

Presidential Advisory Council on HIV/AIDS (PACHA)
79th Meeting
December 6, 2023

Council Members—Present

Marlene McNeese, PACHA Co-Chair, Assistant Director, Houston Health Department, Houston, TX
Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, Co-Chair, Professor, Duke University School of Nursing, Vice Chancellor, Nursing Affairs, Duke University, Durham, NC
Guillermo Chacón, President, Latino Commission on AIDS; Founder, Hispanic Health Network, New York City, NY
Philip Chan, M.D., M.S., Associate Professor of Medicine, Brown University, Providence, RI
Tori Cooper, M.P.H., Director of Community Engagement for the Transgender Justice Initiative, Human Rights Campaign, College Park, GA
Raniyah Copeland, M.P.H., Principal, Equity & Impact Solutions, Los Angeles, CA
Mackenzie Copley, Co-Founder and CEO, One Tent Health, Washington, DC
Alicia Diggs, M.P.H., Manager, Office of Community Engagement, Center for AIDS Research, The University of North Carolina at Chapel Hill, Greensboro, NC
Jennifer Kates, Ph.D., Senior Vice President and Director of Global Health & HIV Policy, KFF, Washington, DC
Paul Kawata, M.A., Executive Director, NMAC, Washington, DC
Duvia Lozano, LMSW, Program Director, Chicanos Por La Causa, Inc., Phoenix, AZ
Tiommi Luckett, National Organizer, Transgender Law Center, Little Rock, AR
Jesse Milan Jr., J.D., President and CEO, AIDS United, Washington, DC
Deondre Moore, Ambassador, The Elizabeth Taylor AIDS Foundation, Beaumont, TX
Leo Moore, M.D., M.S.H.P.M., Medical Director for Clinic Services, Los Angeles County Department of Public Health, Los Angeles, CA
Laura Platero, J.D., Executive Director, Northwest Portland Area Indian Health Board, Portland, OR
Kayla Quimbley, National Youth HIV and AIDS Awareness Day Ambassador, Advocates for Youth, Columbus, GA
Natalie Sanchez, M.P.H., Director, UCLA Family AIDS Network, Los Angeles, CA
Patrick Sullivan, D.V.M., Ph.D., Dipl. ACVPM, Charles Howard Candler Professor of Epidemiology, Rollins School of Public Health, Emory University, Atlanta, GA
Jeff Taylor, Executive Director, HIV and Aging Research Project, Palm Springs, CA
Marvell Terry II, Activist and Cultural Organizer, Founder, The Red Door Foundation and the Saving Ourselves Symposium, Memphis, TN
Carole Treston, M.P.H., RN, ACRN, FAAN, Executive Director, Association of Nurses in AIDS Care (ANAC), Philadelphia, PA
Dafina Ward, J.D., Executive Director, Southern AIDS Coalition, Bluffton, SC
Darrell P. Wheeler, Ph.D., M.P.H., M.S.W., President, State University of New York at New Paltz, New Paltz, NY

Council Members—Absent

Hansel Tookes, M.D., Assistant Professor, Department of Medicine, University of Miami Miller School of Medicine, Miami, FL

Staff

B. Kaye Hayes, M.P.A., PACHA Executive Director, Designated Federal Officer; Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP); Deputy Assistant Secretary for Infectious Disease, Office of the Assistant Secretary for Health (OASH), U.S. Department of Health and Human Services (HHS)

Caroline Talev, M.P.A., Alternate Designated Federal Officer for PACHA, Senior Management Analyst, OIDP, OASH, HHS

Federal Partners

Sharonda Brown, Deputy Director of Operations, OIDP, OASH, HHS

Tracy Carson, J.D., Deputy Director, Office of Foreign Assistance, U.S. Department of State

William Dilday, Interdepartmental Liaison, U.S. President's Emergency Plan for AIDS Relief (PEPFAR), U.S. Department of State

Nelly Gazarian, Senior Policy Analyst, OIDP, OASH, HHS

Maureen Goodenow, Ph.D., Director, Office of AIDS Research, National Institutes of Health (NIH)

Timothy Harrison, Ph.D., Principal Deputy Director, OIDP, HHS

Heather Hauck, M.S.W., LICSW, Deputy Associate Administrator, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

RDML Timothy H. Holtz, M.D., M.P.H., FACP, FACPM, U.S. Public Health Service, Deputy Director, Office of AIDS Research, NIH

David Johnson, M.P.H., Deputy Assistant Secretary for Health, Office of Regional Health Operations, HHS

Jessica Lee, Medical Officer, Center for Medicaid and Children's Health Insurance Program Services, Centers for Medicare & Medicaid Services (CMS)

Robyn Neblett-Fanfair, M.D., M.P.H., Principal Deputy Director, National Center for HIV, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis Prevention, Centers for Disease Control and Prevention (CDC)

CAPT John Oguntomilade, Ph.D., M.P.H., B.D.S., Regional Director, HIV Prevention through Active Community Engagement (PACE) Program Region 4, HHS

Harold J. Phillips, M.R.P., Director, White House Office of National AIDS Policy (ONAP)

Kristin Roha, M.S., M.P.H., Public Health Advisor for HIV, Substance Abuse and Mental Health Services Administration (SAMHSA)

CDR Michelle Sandoval-Rosario, Dr. P.H., M.P.H., C.P.H., Regional Director, HIV PACE Program Region 9, HHS

Michelle Schreiber, M.D., Deputy Director of the Center for Clinical Standards and Quality, CMS

Adrian Shanker, Senior Advisor, LGBTQI+ (lesbian, gay, bisexual, transgender, queer, and intersex) Health Equity, OASH, HHS

Opening Remarks

Marlene McNeese and Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, PACHA Co-Chairs

Ms. McNeese called the meeting to order at 11:02 a.m. ET and welcomed the participants. She described PACHA's charge, charter, and membership, explaining that PACHA advises the HHS Secretary and the White House (via ONAP) but does not have any regulatory or funding authority. (See [HIV.gov](https://www.hiv.gov) for more information.) Dr. Guillamo-Ramos hoped the Council would bring to light creative approaches to achieve the goals set by the *Ending the HIV Epidemic in the U.S.* (EHE) initiative and the National HIV/AIDS Strategy (NHAS). Ms. McNeese urged PACHA to be daring and bold in its efforts to reshape the HIV epidemic. (This meeting was broadcast live online; the recorded broadcast is available [online](#).)

Welcome from the OASH

Sarah Newman Boateng, Principal Deputy Assistant Secretary for Health, OASH, HHS

Ms. Boateng welcomed the participants on behalf of ADM Rachel L. Levine, M.D., Assistant Secretary for Health. PACHA's advice and counsel is critical to the OASH in its work to achieve healthy people, healthy communities, and a healthy nation. Ms. Boateng applauded B. Kaye Hayes, M.P.A., Deputy Assistant Secretary for Infectious Disease, Director of OIDP, and PACHA Executive Director, for keeping HIV at the forefront of all of the OASH's work on infectious diseases.

Ms. Boateng thanked the PACHA members and partners for their work and unwavering dedication to ending HIV, including six Council members who agreed to extend their terms: Guillermo Chacón; Raniyah Copeland, M.P.H.; Alicia Diggs, M.P.H.; Dr. Guillamo-Ramos; Laura Platero, J.D.; and Darrell P. Wheeler, Ph.D., M.P.H., M.S.W. She recognized PACHA's subcommittee Co-Chairs, including leaders of the new Subcommittee on Aging with HIV, Long-Term and Lifetime Survivors.

At its June 2023 meeting, PACHA heard about rising rates of syphilis and the worrisome overlap between syphilis and HIV. In response to recommendations by PACHA and others, HHS created the National Syphilis and Congenital Syphilis Syndemic Federal Task Force, chaired by ADM Levine. The Task Force identified 14 priority jurisdictions facing a high burden of syphilis. Ms. Boateng thanked Ms. Hayes; Timothy Harrison, Ph.D., Principal Deputy Director of OIDP; and their colleagues for coordinating the Task Force's work.

The 35th World AIDS Day on December 1, 2023, was an opportunity to commemorate people with HIV around the world and to recognize the courage and passion of those who have been essential to making progress against HIV/AIDS. Ms. Boateng called for a moment of silence to honor those lost. The agenda for this meeting builds on the theme of World AIDS Day, "Remember and Commit."

Ms. Boateng urged the participants to reach out to the PACE teams in HHS regions 4, 6, and 9 for assistance with meeting EHE and NHAS goals. Also, HHS is accepting nominations for new PACHA members through January 5, 2024. Ms. Boateng swore in new PACHA member Jeff Taylor.

Roll Call

B. Kaye Hayes, M.P.A., PACHA Executive Director; Director, ODP; Deputy Assistant Secretary for Infectious Disease, OASH, HHS

Ms. Hayes called the roll.

World AIDS Day 35: Remember and Commit

Marlene McNeese and Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, PACHA Co-Chairs

Dr. Guillamo-Ramos reiterated that World AIDS Day was an opportunity to recognize those around the world affected by HIV/AIDS and to reflect on lives lost, battles fought, and progress made. He called for a pause in the meeting for participants to remember or honor someone in the name of World AIDS Day. Dr. Guillamo-Ramos saw World AIDS Day as a rallying cry to commit to innovation and cooperation toward a brighter, healthier tomorrow.

Getting to the Goal of Reducing New U.S. HIV Transmissions by 90 Percent by 2030

*Facilitators: Patrick Sullivan, D.V.M., Ph.D., Dipl. ACVPM, PACHA Member
Dafina Ward, J.D., PACHA Member*

*Panelists: Oscar De La O, Vice-President and Founding Member, Bienestar Human Services, Los Angeles, CA
Venita Ray, Founder and Social Justice Movement Strategist Consultant,
Venita Ray Consulting
Maurice Williams, Artist and Advocate*

NHAS Update

Harold J. Phillips, M.R.P., Director, ONAP

On World AIDS Day, the White House released a fact sheet, [The Biden-Harris Administration's Efforts to End HIV/AIDS At Home and Abroad](#), and the [National HIV/AIDS Strategy 2023 Interim Action Report](#), highlighting collaboration across Federal agencies. Data show that the effort to end HIV is moving in the right direction, but the pace is not equal across all populations and communities. The Interim Action Report calls for accelerating action at the Federal, State, local, and community level and continued focus on priority populations. Some successes in tackling discrimination include the Food and Drug Administration (FDA) ending the ban on gay and bisexual men donating blood and the Department of Justice finding that Tennessee's HIV criminalization laws violate the Americans with Disabilities Act.

Mr. Phillips said the EHE and NHAS goals are aspirational, and current funding is insufficient to meet the targets, but the administration continues to pursue those goals. Notably, the United States has among the lowest rates of viral suppression among people with HIV. Jurisdictions with high rates of preexposure prophylaxis (PrEP) uptake tend to be counties that have large cities; PrEP uptake remains low among Black and Latinx populations.

The Ryan White HIV/AIDS Program continues to excel, with viral suppression rates of nearly 90 percent among its clients and declining geographic and demographic disparities among the populations it serve. The Ryan White program and PEPFAR use disaggregated data to better understand the populations they reach and how to close gaps to improve overall outcomes. Mr. Phillips said there is much more to do to end HIV, particularly to ensure Medicaid and Medicare beneficiaries receive the kind of high-quality care that the Ryan White program provides.

Panel Questions and Answers

Where are we now in our path toward the prevention and care goals for 2030?

Mr. De La O said the tools to reduce HIV are available, but it is time to examine how they are deployed and how those strategies resonate with stakeholders. Discussions at the local level do not always include stakeholders (even within local HIV planning councils). Consumers must be aware of and understand initiatives that aim to improve their well-being, particularly those who are marginalized, stigmatized, and traumatized. Advocates must do a better job disseminating information beyond the HIV community to reach the media and elected officials. Stigma continues to be the top issue affecting the Hispanic community at risk for HIV in Los Angeles, hindering access to prevention and treatment. The campaign for marriage equality centered on changing hearts and minds; a similar approach is needed to address the persistent stigma around HIV. By better mobilizing communities, the EHE and NHAS goals could be achieved faster.

Ms. Ray emphasized that biomedical tools are not enough to end HIV. Despite the disproportionate impact of HIV on Black people, particularly Black women in the South, few strategies target those populations. The people working at the local level are the closest to the problems, but they do not get enough money to implement solutions. The Ryan White program is laudable but serves only a fraction of people in need. There is insufficient discussion about the role of race, and recent high-profile efforts around Black women with HIV have had little impact. The admission by Federal representatives that the country's strategies might end HIV for some but not everyone is unacceptable, and the Federal government is not talking about plans brought forth by advocacy organizations to find equitable solutions. Strategies must go beyond the biomedical tools to incorporate the social, racial, and ethnic issues that affect HIV. The Federal government can and should do more to end HIV criminalization. The country cannot rely on education, PrEP, and testing to end HIV without expanding its focus to discrimination. Race has been recognized as a determinant of health but is not part of the strategies to improve health. The HIV community is not getting the partnership it needs to end HIV in the United States.

Mr. Williams said efforts to address stigma and decriminalization do not always translate into individuals feeling comfortable talking about their status. His mother died as a result of complications of HIV because she did not accept her diagnosis or receive adequate care. The cultural shift needed to eliminate HIV stigma has not happened. Resources are available, but individuals must work to find them, which requires knowledge, time, and effort. Renewed commitment to addressing HIV is needed, as is continued focus on a cure. Young people feel invincible, and they do not take the threat of HIV seriously because they lack information or are not getting the message from experts in the community who have direct experience. People with HIV must be part of the research planning process. Initiatives to address HIV must take into account the whole person and how interventions affect individuals and their families.

How can we reach the people who are closer to the solutions?

Ms. Ray said disparities persist because the same solutions are put forward without recognizing the persistent barriers or telling the real story. For example, PrEP uptake is high among White people but low among Black and Hispanic people because PrEP product marketing is geared toward White people. People with HIV must demand that policies include racial justice issues. Thanks to the HIV community, quality of life is now part of the Federal discussion. The community has also engaged with the Federal government on molecular HIV surveillance, but its opposition has not been taken seriously. More work can be done to encourage racial justice in philanthropy (as described by [*A Declaration of Liberation: Building a Racially Just and Strategic Domestic HIV Movement*](#) and [*Racial Justice in HIV Philanthropy Guiding Principles*](#)). More focus is needed on the South, especially in rural communities. When policymakers present data without the context that recognizes the intersection of racial/ethnic, gender, and other inequities, they perpetuate stigma.

Mr. De La O added that resistance to PrEP in his community stems from lack of trust. PrEP is prescribed in medical settings, and many—particularly undocumented people—do not trust medical providers. Bienestar got a medical license to provide PrEP to its clients. That license also allowed the organization to begin screening for sexually transmitted infections (STIs), which has brought many people in who would not see other providers. Some entities forget the importance of trusting relationships, especially for marginalized people facing racial and social inequities. Mr. De La O called for more collaboration between trusted community partners and medical providers; community-based organizations can help individuals navigate the medical process and provide some services outside of medical settings.

How can grassroots organizations and nontraditional providers bring creative solutions to common goals and reach multiple generations—not just around biomedical tools but also the importance of addressing oppression and injustice?

Mr. Williams emphasized the need to build trust. He described how his doctor helped him shift his mindset around HIV by being generous with her time, resources, and knowledge and encouraging him to take part in local boards and give input on research. Mr. Williams said his relationship with his doctor goes beyond the usual patient-provider interaction; she created a bridge for him to become an activist. Meeting people where they are includes reaching out through social media and relevant marketing. People need to see themselves; representation matters, Mr. Williams emphasized.

What is working for community-based organizations, and what is missing?

Mr. De La O said the professed goal of addressing racial and ethnic inequality is not translating to how funding is awarded or allocated. Rather than confining their work to a menu of HIV services, Bienestar staff look at the whole person and determine the challenges a client needs to address before that person can think about health and wellness. In addition, Bienestar facilitates opportunities for providers to engage and discuss specific challenges. Mr. De La O said trusted providers are called on to reengage people who have dropped out of care—but they often bring them back to the same system, regardless of the reason for dropping out. Broadly speaking, more communication is needed across the system to enhance cultural skills so community members feel comfortable seeking services. Structural barriers in clinical settings prevent the achievement of ideal health outcomes. Mr. De La O called for a return to coalition-building. Furthermore,

local organizations, including health departments, need more flexible funding so they can channel resources where they are most needed.

What one thing can be done to achieve the goal of reducing HIV?

Mr. Williams noted the importance of having a support network that feels representative (described as “by us, for us, and near us”). Mr. De La O urged recognition that some people are stigmatized and marginalized even before they are diagnosed with HIV; embracing and meeting the needs of the whole person makes a big difference. Ms. Ray suggested defining what constitutes meaningful community engagement and formalizing structures to support it. She also recommended more funding for people on the front lines to enact solutions.

Discussion

Mr. Chacón pointed out that only 3 percent of Federal funding goes toward prevention; advocates should educate Congress and others that preventing one case of HIV saves the health system more than \$1 million. (Via chat, Dr. Wheeler said education should also emphasize that it would not be appropriate to simply move money now allotted for treatment over to prevention.) Stakeholders and advocates must translate the goals of the Federal agenda into actions at the local and State level.

Paul Kawata, M.A., asked the panelists what they would say or ask of HHS Secretary Xavier Becerra if they had the chance. He also asked how to encourage HHS to stand up against racism, homophobia, xenophobia, and transphobia. Mr. De La O said he would urge the Secretary to launch a campaign to change hearts and minds around HIV. HHS and others appear to prioritize research and scientific data without calls for action to remove stigma. Ms. Ray reiterated the need to better define and engage HIV communities and to acknowledge that HIV is a racial justice issue. Dealing with HIV means addressing issues upstream, not just at the clinic door. Furthermore, the community is waiting on Sec. Becerra to update the HIV Organ Policy Equity (HOPE) Act (which allows for research into transplanting organs from HIV-positive donors into HIV-positive recipients), which could reduce discrimination and help people with HIV get medical care.

Ms. Ray explained that the *Declaration of Liberation* challenges existing power structures and calls for a shift in the entrenched mechanisms of how business is done, how organizations work, and how funding is allocated. She said the country is not willing to address its history of racism. At all levels, people want to maintain the status quo.

Carole Treston, M.P.H., RN, ACRN, FAAN, said ANAC recommends building and diversifying the health care workforce so that more providers are representative of the communities they serve, improving community engagement and moving more people from volunteer positions to leadership roles. Mr. Williams pointed out that not only would the approach increase representation, it would also contribute to local economic development. He suggested more funding to support training for people within the community so that their talent and experience are retained. Mr. De La O added that education debt is a significant problem, so there should be mechanisms to incentivize providers to work in their home communities. Ms. Ray called for compensating people with HIV for their expertise and advice and elevating them to decision-making positions. She also recommended revising language and approaches to HIV care to

emphasize that all health care providers are working toward high-quality, whole-person care, rather than treating people with HIV like children or criminals.

Addressing the Needs of People Aging with HIV, Long-Term and Lifetime Survivors

Alicia Diggs, M.P.H., and Jesse Milan Jr., J.D., PACHA Members, Co-Facilitators

Half of U.S. people with HIV are age 50 or older, and most people born with HIV are in their 30s. Long-term and lifetime survivors live with HIV for decades. Clinical data suggest that older adults with HIV will pose a substantial challenge to public health services in the coming years.

Medical Issues around Long-Term HIV

Jeffrey Kwong, D.N.P., M.P.H., AGPCNP-BC, FAANP, FAAN, Professor, Division of Advanced Nursing Practice, Rutgers School of Nursing

By 2030, 70 percent of U.S. people with HIV will be age 50 or older. The main health problems among aging people with HIV are comorbidities, which people with HIV experience earlier than people who do not have HIV. For people with HIV, the number of comorbidities increases with each decade of life, and women experience more multiple comorbidities than men. People with HIV are at increased risk for cardiovascular disease, diabetes, chronic kidney diseases, Alzheimer's disease and related dementia, and lung cancer. Older people with HIV also have high rates of conditions that predispose them to frailty (e.g., visual, hearing, and mobility impairment). On top of these risks, older adults with HIV face social and environmental factors that affect their access to care and overall health, and they are likely to use multiple medications. Even well-controlled, undetectable HIV has physical effects at the cellular level that contribute to morbidity. In one study, 30 percent of nonhypertensive people with HIV taking antiretroviral therapy (ART) developed hypertension.

Clinicians struggle with the lack of evidence-based guidelines for managing people with multiple comorbidities, particularly people with HIV who have multiple conditions. Recent data suggest that people with HIV with low to moderate risk of cardiovascular disease would benefit from starting statin therapy earlier than current guidelines recommend. Providers caring for older adults with HIV must also take into account anxiety, depression, and other mental health issues; alcohol and substance use; and stigma and ageism.

Dr. Kwong cautioned about the shortage of health care professionals equipped to address the geriatric population in general. He called for partnerships among HIV providers and specialists in aging to provide high-quality care for all. Notably, some proportion of older adults with HIV will need skilled nursing care in long-term care facilities, but 64 percent of people with HIV did not receive ART while living in such facilities. Other clinical challenges include missed opportunities for HIV screening, early detection, and PrEP. As a result people with HIV diagnosed later in life typically have more advanced disease. Dr. Kwong called for more research on aging with HIV and more workforce education on caring for older adults with HIV.

Lived Experience of Long-Term HIV

Jeff Berry, Executive Director, The Reunion Project, and Antoinette Jones, Co-Executive Director, Dandelions, Inc.

Mr. Berry reminded the participants of the global implications of long-term HIV. As longtime advocates and activists age, more formal, structured mechanisms are needed to engage people around the issues of aging with HIV. Increasing research literacy and including more people with HIV in clinical research advisory boards will help.

Ms. Jones pointed out that most medical guidelines on diseases associated with aging target people over age 40. No research or guidelines address comorbidities among long-term survivors who acquired HIV perinatally or at a young age (a.k.a. dandelions). Dandelions, Inc., advocates for including people born with HIV in research trials and for earlier cancer screening.

Mr. Berry expressed that financial survival is a major concern for long-term survivors, particularly with the high costs of HIV medications under Medicare's Part D prescription drug insurance and rising housing costs. Some people with HIV spend down their assets or even divorce their spouses so that they qualify for long-term care benefits. The lack of long-term care facilities that offer competent, compassionate care for the LGBTQI+ community is alarming.

Ms. Jones appreciated that in recent months, awareness of the challenges that dandelions face has increased. These long-term survivors have dealt with internal and external stigma their whole lives. Keeping their HIV status a secret has been a norm. Like all other people with HIV, dandelions want to be recognized, included, respected, and valued. Mr. Berry added that stigma varies widely depending on the provider, the setting, and the community, and it has a substantial impact on mental health. Ms. Jones noted that millennials and Generation Z have endured a staggering combination of social, political, and economic upheaval, and layering that on to a lifetime of HIV increases the impact on well-being. She said the EHE initiative seems entirely focused on medications, without regard for issues like housing, food security, child care costs, wages, and lack of insurance that make it difficult to access or adhere to medical regimens.

Ms. Jones called for including more long-term survivors of HIV in decision-making bodies and an open conversation about the implications of the HOPE Act and the need for more research on transplantation. Mr. Berry recommended creating a Federal leadership position around older adults with HIV to prioritize and coordinate work across Federal agencies.

Policies to Address Long-Term HIV

Ronald Johnson, Chair, U.S. People Living with HIV Caucus

With the growing proportion of U.S. people with HIV over age 50, policy goals should center around enabling older adults with HIV and long-term and lifetime survivors to maintain good physical, mental, and sexual health and a good quality of life. Attention to these issues has increased in recent years, and the knowledge and research base has grown with direct input from people affected and their increasingly visible advocacy organizations. As a result, the field has reached remarkable consensus on the challenges that policies should address specifically for older adults with HIV and long-term and lifetime survivors:

- Access to comprehensive, integrated health care that addresses multiple comorbidities among older adults with HIV
- Transition to Medicare and integration of Medicare with private insurance and the Ryan White program
- Availability of mental health programs and substance and alcohol use treatment programs

- Access to housing, food and nutrition, employment, and other socioeconomic support services
- Impact of COVID-19 and mpox
- Availability of long-term care facilities and in-home care
- Programs that address loneliness and social isolation (identified by the World Health Organization as a serious public health threat)
- Elimination of stigma and discrimination, including ageism
- Strengthening the workforce and integrating HIV knowledge and training into geriatric care

Mr. Johnson noted that many medical problems that older people with HIV face are related more to aging than HIV-related illness. The most recent NHAS includes an objective of expanding the capacity to provide whole-person care to older adults with HIV and long-term survivors. The Ryan White program and the Older Americans Act are key elements of the Federal response. As part of the Older Americans Act, the Administration for Community Living requires States to detail how they will ensure services for older adults with HIV; it has also proposed updating the act to require that people with HIV be defined as a population in great economic and social need. Mr. Johnson urged participants to monitor State responses to new guidelines.

To address the challenges described, Mr. Johnson suggested working with the administration and meaningfully engaging with the HIV community toward the following:

- Foster the development of models of comprehensive, integrated health care to improve the quality of care for people aging with HIV.
- Broaden support for social services for people aging with HIV, including programs that support social connections for older adults living with HIV.
- Support the development of models for long-term care, including home-based long-term care, that reflect quality care.
- Develop proposals for reauthorizing the Older Americans Act that codifies the designation of older adults living with HIV as a population of greatest social need.
- Create programs and policies that address the unique concerns of lifetime HIV survivors.

Discussion

Ms. Copeland called for more research. Ms. Jones said that as a participant in an NIH Center for AIDS Research panel, she called attention to the exclusion of lifetime HIV survivors from studies. The health issues that dandelions face are likely a preview of what other people with HIV will experience later in life, so they should be of interest to researchers. Ms. Jones also urged more accountability for disseminating research findings and recommendations, noting that the lack of understanding about the overall health of lifetime survivors can lead to premature death. Moreover, many lifetime survivors underwent testing as babies and may be experiencing comorbidities now as a result. Mr. Berry said more money is needed for community-driven research and advocacy, so that people with HIV are involved in research at every stage, beginning with study design and including the development of enrollment and information materials that use respectful, person-first language.

A number of issues and resources came up via chat:

- ANAC offers a free on-demand [education program](#) for health care workers in long-term care facilities that serve people aging with HIV.
- Mr. Taylor said the housing cost crisis is forcing many older people with HIV out of expensive urban areas with good health care and services to less expensive areas with fewer resources and supportive social networks. In addition, people with long-term disability insurance from their jobs will lose that coverage at age 65 and will have to subsist on Social Security benefits that they have not paid into for decades.
- Ms. Ward raised the need to support intergenerational leadership, shared learning, and collaboration.
- PEPFAR is addressing aging and HIV issues globally—for example, with innovative models for integrating care for HIV and noncommunicable diseases, especially hypertension, and by expanding surveys to include people up to age 70.
- [State plans on aging](#) are available to the public.
- The webinar “HIV Cure Research in People Who Acquired HIV in Early Age” is available on [Facebook](#) and [YouTube](#).
- The [Center for Medicinal Cannabis Research](#) has information on HIV research.
- [Kristine Erlandson](#) at the University of Colorado, Denver, has conducted pilot studies on diet and exercise to prevent cardiovascular disease among aging people with HIV.

Addressing the Needs of Trans Men and Nonbinary Individuals

Facilitators: Tori Cooper, M.P.H., PACHA Member

Tiommi Luckett, PACHA Member

Panelists: A. J. Scruggs, CEO and Executive Director, Visible Truth 365, Philadelphia, PA

Ja'Mel A. Ware, Entrepreneur

*D'Jamel Young, Executive Director and Transmasculine Advocate, TMSM
Connect and Emory University School of Medicine, Atlanta, GA*

Panel Questions and Answers

What does it mean to you to be a trans man?

Mr. Young emphasized that there is no one way to be trans—it simply describes a person who identifies as different from the gender they were assigned at birth. As a Black man of trans experience, he wants the same things most people want (e.g., happiness, financial freedom, love, and acceptance), but he is constantly fighting for his safety as a Black man.

Mr. Ware noted that his trans identity is a manifestation of his spirit, but because he is a Black person first, he has to work harder to bring his dreams to life, and he must always prioritize his safety. Representation is essential. Mr. Ware said that as a Black trans man who is also queer, he often has to explain to others the differences between gender identity and sexuality. As a trans man who has given birth, he is heavily involved in the fight for reproductive rights. Because he embodies multiple identities, he is hyperaware of his self and surroundings at all times.

Mr. Scruggs said that as a Black man, he feels responsible for his own well-being and for protecting his community. He prioritizes leadership and responsibility first and being trans second.

How do you address the attacks from people who dispute notions of sexual orientation and gender identity?

Mr. Scruggs said that in response to political attacks on LGBTQIA+ students, advocates should highlight that students just want to go to school and express themselves. Trans people can attest that stigma and discrimination compounds the challenges of being a teenager. It is important for adults to exercise their voting rights to protect young people in school. Trans people can also speak up in the workforce—for example, by pointing out loopholes in policies that protect against discrimination based on sexual orientation but not gender identity.

Mr. Ware said that as an entrepreneur, he recognizes that business thrives on innovation. But people who do not feel safe at work cannot give their best in the workplace or in the world. Mr. Young agreed, adding that his concerns about his safety at work affect his mental health.

Why is PrEP not reaching trans men?

Mr. Young said there are few resources specifically for trans men, and some still believe they are not at risk. Program funding and public awareness campaigns rarely include trans men, so they are unaware of their risks or their options. Furthermore, the lack of trans inclusion in research results in an absence of information about how treatment options affect trans people. Research should include trans people intentionally and be designed to answer questions relevant to the trans community.

Mr. Scruggs added that from his experience presenting around the country, most trans men know nothing about PrEP or the concept of treatment as prevention. Notably, there is no research on the effects of PrEP on people taking testosterone or what happens as trans men age. Mr. Scruggs highlighted the lack of education and the erasure of trans men from the research landscape. Ms. Cooper acknowledged that trans people want to be included in research but also do not want to be guinea pigs.

Why does research focus on trans women but not trans men?

Mr. Scruggs said masculinity is not policed as much as femininity is, and the discussion turned to reasons why trans men are treated differently by society. Mr. Young said people of opposing views target trans women more than trans men because of gender norms and expectations. Ms. Luckett noted that violence shows up differently for trans women than trans men, and trans masculinity is tested in different ways.

Why is gender-affirming care important, and what does reproductive health care look like for a trans man who is also a birthing parent?

Mr. Ware explained that when he and his partner decided to have a child, he faced questions about the rationale for his choice, which triggered depression and anxiety. Other than his obstetrician, no one in his community was prepared to talk about the postpartum experience for a trans man, leaving him alone to navigate a system that sees birth as a right exclusive to women. Even therapists were reluctant to take him as a client. Trans men need networks of people who

can relate to their experiences; addressing mental health is challenging enough without having to leave part of oneself out of the conversation.

What do reproductive health care and justice look like for trans men?

Mr. Young said the impact of gender dysphoria is underestimated. He appreciated that more providers are willing to support trans people, but they are still not initiating conversations about family planning and goals. Because of inadequate or misguided information, many trans men do not have the opportunity to carry a child or store eggs before they transition. Mr. Scruggs noted that he was referred to a women's center for care; renaming service sites with gender-neutral names would lessen one barrier to getting care. He called for providers to initiate conversations with trans men about family planning as a standard of care. Such conversations should take place at every visit, because an individual's goals change over time.

Mr. Scruggs said he was told it would be impossible for him to have children after taking testosterone for 10 years. Mr. Ware said he received no information about the relationship between testosterone and fertility, and there is no research on the topic. When he began trying to become pregnant, he was told to wean off testosterone and see what happens.

Mr. Young said being in a gynecologist's waiting room is an uncomfortable experience for a trans man and for the women there. Many trans men never seek such care. Trans men may have grown up with little or no information about menstruation, sexual health, or what it means to feel affirmed in one's body. Individuals need providers who can help them take care of themselves.

In keeping with EHE goals of community engagement, how can we meaningfully involve people with HIV to address HIV in the trans masculine community?

Mr. Young suggested building more trans-inclusive HIV prevention programs that offer education, community needs assessment, trans-led advisory boards, training and capacity-building, support and mentoring. More collaborative efforts are needed.

Mr. Scruggs pointed out that trans men are left out of data collection when their numbers are small, which erases them from the data. Trans men should be counted, because data translate to money and resources. Mr. Scruggs called for coalitions that include trans men and women and nonbinary people so that no one is left behind.

If you could advise Sec. Becerra directly, what would you say?

Mr. Young hoped the Secretary would acknowledge the existence of trans men and recognize the barriers and policies that affect them. He called for support and funding for research that centers the trans male experience; Mr. Ware added that some research should specifically address the role of testosterone in the health of trans men. Mr. Young specified that trans people should be involved in conducting research as well as participating.

Mr. Young noted that language plays a role in social justice, so it is time to move toward more accurate terminology, such as "assigned female at birth." Mr. Scruggs said inclusion means adding, not erasing others. Mr. Ware proposed mandating use of inclusive language, particularly around reproductive health, such as the phrase "women and birthing parents."

Discussion

Mr. Scruggs said reaching out to local representatives is the first step toward meaningful community engagement and political change. Once a relationship is established, advocates can find areas of common interest with policymakers. People connect with their hearts, and there are plenty of people in government who care about LGBTQIA+ people, said Mr. Scruggs.

Mr. Young pointed out that there is no central resource of information about the trans-masculine experience that can inform efforts to address stigma around HIV. Until an information hub is created, participants can learn more from TSMConnect.org and through Mr. Scruggs' social media platforms (@dalavendarbandit).

The following resources were offered via chat:

- [Research](#) demonstrates that gender-affirming care is part of good mental health.
- The Mayo Clinic website offers a section on [gynecologic care for trans men](#).
- The United Kingdom's National Health Service describes [gender dysphoria](#).
- For more narratives about trans men, watch Transworld Atlanta on Amazon Prime or Tubi.

Public Comment

Terri Wilder of SAGE said that researchers who study HIV and aging face critical challenges, especially those not affiliated with the AIDS Clinical Trial Group. The funding application process is daunting. Because NIH's institutes are centered on specific body organs, it is not clear which institute's interests align with a researcher's HIV and aging study proposal. Researchers expressed a dire need for a centralized system for applying for HIV and aging research grants. When scientists facing insurmountable barriers to accessing funding, it is not clear how groundbreaking discoveries can be expected. The looming specter of potential NIH budget cuts underscores the urgency for a clear, centralized application mechanism for HIV and aging research funding that would empower researchers to navigate the system effectively and efficiently. Ms. Wilder called on PACHA to advocate for a transparent, accessible, and supportive system for HIV researchers, without which, the potential for significant advancements in HIV and aging research remains stifled. The clock is ticking, and answers are needed now. Stories abound of researchers waiting years to get through the application process. Bureaucracy cannot be allowed to prevent dedicated researchers from diving into the work or to demoralize them before they even start. A growing community of researchers are eager to delve into HIV and aging, and advocates must help them. People living with HIV, especially the aging population, long-term survivors, and lifetime survivors, deserve every effort to accelerate the pace of discovery. Ms. Wilder urged PACHA to recommend that NIH immediately create a centralized system for HIV and aging research grants.

Vanessa Johnson of Ribbon spoke on behalf of the EPIC Movement, a transformative change movement led by Black cisgender women living with HIV. The United States is undergoing an unprecedented upheaval of civil and human rights. Long-term and lifetime survivors bear witness to what a combination of community, government, academic institutions, service organizations, and private entities did to stop a surge of death that started 40 years ago. Only by pursuing wellness for individuals, families, communities, and institutions through true

partnership can this nation reverse the harm done and protect its future. To do so, the HIV movement must continue to uplift and empower women with HIV by promoting and supporting their leadership. Such leaders can compel individuals and entities with decision-making authority and resources to work toward the following three actions:

- Invest in establishing a “kitchen cabinet” of women leaders at the Federal level. Many women warriors and leaders over the age of 50 have grown alongside the HIV movement and continue to represent vast segments of the Black community and Black women.
- Give communities money directly. Research and medical efforts have increased life expectancy for people living with HIV but they will not end the HIV epidemic. Investing in networks of people living with HIV can strengthen engagement and civic participation, allowing for a more comprehensive approach to addressing various critical issues, including social justice.
- Convene a national summit on the four priority populations most affected by HIV, building on the work of the NHAS. More data about and understanding of these populations is needed to determine what is happening within the priority groups, especially Black women.

See the appendix for written submissions.

PACHA to the People: Community Engagement Session

PACHA invited all those participating to speak. Key comments are summarized here according to the main themes.

Update the HOPE Act

The HIV community should express support for revising the HOPE Act and removing the requirement that organ transplants between donors and recipients with HIV be conducted under research settings, so that such procedures can take place under normal care circumstances. Ms. Hayes said that HRSA and [OIDP](#) recognize that transplants are key to living longer with HIV, and both are looking closely at the HOPE Act.

Follow-Up Item

PACHA staff will seek more information for the Council about proposals to revise the HOPE Act from subject matter experts.

Address the HIV Workforce

The attrition of medical providers trained in HIV care, the insufficient numbers of geriatricians, and decreases in the general health care workforce all pose a threat. PACHA should consider recommendations such as the following:

- Boost the health care workforce for older adults with HIV by increasing reimbursement under Medicare and the Ryan White program and offering loan forgiveness or scholarships to people who pursue relevant specialty training.
- Engage pediatricians in HIV prevention. There are many missed opportunities for screening and prevention among young people.

- Educate providers about [doxycycline post-exposure prophylaxis](#) (PEP), which could transform bacterial STI prevention, including in people with HIV and people taking PrEP
- Recommend more collaboration with pharmacists. Most people have access to a pharmacist. Some States allow pharmacists to prescribe PrEP through collaborative provider agreements.
- Make sure that collaborative work between PACHA and the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and Sexually Transmitted Disease Prevention and Treatment (CHAC) addresses the workforce considerations raised at this meeting.
- Urge SAMHSA to increase funding for substance use disorder and mental health treatment for people with HIV.
- Engage more social workers and medical and nonmedical case managers in clinical units.

Consider Consent for HIV Testing

New York State does not require written consent for HIV testing, only direct oral notice. It is considering legislation that would require only indirect notice, such as a poster or video in a waiting room. Indirect notice might not reach people who are visually or hearing impaired or who have limited English proficiency. Opting out of testing is a meaningful exercise, and screening without consent undermines other HIV testing strategies, such as home testing. PACHA should address the issues around consent before CDC finalizes its updates to HIV screening guidelines.

Address Sperm Donation Regulations

The UK is reviewing its [in vitro fertilization \(IVF\) laws](#) to remove prohibitions for people living with HIV. Since 2006, FDA has prohibited people living with HIV to be a part of the IVF process as an egg donor, sperm donor, or surrogate. PACHA should address these restrictions.

Include Undocumented People with HIV

PACHA subcommittees should include undocumented people with HIV in their deliberations. Some organizations have resources separate for undocumented people with HIV (separate from EHE funding).

Address HIV Stigma in the Latinx/Hispanic Community

Language justice means going beyond translation and interpretation to ensure people understand the information provided. Fear of stigma and violence can prevent people from seeking services.

2023 Year in Review: PACHA Discussion and Reflection

Marlene McNeese and Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, Co-Chairs

Workforce Issues

Ms. Treston said workforce issues cut across all the topics raised and should be addressed by PACHA, perhaps with a separate subcommittee. Dr. Guillamo-Ramos noted that workforce issues are being addressed in the EHE Subcommittee and in collaboration with the CHAC.

Mr. Chacón emphasized that with the growing number of older adults with HIV, more awareness is needed about who will be most affected by the workforce shortage. He added that PACHA members have a duty to bring the issues raised at PACHA and other professional meetings back to their own organizations and networks, which is the best way to advance the agenda in a difficult political environment with critical funding in jeopardy. Mr. Chacón reminded the group that the [National Hispanic/Latinx Health Leadership Summit](#) will take place in Washington, DC, on May 6–7, 2024.

Jennifer Kates, Ph.D., suggested that addressing workforce issues through a panel discussion would be helpful. Ms. McNeese said PACHA has convened topical meetings outside of regular Council meetings, which might be another good option for tackling the broad topic of workforce.

Strategic Planning

Dr. Kates pointed out that PACHA’s subcommittees can identify policy levers and other avenues for taking on the challenges raised. To avoid issues being caught up in subcommittee silos, Dr. Kates advised Council members to review the meeting minutes, think about what each subcommittee could address, and look for opportunities for subcommittees to collaborate. Also, the PACHA Co-Chairs should consider a strategy session with the subcommittee Co-Chairs.

Ms. McNeese said PACHA hopes to create a strategic plan for 2024 in the coming months. PACHA will continue to work on molecular HIV surveillance, among other issues.

Mr. Milan proposed that PACHA ask HHS’ Office of Legislative Affairs for advice on how to advance PACHA’s agenda in relation to the Older Americans Act and the HOPE Act. He suggested asking the CHAC liaison for insights on effective models in the Ryan White program for long-term care for people with HIV as well as how CDC plans to address PrEP access in its updated guidelines.

Stigma, Discrimination, and Misinformation

Dr. Guillamo-Ramos said progress is being made toward ending HIV, but that progress is uneven, and HIV incidence is increasing among some populations, such as young men of color who have sex with men. He hoped PACHA would increase its focus on HIV among young people, along with other priority populations. Mr. Phillips emphasized the need to combat stigma, discrimination, and misinformation—some of which is amplified by State legislation—as part of all efforts to end HIV.

National PrEP Program

To capitalize on the support of the Biden-Harris administration, Mr. Phillips suggested focusing on a national PrEP program and barriers to viral suppression, such as inadequate services for Medicaid and Medicare beneficiaries, social determinants of health, and the paradox of reengaging participants in systems of care that did not work for them.

Dr. Wheeler noted that systems reinforce themselves to survive; change requires dismantling powerful forces designed to maintain the status quo. He called for joining forces across populations and priorities to take on a common enemy. Working together for the common good is especially challenging in a vitriolic climate in which facts and truth are disregarded.

Ms. Copeland said the Stigma and Disparities Subcommittee is holding a strategic planning meeting in February, and it will continue its discussion about a national PrEP program. PrEP is a good example of how stigma leads to disparities in uptake of great biomedical tools. Mr. Milan suggested PACHA offer some specific recommendations about the structure and placement (i.e., overseeing agency) of a national PrEP program, with input from all the subcommittees. When discussing PrEP, Dr. Moore urged PACHA to keep PEP in mind, as many do not know it is an option. Dr. Sullivan said PACHA should address equity around PrEP. He noted that States with PrEP programs do a better job with equity, and Medicaid expansion also increases availability of PrEP within States. Dr. Moore called for more funding for navigators to connect people with HIV with care and services. Navigation should be a key component of a national PrEP program.

Closing Remarks and Adjournment

Marlene McNeese and Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, PACHA Co-Chairs

Ms. McNeese urged all Council members to serve on at least one subcommittee. She and Dr. Guillamo-Ramos will each serve on two subcommittees so that Council leadership has a presence in each. Ms. McNeese praised the outstanding work of Ms. Hayes and the OIDP staff for their support of PACHA. Dr. Guillamo-Ramos appreciated the hard work and tremendous enthusiasm of PACHA members, particularly the energy and creativity of the newest members. The meeting adjourned at 5:50 p.m.

Appendix: Written Public Comments



“All Round the World, Same Song.” 79th PACHA Meeting - Public Comment

December 6, 2023

Thank you to the Presidential Advisory Council of HIV/AIDS for the opportunity to share this public comment with you.

My name is Vanessa Johnson, and I am a Co-Executive Director for Ribbon, located in Largo, MD. I am here on behalf of the EPIC Movement, a transformative change movement led by Black cisgender women living with HIV.

Today, the disease we are talking about is HIV. However, as many concerned individuals and entities have noted, we must fight the dis-ease that is destroying individuals, communities, and societies across the globe. Even the United States, with its economic might, is no longer immune from this destruction because we are out of balance with ourselves, the environment, and the universe. Our nation is undergoing an unprecedented upheaval of civil and human rights.

We, long-term HIV survivors over 50 years old and Lifetimers, bear witness to what a combination of community, government, academic institutions, service organizations, and private entities did to stop a surge of death sweeping across the nation and the globe that started 40 years ago. Yet, there is so much more to do.

Only by pursuing "wellness" for individuals, families, communities, and institutions in true partnership with the spectrum of communities across this nation can we reverse the harm done and protect a future.

How do we do this in the HIV movement?

We must continue to uplift and empower women living with HIV by promoting and supporting their leadership in this movement. We are the Harriet Tubmans who lead people to freedom from internalized HIV stigma, the Sojourner Truths who speak the truth about the injustices we face as women, the Byllye Averys fighting for wholistic health inclusive of sexual health and reproductive rights, and the Audre Lorges who advocate that we do not live single-issues but the Kimberlie Crenshaws who live intersectional lives.

We compel individuals and entities with decision-making authority and resources to work in meaningful partnership with networks of people living with HIV to take the following actions:

1. **Action - Invest in establishing a "kitchen" cabinet of women leaders at the Federal level.**

It is a fact that women often initiate movement building from the kitchen, which makes sense because we feed ourselves, our loved ones, friends, neighbors, and co-workers. The food we give is not just a source of nutrition but also a way to show compassion, empathy, and encouragement that sustains many. Many women warriors and leaders over the age of 50 have grown with the evolution of the HIV movement and continue to represent vast segments of the Black community and Black women. Their work improves the quality of our lives we come in contact.

2. Action - Give the communities the money.

It's important to acknowledge the progress that research and medical efforts have made in increasing the longevity of life for people living with HIV. However, these efforts will not end the HIV epidemic. Investing in networks of people living with HIV can strengthen engagement and civic participation, allowing for a more comprehensive approach to addressing various critical issues, including the obtainment of social justice.

3. Action - A national priority populations summit.

This national summit must focus on the four priority populations most impacted by HIV. Without building off the work of the National HIV/AIDS Strategy, it's difficult to see how we can end this epidemic. We must also truly understand the data, or the lack thereof data, to understand better what is happening within these groups, especially Black women. We need to do better to make progress towards ending this epidemic.

Thank you.

Written Testimony: 1 - Demarcus Matthews

From: Demarcus

Sent: Wednesday, November 8, 2023 11:51 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) <PACHA@hhs.gov>

Subject: Molecular HIV surveillance recommendations

Dear PACHA members,

I am reaching out in support of CHLP's statement which acknowledges that we should be delaying any further MHS-related funding announcements until concrete, written protections are implemented everywhere to ensure public health surveillance data can never be used against PLHIV. MHS represents a reactive and invasive set of tools and strategies that come at a great cost to established, evidence-based, and affirming approaches to retain PLHIV in care and prevent HIV diagnoses.

I call on PACHA and CDC to take further action and preserve the fragile public trust that remains in public health after a long history of approaches that have harmed our most marginalized communities affected by the HIV epidemic. We need to act to protect all public health information, including but not only MHS-data, from ever being accessed by law enforcement, corporations, criminal legal courts, immigration enforcement and youth detention and protective services systems. Those firewalls need to be in place before, not after, MHS is implemented.

I commend PACHA on recommending opt-out options for PLHIV on the use of their drug resistance data being used for CDR activities, and believe CDC must implement those options and more to guarantee informed consent is at the foundation of public health surveillance.

Sincerely, Demarcus
Mathews

Written Testimony: 2 – Roberto Elguera

From: Roberto Elguera

Sent: Sunday, December 3, 2023 7:57 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) <PACHA@hhs.gov>

Subject: HSV Research Funding

Dear PACHA,

I am writing in support of Additional FUNDING for the cure, treatment, and prevention of Herpes Simplex Virus, Types 1 and 2 in America. Public funds are critically needed at NIH, CDC, HRSA, and other DHHS partner agencies specifically for the advancement of this work. The landscape for HSV in this country is dire, there have been no advances in 40 years, and more federal action is needed urgently. Herpes Simplex Virus is not benign. Although mostly associated with symptomatic episodes of either oral or genital lesions, HSV is also a neuropathic, chronic infection that lives in the peripheral and central nervous system. While most cases are self-limited, there is a risk for severe disease, especially in the immunocompromised.

Additionally, as neuroinflammation is possible, HSV is associated with several neurological complications and is being studied for association with Alzheimer's Disease. HSV is also a widely recognized driver of the HIV epidemic and approximately 40% of HIV cases are HSV-related. HSV also kills approximately 1,000 infants annually as a result of neonatal herpes which is currently not a reportable condition. Prevalence of HSV is shockingly high, yet most HSV+ are private about their condition, or in the closet, due to the heavy social stigma. HSV-1 impacts 1 in 3 Americans. HSV-2 impacts 1 in 6. Also, like many health disparities, it impacts minorities and LGBTQ populations at higher rates - nearly half of Black women in our country have genital herpes.

More than 70% of Mexican Americans have HSV-1. There are nearly half a million new cases of HSV in America every year. The current treatment for HSV was invented nearly 40 years ago and is only 50% effective. There is almost nothing in the pipeline for clinical trials for vaccines or treatment. NIH has indicated HSV is a priority – yet little progress is being made. There is no accurate diagnostic test for diagnosing asymptomatic infection, and without accurate testing, the virus is spread (most often from those unaware of their HSV+ status) with no prevention whatsoever. Americans deserve better. Please let me know if we can meet to discuss this critical public health issue.

Sincerely,
Roberto
Elguera

Written Testimony: 3 – Jeff Scott

From: Jeff C Scott

Sent: Sunday, December 3, 2023 12:47 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) <PACHA@hhs.gov>

Subject: HSV 1 & 2

Dear PACHA,

I am writing in support of additional FUNDING for the cure, treatment, and prevention of Herpes Simplex Virus, Types 1 and 2 in America. Public funds are critically needed at NIH, CDC, HRSA, and other DHHS partner agencies specifically for advancement of this work. The landscape for HSV in this country is dire, there have been no advances in 40 years, and more federal action is needed urgently. Herpes Simplex Virus is not benign. Although mostly associated with symptomatic episodes of either oral or genital lesions, HSV is also a neuropathic, chronic infection that lives in the peripheral and central nervous system.

While most cases are self-limited, there is risk for severe disease, especially in the immunocompromised. Additionally, as neuroinflammation is possible, HSV is associated with a number of neurological complications, and is being studied for association with Alzheimer's Disease. HSV is also a widely recognized driver of the HIV epidemic and approximately 40% of HIV cases are HSV-related. HSV also kills approximately 1,000 infants annually as a result of neonatal herpes which is currently not a reportable condition. Prevalence of HSV is shockingly high, yet most HSV+ are private about their condition, or in the closet, due to the heavy social stigma. HSV-1 impacts 1 in 3 Americans. HSV-2 impacts 1 in 6. Also, like many health disparities, it impacts minorities and LGBTQ populations at higher rates - nearly half of Black women in our country have genital herpes. More than 70% of Mexican Americans have HSV-1.

There are nearly half a million new cases of HSV in America every year. The current treatment for HSV was invented nearly 40 years ago and is only 50% effective. There almost nothing in the pipeline for clinical trials for vaccine or treatment. NIH has indicated HSV is a priority – yet little progress is being made. There is no accurate diagnostic test for diagnosing asymptomatic infection, and without accurate testing, the virus is spreads (most often from those unaware of their HSV+ status) with no prevention whatsoever. American's deserve better. Please let me know if we can meet to discuss this critical public health issue.

Sincerely

James Lee