapers…

“I was traumatized by that. I tried to reach out to my mother, who kept referring to him as a thing—‘poor thing,’ she’d say—as if this is where you end up if you live the gay ‘lifestyle,’ like the plague that’s referred to in Revelations. He died in March of 1993 and I tested positive that summer. I think I had an underlying self-destructive element that stemmed from...
loss, rejection, and internalized homophobia. In retrospect, I feel my testing positive for HIV was a self-fulfilling prophecy.”

NOW

NINETEEN YEARS AFTER HIS HIV diagnosis, Vassilarakis is a healthy guy—a marathoner, in fact. He is a full-time HIV outreach worker and a full-hearted spoken-word artist. His life today is a long, hazardous road from where he started in those matter-of-factly hopeful weeks after his diagnosis and the life-threatening years that followed.

“Initially, after learning about my status, I made a largely successful attempt to take back my life and live a healthier lifestyle. I imagined I would live until 2000 and I intended to live each day as if it were my last, enjoying them to the fullest. I didn’t think I’d live to see the year 2001.”

HARSH REALITY

“I wasn’t prepared for all the stigma and rejection associated with disclosure. For someone whose identity and self-worth was so dependent upon being sexually desired, the rejection was devastating. I went into the closet about my status. This made me feel horrible about myself when I would engage in sex but not as bad as being rejected for having HIV.

“I had already begun to experiment with drugs, but now they made it easier to hook up without disclosing. Eventually, I found myself caught in the grips of a crystal meth addiction for many years. I unraveled in the intensity of the drug-driven sex and ended up a homeless, strung-out, intravenous crystal meth addict with little more than my life and the clothes on my back.

“In October, 2006, with few options and death breathing down my neck, I checked into a rehab program within a Pentecostal church in the South Bronx. I made the mistake of disclosing my sexual orientation and the pastors regularly made an example of me during Wednesday and Sunday services, asking God to have mercy on those suffering from homosexuality and quoting [so-called] anti-gay scriptures in the Bible. After a month of judgment and scrutiny, I was back on the street again.

“I walked almost 50 blocks to the
opposite side of the Bronx to a friend’s apartment, hoping he would let me in to use his computer. I Googled ‘drug treatment homeless NYC’ and a list of places came up. I closed my eyes, put my finger on the screen and made the call to the one on which my finger had landed, a six- to-nine-month inpatient program in Harlem. It was a step up from a homeless shelter or a minimum-security correctional facility.

“I stayed there for a year with hundreds of other residents who had either been released to the facility as a condition of their parole, as an alternative to incarceration, or who, like me, had walked in homeless off the street. I never disclosed my sexual orientation or HIV status out of concern for my safety and well-being.”

HARLEM UNITED

DURING THE YEAR HE SPENT IN drug treatment, Vassilarakis made his way to Harlem United, a nearby HIV/AIDS support center without which, he says, “I don’t know if I would have made it through.” Group support allowed Vassilarakis to start processing “gay,” “HIV-positive,” and “addict” in a safe place with others who were working through the same issues of identity. Today, he’s an outreach worker at Harlem United, helping others trying to make it through.

“To date, I am four years free of my crystal meth addiction. In 2010 I took on the challenge of running 26.2 miles in the NYC Marathon to benefit Harlem United. I made this decision for two reasons. One was to affirm life 19 years after my HIV diagnosis. My CD4 count hovers in the mid 600s to mid 700s while my viral load remains around or below 3,500. My primary care provider and I have the meds talk frequently enough, but I will hold off for now. In the meantime, I keep a positive outlook and live the healthiest lifestyle I possibly can.

“Even early on, despite how flaky and irresponsible I was in other areas of my life, I was always pretty good about remaining engaged in care and keeping my finger on the pulse of what my HIV was doing. The doctor who tested me subscribed to the ‘hit early, hit hard’ belief about starting treatment. Every time I went to see him he made a strong case as to why I should start my meds. I was hesitant to comply because I knew I was too flaky, scattered, and transient to be able to adhere to a regimen properly.

“I left his care and sought out a doctor who supported my decision to wait, given my circumstances at the time, that my CD4 counts were still up in the 900+ range and that my viral load was virtually non-existent. In retrospect, I am glad I listened to my gut. The medications that were considered cutting edge at the time were just not as sophisticated and way more toxic than what we have available today. I also had a difficult time remembering to take a multivitamin on a daily basis; I can’t imagine how I would have done with meds where it was imperative that doses not be missed. Add the insanity of my active addiction and homelessness and I am sure that I’d be experiencing all sorts of complications and would have developed some kind of resistance to meds by now. Having said all that, I would have taken them if my labs had reflected that I needed to.

“I give a lot of consideration to what I put in my body by way of my diet. I am not vegan or vegetarian, but I do love to eat raw foods and I’m having a total love affair with my Breville juicer! I have also adopted a fitness lifestyle that goes beyond just lifting weights at the gym. I have run two NYC Marathons and several half marathons. I believe that diet and running keep my heart and my blood healthy.”

HIV IGNORANCE

VASSILARAKIS HAS BEEN REFUSED an apartment because he disclosed he had HIV to the owner, who feared her toddler would somehow be exposed to the virus. He knows the look of fear on a friend’s face after sharing the same drinking glass. As an outreach worker, he has a front-row seat to the work that remains in the battle to overcome ignorance and fear. As Vassilarakis says, “We can never take for granted that people are aware, especially in our own community and social circles.

“I was once facilitating an HIV/AIDS 101 at a local community college in the Bronx and someone asked if it was true that soaking in a bath with bleach after possible HIV exposure due to unprotected sex would prevent infection. I asked if anyone present would like to answer and a few hands went up. The person I called on said ‘No, soaking in a bath won’t, but drinking some will.’ I was floored.

“When my good friend, who had just joined me at an HIV/AIDS event where I was performing some poetry, freaked out that I had sipped from his cup, another friend who was there said, “Well, you can’t really blame him.” I felt gut-punched. Later, I put the experience into a poem I wrote called Infected/Affected that includes these lines:”

You don’t select what family you’re born into
But you do choose your friends
These days I pick mine wisely
I can say pretty confidently that those whom I love
Have as much love for me
Every once in a blue I am disappointed
When one refuses to drink from the same glass or bottle I have
Or pulls out the disposable paper plates for me
While everyone else eats from regular
dishes and cutlery
So I wash my food down
With gulps of reality
And wonder where I fell short
What opportunities have I missed to educate my peeps
Then I cease the moment and teach

FAITH
HOW DOES ROB VASSILARAKIS KEEP steady these days? Where does he find hope and strength? “There is power and freedom in prayer,” he says simply. If the God of his prayers has shut some doors in his life, it seems clear Vassilarakis has his eyes on the open windows.

“I tried reaching out to my mother a few times, but she had become a religious fanatic and her sermons and crying on the phone would leave me feeling emotionally depleted, leading me to severe bouts of depression. I eventually had to make the decision to sever all ties with her without ever telling her about my HIV status.

“There is no rhyme or reason why I should be alive and as healthy as I am all of these years later except for and through God. Through prayer I maintain in conscious contact with the God of my understanding, not the one who was depicted for me in my youth. My relationship with Him is one that I continue to develop through prayer and meditation.

“For many years I rejected organized religion because I felt they rejected me. In turning my back on them, I also turned my back on God, but He was always there for me. Many crystal meth addicts don’t make it back from where I’ve been. They have their physical and mental health irreversibly damaged, their cognitive or motor skills impaired, and those with compromised immune systems deplete them further, sometimes to the point of no return. I have been spared of all that.

“All of my faculties have been restored. I am in the best shape of my life, despite all of those years that I abused and disrespected my body. This is one of countless examples of how God continues to work in my life.

“I don’t say any of this to brag. I say it in acknowledgment and in acceptance that God has another plan for me.”

7 Years
BY “SIMPLY ROB” VASSILARAKIS

The presence of antibodies
Is what they look for
When they test for HIV
I was 22 years old in 1993
10 years since the first cases
Had been reported about in NYC
Now spread throughout its various communities
No longer ‘them’
Cuz now it’s ‘we’
But that didn’t stop me
From testing the breaking point of invincibility

I stepped into the room that smelled of sterility
Where I waited for what seemed like an eternity
To see what the results of my test would read
“Your test came back positive,” he said
Nothing less
Nothing more
Unable to look me in the eye he stared down at the floor
He’d never delivered an HIV positive test result before
My impulse to bolt out the door
Was outweighed by the need to make sure
That the doctor felt secure
So I stayed and was counseled some more
“7 Years” (to live) were some words I grabbed onto
“Treatment options” and “not a death sentence” were some others

Had I been another
I might have jumped in front of the #2 train

Like my girl Sharonda’s lil’ brother
Or hanged myself in the bathroom
With an extension cord
Like my boy Pito’s baby mother
After they discovered
That the baby has “the monster” too
But instead of suicidal ideation
I found that I had the will to live
And that I actually possessed
The power...To forgive

Forgive myself for the choices I had made
And the actions I had spoken
Forgive the one who infected me
Because he’s dead
And I have a long life ahead

Forgive my mother
For her religious convictions
Which allow her to believe in a god
Whose answer to drug addiction and homosexuality
Are AIDS and HIV

Forgive the doctor
For his contradictions
For his inaccurate depictions
For pushing mad prescriptions
For his 7 year prediction
Which caused me for some years
To reside within my fear

It’s been 19 and I’m still here
It’s been 19 and I’m STILL here
And I’m not going anywhere
Anytime soon

WATCH ROB ON YOUTUBE
youtube.com/watch?v=HWna7jnYBM0&feature=related
youtube.com/watch?v=E67ihU2U2zM
or visit positivelyaware.com
TOGETHER
WE ARE
GREATER
_THAN AIDS.

JOIN THE MOVEMENT
Facebook.com/GreaterThanAIDS