

## Editor's Note

By Jason Cianciotto, Director, Public Policy, GMHC

**WELCOME TO THE INAUGURAL ISSUE** of *SeroZero*, a new quarterly insert in POZ magazine produced by the Public Policy team at Gay Men's Health Crisis (GMHC). "SeroZero" refers to our goal to prevent new infections (seroconversion) and ensure that people living with HIV achieve optimal health and viral suppression. Building from the best of *Treatment Issues*, our previous insert, *SeroZero* will feature information about prevention and a variety of public policy issues affecting people living with HIV across the country. It will also feature inspiring stories from members of GMHC's Action Center, which empowers people living with HIV/AIDS to advocate for their needs.

In this issue we open with a powerful personal testimony from Sharon Vail, a long-time Action Center member living with AIDS since 1999. Approximately 20% of all new HIV infections occur in women and, like Sharon, many who fought through the early days of the epidemic are now over age 50. In the first of a regular column titled "Research Roundup," GMHC Community Coordinator Sarah Glasser walks us through recent research on women over 50 living with HIV and finds that there is a great need for more information about their needs and experiences.

In "Releasing Health," another regular column, Ronald Reginis shares how his experience at the intersection of HIV and the criminal justice system inspired his passion to help formerly incarcerated people living with HIV reintegrate and reconnect with society. Ron was recently honored as one of the POZ 100 in 2013 and he co-chairs the GMHC Action Center Prison Health Think Tank.

We close with Demetrius Thomas, GMHC Policy Associate, asking, "What's really new about the HIV epidemic and young Black MSM?" Demetrius responds to the notion that Black men who have sex with men (MSM) are the "new face of HIV" and shares GMHC's focus on the disproportionate affect of HIV on young Black MSM. As Demetrius shares, we will never reach sero zero unless we address the socio-economic disparities, stigma, and discrimination driving the epidemic.

## I'm Still Here, Thank God

By Sharon Vail, Member, GMHC Action Center

**MY NAME IS SHARON DELORES VAIL**, born to Mr. and Mrs. Melvin Vail, Sr. I'm 52 years old and the first child out of three. I have one sister and one brother. I've been living with AIDS since 1999.

I've had HIV ever since Magic Johnson made his announcement. I've had my days, ups and downs, but thanks to my God and savior, Jesus Christ, I've been blessed and am still living, still on medication. I am fortunate to have three daughters and eight grandchildren living in Queens.

When I was first diagnosed, I was scared and crying. I wanted to get high to kill the pain and kill the disease. I don't remember how old I was. I was working at that time. If it wasn't for my baby's pediatrician looking at my glands (she decided to give me an HIV test), I would not have known. When she told me I had HIV, I didn't know anything about it. I denied that I had HIV. I thought it was like chicken pox where you took a pill and it would be fine.

When I was first diagnosed, I was on AZT. When my mother and father found out I was sick, they rushed me to a specialist who said I had AIDS. The doctor took me off AZT. It was making me sick and lose weight. Throughout the years, I've seen myself wasting, as the weight just drifted off my body. I was thin and 75 pounds. Now I'm 175 pounds.

My family didn't know about my virus until I caught an infection. They did not know anything was wrong with me because I put myself into Jamaica Hospital. I thought I could get a prescription and go home. It was not so. I was inflamed. I hated the doctors. I hated my life. I hated drawing blood every hour.

I saw my mother talking to my oldest daughter. They kept holding each other. I kept telling my doctor not to tell my family, that it would tear my mother to pieces and hurt my father like hell. This happened around July 3, 1999. I was sedated. When I woke up I saw my father and he said, "I know what's wrong with you." I said, "I caught a piece of bad dick." He laughed and he said, "No, baby, I told you I would

find out what's wrong with my child." He took care of me ever since.

To this day I am taking medication morning and night, going to my programs and support groups faithfully, staying out of trouble, and off of drugs.

I am now in a relationship and it's going well. He supports me, too. He is with me 100%. Whenever I have a question he is there. When I need a place to cry, he is there. He always tells me not to worry and that I am not alone. I have a family network, a host of uncles and aunts who support me. My mother and father also took care of me for a while.

It's a hell of a lot different from 1999 and now. I've gained a lot of weight. I've been doing good. I see myself changing. This is the first time I've written about my affliction. I'm coming out of myself.

As I grew older—after I turned 40 and up—I've been wiser. I've seen myself changing a lot. I'm speaking more about HIV and AIDS, but I do not like the word AIDS. I was told I was HIV positive and I always stuck to that. Nonetheless, I'm carrying this disease. It will not take me out. It will not make me kill

myself. It's making me stronger and the medications are too.

To young people, keep condoms. Ask your partner if they are positive, female to female, male to male, or female to male. It's not easy living with AIDS.

To people with HIV and AIDS, find a group setting (support group, AA or NA meeting).

If you're newly diagnosed, take your medications. It's no joke. I had a stroke as well because I was in denial and wasn't taking my medicine.

Newly diagnosed people should call a hotline and speak to someone. Talking to someone helped me. I wanted to kill myself and I said, "Shit, I'm going to die anyway." I got higher and higher. I couldn't get higher than I was. But then, I talked to someone. I asked God, "Please let me live. Let me live the next day. I do not want to die. Keep me in your arms. Give me your strength."

People who are diagnosed should share their story. They need to let the world know they are not ashamed. That's why I want to share my story. I am now undetectable.

## Research Roundup: Women Over Age 50 and HIV

By Sarah Glasser, Community Coordinator and AVODAH Fellow, GMHC

**WOMEN OVER 50 LIVING WITH HIV** are a particularly under-researched demographic. Specific criteria for diagnosing women with HIV were not even established until almost 15 years into the epidemic.<sup>1</sup> What do epidemiological data and academic research tell us about HIV and aging specifically for women? Given that almost 25% of newly diagnosed elders (50 and older) are women, are there specific factors that place them at higher risk?<sup>2</sup> One recent analysis found menopause to be a factor, as postmenopausal women can experience more instances of vaginal dryness, which can lead to tearing during sexual activity and increased risk of HIV transmission.<sup>3</sup> This edition of

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*Research Roundup* summarizes additional contemporary, peer-reviewed research on women aging with HIV/AIDS.

**Akers, A., Bernstein, L., Henderson, S., Doyle, J., & Corbie-Smith, G. (2007). Factors associated with lack of interest in HIV testing in older at-risk women. *Journal of Women's Health, 16*(6), 842–858.**

This study analyzed HIV testing habits of older women receiving services at a medical clinic in Georgia. Researchers interviewed 514 women, aged 50 to 95, and found that only one-third had ever received an HIV test. They also paid special attention to whether or not high-risk older women participated in testing. Women in the study were considered high risk if they engaged in sexual intercourse with high-risk male partners, such as men who engage in IV-drug use, sex work, or who are formerly incarcerated. The results: Only 45% of older, high-risk women were interested in taking an HIV test, citing lack of need, perceived lack of risk, or having been previously tested as justification. High-risk women who were uninterested in testing were more likely to be older than

the other participants and more likely to be African American.

**Brennan, D. J., Emlet, C. A., Brennenstuhl, S., & Rueda, S. (2013). Sociodemographic Profile of Older Adults with HIV/AIDS: Gender and Sexual Orientation Differences. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement*, 32(1), 31–43.**

Brennan and associates analyzed data from the Ontario HIV Treatment Network Cohort Study of people 50 and older living with HIV/AIDS. Approximately 11% of participants were women age 50 and older. Over two thirds of participants were living with HIV for more than a decade and almost 90% had an undetectable viral load. Women aging with HIV/AIDS who participated in the study experienced higher levels of stigma, poor self-image, and maladaptive coping skills than other participants. However, these women also reported high levels of social support, good health and were less likely to engage in cigarette and alcohol use.

**Lovejoy, T. I., Heckman, T. G., Sikkema, K. J., Hansen, N. B., Kochman, A., Suhr, J. A., ... & Johnson, C. J. (2008). Patterns and correlates of sexual activity and condom use behavior in persons 50-plus years of age living with HIV/AIDS. *AIDS and Behavior*, 12(6), 943–956.**

This study included 290 individuals over age 50 living with HIV/AIDS and assessed their use of condoms. Researchers found that only 20% of the heterosexual women in the study were sexually active. They were more likely to be wealthy, report good health and be in a relationship. However, only 12% regularly used condoms. Four percent of these women reported that they were in a seroconcordant relationship, where both partners are living with HIV, and practiced irregular condom use. Three percent of the women in the study were in a serodiscordant relationship, where the woman is positive and her partner is not, and practiced irregular condom use. Irregular condom use was associated with being in a primary relationship and knowing less about HIV/AIDS.

**Golub, S. A., Botsko, M., Gamarel, K. E., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2013). Dimensions of psychological well-being predict consistent condom use among older living with HIV. *Ageing international*, 38(3), 179–194.**

Golub and associates studied factors that increased the likelihood of condom usage among HIV-positive

women over age 50. They found that having “purpose in life,” “environmental mastery” and “autonomy” significantly increased likelihood of condom use. “Purpose in life” was defined as the process of seeing a deeper meaning to challenges in life. The authors suggest this may reflect individuals’ spirituality and that having spiritual practice may increase desire to participate in preventative behavior. “Environmental mastery” and “autonomy” may increase condom usage because they indicate that a woman in a relationship feels more comfortable discussing contraception and advocating for her sexual needs.

*There is also a great need  
for formative research  
on transgender women  
aging with HIV.*

**Bianco, J. A., Heckman, T. G., Sutton, M., Watakakosol, R., & Lovejoy, T. (2011). Predicting adherence to antiretroviral therapy in HIV-infected older adults: the moderating role of gender. *AIDS and Behavior*, 15(7), 1437–1446.**

Joseph Bianco and his fellow researchers sought factors that increase adherence to antiretroviral therapy for women living with HIV over age 50. Just over half of the women in the study properly took their antiretroviral medications. Those who engaged in avoidance coping (ignoring a stressor to protect oneself) and who had fewer social supports were found more likely to be depressed. However, the study did not find a significant correlation between lack of social support, avoidance strategies, depression and adherence. In fact, researchers found no psychological or sociological factors that predicted a woman’s medication adherence.

**Psaros, C., Barinas, J., Robbins, G. K., Bedoya, C. A., Safren, S. A., & Park, E. R. (2012). Intimacy and sexual decision making: Exploring the perspective of HIV positive women over 50. *AIDS patient care and STDs*, 26(12), 755–760.**

In this qualitative study, 19 women living with HIV over age 50 were interviewed about their sexual choices. For these women, the main barriers to sexual and

romantic relationships were fear of stigma, negative body image, and discomfort around disclosure. Stigma decreased rates of sexual and romantic pairings because they were afraid of being judged as "dirty" or "bad." Negative body image, caused by the side effects of HIV medications and/or menopause, also affected romantic and sexual pairings. Moreover, discomfort about disclosure affected the rate of sex and intimacy. This discomfort came from past negative experiences, where the women experienced rejection, as well as from fear of future rejection.

**IN MY REVIEW OF CONTEMPORARY RESEARCH** on aging among women living with HIV/AIDS, I found that most studies focused predominately on condom usage and included small sample sizes and narrow

scopes of study. Many articles included female subjects but did not separate women and men in their analysis. As a result, there is a dearth of information about the specific challenges experienced by aging women with HIV. Future studies would benefit from analyzing beyond just sexual activity, with a more holistic focus. There is also a great need for formative research on transgender women aging with HIV, all of which would better inform prevention, treatment and support services for women.

#### **Endnotes**

- 1 Brennan, D. J., Emlet, C. A., & Eady, A. (2011). HIV, sexual health, and psychosocial issues among older adults living with HIV in North America. *Ageing International*, 36(3), 313–333.
- 2 Centers for Disease Control. (2013). HIV among older Americans. Retrieved January 23, 2014 from [http://www.cdc.gov/hiv/pdf/library\\_factsheet\\_HIV%20AmongOlderAmericans.pdf](http://www.cdc.gov/hiv/pdf/library_factsheet_HIV%20AmongOlderAmericans.pdf).
- 3 Brennan, 2011.

## **Releasing Health: Reintegration and Me**

*By Ronald Regins, Co-chair, GMHC Action Center Prison Health Think Tank  
Honored as one of the 2013 POZ 100*

**LIVING WITH HIV AND AIDS** has been a trial in itself. Add to that a lifestyle that included addiction and criminality, and you have a recipe for disaster. I was incarcerated when the AIDS epidemic was at its peak of intensity and urgency. My life was out of control, and dealing with addiction, sexuality and a morbid disease was overwhelming.

Sometimes it was easier to remain in prison because HIV to me *was* a prison for "bottom feeders" and society's predators. My thought process at the time was that it was my just deserts. In an environment like prison, all the stigma of HIV becomes triple-fold due to fear, ignorance and peer pressure. Having to hide my disease interrupted much needed treatment and kept me off a medication regimen for two decades.

Today, two of my passions are reintegration and increased socialization for people who were incarcerated because I witnessed firsthand man's inhumanity

to man. The cruelties suffered by most of my fellow inmates who were HIV positive and homosexual I wouldn't wish any human being to endure. I became one of the ringleaders of that cruelty, hiding my guilt, anger, shame and sexuality by transferring my affliction onto others. However, that was a different time and I had a different mindset.

Today, I strive to ensure that any prisoner—gay, straight or otherwise identified—can have the continuity of care that I enjoy today. It shall be my legacy to find ways for a person who is HIV positive and happens to fall into the prison system to learn how to navigate services, become a true partner in their own care, be assertive about their treatment, encourage dialogue with providers and, most importantly, shed that "Scarlet Letter" of HIV/AIDS. That stigma will certainly impede them from returning to their communities as law abiding, productive members of society.

For me, sobriety and treatment adherence are just two of the main keys to my successful reintegration process. A third and vital component has been my involvement in the Action Center and Prison Health Think Tank at GMHC. When someone asks me what the Action Center is, I say, "It's where consumers become citizens," because for me it is actually the first place I felt like a citizen post-diagnosis.

Through GMHC's Action Center, I first met with former New York State Senator Thomas Duane. It was cathartic seeing for the first time a man who was openly

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gay, HIV-positive and a mover and shaker in city and state government. To be quite frank, in the not too distant past, my self-perception was if you touch me, you got dirty. Being able to rub elbows with elected officials, form opinions, have intelligent discourse and help influence policy has been so vital in my personal growth. I am now able to live life at my personal best.

Today I know that life is for the living and I also have learned to “frame” my treatment. My health

regimen is my cure. I am far beyond survival. I have survived.

If one person will allow me to be a template for reintegration and increased socialization, then my job is done. I think a place like GMHC, interactions created by the Action Center, and community-based organizations like Village Care, HELP/PSI and AIDS Service Center NYC are the best medicine for someone ready to rejoin the living.

## What's Really New About the HIV Epidemic and Young Black Men?

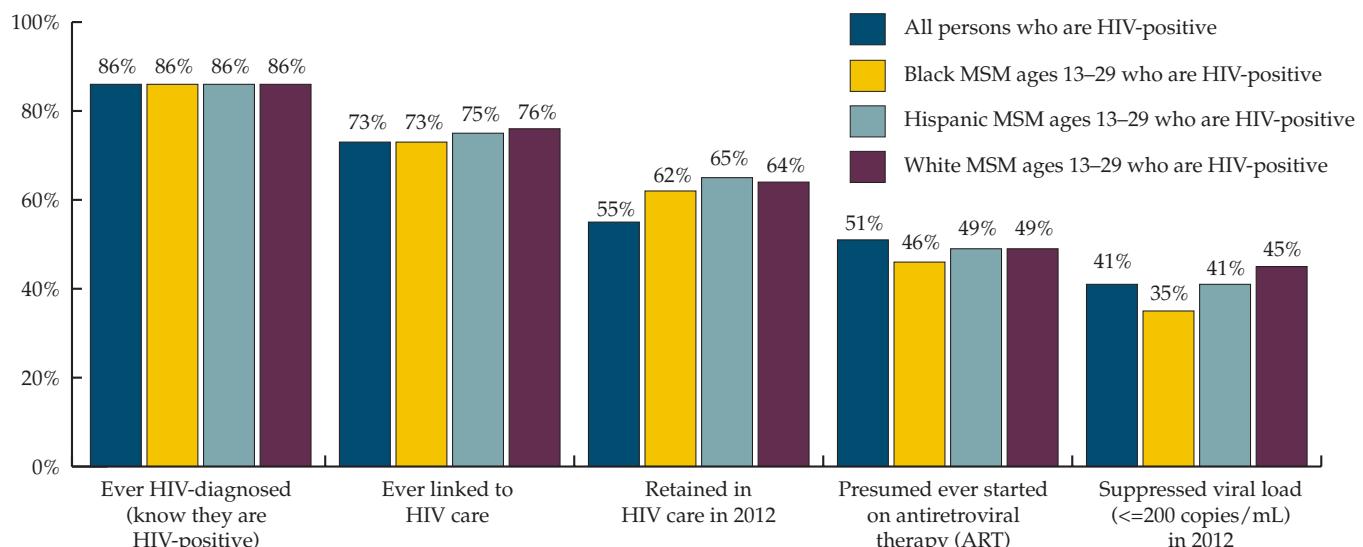
By Demetrius T. Thomas, Policy Associate, GMHC

**SINCE THE BEGINNING OF THE EPIDEMIC**, HIV in the U.S. has been widely described by mainstream media as a White, homosexual disease. What hasn't been as widely reported, at least until recently, is the disproportionate impact of HIV on the Black community, particularly on young Black MSM (men who have sex with men). In December 2013, the *New York Times* published an article titled “Poor Black and Hispanic Men Are the Face of H.I.V.” Citing data from the U.S. Centers for Disease Control and Prevention (CDC), it reported that “[w]hen only men under 25 infected through gay sex are counted, 80 percent are black or Hispanic.” The *Times* article depicted an epidemic among MSM of color with insurmountable problems

and no long-term solutions. In fact, there are solutions. They begin with government, the LGBT community, HIV service organizations, those affected by HIV, and the community at large recommitting and reengaging to fight the epidemic, with particular attention to young Black MSM.

Since the impact of HIV/AIDS on MSM of color became above the fold, front-page news, some have incorrectly labeled Black MSM “the new face of the epidemic.” The fact is HIV has always had a racial and socio-economic divide. For the past 25 years, CDC surveillance reports have shown the ever-increasing toll of HIV on Black America. As early as 1996, the CDC reported that Blacks outnumbered and had the

**Figure 1: Comparison of HIV-positive Populations Living in New York City in Selected Stages of the HIV Continuum of Care at the End of 2012\***



\*Data provided to GMHC by the New York City Department of Health and Mental Hygiene, February 4, 2014.

# SEROZERO

EDITOR: JASON CIANCIOOTTO

ASSISTANT EDITOR: LYNDEL URBANO

ASSOCIATE EDITORS: DEMETRIUS THOMAS AND SARAH GLASSER

ART DIRECTOR: ADAM FREDERICKS

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highest percentage of persons living with HIV/AIDS of all racial and ethnic groups. This trend is magnified in locations with greater health disparities, high unemployment, poor access to education, and more drug abuse/use.

In July 2013, President Obama launched the National HIV Care Continuum Initiative, which provides critical guidance on addressing this disparity. The initiative focuses on addressing gaps in HIV/AIDS care for all infected, from HIV diagnosis to the goal of viral suppression. In February, GMHC worked with the New York City Department of Health to produce a care continuum specific to young MSM ages 13 to 29 by race/ethnicity. As illustrated in Figure 1, compared to their racial/ethnic peers, young Black MSM are less likely to be linked to and retained in care, least likely to start antiretroviral therapy (ART), and more likely to fall out of care before reaching viral suppression. This underscores the need for young Black MSM to be connected to HIV specialists who prescribe the most effective medical treatment and for health care and support systems needed to ensure long-term viral suppression.

Epidemiological studies and biomedical interventions are critical to bridging these gaps in care for young Black MSM. However, they are not the complete solution. We also must address socio-economic disparities and the cultural and institutionalized stigma and discrimination that drive the epidemic. Only then can we prevent young Black MSM from even becoming infected.

GMHC will soon publish "Breaking the Silence: A Call to End the Disproportionate Impact of HIV on Black MSM." This human rights report addresses the drivers of the epidemic and provides answers to the questions left by the *Times* article. The report is organized into five actions. The first, "A Call to Action," highlights the state of HIV/AIDS among Black MSM. "Rates for Action" provides a comprehensive overview of epidemiological data on Black MSM nationwide, in New York City, and in the South. "Causes of Action" summarizes research on the health disparities, socio-economic inequality, as well as familial, cultural, and institutionalized stigma experienced by young Black MSM. "Organization for Action" describes Outstanding Beautiful Brothers (OBB), GMHC's award-winning HIV prevention program for young Black MSM. The final section, "Course of Action," details critical steps in funding, preventing, creating dialogue, advocating, and mobilizing towards HIV incidence rates that fall below epidemic proportions.

The HIV/AIDS epidemic in the United States is far from over. At the current incidence rate, more than half of the population of young Black MSM could seroconvert in the next decade. While this disproportionate impact isn't new, we must leverage the mainstream attention that is new to chart a visionary course of action, focused on cutting edge, culturally competent, effective prevention and treatment programs for young Black MSM.

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