

## \*NEWSLETTER\*

VOLUME MMXXIV - ISSUE

Febuary - March 2024

# HIV + Aging Research Project | PS

## Coming Soon HARP-PS HIV+ Village Facebook Group

- Opportunity to Connect Other Longterm Survivors in Our Community.
- Learn About the Latest Research & News on HIV Treatments and a Cure.
- Have Fun Exercising and Creating Nutritious Meals.
- Explore New Social Activities and Make New Friends.

## Find This and Much More Within a Supportive HIV+ Aging Community of Your Peers!



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Waheedah Shabazz-El Director of Community Outreach for The Reunion Project.

## Oh, Say Can you See HIV

## The impact of social and economic inequities in Black communities is HIV.

In honor of National Black HIV/AIDS Awareness Day (NBHAAD), I'm reminded of the first time I came to know of HIV in the Black community-in the public housing project community where I was living in 1982. Just a year earlier, the CDC reported the first known cases of what we now call AIDS in its Morbidity and Mortality Weekly Report (MMWR). In that first month they saw 26 cases, one of whom was African American.

The year was 1982. I was attending Community College and had just purchased my first car. I lived in public housing in Philadelphia, as did my brother-in law Ronald, a decorated Marine Vietnam War Veteran who had just mysteriously died. While it was generally understood that he had overdosed (he was injecting drugs at that time), there was some chatter in my Black community that Ronald had died from AIDS. When the local funeral home only offered a cremation memorial service for

Ronald, that validated for us (at least in our minds) that indeed it was AIDS.

After 1981, HIV cases increased in the Black community each year until finally, in 1990, the number of new cases of HIV among African Americans exceeded the number of cases of HIV in whites, and it has remained that way ever since.

Part of the culture among some in the Black community is that you should "mind your own business." HIV has been the elephant in the room which we have tried our utmost to ignore. But we can no longer afford to ignore HIV or be confused about it-because HIV has become our business. The conspiracy theories surrounding the origins of HIV become less important as research reveals that HIV thrives in communities, particularly Black communities, where social and economic inequity and minimal access to basic human rights has become the norm.

For Black communities, HIV is in some ways more of a social condition than it is a medical condition. A clear case of cause and effect. HIV is more than a virus-it is the proof positive of social and economic inequity, or systemic suppression of basic human rights-which results in increased vulnerabilities to acquiring HIV in the first place.

Let us not confuse risks factors with vulnerabilities. They are not the same thing.

Risk factors are ways in which HIV is transmitted. Blood via needle sharing or tattoos. Semen. Anal and vaginal fluids via condomless sex with a person with HIV who may not be virally suppressed. Breast milk from a person who has HIV and may not be virally suppressed.

Vulnerabilities are social and economic factors that lead to contracting HIV in the first place. Including, but not limited to, food insufficiency, unstable housing, lack of health care, poverty, and lack of employment opportunities with living wages. Lack of educational opportunities. Linguicism. Library closure. Untreated mental health problems. Underfunded substance rehabilitation programs or youth development programs. Higher rates of incarceration that destabilize families and impact political power in Black communities. People with advanced HIV and AIDS may qualify for disability benefits that limit their ability to earn additional income. Many of these factors occur in lower educational and impoverished urban areas, however limited health care access and limited transportation infrastructure become vulnerabilities for Black people living in rural areas.

Despite advances in HIV prevention, the sheer abundance of social economic factors that persist in Black communities has provided a fertile environment for HIV to flourish. This helps explain reports that show African Americans, more than any other race, have the highest rates of HIV cases in the nation. Even though Black people make up just 14% of the U.S. population, we account for nearly half of those living and dying with HIV and AIDS. In 2017, AIDS was the eighth leading cause of death among Black women ages 35-44, and the sixth leading cause among Black men ages 35-44.

Oh Say Can You See HIV, Continued Page 3

#### *Oh, Say Can You See, Continued from Page 2*

As we acknowledge National Black HIV and Awareness Day each year, we cannot ignore the ongoing challenges and impact of the many social and economic factors that persist in Black communities.

With the devastating impact of these social and economic inequities in Black communities, our direction and demands become crystal clear. As a community, our direction must be an upward bound movement which honors our heritage and reflects our perseverance and resilience. As a society, we cannot afford to be silent on the issue of AIDS-because silence has not worked in our favor. Our collective silence has resulted in too many unnecessary deaths of Black men and women. As we continue to make our case for true liberation, we must demand to be liberated from discrimination, and the well-worn path of social and economic inequities, that have allowed HIV to establish a foothold in Black communities.

So, on this National Black HIV and AIDS Awareness Day, as my memories are stirred of the first time I came to know of HIV in the Black community, in the public housing project where I was living in 1982, it reminds me of a story yet to be written-of Black Communities liberated from the AIDS epidemic.

Painful as it is, our pain has purpose, and our purpose is liberation.



## POSITIVELY AGING PROJECT 2024

## Is proud to announce that Waheedah Shabazz-Ei will be the Keynote Speakers at this year's event. Saturday September 21, 2024 at the Mizell Center!

Waheedah Shabazz-El is a Black American Muslim woman and retired postal worker, diagnosed with AIDS in 2003. A Community Organizer, Strategist & Trainer, a graduate of Project Teach and a longtime member of ACT-UP Philadelphia.

Waheedah is a founding member of Positive Women's Network-USA and is currently advancing a national alliance of HIV long-term survival with The Reunion Project.

In the area of HIV Cure Research Waheedah is chairperson Emeritus for the Delaney Collaboratory BEAT HIV Cure CAB at the Wistar Institute as well as the Penn CFAR CAB.

Her proudest moments: A White House reception in 2010, invited by President Barack Obama. Delivering the Closing Plenary address at the XVIII International AIDS Conference in Vienna, Austria, representing the USA. A speech on World AIDS 2008 at the gravesite Dr King and Coretta Scott King in Atlanta.



### The lesser known Sexually Transmitted Infection Mycoplasma Genitalium

Mycoplasma Genitalium (MGen) is a Sexually Transmitted Infection (STI). MGen is not as well-known as our other more commonly known STIs such as chlamydia and gonorrhea. In fact, MGen makes up only 1-4% of STI cases in the general population in the United States.

MGen can cause infection amongst people of any gender, and can infect the cervix, inside the penis, or the rectum. It is •unclear whether or not MGen can spread through oral sex. Most people with MGen are asymptomatic, and do not develop complications, and actual infections. In fact the significance of MGen in asymptomatic individuals is uncertain.Therefore, the

routine testing of asymptomatic people for MGen is NOT recommended in international guidelines.

Patients with persistent STI symptoms after being treated adequately, and with compliance for chlamydia, and gonorrhea may be considered a candidate for MGen testing.

The Nucleic Acid Amplification Test (NAAT) is the preferred, and easiest method for detection of MGen from urine, rectal swab, or vaginal swab.

Treatment for MGen can be tricky, and depends on whether the particular strain is sensitive or resistant to various antibiotics. Doxycycline usually is part of the treatment regimen.

Finally the CDC recommends treating the partner with the same antibiotic regimen that was provided to the patient.

#### WANT TO KNOW MORE ABOUT MGEN? Scan or Click Here



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## **Happenings At HARP-PS**



#### THANK YOU TO THE AMAZING DR. JILL GOVER!

Dr. Jill Gover ("Dr. G.") has been a longtime supporter of HARP-PS, and for the past three years, an invaluable member of our Board of Directors. Though Dr. G's tenure on the board has come to an end, we want to express our upmost appreciation for her work on the HARP-PS board.

During her time with us, Dr. G. helped our organization grow and thrive – whether it be the numerous articles she wrote for our newsletter, her calm and steady guidance through both good and difficult times, her participation

in our educational initiatives, or her continued support of HARP-PS through our fundraising initiatives. We will miss Dr. G. and thank her for her work on our board!



## EXCITING NEWS ABOUT OUR EXECUTIVE DIRECTOR JEFF TAYLOR

A Special Congratulations goes out to our Executive Director, Jeff Taylor for his recent appointment to **The Presidents Advisory Board on HIV & AIDS (PACHA)**. This special honor comes after a long and storied career as an HIV/AIDS activist and founder of the HIV+ Aging Research Project.

Jeff Taylor, a long-term survivor has been active in HIV research advocacy since enrolling in the first AZT trials in the late '80s. He has served on the community scientific subcommittee of the AIDS Clinical

Trials Group and as a community representative to the National Cancer Institute's AIDS Malignancy Consortium, where he was a part of the HPV Working Group and the ANCHOR Study.

Jeff previously served on the Department of Health and Human Services Antiretroviral Guidelines Panel. He is currently on community advisory boards for the CARE Collaboratory, the UCSF Gladstone amfAR Cure Institute and the UCSF DARE Collaboratory for HIV cure research. He's also on the AIDS Treatment Activists Coalition's Drug Development Committee, which meets regularly with pharmaceutical and Food and Drug Administration on HIV drug development issues.

Congratulations and THANK YOU for your hard work throughout the years!



#### CONGRATULATIONS TO JIM FERGUSON, NEWLY APPOINTED DIRECTOR OF PROGRAMS FOR THE HIV+ VILLAGE PALM SPRINGS

Jim came to HARP-PS just over a year ago and has made an indelible mark on our organization as a tireless, hard-working volunteer responsible for publishing our newsletter, assisting with, and guiding our fundraisers and being a vital support for all our educational initiatives. He will continue to volunteer in those capacities.

Recently Jim was named Director of Programs for our long-standing HIV+ Village Palm Springs which he has been involved in, as a volunteer over the past 8 months. Prior to joining HARP-PS, Jim, a Palm Desert

resident, worked in the travel industry for 30 years including as Vice President of Lodging for Expedia and co-founder and President of HotelMobi. Congratulations & Welcome Aboard to Jim in his expanded role!



Ami I. Student, PsyD Licensed Clinical Psychologist

## Finding Purpose in the Face of HIV and Chronic Pain

Physical pain has always been a part of the HIV experience. As people live longer with HIV, new chronic pain conditions (e.g., neuropathy, avascular necrosis, lower back pain, and gastrointestinal pain) have emerged. Although there are several theories of how they develop, their root causes remain scientifically elusive. Reversing your course of chronic pain can be tricky, and options for controlling pain can be limited.

Medicine has historically struggled when addressing complex problems. If we add the challenges of HIV, and for some, the difficulties of stigma, homophobia, transphobia, sexism, and/or racism, you may have found yourself lost in a system that invalidates and minimizes your pain. Moreover, your efforts to manage pain—attending medical appointments, avoiding triggers, "pushing through" flares, taking medications, wrestling with health insurance—may have become a "full time" job, which can become exhausting and demoralizing.

As a health psychologist, I work at the intersection between

physical and mental health. I specialize in working with folks who have chronic illnesses like HIV, but also specifically treat chronic pain.

Among several areas I address in treatment, is the loss of purpose and meaning that can come from living with pain. I work with you to clarify what you find fundamentally important, and explore how to approach these underlying values in new and more pain-accessible ways.

One method to start exploring what you value is to ask yourself: "if I went to sleep and all my difficulties with pain magically stepped out of the way, what would I want my life to be about when I wake up?" What we are looking for is not the actual activities themselves, but what is important to you about those activities. For instance, if you were to respond, "I'd probably pick up a friend and go camping in Yosemite," I might ask "what about doing that is important – what are the qualities about that trip that feel meaningful? Is it the connection with another person? The adventure of such a trip? The challenge of doing something uncertain? Is it enjoying the beauty of the natural world? Or is it the sense of freedom that comes with a road trip?" Once we figure out what is important about that activity, we can get a sense of what values are important to you – values that are likely unmet and distant now that you have pain.

Values are like directions on a compass; they have no endpoints. They are simply directions we believe are worth traveling toward. If you value connection with others, but that has been lost in your pain experience – how do we build more connection in your life now (even if it looks vastly different than before)? What would be one, small, realistic step in the direction of your values that you could institute today? Maybe it's texting that friend you've lost touch with? Or talking to that neighbor a little longer?

One strategy for more flexibly engaging your values is to notice when your mind inserts a "but" into your thoughts. For instance, let's imagine you are pursuing a value of connection and you consider scheduling lunch with a new acquaintance. However, your mind jumps in with the thought, "It would be great to meet them for lunch, but I'm in a lot of pain today." Following that thought makes lunch unlikely, as well as any other options for connection. What, however, might change if you were to swap an "and" for the "but"? "It would be great to meet them for pursuing your values; instead, it becomes a hurdle to navigate on your way to connection. Maybe you go to lunch even while in pain? Maybe you change the location or length of the visit to accommodate your pain flare? "But" keeps us stuck, while "and" allows us to pursue our values – even with pain.

Living with HIV and chronic pain can bring a harrowing level of challenge. Psychological approaches can help you interact with your pain in more helpful ways, and help you retake some of the ground lost in the struggle. I invite you to pull out your compass, reorient towards your values, and start moving towards what is important.



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## **Up Coming Events For Your Calendar**



Positive Life Series

Positive Life Series

March 5th, 2024 6:00PM Beyond Testosterone Speaker: Nelson Vergel



April 2nd, 2024 6:00PM CROI UPDATE Speaker: Golkoo Morcos Bios Clinical Research



May 7th, 2024 6:00PM HIV and Spirituality Speaker: Dr James Mellon Global Truth Center



## **Assistance Resources**



## A Very Special Thank You To Our Volunteers!

Ken Vergonet – Social Media Manager Extraordinaire Jim Ferguson – Layout of Newsletter, And a Lot of Other Things! Chad Sain – Photographer (Chad Sain Photography) Scott Graf, Positive Life Series and More!