# Presidential Advisory Council on HIV/AIDS (PACHA)

# 78<sup>th</sup> Meeting University of Charleston Charleston, WV September 20, 2023

#### **Council Members—Present**

Gregg H. Alton, J.D., San Francisco, CA

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

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

Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, Dean and Professor, Duke University School of Nursing, Vice Chancellor, Nursing Affairs, Duke University, Durham, 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

Rafaelé Narváez, Co-Founder and Director of Health Programs, Latinos Salud, Wilton Manors, FL

Michael Saag, M.D., Associate Dean, Global Health, School of Medicine, and Professor of Medicine, Division of Infectious Disease, The University of Alabama at Birmingham (UAB); Director, UAB Center for AIDS Research, Birmingham, AL

Natalie Sanchez, M.P.H., Director, UCLA Family AIDS Network, Los Angeles, CA

John Sapero, Director, Ending the HIV Epidemic, Collaborative Research LLC, Phoenix, AZ

Justin C. Smith, M.S., M.P.H., Director, Campaign to End AIDS, Positive Impact Health

Centers, Atlanta, GA; Dr.P.H. candidate, Harvard T. H. Chan School of Public Health

Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, Lead Provider and HIV Specialist, Eau Claire Cooperative Health Centers (Now Cooperative Health), Columbia, SC

Patrick Sullivan, D.V.M., Ph.D., Dipl. ACVPM, Charles Howard Candler Professor of Epidemiology, Rollins School of Public Health, Emory University, Atlanta, GA

Marvell Terry II, Activist and Cultural Organizer, Founder, The Red Door Foundation and the Saving Ourselves Symposium, Memphis, TN

- Hansel Tookes, M.D., Assistant Professor, Department of Medicine, University of Miami Miller School of Medicine, Miami, FL
- Carol Treston, M.P.H., RN, ACRN, FAAN, Executive Director, Association of Nurses in AIDS Care, Philadelphia, PA
- Dafina Ward, J.D., Executive Director, Southern AIDS Coalition, Bluffton, SC

#### **Council Members—Absent**

Raniyah Copeland, M.P.H., Principal, Equity & Impact Solutions, Los Angeles, CA Marlene McNeese, PACHA Co-Chair, Assistant Director, Houston Health Department, Houston, TX

Marc Meachem, M.B.A., Head, External Affairs, ViiV Healthcare North America, Washington, DC

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

Darrell P. Wheeler, Ph.D., M.P.H., M.S.W., President, State University of New York at New Paltz, New Paltz, NY

Liaison: Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and Sexually Transmitted Disease (STD) Prevention and Treatment

Wendy Armstrong, M.D., FIDSA, Professor of Medicine, Emory University; Executive Medical Director, Ponce de Leon Center, Grady Health System, Atlanta, GA

#### 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

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, HRSA Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, Indian Health Service

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, STD, and TB [Tuberculosis] Prevention, CDC
- Yemisi Odusanya, M.P.H., Senior Program Advisor, HRSA
- CAPT John Oguntomilade, Ph.D., M.P.H., B.D.S., Regional Director, HIV Prevention through Active Community Engagement (PACE) Program Region 4, HHS
- Kristin Roha, M.S., M.P.H., Public Health Advisor for HIV, Substance Abuse and Mental Health Services Administration
- CDR Michelle Sandoval-Rosario, Dr. P.H., M.P.H., C.P.H., Regional Director, HIV PACE Program Region 9, HHS
- Adrian Shanker, Senior Advisor, LGBTQI+ (lesbian, gay, bisexual, transgender, queer, and intersex) Health Equity, OASH, HHS

# **Opening Remarks**

John Sapero, Co-Chair, PACHA Ending the HIV Epidemic in the United States (EHE) and the National HIV/AIDS Strategy (NHAS) Subcommittee, and Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, PACHA Member

Mr. Sapero called the meeting to order at 9:01 a.m. ET and welcomed the participants. He and Dr. Stewart acted as co-chairs for this meeting in the absence of PACHA Chair Marlene McNeese. Mr. Sapero announced that, following this meeting, he and six other PACHA members will have completed their terms on the Council: Dr. Stewart; Gregg H. Alton, J.D.; Marc Meachem, M.B.A.; Rafaelé Narváez; Michael Saag, M.D.; and Justin C. Smith, M.S., M.P.H.

Dr. Stewart welcomed the new PACHA members who would be sworn in at this meeting. She recognized A. Toni Young, founder and executive director of the Community Education Group, who spoke at PACHA's March 2023 meeting about the intersection of substance use disorder (SUD) and HIV in rural Appalachia. Ms. Young inspired PACHA to hold its public meeting in Charleston. (This meeting was broadcast live online; the recorded broadcast is available online.)

## **Welcome from the University of Charleston**

Martin Roth, Ph.D., President, University of Charleston, WV

In welcoming PACHA to the campus, Dr. Roth described the university's academic offerings in health care. He emphasized the university's goal of preparing students for productive work, enlightened living, and community involvement. Dr. Roth encouraged the meeting participants to tour the campus and visit its facilities.

# **Welcome from the Assistant Secretary for Health**

ADM Rachel L. Levine, M.D., Assistant Secretary for Health, HHS

ADM Levine appreciated the steadfast leadership and vision of Ms. McNeese, PACHA Chair, and thanked Mr. Sapero and Dr. Stewart for guiding the meeting in her absence. ADM Levine also praised B. Kaye Hayes, M.P.A., Deputy Assistant Secretary for Infectious Disease, Director of OIDP, and PACHA Executive Director,, as a relentless force and committed champion for public health. She thanked PACHA members and partners for their dedication to ending HIV.

ADM Levine said the recent U.S. Conference on HIV/AIDS emphasized the tremendous contributions of Black women in addressing HIV as well as the disproportionate impact of HIV on Black women. The conference also highlighted the Biden-Harris Administration's and HHS Secretary Xavier Becerra's commitment to health equity. ADM Levine commended PACHA's effort to hold public meetings around the country, known as PACHA to the People, for bringing pressing issues to the forefront. For example, following presentations at the June 2023 PACHA meeting in Phoenix, AZ, about the rise of syphilis, PACHA quickly passed a resolution calling on HHS to establish a Federal task force and take other immediate steps to address the threat of syphilis. ADM Levine said HHS and the White House responded rapidly, standing up a task force to evaluate syphilis data, testing options, and treatment and prevention mechanisms.

ADM Levine pointed out that Appalachia includes 57 counties in Pennsylvania, where she served as the State's physician general and later the secretary of health. Addressing SUD and opioid use disorder is critical to containing infectious diseases and ending the HIV epidemic. Rural Appalachian counties face specific challenges that require tailored interventions—but they also have many professionals who can help take on those challenges. ADM Levine was confident that with cooperation, the region can succeed in increasing the number of people who know their HIV status, are linked to care or preventive treatment, and achieve viral suppression.

ADM Levine recognized the seven PACHA members completing their terms. She expressed deep gratitude for their unwavering commitment to PACHA, HHS, and the HIV community. ADM Levine swore in 13 new PACHA members: Philip Chan, M.D., M.S.; Mackenzie Copley; Paul Kawata, M.A.; Duvia Lozano, LMSW; Tiommi Luckett; Jesse Milan Jr., J.D.; Deondre Moore; Natalie Sanchez, M.P.H.; Patrick Sullivan, D.V.M., Ph.D., Dipl. ACVPM; Marvell Terry II; Hansel Tookes, M.D.; Carol Treston, M.P.H., RN, ACRN, FAAN; and Dafina Ward, J.D.

#### **Discussion**

Joe Solomon presented a certificate to ADM Levine on behalf of SOAR WV, a community-based group that promotes the health of people impacted by drug use. SOAR WV recognized her as a leader and inspiration for her work distributing free overdose prevention medication in Pennsylvania in 2019. Following ADM Levine's lead, SOAR WV initiated an annual free naloxone distribution day in 2020 in two counties in West Virginia, expanding to all 55 counties in the State by 2022 and all of Appalachia in 2023.

#### Roll Call

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

Ms. Hayes called the roll.

## **Epidemiology of HIV in Appalachia**

Facilitators: Michael Saag, MD, PACHA Member

Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, PACHA Member

#### **State Epidemiology**

Matthew Christiansen, M.D., M.P.H., State Health Officer, Commissioner, West Virginia Bureau of Public Health

Dr. Christiansen explained that, historically, West Virginia had a low incidence of HIV, but it has increased in recent years, primarily driven by increases in injection drug use and illicit substance use. In West Virginia, social determinants of health pose significant barriers to linking people to care for addiction and HIV and sustaining that care. Dr. Christiansen emphasized the need for a holistic approach that addresses all the drivers of addiction to address HIV and other disorders related to injection drug use.

In 2021, most HIV cases in West Virginia involved men between the ages of 25 and 44 years. Of those newly diagnosed, 78 percent were linked to care within 3 months, but 10 percent were not linked to care within 1 year. As the prevalence of HIV has increased, the State has increased access to services, increasing the number of providers who treat addiction and offer medication-assisted treatment (MAT) and the number of residential recovery programs and treatment beds. The Governor's Council on Substance Abuse Prevention and Treatment is a multidisciplinary group focused on connecting people to care. The Bureau of Public Health recently published its HIV and Hepatitis C Elimination Plan and is developing a corresponding implementation plan.

A Statewide review revealed missed opportunities to identify cases of HIV, hepatitis, and syphilis. The State is monitoring four clusters of HIV. Most HIV cases occur in urban areas of the State, where progress is being made toward getting more people into care and preventing HIV transmission. Dr. Christiansen noted that people in rural areas face barriers to treatment, screening, and prevention. He praised the workers on the ground in various settings who are doing an amazing job responding to the incidence of HIV and SUD, many of whom are implementing novel approaches.

#### **Local Epidemiology**

Michael E. Kilkenny, M.D., M.S., CEO and Health Officer, Cabell County-Huntington Health Department

Dr. Kilkenny noted that CDC field officers came to Huntington in 2018 to help the city establish HIV services in response to alarming increases. Once the city recognized the outbreak, it immediately implemented the principles of the EHE initiative. Huntington is not far from Scott County, IN, which experienced an HIV outbreak in 2015. Huntington recognized that the high use of injection drugs in the city could put it at risk for a similar outbreak. The health department took measures to prepare for a potential outbreak, including establishing the State's first government-sponsored syringe services program (SSP). Having that program in place before the 2018 outbreak was key to managing it successfully. A CDC epidemiologist was working on site with the health department at the onset of the outbreak, which also proved helpful.

Dr. Kilkenny observed that buy-in from Marshall University's medical school and the large, local Federally Qualified Health Center (FQHC) was also critical. Cabell County expanded its HIV diagnostic and treatment capacity and added more opportunities to provide preexposure prophylaxis (PrEP) for people who inject drugs. Dr. Kilkenny noted that in response to a survey, 85 percent of harm reduction program participants expressed interest in PrEP, but when it became available, only 15 percent took advantage of it. Understanding the reasons for low PrEP uptake is an important next step.

#### **Discussion**

Dr. Christiansen acknowledged that West Virginia is not an EHE jurisdiction, but the State has strong partnerships with Federal agencies and Federal funding to address HIV and hepatitis. Dr. Kilkenny said that despite the 2018 outbreak and rising incidence, the overall number of cases in the State remains comparatively low. Emergency funding provided for the COVID-19 pandemic response demonstrated what the State could achieve with adequate funding for HIV. West Virginia is aligned with the NHAS and has infrastructure in place to support a strong HIV response when more resources become available, said Dr. Kilkenny.

Dr. Christiansen offered more detail about the four HIV outbreaks that the State is monitoring. Although sexual behavior is a factor in transmission, the rise in HIV cases corresponds more strongly with increasing injection drug use, particularly among people who are hard to reach, such as those who have SUD, are unhoused, are in and out of addiction care, and are unable to comply with medication regimens. Dr. Christiansen noted that individuals who are able to maintain MAT are also able to maintain PrEP or HIV treatment regimens. Dr. Kilkenny said the demographics of HIV in West Virginia differ from the national picture, affecting primarily white people in their 20s and 30s who use injection drugs, although the State has not lost sight of the continued risk of HIV among the LGBTQI+ population. A PACHA member noted that innovative programs are reaching people in need; rather than describing populations as "hard to reach," the onus should be on the programs to be more accessible.

Dr. Christiansen pointed out that State law limits the capacity of SSPs, which poses difficulties for organizations serving people who use injection drugs. He recognized that the law does not acknowledge the science behind SSPs. The Bureau of Public Health is working to provide services within legal limits. Dr. Kilkenny explained that the current law represents a legislative compromise that was enacted to prevent outlawing SSPs altogether. He was hopeful that eventually the State would enable public health providers to implement best practices.

Despite the fact that HIV mostly affects white people in West Virginia, it also disproportionately affects Black people and other minority people in the State, said Dr. Christiansen. He recognized the need to consider equity and adapt the public health response as needed. Tactics include engaging people with lived experience in planning and response to dispel the stigma around HIV and SUD. For example, placing people with lived experience in hospital emergency departments to communicate with patients and providers has been very successful in improving services and mitigating stigma. The State has also received waivers and grant funding to pay for peer services in criminal justice settings, Dr. Christiansen noted.

Dr. Christiansen indicated that West Virginia will receive approximately \$1 billion from the opioid abatement settlement over 10 to 15 years. The State recently established a foundation that

will determine how that money is spent. Dr. Kilkenny added that \$1 billion is not enough to solve the problem of SUD in West Virginia.

Dr. Kilkenny described potential reasons for the low uptake of PrEP, most notably the fact that people misjudge their own risk for disease transmission. Housing insecurity is another significant factor, along with mistrust of the government and health care systems. Regarding low HIV screening rates, Dr. Christiansen said the State's *HIV and Hepatitis C Elimination Plan* proposes that more systems, including criminal justice, require individuals to opt out of routine HIV screening (rather than opt in), which should identify more cases.

Dr. Christiansen appreciated PACHA's capacity to raise awareness of HIV in West Virginia. He said the syndemic of HIV and other infectious diseases overlaps with the issue of injection drug use, so more focus on mobilizing Federal resources to address SUD would help the State. Dr. Christiansen emphasized that the drivers of HIV and SUD are multifactorial, so multidisciplinary collaboration that includes State and Federal partners, the private sector, and other stakeholders, such as those focused on workforce development, is needed.

# Addressing HIV and Substance Use in Appalachia

Facilitators: Gregg Alton, J.D., PACHA Member

Vincent Guillamo-Ramos, PhD, MPH, LCSW, RN, ANP-BC, PMHNP-BC,

AAHIVS, FAAN, PACHA Member

Panelists: James Berry, D.O., Professor and Chair, Department of Behavioral Medicine and

Psychiatry, Director of Addictions, West Virginia University

Judith Feinberg, M.D., Professor of Behavioral Medicine and Psychiatry,

Professor of Medicine/Infectious Diseases, Dr. E.B. Flink Vice Chair of Medicine

for Research, West Virginia University

Bishop Robert Lee Haley III, Pastor and CEO, Bright Futures Now, Inc.

Sally Hodder, M.D., Professor of Medicine, Director, West Virginia Clinical &

Translational Science, West Virginia University

Reverend James L. Patterson, CEO, Partnership of African American Churches

Lyn M. O'Connell, Ph.D., Assistant Professor, Associate Director of Addiction

Sciences, Marshall Health

Panelists introduced themselves and offered some key insights to set the stage for the discussion. Dr. Feinberg pointed out that the State has very few specialists, so recent work has focused on training more primary care and addiction treatment providers in diagnosing, treating, and managing HIV, hepatitis B, and hepatitis C. Dr. Hodder noted that West Virginia leverages the Project ECHO model, which links providers with national experts for education and consultation. Bishop Haley underscored the failure of State leadership to recognize and fund effective local programs. Rev. Patterson observed that efforts must intentionally include people of color, because the State and its HIV outbreak are predominately white. Dr. O'Connell emphasized the need for an integrated, holistic approach to overall well-being, with minimal barriers to care and services.

#### **Questions and Answers**

# What role does stigma—against people with HIV and people who use injection drugs—play in preventing progress and how can it be addressed?

Dr. O'Connell said the State is creating a broad public awareness campaign around stigma, with targeted sub-campaigns that address particular populations. She noted the need to build capacity so that all organizations are working together to mitigate stigma. Rev. Patterson said one key step toward eliminating stigma is ensuring that all providers and their staff, in every setting, treat individuals with care, compassion, and respect. Bishop Haley said that engaging medical students and residents in community care clinics has helped build trusting relationships. Dr. Berry observed that SUD is so pervasive that it touches everyone, which has helped decrease stigma. He echoed that bringing trainees into contact with people facing addiction and disease carries a significant emotional impact that goes a long way.

# What is your organization's relationship to law enforcement around issues related to SUD and HIV?

Dr. O'Connell described a grant project designed to educate first responders about stigma. It initially faced resistance, but eventually first responders appreciated increased access to mental and physical health liaisons who can help link individuals to programs and services. Over time, first responders have come to rely on crisis intervention teams that include mental health providers, especially for incidents related to people who are unhoused, for example. Dr. Berry said the climate has changed with the realization that "we can't arrest our way out of this problem." There is growing understanding that targeting one source of drug supply is ineffectual, and attention must focus on tackling the root causes of addiction.

# What are the unique challenges and successes related to managing public health among rural populations?

Dr. Berry said the COVID-19 pandemic erased longstanding barriers to telehealth, which has increased access to care. People who lack internet access have been incredibly creative, using connections at fast-food restaurants, for example. Bishop Haley pointed out that his church offers computers and space for individuals to take part in private telehealth care and supports them in using the technology and signing up for available public services.

Dr. Hodder said the pandemic also demonstrated the importance of mobile health vans. Also, local partnerships and cultural competence are crucial to connecting effectively with people in their communities. Dr. Feinberg added that involving local residents with lived experience in research is important for understanding. She said CDC came to West Virginia to research the epidemiology of an HIV outbreak but failed to involve the local health department staff in its work. Appalachian culture is clannish and mistrustful of outsiders, said Dr. Feinberg, so respectful community engagement is essential.

#### What solutions do you recommend to improve West Virginia's HIV response?

Dr. Feinberg called on the Federal government to reevaluate which jurisdictions should benefit from EHE. West Virginia is resource-poor, and its HIV incidence has more than doubled in just a few years. In addition, the ban on spending Federal funds on syringes poses a significant barrier to SSPs, because syringes are the most expensive item in such programs. Dr. Feinberg emphasized that since West Virginia passed its law regulating SSP capacity, the number of

programs has decreased by half (from 16 to 8), despite the State having the highest incidence of injection drug use and hepatitis. Dr. Feinberg said it is hard to address these problems without the commitment of State legislators, and she found it incredible that the State legislature does not acknowledge the solutions.

Rev. Patterson suggested redefining equity and acting to achieve it. Specifically, equity is not equal access but rather applying resources commensurate with the need. Equitable funding is vital. Rev. Patterson said his organization has trained a cadre of community health workers (CHWs) who can help with HIV education and prevention, but without adequate funding, they cannot be deployed. Similarly, Bishop Haley urged elected leaders to go out into the community, see what is working, and fund it. Moreover, government entities must follow up on the commitments they make, said Bishop Haley; government at every level, from Federal to local, has not kept its word to the people of West Virginia.

Dr. Hodder called for establishing an NIH research hub in West Virginia that engages local communities, so that people will buy in to effective therapies when they are available. Research should involve CHWs and ambassadors in communities to gain traction. Dr. Feinberg pointed out that all of the research on HIV comes from urban America.

Dr. Berry said West Virginia is a mental health care desert. More funding and mechanisms are needed to train and retain mental health care providers in the State.

Dr. O'Connell stressed the need to fund prevention, noting that grant funding does not support using CHWs for prevention and can be so narrowly focused that it creates silos and discourages partnerships. One success has been State grants that support local partnerships and broad care for direct services. Dr. O'Connell called for more funding that supports systems broadly and funding for programs that include children and partners of people affected by SUD. Finally, the State needs more safe and supportive housing for people leaving recovery centers or incarceration. Without viable housing, it is not realistic to think people will not relapse, Dr. O'Connell said.

# What solutions do you recommend to address behavioral health and related factors in West Virginia?

Dr. Feinberg underscored the lack of trained, committed health care providers and the difficulty of retaining trained providers in rural areas that lack basic services. Continuing to find ways for nurse practitioners and other nonphysicians to provide care is one way to increase the pool of skilled providers. Dr. Feinberg said people in rural areas need the kind of access to wraparound services that the Ryan White HIV/AIDS Program provides in urban areas. Consideration should be given to expanding the Ryan White program network. Dr. Hodder added that primary care providers should be trained to treat HIV. In addition, most providers across the State know each other, and the State could leverage that familiarity to increase communication.

Dr. Feinberg said HRSA's criteria for what constitutes a rural area are not realistic and do not apply to some of West Virginia's smallest communities. She said Federal government definitions of "rural" vary across departments and agencies, which complicates organizations' efforts to seek Federal grants.

Dr. Berry suggested giving primary care providers more tools to manage mental health issues and addiction treatment with support from specialists—for example, using Project ECHO. CMS offers payment models for primary care providers working in regular consultation with specialists, but that model is not yet available in West Virginia. Dr. Berry suggested a Federal mandate to include addiction and HIV treatment in curricula and credentialing for nurse practitioners, physician assistants, family medicine practitioners, and other health professionals. Dr. Feinberg added that the State's *HIV and Hepatitis C Elimination Plan* suggests more provider training on hepatitis C, and a Federal mandate would strengthen that effort. No one in West Virginia should have the authority to prescribe medications without knowing how to prescribe buprenorphine, said Dr. Feinberg.

#### What solutions do your recommend to ensure meaningful community engagement?

Bishop Haley described partnering with other local organizations to provide food and using the opportunity to learning about individuals' needs and linking them to available services. Rev. Patterson said his organization wen to individuals' houses to provide COVID-19 testing and vaccinations. It also received grant funding for a large-scale, prevention-based program in schools. Being visible in the community and responding directly to community needs is effective, Rev. Patterson concluded.

Dr. O'Connell noting that embedding trainees in communities through paid internships and placements has been effective for both engagement and retention. Paying people with lived experience to be advocates has helped foster the growth of recovery-friendly employers. Bishop Haley pointed out that individuals and communities cannot wait for Federal money, they must figure out ways to address their problems. "We can't wait for the politics to shift or for people to start caring about people," said Bishop Haley. "We don't have a political problem, we have a heart problem: people just don't care anymore."

#### Discussion

Dr. Feinberg elaborated on the nature of HIV and hepatitis C transmission in West Virginia, indicating that SUD is fueled by various factors, including intergenerational substance use in families, despair, and homelessness. Dr. Hodder said isolation and domestic violence are key drivers of SUD among women. Bishop Haley added that the current political climate leaves many people without hope. Rev. Patterson said programs seek to offer people whatever they need in the moment, recognizing that some are not ready to begin recovery treatment.

Dr. Feinberg noted that rural communities rely heavily on FQHCs. She is working to expand the capacity of FQHCs to provide harm reduction services, addiction treatment, and HIV screening and treatment. Dr. Berry pointed out that hospital emergency departments are overwhelmed with patients who need mental health and addiction treatment. He said more work is needed to treat people before they reach the point of acute crisis.

Dr. O'Connell said universities have partnered to embed MAT training into the curricula for nurses and physicians across the State. Other panelists indicated that nurse practitioners are actively involved in providing care for SUD, training peers, and taking part in research.

Dr. Feinberg suggested PACHA recommend removing the Federal ban on funding syringes in SSPs, because the State is moving in the opposite direction. Dr. Berry said providers cannot

practice evidence-based treatment; for example, the State imposed a moratorium on opioid treatment programs and has only nine approved methadone programs, despite leading the country in opioid deaths. Dr. Berry called for increasing access to approved treatments.

Dr. O'Connell offered more details on the Statewide partnership to create a broad anti-stigma campaign. The partnership included leaders with lived experience facing stigma and developed a strategic plan to get feedback on its work. Dr. O'Connell said that programs created within West Virginia can work elsewhere because they embody flexibility, communication, and responsiveness. However, programs developed outside the State do not work in West Virginia.

# Community Efforts to Address the HIV Epidemic in Appalachia

Facilitators: Leo Moore, M.D., M.S.H.P.M., PACHA Member

Justin Smith, M.S., M.P.H., PACHA Member

Panelists: Nakia Austin, M.A., CEO and Co-Founder, The Healing House, Inc.

Angie Settle, D.N.P., APRN, BC, FNP, CEO, West Virginia Health Right, Inc. LaDawna Walker-Dean, Ph.D.(c), M.S.W., B.S.W., Program Director, West Virginia Minority Health Initiative, Marshall University Minority Health Institute,

College of Health Professions, Marshall University

Christine Teague, Pharm.D., M.P.H., AAHIVP, Director, HIV Care Ryan White

Program, Charleston Area Medical Centers

#### **Questions and Answers**

#### What are you most proud of in your programs, and what made that work?

Dr. Settle said West Virginia Health Right canvassed the community to determine what it wanted and opened a clinic in west Charleston that responded to those needs. The new clinic provides links to housing, behavioral health care, employment services, children's programs, and more, all under one roof. Dr. Settle emphasized that charitable organizations providing free care are among the most valuable assets in community health.

Dr. Teague said her program saw that locating a clinic in a hospital was not working for people who were unhoused and facing addiction. The program partnered with another community organization and used COVID-19 funding to set up a mobile to offer quick, seamless access to care, subsequently increasing engagement and the number of people with undetectable viral loads. Program staff have worked to rebuild trust with clients who faced stigma in the health care system. Other major achievements are the implementation of universal HIV screening with an opt-out approach and screening all incoming clients for SUD and linking them to care.

Ms. Walker-Dean was tasked with developing a minority health profile for the State but had a very tight budget. She piloted a program in Cabell County, then partnered with organizations around the State to assess chronic diseases among minorities using a community needs assessment. Her office offered HIV testing through university health fairs and drive-through health settings; it also hosted workshops to educate people about HIV testing. These efforts got the attention of the private sector, leading to a substantial grant to expand programs.

Ms. Austin explained that The Healing House faced unfortunate timing, starting up in March 2020. She is most proud that the organization exceeded its targets and created an environment where women affected by trauma can thrive. The Healing House offers behavioral health and other supportive services to help women overcome challenges they thought were insurmountable.

#### What is your experience collaborating with partners?

Ms. Walker-Dean said partnerships are crucial to avoid duplication of effort and to break down silos. She called on stakeholders to work together to advocate for laws prohibiting health disparities in West Virginia and requiring cultural competency training for health care practitioners. Dr. Settle said West Virginia Health Right relies on health care specialists who donate their time. Partnering with the local Ryan White program has been instrumental in educating people about SSPs and PrEP, for example. With private-sector funding, Health Right expanded HIV testing and linkages to care. Dr. Teague reiterated that providers in the field all know each other, which helps them make referrals and linkages quickly. She added that planning how to address issues outside of one's jurisdiction is critical to ensuring appropriate care.

#### What else needs to be done, and how can PACHA help?

Dr. Settle suggested more funding for innovative programs that go beyond the basics of health care to help people establish healthy lifestyles. She also called for increasing opportunities for free and charitable care organizations to apply for grant funding. Dr. Teague echoed the call to reconsider EHE status for West Virginia based on current data. She proposed replicating the Ryan White program model of comprehensive care and wraparound services for people with SUD. Ms. Walker-Dean said the State needs more funding, including funding dedicated to minority health and HIV prevention, and legislation addressing health care disparities and cultural competency training for health care practitioners. Ms. Austin asked for equitable access to grants and funding, noting that her new organization was repeatedly denied resources because it has no financial history, despite evidence supporting the effectiveness of its work.

#### **Discussion**

Participants discussed the availability of services and care for women. Health Right is a primary source of care for women living in shelters. Dr. Teague said organizations partner closely, but she gave an example demonstrating that without a formal infrastructure for housing, health care, and other services, individuals at high risk can fall through the cracks. Ms. Austin emphasized that no single organization can meet all needs. Ms. Walker-Dean noted some progress, pointing out that all pregnant women in West Virginia now get an HIV test so they know their status and can be linked to HIV care if needed.

To reach younger populations, The Healing House established a strong social media presence and provides a deeply caring, compassionate environment that engages women of all ages. Ms. Walker-Dean said she relies on her contacts across the State to encourage students to take part in health fairs. Dr. Settle credited her staff with staying attuned to what younger people want and need. Dr. Teague noted that outreach and activities must be tailored by population, recognizing that some of those at highest risk do not have access to technology. She also said that CHWs and peer recovery workers can establish rapport, which helps with education and awareness.

Mr. Terry urged PACHA members to activate their own organizations to support and amplify the work of West Virginia's community-based programs. Dr. Moore summarized some takeaways from the discussions and site visits, including the need to meet people where they are, acknowledge medical mistrust and work to rebuild relationships, commit to serving the community over the long haul, and create safe and supportive spaces that offer more than pills. He appreciated the call for small and charitable organizations to have more access to funding and the concept of grant funding specifically for new nonprofit organizations. Dr. Moore acknowledged the request for more Federal funding, especially for prevention, and the concept of a Ryan White program for people with SUD.

## **Perspectives from the Appalachian Regional Commission (ARC)**

Gayle Conelly Manchin, M.A., Federal Co-Chair, ARC

Ms. Manchin explained that the ARC was created in response to extreme poverty in West Virginia. The ARC seeks to ensure that the people of Appalachia have the same opportunities as others around the country for education, jobs, and growth. The COVID-19 pandemic highlighted persistent disparities related to internet access that prevent some residents from taking part in virtual school, remote work, and telehealth. The ARC is now investing in broadband and data infrastructure as part of its mission to improve the quality of life for Appalachians.

The ARC's bottom-up approach relies on individual communities to initiate and design programs and get support and funding from their State. Then, the State brings the program to the ARC for additional funding. The approach cements a sense of local ownership.

Ms. Manchin said the ARC recognizes that completing a treatment program is just the beginning of recovery. People need to regain their lives and livelihoods to thrive. All sectors have a role, said Ms. Manchin, but the business community in particular must step up and give people in recovery a second chance. Individuals also need safe housing, transportation, child care, and support systems to restore their sense of purpose, so they can become assets to the community, not liabilities. To that end, the ARC's Investments Supporting Partnerships in Recovery Ecosystems (INSPIRE) Initiative funds projects that offer a continuum of care. Its most recent funding opportunity, the Appalachian Regional Initiative for Stronger Economies (ARISE), requires collaboration across at least two Appalachian States in an effort to promote collaboration and sharing of best practices.

The Appalachian region encompasses 26 million people in 423 counties; only Texas and California cover a larger population. If all those counties worked together, said Ms. Manchin, they would have a substantial impact not just on the region but on the country. She thanked all those present for their compassion, commitment, and dedication to their work.

#### Discussion

Ms. A. Toni Young appreciated the work of the ARC, which she called a model for collaboration across State lines. Because 40 percent of Appalachian counties touch more than one State, Ms. Young called for revising legislation to allow Appalachian counties to move grant money across State lines. She also appreciated PACHA for holding its public meeting in Charleston so members could see firsthand how HIV affects Appalachia.

#### **Public Comment**

Iris Sidikman of the Women's Health Center of West Virginia said that in in 2018, the Kanawha County Health Department shuttered its SSP due to political pressure. In 2021, Charleston was at the epicenter of an HIV outbreak that the head of HIV prevention at the CDC called the most concerning in the nation. The CDC came to Charleston that year, and their report made three things became painfully clear. The spread of HIV is linked to intravenous drug use; low-barrier SSPs are the best way to address it; and people who use drugs are being treated very badly by medical professionals. In April 2021, the Charleston City Council voted to further criminalize harm reduction. Today, Charleston has one operating SSP (at West Virginia Health Right). It is touted as being the gold standard, despite Charleston's restrictive laws outlawing the kind of needs-based SSPs that are the actual gold standard for harm reduction. In 2022, the LIGHT Project, an SSP in Morgantown, distributed 612,744 syringes. During that same time period, West Virginia Health Right in Charleston distributed 3,960, which amounts to fewer than 80 syringes a week in the epicenter of the HIV and overdose epidemics in West Virginia. The Women's Health Center of West Virginia tried to open another SSP in Charleston this year. Despite an outpouring of support at a public hearing, the City Council voted 9 to 17 to deny the request to open this lifesaving program. Without such approval, it is a misdemeanor to distribute syringes in Charleston. The mayor of Charleston, Amy Goodwin, a democrat, voted against approval, claiming she wanted to hear from more experts, despite the CDC's visit as HIV cases spiked during her first term as mayor. The Women's Health Center is legally barred from providing the best tool available to prevent the spread of HIV in Charleston. The city of Charleston needs to do better. People who inject drugs are not being cared for here, and people will continue to get sicker until Mayor Goodwin and the Charleston City Council prioritize science, medicine, and the lives of citizens who are most at risk.

Carl Schmid of the HIV+Hepatitis Policy Institute, a former PACHA member, appreciated the work of those retiring from PACHA and congratulated the new members. He hoped PACHA would continue to focus on improving PrEP uptake and addressing disparities. There is no national PrEP program today, but there are things the government can do now. For one, private insurers are still illegally charging people for PrEP and associated services. The Center for Consumer Information and Insurance Oversight at CMS oversees the regulation of private insurance along with the Department of Labor, which oversees employer plans. It must do more to ensure compliance and take action against guilty insurers. State regulators must do the same. Insurers must provide prescribers the necessary billing codes. The new International Classification of Diseases, 10<sup>th</sup> edition (ICD-10) coding and billing guide will help, but this information must be better communicated. The CDC must also be involved and work with all parties. Now that the U.S. Preventive Services Task Force has recommended long-acting PrEP, new guidance from the Federal government is needed on what and when insurers must cover without cost sharing. Secondly, the CDC must ensure that it, along with its grantees, is doing everything possible to provide PrEP services. While CDC does not pay for drugs, it can pay for laboratory tests and associated services. Today, there are no reports on how many States are using this new flexibility. The HIV+Hepatitis Policy Institute also suggests that there be more opportunities for directly funded community-based organizations to carry out PrEP activities. The bottom line is that more reporting and accountability from the CDC is needed. Finally, more data is needed on HRSA's PrEP program for community health centers, which is currently funded at \$157 million and provides grants to 412 clinics. Some State data include high-level

results, but there are no individual clinic data nor data on gender, gender identity, sexual orientation, race, or ethnicity. PACHA has gone on record asking for this information. Mr. Schmid suggested asking HRSA to look closer at the reported outcomes and provide technical assistance to correct deficiencies. For example, 10 clinics are funded in Alabama and Georgia. But while Alabama reports 732 PrEP users, Georgia only reports 71, so something is not right there, said Mr. Schmid. He said he stands ready to help PACHA continue to address efforts to expand PrEP.

Aaron Tax of SAGE, said his organization works tirelessly to foster inclusive communities and keep LGBTQ aging issues at the forefront of the national conversation, including those affecting people with HIV. SAGE applauds PACHA for introducing the resolution that supports the removal of the upper age limit from the CDC's HIV testing guidelines. This change is long overdue and has the potential to profoundly impact the lives of older individuals in the United States. It is concerning that so many older people, as well as their health care providers, tend to underestimate the vulnerability of older people to HIV. A recent meeting convened by SAGE on the subject of HIV testing in older populations brought forth poignant stories from those affected. One older person living with HIV shared that they were diagnosed with AIDS at age 75 but had never been offered testing before then, despite disclosing their history of sexual activity with both men and women. This narrative echoed the experiences of many who endured mysterious symptoms and late-stage HIV diagnoses. Regrettably, older individuals diagnosed with HIV often find themselves at an advanced stage of the disease, indicating prolonged periods of undiagnosed HIV. The CDC's HIV testing guidelines have not seen significant updates since 2006, and they still do not recommend routine HIV testing for those age 65 and older. The lapse has had severe consequences, with many individuals over 64 receiving late-stage diagnoses, and some tragically losing their lives.

Mr. Tax highlighted the progressive step taken by New York State in November 2016, when it eliminated the upper age limit for recommended HIV testing. This forward-thinking action underscored the importance of testing across all age groups and emphasized the urgency of revising national guidelines. It is imperative that CDC follow suit. Removing the upper age limit from its HIV testing guidelines is not just a matter of policy, it is a matter of saving lives. Advocating for routine HIV testing regardless of age is a pivotal stride toward early detection, treatment, and prevention services and ultimately improves public health outcomes.

Danielle Maness of the Women's Health Center of West Virginia said that everyone present is familiar with the success of low barriers to insurance programs and harm reduction programs and access to PrEP and post-exposure prophylaxis in reducing HIV transmission. The science is strong, and it is simply not debatable. Some folks in this community believe enough is being done to prevent HIV because preliminary data suggest that HIV rates in Kanawha County are decreasing. Ms. Maness said that any single additional HIV diagnosis here is unacceptable. Despite the ability to eliminate HIV transmission, Kanawha County is failing. The CDC's investigation of HIV transmission in the county in 2021—during the most alarming HIV epidemic in the country at that time—outlined that it was a priority to implement multiple interventions. One of those recommended interventions was low-barrier SSPs. Now, 2 years later, Kanawha County still only has one provider operating a low-census SSP. One SSP in the city of Charleston is not enough. Eight in the State of West Virginia is not enough.

As mentioned previously, Ms. Maness continued, the Women's Health Center's proposal to open an SSP was voted down by the City Council in August 2023. The proposal met all mandates and restrictions defined by State and city regulations. Regardless, the mayor and 16 City Council members still voted against the program. Here today are gathered a vast array of HIV experts discussing evidence-based interventions to confront the HIV epidemic, and Ms. Maness hoped Mayor Amy Goodwin, the Charleston City Council members, and West Virginia State legislators were listening when existing reputable, licensed health care clinics are essentially banned from opening evidence-based, comprehensive, harm reduction programs. The hands of clinicians are tied, and HIV will continue to impact communities, increase the burden on the already overwhelmed health care systems, and have a substantial negative financial impact on the State. Most importantly, patients, neighbors, friends, and families are being denied basic health care services that could eliminate the transmission of HIV and hepatitis and reduce morbidity and mortality for the community. The citizens of Charleston and all of West Virginia deserve access to lifesaving, low-barrier, comprehensive, harm reduction programs.

Mike Weir of NASTAD, which represents governmental public health officials who administer HIV and hepatitis programs in the United States, highlighted the organization's recently released membership consensus statement on HIV cluster and outbreak detection and response (CDR) and molecular HIV surveillance (MHS). NASTAD recognizes that health departments and community partners have expressed concerns about CDR and MHS strategies—specifically, that new surveillance technologies may subject people living with HIV and people seeking HIV prevention services to increased risk of prosecution, misuse of surveillance data in criminal or civil proceedings, or adverse actions by immigration authorities. Under the leadership of the NASTAD Board of Directors' Program and Policy Committee, NASTAD's staff and members developed recommendations to implement CDR and MHS strategies in ways that reflect the values and priorities of NASTAD and health departments. The recommendations are the result of feedback collected from NASTAD members and address five topics: community engagement, protection of public health data, assessing and addressing HIV criminalization, flexible implementation and resources, and CDR program utility and evaluation. The full recommendations can be found on the NASTAD website.

Mr. Weir highlighted some specific items from NASTAD's consensus statement. NASTAD members called for a technological and regulatory barricade between identifiable health department data and civil, criminal, or administrative proceedings. Specific recommendations for the CDC include providing jurisdictions the ability to apply for a waiver from requirements to implement MHS if their existing HIV criminalization or data privacy laws allow HIV surveillance data to be used in criminal investigations or criminal, civil, or administrative proceedings. Members identified HIV criminalization as a significant barrier to adequately implementing MHS and a limitation on the ability of health departments to share data with other jurisdictions that have HIV criminalization statutes. NASTAD membership also recommends a focus on flexibility for tailored local solutions to implement CDR activities. Health department members also called for more research on the utility of CDR and MHS strategies. NASTAD supports CDR strategies as one of the many tools to work toward EHE goals. NASTAD encourages health departments to continue engaging with their communities, State leadership, and partners around issues related to CDR and MHS. NASTAD commits to providing leadership support and technical assistance to health department members.

Joe Solomon, Charleston City Council member, called the Council's vote against allowing a new SSP "tragic" and said he wished he could apologize on behalf of the whole city for the Council blocking the Women's Health Center from bravely opening a much-needed SSP. Although a majority voted to block the SSP, Mr. Solomon said he was embarrassed and deeply sorry by the result in "the overdose capital of America." The city and the county lead the State in fatal overdoses since 2018, which was the year the health department lost its harm reduction program (another story of politics). A few years later, Charleston saw an HIV outbreak, which everyone was warned about. CDC called it the most concerning HIV outbreak in the nation. Now, Charleston is the overdose capital and the HIV capital. The city is on fire, said Mr. Solomon, and desperately needs PACHA's help to advocate for evidence-based SSPs in West Virginia. Mr. Solomon said he first visited West Virginia 10 years ago because he was concerned about environmental justice issues. At a public gathering, he was asked how he could help. The participants said, "We need your help. We need your spirit. We need your ideas. We need your voices. We need your creativity. We need your bravery. We need your courage. Figure it out, Joe. Figure it out." Mr. Solomon heard the call and moved to West Virginia. When he learned more about the overdose crisis, he applied to a doctoral program in health (where he is now in his second year). He also won a seat on the City Council.

Mr. Solomon presented data from the Women's Health Center of West Virginia showing the percentages of 2022 syringe distribution around the State for the few programs left. Morgantown has a cluster of HIV cases but is holding off an HIV outbreak so far among people who use injection drugs. By comparison, Charleston and Cabell County represent a very small percentage of syringe distribution. Mr. Solomon said the city needs help, although he did not have a list of steps that should be taken. Even more than money, Charleston needs the voices, courage, boldness, and ingenuity of entities like PACHA, and those entities need to keep coming back to the city to help figure things out. In closing, Mr. Solomon invited all participants to the 25th Mutual Aid Health Fair in Charleston, a monthly even that provides food and other services for people who use drugs and others who want to engage.

Kimberly Neff of Herpes Cure Advocacy said that Goal 5 of the 2020 Sexually Transmitted Infections (STIs) National Strategic Plan is to achieve integrated, coordinated efforts that address the STI epidemic. The concept of a syndemic approach—linking related public health issues that interact synergistically—is foundational in the STI strategic plan and key to achieving its goals. Herpes Cure Advocacy is a nonprofit organization with the goal of cure, treatment, and prevention for herpes simplex virus (HSV) types 1 and 2. The field of herpes has gained momentum in recent years through the efforts of Herpes Cure Advocacy, including an addendum to the 2020 strategic plan that will outline a national strategy to cure, treat, and prevent HSV. Herpes and HIV are related epidemics. Epidemiological studies have indicated a strong and consistent synergistic relationship between HIV and HSV infection. The risk of HIV infection is approximately tripled in the presence of HSV-2 infection and five times higher for those with incident HSV-2 infection. In fact, nearly 30 percent of HIV cases are directly attributable to genital herpes infection, especially in areas of high HIV prevalence. This rate is higher than any other STI, yet herpes is currently spreading in America with no public health intervention and only moderately effective treatment. There has been no medical innovation in nearly four decades. Nearly 50,000 cases of genital herpes occur every month, compared with less than 1,000 cases per month of mpox at its peak last summer. Given the syndemic nature of HSV and HIV, development of a vaccine for herpes could prevent transmission and reduce the global

burden of both HSV and HIV/AIDS. Herpes Cure Advocacy requested that the HIV Prevention Trials Network (HPTN) add herpes to its research portfolio, which would allow HPTN funds to be allocated for herpes vaccine research. As of now, tuberculosis, mpox, and coronavirus have been designated as diseases related to HIV within the HPTN. While also incredibly important, their link to HIV acquisition is not comparable to herpes. Herpes Cure Advocacy also requests a special task force or a PACHA subcommittee dedicated to the silent epidemic of herpes. Herpes should be included in Federal treatment and prevention programs for HIV and in every Federally funded clinic and clinical program for HIV in America. Prioritizing HSV vaccine development can help reduce the global health burden of HSV and HIV infections.

Lucifer Aldithley of Valkyrie Harm Reduction in Birmingham, AL, said studies have shown that proper access to affordable housing increases the quality of life. For people living with HIV, housing helps them take their HIV medications regularly, and not having to worry about living on the street also prevents relapse and increases the ability to access resources that they would not be able to access if they were unhoused. Suggestions to help the situation include but are not limited to more affordable housing locations; decriminalizing being unhoused; removal of hostile architecture; lowering paperwork requirements, because not everyone has access to or can easily obtain their birth certificate for Federal or low-income housing; and stopping gentrification in low-income areas, which is just an excuse for landlords to raise rent to untenable standards. Also, States without access to SSPs or proper sterile equipment, such as Alabama, continue to see a rise in preventable communicable infections. One way this could be resolved is SSPs. Another is implementing the ability for private citizens to engage in peer-to-peer distribution of sterile equipment and naloxone without reprisal from law enforcement. SSPs, which are currently illegal in Alabama, have shown to lead to a 50-percent decrease in infectious disease, a fivefold increase in seeking treatment for substance abuse, and a threefold increase in eventually becoming abstinent for all drugs, if one so chooses. The evidence also demonstrates that SSPs do not increase illegal drug use or crime. Many police and other first responders support SSPs because they reduce the likelihood of needle-stick injuries. Because Alabama has five counties on the nation's list of counties most vulnerable to HIV and hepatitis C infections and outbreaks and a 20-percent increase in drug overdoses during the last year, there is an urgent need for SSPs. Mr. Aldithley asked what the Federal government intends to implement to give States incentives to establish SSPs where they are currently illegal.

See Appendix A for written submissions.

# **PACHA** to the People: Community Engagement Session

PACHA invited all those participating (in person and virtually) to speak. Key comments are summarized here according to the main themes.

#### **Harm Reduction Programs**

- Consider allowing Federal funding to be spent on syringes in SSPs, but keep in mind the
  potential backlash given the precarious political situation in West Virginia and in
  Congress.
- Provide Federal funding for small, local demonstration projects to assess the impact of peer-to-peer or third-party distribution of clean syringes and use the findings to advocate for new State laws and policies.

- Advocate for safe smoking supplies, such as clean glass pipes, which can decrease injection drug use.
- Continue to advocate at all levels for the implementation of best practices that are upheld by scientific evidence.
- Incorporate medical care into harm reduction programs by training SSP staff to test for HIV (using an opt-out approach), rapidly link people to care, and provide support and medications.
- Engage with individuals in the community to demonstrate how harm reduction programs make communities safer.
- The criteria for obtaining clean needles are very difficult to meet and sustain over time.

#### **Increasing Access to Care**

- Engage more MAT providers, particularly in rural communities, and educate them about testing and treating HIV and hepatitis.
- Access to care is complicated by needless red tape that can take weeks or even months.

#### **Expanding Access to Funding**

- Maintain the 340-B drug pricing program, which helps eligible organizations stretch their scare Federal funding dollars.
- Create a mechanism for community-based organizations to move Federal grant money a cross State lines, rather than continuing to rely on strategies developed to address HIV in urban settings.
- Encourage private organizations, such as AIDS United, to reconsider their criteria for support so that their funding reaches a broader range of community entities.

#### **Opioid Abatement Settlement Funds**

- West Virginia citizens should hold accountable the State foundation that determines how the opioid abatement funds will be spent, ensuring that money goes to relevant efforts.
- Settlement money should go to communities that have been affected, but many believe the distribution will be affected by State politics. Every State is setting up its own plan and structure for disbursement. Therefore, it is especially important for individuals to vote and hold States accountable. States must be encouraged to report their spending publicly and in detail.
- The <u>Community Education Group</u> created the Appalachian Opioid Remediation Dashboard, which will show how cities, counties, and States use their funds.

#### Housing Opportunities for Persons with AIDS (HOPWA) Program

- Increase available affordable housing, especially in places that have HOPWA funding but no housing available.
- Securing HOPWA housing is particularly complicated for people who use injection drugs, in part because of landlord resistance.

#### **Ryan White Program Planning**

• West Virginia has no formal planning group of its own. Two counties are part of the Washington, DC, eligible metropolitan area (EMA), and some other counties are part of the Ohio EMA.

#### Representation

- PACHA should include more members working in the field of harm reduction.
- PACHA membership should reflect more geographic diversity.
- PACHA should have more consumer involvement, including more people with HIV.
- Stakeholders should organize and advocate, assist clients with registering to vote, and run for office, starting at the local level.
- More community members should be actively engaged in local planning, especially people with HIV.
- West Virginia should have more representation on the DC and Ohio Ryan White program EMA planning councils.

#### Other

• Individuals in recovery need support to prevent recurrence. Harm prevention should be a top focus.

#### PACHA Discussion and Review of Resolution

John Sapero and Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, PACHA Members
The Stigma and Disparities Subcommittee brought forth a resolution for consideration. Mr.
Smith, Subcommittee Chair, explained that CDC is updating its guidance on HIV testing.
Currently, CDC recommends routine HIV testing for people ages 13–64. The resolution requests that CDC remove the upper age limit, instead recommending HIV testing for people ages 13 and older, recognizing, for example, that older people are at high risk of having advanced disease at the time of diagnosis.

The draft resolution did not address the recommended frequency of HIV testing for older people. A participant noted that CDC is reviewing the scientific evidence around testing as part of its update process. Council members agreed that the resolution language should mirror the current CDC guidance, which indicates that HIV testing should be performed at least once as part of routine health care and that those at higher risk should be tested at least once a year. The resolution was revised as suggested, along with other minor editorial changes.

**Vote:** The Council unanimously approved the resolution as amended (see Appendix B).

Mr. Milan raised concerns about two pressing issues. First, the reauthorization of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), a successful program that has saved millions of lives around the world, remains in question. Second, the U.S. House of Representatives has proposed drastic budget cuts to the Federal HIV portfolio, including the Minority AIDS Initiative and the Ryan White Part F AIDS Education and Training Center Program. Mr. Milan recognized that there is insufficient time to develop resolutions on these matters, given that Congress must pass a Federal budget by September 30. He suggested PACHA ask the HHS Secretary and his legal affairs office to do everything possible to support PEPFAR reauthorization and protect the Federal HIV portfolio from budget cuts.

PACHA members agreed with Mr. Milan, and Mr. Milan offered to draft a letter to the Secretary for PACHA consideration. Mr. Kawata requested the letter stress the importance of passing a funding bill for Federal HIV programs without the currently proposed riders, one of which includes language against providing care for transgender people.

**Vote:** The Council unanimously approved writing a letter to the Secretary indicating that PACHA urges the HHS Secretary to (1) make PEPFAR reauthorization among his highest priorities and (2) work with the HHS Office of the Assistant Secretary for Legislation on an approach to ensure that the Federal HIV portfolio is protected from proposed severe budget cuts (see Appendix C).

Mr. Kawata requested an orientation for new PACHA members that covers, for example, the mechanisms PACHA uses to communicate its concerns and what steps are appropriate.

Follow-Up Item: PACHA staff will arrange an orientation for new Council members.

## **Closing Remarks and Adjournment**

Several retiring members of PACHA expressed their gratitude to the Council and staff and described their terms as an excellent experience. Many said it has been an honor to serve on PACHA. A number of new members added their gratitude for the opportunity to join the Council's work. It was suggested that ongoing PACHA efforts continue to address prevention, including prevention of addiction and response to families affected by addiction, as well as promotion of overall well-being as a means to decrease the risk of HIV. Mr. Sapero highlighted the outstanding work of Ms. Hayes and the OIDP staff, who offer a wonderful example of collaborative, community-focused, and innovative leadership.

Dr. Stewart announced that PACHA will meet next on December 5–7 in Houston, TX. She adjourned the meeting at 6:11 p.m.

# **Appendix A: Written Public Comments**

PACHA Meeting Charlestown, WV September 20, 2023 Public Comments

My name is Julie Scofield and I reside in Staunton, VA, a 220-mile drive east from Charlestown. My small city shares more in common with West Virginia than much of the rest of the Commonwealth of Virginia.

As some of you know, prior to moving to Virginia, I was the founding Executive Director of NASTAD and served in that capacity for 22 years. Recognizing the importance of bringing new leadership to the movement, I exited in 2015. I'm currently a member of the Health Services Committee of a very small, 5-year-old community serving organization in Staunton – the Shenandoah LGBTQ Center.

I begin my comments today with a true story. In March of this year, a 38-year-old Black gay man went to the emergency room of a small community hospital outside of Charlottesville, VA because he thought he had a bad case of COVID. Three months later, he died of advanced HIV disease, what we would have in the past called full blown AIDS. He had KS with foot lesions so bad he could not walk, PCP pneumonia and PML brain lesions that destroyed his cognitive functions and vision.

No one will ever know the truth about all the ways the system completely failed this man. Here are a few things to consider:

- --While he was very private about his sexuality, he was very much connected to people working in the HIV field at the highest levels and knew about all the tools to stay healthy PrEP, treatment, U=U, etc.
- --One of his best friends who helped the family navigate end of life care had been living with HIV for years, yet he was told this diagnosis was new.
- --When asked about Ryan White Services, the ID doc at the hospital responded that they "would research that."
- --He told another friend he was positive and undetectable and had acquired HIV through needle use.
- --He didn't seek care earlier than he did because he thought he didn't have health insurance (his Medicaid application was approved but he was unaware of that until presenting at the hospital).
- --At his funeral, there was no mention that he was gay and no mention of the mysterious disease that killed him.

This is 2023 but feels like 1983.

The needs of the Shenandoah LGBTQ Center are significant and highlight why it's so difficult to move out of the shadows of the past. Channeling the late great Humberto Cruz, I'm going to give you the top five issues that must be addressed if we are to address HIV and more in our community.

- 1. Data We are working to build strong relationships with our major medical center Augusta Health and our regional health department. That said, getting data from both entities has been difficult. We do know that our city has rates of Hep C, HIV and overdose ED visits higher than the Commonwealth overall. We are still trying to get current STI data we hear Syphilis rates are very high.
- 2. Syndemics We know we have significant rates of substance use disorders (SUDs), with a very high level of Meth use. We also know that the health department is extremely siloed, and knowledge of funding streams is extremely limited as is capacity at all levels. Having sponsored many a meeting between SAMHSA, CDC and HRSA through the years, this situation is totally unacceptable. People in the Shenandoah Valley experience polydrug use and risk of HIV, Hep C, STIs and more. Integration is essential.
- 3. Stigma The gay community around here is nearly invisible and I'm certain this contributed to the system failure mentioned above. The Center is working overtime to build community and do outreach, but the community is diverse, and outreach is challenging. Also, no one talks about HIV anymore. Frankly, we need some good old-fashioned social marketing campaigns designed for Appalachia about HIV, about meth, about stigma, about testing, etc.
- 4. Funding The Center has a fledgling community health worker program that has been in great demand and served so many young LGBTQ people, helping them address basic needs for shelter, food, transportation, etc. Imagine raising funds to sustain such an important program in nickels and dimes \$1,000 dollars at a time. The Health Services Committee is also interested in expanding testing opportunities and access to services including PrEP and DoxyPEP. We need resources but lack the capacity to write all the grants and manage all the reporting, etc. Please make it easier for small organizations to compete and access funding.
- 5. Health Care Access I know we are not supposed to talk about single payer health care because President Biden doesn't support it but....**we all have to start talking about single payer health care**. I do not believe we can end the epidemics without it. We have hovered around 30,000 to

40,000 new HIV infections since the first incidence estimates were developed around 2008. Finding new infections nationwide is like looking for needles in haystacks. And, in the South where many states have NOT expanded Medicaid and will NEVER use EHE or any other funds to truly meet the needs of Black gay men and other marginalized populations, it is the only way forward. Imagine if everyone had easy access to regular health care. Those of us concerned about ending the epidemic need to join broader movements for health care access.

My last word for today is <u>accountability</u>. There is none. We all know there are reporting requirements, evaluation requirements, grant requirements that are extremely burdensome at every level. Yet, where is accountability? Here are my questions about that:

- --Can EHE grantees demonstrate success? How much money is left unspent? --Can any jurisdiction demonstrate that they target their Federal resources
- based on their epi profiles?
  --Is the recent situation in Tennessee a test case for reallocating Federal funds to organizations that can better target funds to communities in need?

I want to thank PACHA for visiting Appalachia. I was born in the region and understand some of the complexity of needs faced by Appalachian communities. The needs of the region are complex and different from those of most other areas of the country. I hope the visit helps paint a better picture of diverse needs for our region.

Respectfully submitted,

Julie Scofield 220 Lake Avenue Staunton, VA 24401 301-455-2558 Jscofield08@gmail.com From: Patrick R Ingram

Sent: Tuesday, September 5, 2023 5:31 PM

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

**Subject:** Ready Set PrEP Program Changes

Good afternoon, Dr. Abbott and members of the Presidential Advisory Council on HIV and AIDS,

My name is Patrick Ingram, and I am a supervisor at Hennepin County Public Health Clinic, doing business as the Red Door Clinic. Our clinic provides public health and, more specifically, sexual health care to thousands of Minnesotans a year. I oversee the PrEP program, and we have just been advised that shortly, only FQHCs will be able to utilize HHS' Ready Set PrEP program. This is highly concerning, as over 600 Twin Cities Metro Region patients are being prescribed PrEP in our public health clinic. Additionally, most individuals who utilize Ready Set PrEP are of color and from communities disproportionately impacted by HIV.

I am reaching out in good faith and in an attempt to address the possible continuity of coverage for our community and residents within Hennepin County. Please clarify if Ready Set PrEP provides exceptions for public health clinics. I have made multiple attempts to call the Ready Set PrEP line at 844-419-8708, and my calls and voicemails have yet to go answered.

Meanwhile, we continue to screen over 50 calls a day from patients advised by Ready Set PrEP that their patient assistance program coverage for PrEP is no longer covered because our public health clinic is not an FQHC. Patients are not being directed on recommended steps or any additional information, which is not helpful. I have called and have found that after 3 minutes, my call goes directly to voice mail. Any insight and support that ultimately benefits our patients will be helpful. If Ready Set PrEP will not provide exceptions to public health clinics, this may mean that hundreds if not thousands will no longer continue PrEP.

Sincerely,

# Patrick Ingram, MHSA

They/Them/He/His Community Health Specialist – PrEP Coordination Office: 612-386-9123 | Fax: 612-766-2428

Schedule a meeting

patrick.ingram@hennepin.us | https://www.hennepin.us



Connect: Facebook | Twitter | YouTube | LinkedIn | Instagram

Sent: Monday, September 18, 2023 11:32 AM

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

Subject: Copy of my Public comment to share with council

Hey there,

Please share this with the council before or after the meeting

Studies have shown that proper access to affordable housing increase the betterment of every part of a persons life exponentially i.e helping people take their meds regularly and not having to worry about living on the street also prevents relapse and increases the ability for said person access resourses that they would not be able to access unhoused. What does the government intend to implement with this situation? Including but not limited to more affordable housing locations, lowering the paperwork requirements (not everyone has access or can easily obtain their birth certificate) and stopping gentrification in low invome areas. Which is an excuse landlords use to raise rent to unattainable standards? Also, states without access to Syringe Service Programs (Alabama for instance) and proper sterile equipment continue to see a rise in preventable communicable infections. One way this could be resolved is Syringe Service Programs or implementing the ability of private citizens to engage in peer to peer distribution of sterile equipment and intramuscular Naloxone without replrisal from law enforcement. Syringe exchange programs, which are currently illegal in Alabama, have shown to lead to a 50 percent decrease in infectious disease, a five-fold increase in substance abuse treatment seeking, and a three-fold increase in eventually becoming abstinent for all drugs. Evidence demonstrates that syringe exchanges do not increase illegal drug use or crime and many police and other first responders support the measure as it reduces the likelihood of needle stick injuries. Because Alabama has 5 counties on the Nation's list of vulnerable counties (vulnerable to HIV and HCV outbreaks) and a 20 percent increase in drug overdose during the last year, there is an urgent need for

syringe exchange services here. What does the Federal gov intend to implement to give states incentives to initiate such programs?

Lucifer "Luci" Aldithley - They/Them Valkyrie Harm Reduction

"When the power of love overcomes the love of power, the world will know peace." - Jimi Hendrix

Hello everyone,

My name is Iris Sidikman, I use they/them pronouns, and I am the Harm Reduction Program Coordinator at the Women's Health Center of West Virginia.

I want to talk about HIV right here in Charleston.

In 2018, the Kanawha-Charleston Health Department shuttered its syringe service program due to political pressure. Three short years later, in 2021, Charleston was at the epicenter of a HIV outbreak that the head of HIV prevention at the CDC called the "most concerning in the nation". The CDC came to Charleston that year, and in their Epi-Aid report three things became painfully clear: the spread of HIV is linked to intravenous drug use, low-barrier syringe service programs are the best way to address it, and people who use drugs are being treated very badly.

In April 2021, Charleston's City Council voted to further criminalize harm reduction and today in Charleston, we have ONE operating syringe service program, at West Virginia Health Right. It is touted as being the "gold standard" despite Charleston's restrictive laws outlawing the kind of needs-based SSPs that are the actual gold standard in the world of harm reduction. In 2022, the LIGHT Project, a syringe service program housed in Morgantown's Milan Puskar Health Right, distributed 612,744 syringes. During that same time period, WV Health Right's program here in Charleston distributed 3,960 - amounting to fewer than 80 syringes a week in the epicenter of the HIV and overdose epidemics here in WV.

You might be wondering how I know this. I know this because we, at the Women's Health Center of WV, tried to open another syringe service program here in Charleston this year. Despite our effort and an outpouring of support at a public hearing, the city council voted 9-17 to deny our request to open this lifesaving program. "No" votes included Democratic Mayor Amy Goodwin, who claimed she wanted to hear from "more experts"- despite the CDC's visit as HIV cases spiked during her first term as mayor. We are being legally barred from providing the best tool we have to prevent the spread of HIV here in Charleston.

The City of Charleston needs to do better. People who inject drugs are not being cared for here, and people will continue to get sicker until Mayor Goodwin and Charleston City Council prioritize science, medicine and the lives of their citizens who are most at risk.

Thank you.

# Public Comment to the Presidential Advisory Council on HIV/AIDS September 20, 2023

Good afternoon,

I am Mike Weir, Associate Director of Policy and Legislative Affairs at NASTAD, a non-partisan non-profit association that represents public health officials who administer HIV and hepatitis programs in the U.S. with the goal of ending the HIV and hepatitis epidemics through advocacy, capacity building, and social justice.

I am here today to alert you of NASTAD's recently released membership consensus statement focused on HIV Cluster and Outbreak Detection and Response (CDR) & Molecular HIV Surveillance (MHS).

HIV Cluster Detection and Response is a key activity in Ending the HIV Epidemic (EHE) efforts. Quickly identifying and responding to clusters and outbreaks provides opportunities to disrupt HIV transmission and can assist in identifying and addressing gaps in prevention and treatment services. However, NASTAD also recognizes that health departments and community partners have expressed concerns about these strategies — concerns that new surveillance technologies may subject people living with HIV (PLWH), and people seeking HIV prevention services, to increased risk of prosecution, misuse of surveillance data in criminal or civil proceedings, or adverse actions by immigration authorities.

Under the leadership of the NASTAD Board of Directors Program and Policy Committee, NASTAD staff and members developed recommendations to implement CDR and MHS strategies in ways that reflect the values and priorities of NASTAD and health departments. The recommendations are the result of feedback collected from NASTAD members and address the following five topics:

- 1. Community engagement
- 2. Protection of public health data
- 3. Assessing and addressing HIV criminalization
- 4. Flexible implementation and resources to support program infrastructure
- 5. CDR program utility and evaluation

Specific challenges and recommendations are as follows:

#### Community Engagement

It is essential to provide meaningful opportunities for community input, education, and engagement to facilitate continued conversations around CDR and MHS implementation to ensure programs are meeting the community's needs. For community members to participate in these activities, health departments need to involve those most impacted by this work to be part of the process with partners at the local, state, and national/federal levels.

#### Protection of Public Health Data

NASTAD's members call for a technological and regulatory barricade between identifiable health department data and civil, criminal, or administrative proceedings. Putting safeguards in place to protect PLWH from being penalized for participation in surveillance activities would increase engagement in HIV prevention, testing, and care services and build trust between communities and governmental public health.

#### Specific recommendations for the CDC include:

- Provide jurisdictions the ability to apply for a waiver from the requirements to implement MHS if their existing HIV criminalization and/or data privacy laws allow HIV surveillance data to be used in criminal investigations or criminal, civil, or administrative proceedings.
- 2. Engage at federal and jurisdictional levels to strengthen privacy rules around HIV surveillance data so it cannot be used in criminal investigations or criminal, civil, or administrative proceedings.
- 3. Provide additional funding to health departments and technical assistance (TA) on data privacy issues that most impact their jurisdictions.

#### Assess and Address HIV Criminalization

NASTAD members identified HIV criminalization as a significant barrier to adequately implement MHS, and a limitation on the ability of health departments to share data with other jurisdictions that have HIV criminalization statutes. A combination of additional support and TA for individual jurisdictions, along with federal funding to support local educational efforts for state and local legislatures and other law and policy making bodies, around reforming HIV criminalization laws and prosecutorial practices, is necessary to advance these efforts and end the HIV epidemic.

Flexible Implementation and Resources to Support Program Infrastructure
CDR implementation strategies may vary based on HIV prevalence, jurisdictional
resources, laws, and utility of CDR approaches locally. As such, NASTAD's membership
recommends a focus on flexibility for tailored local solutions to implement CDR activities

and providing additional resources to prevention and surveillance programs to support the staffing and other resources needed for CDR activities.

#### CDR Program Utility and Evaluation

More research on the utility of CDR and MHS strategies for health departments is needed to determine the value of the implementation of CDR and MHS strategies in relation to the investment of resources required. The utility of using MHS as a tool to end the HIV epidemic depends on timely data and the ability to use these data to implement an appropriate response that slows or halts HIV transmission.

NASTAD supports CDR strategies as one of many tools to work towards EHE goals. NASTAD encourages health departments to continue engaging with their communities, state leadership, and partners around issues related to CDR, and MHS in particular. NASTAD commits to providing leadership support, advocacy, and technical assistance to members as health departments continue to navigate challenges and opportunities presented by CDR implementation.

Thank you.

# Public Comment by Carl Schmid Executive Director, HIV+Hepatitis Policy Institute Expanding PrEP Access Now

Presidential Advisory Council on HIV/AIDS September 20, 2023

Good afternoon. I am Carl Schmid, Executive Director of the HIV+Hepatitis Policy Institute. While my term on PACHA ended in June, I promised I would continue to be involved. So today I am doing that by offering public comment. Before that I would like to recognize all the members rolling off today for all your work and dedication-it was great to work with each of you over the years. And Congratulations to all the new members. You have a lot of work ahead of you.

One of the areas that I hope PACHA will continue to focus on is improving the uptake of PrEP and addressing the disparities. Even though we don't have a National PrEP Program, there are things that our government can do now.

For one, private insurers are still illegally charging people for their PrEP and associated services. CCIIO, which is the part of CMS that oversees the regulation

of private insurance, along with the Department of Labor, that regulates employer plans, must do more to ensure there is compliance and take action against guilty insurers. State regulators need to do the same. Insurers must also provide prescribers the necessary billing codes to get this right. The new ICD10 code and billing guide will help, but we need to make sure all this information is communicated. The CDC must also be involved and work with all parties.

And now that the USPSTF has added long-acting PrEP to its recommendation, we need new guidance from the federal government on what and when insurers must cover without cost sharing.

Second, the CDC must ensure that it, along with its grantees, are doing all they can to provide PrEP services. While CDC doesn't pay for drugs, they can pay for labs and associated services. To date, we have no reports on how many states are

#### Page 2

using this new flexibility. We also suggest that there be more opportunities for directly funded CBOs to carry out PrEP activities. Bottom line, we need more reporting and accountability from the CDC.

Finally, we need more data on HRSA's PrEP program for community health centers. Currently funded at \$157 million it now provides grants to 412 clinics. While we have some top-level national results and some state data, we still don't have individual clinic data, nor know anyone's gender, sexual orientation or race and ethnicity. PACHA has gone on record asking for this information. We also suggest that you ask HRSA to look closer at the reported outcomes and provide TA to correct deficiencies. For example, 10 clinics are both funded in the states of Alabama and Georgia but while AL reports 732 PrEP users, Georgia only reports 71. Something is not right.

I hope you have found these comments helpful and stand ready to help you as you continue to address efforts to expand PrEP. Thank you.

Carl Schmid cschmid@hivhep.org (202) 462-3042

## **Appendix B: PACHA Resolution**



# Presidential Advisory Council on HIV/AIDS (PACHA) Resolution on Removing the Upper Age Limit of CDC Testing Guidelines

In recognition of National HIV/Aging Awareness Day, September 18<sup>th</sup>, the Presidential Advisory Council on HIV/AIDS (PACHA) stands united in our commitment to address the unique challenges faced by older adults aging and vulnerable to HIV. It is imperative that we recognize and attend to the intersecting issues of aging and HIV, ensuring that older adults receive the support, care, and respect they deserve.

Whereas, the Centers for Disease Control and Prevention (CDC) currently recommends that in all healthcare settings, HIV testing should be performed at least once as part of routine healthcare for all individuals between ages 13 and 64, and further recommends that people at heightened vulnerability to HIV acquisition get tested for HIV at least once a year;

**Whereas**, HIV acquisition is not confined to specific age groups, necessitating a comprehensive and inclusive approach to HIV testing;

Whereas, barriers to HIV testing among people over 50 include low perceived HIV risk and clinician preconceptions about older people;

Whereas, according to CDC data in 2019, 17% of new HIV diagnoses were among persons aged 50 and older;

Whereas, older people are at the highest risk of all age groups for having Stage 3 disease (AIDS) at the time of diagnosis such that in 2021, 34% of people 55 and older were diagnosed with Stage 3 disease (AIDS) at time of HIV diagnosis;

**Whereas**, older adults are at increased risk for immunocompromising conditions such as cancer, which can further increase risk of mortality if HIV is undiagnosed;

Whereas, the existence of an upper age limit in the CDC HIV testing guidelines may inadvertently perpetuate the misconception that older people are not susceptible to HIV acquisition and may deter healthcare providers from recommending HIV testing to this population;

**Whereas**, the evolving landscape of healthcare and advancements in HIV prevention and treatment underscore the importance of ensuring that individuals of all ages have equitable access to sexual health, HIV prevention, and comprehensive age-appropriate healthcare services;

Whereas, current CDC HIV testing guidelines do not mention or include individuals 65 and older who may be at risk for HIV acquisition and may unintentionally reinforce beliefs that people age 65 and older are not vulnerable to HIV acquisition;

Whereas, CDC is currently working to update its HIV testing guidelines to take into the account the current state-of-the-science in HIV, which has evolved substantially since CDC issued its last HIV testing guidance in 2006;

**Be it resolved**, PACHA recommends that CDC remove the upper age limit of its HIV testing recommendations when it releases its revised HIV testing guidelines, such that HIV testing should be performed at least once as part of routine healthcare for all individuals ages 13 and older, and further that people at heightened vulnerability to HIV acquisition receive HIV testing at least once a year.

## **Appendix C: PACHA Letter to the Secretary**



The Honorable Xavier Becerra Secretary Department of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

#### Dear Secretary:

At the 78<sup>th</sup> meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) that took place in Charleston, West Virginia on September 20, 2023, PACHA voted unanimously to send this letter to you requesting your immediate and urgent attention to two important matters concerning the U.S. global and domestic commitment to HIV/AIDS.

We are deeply concerned that current authorization of the President's Emergency Plan for AIDS Relief (PEPFAR) is due to expire on September 30, 2023, and that Congress has not acted to reauthorize this critical piece of legislation that provides foundational support for ending the global HIV epidemic. Created by President George W. Bush in 2003 and having enjoyed strong bipartisan support in Congress for 20 years, PEPFAR is highly regarded as America's greatest contribution to global public health having saved 25 million lives and prevented 5.5 million babies from being born with HIV. Today, PEPFAR funding supports HIV prevention, treatment and care in 50 countries. Its FY 2023 funding is \$6.9 billion, with approximately \$4.9 billion for bilateral HIV efforts and \$2 billion for U.S. contributions to the Global Fund to Fight AIDS, Tuberculosis and Malaria. <sup>1</sup>

We urge you to use your influence as Secretary to support reauthorization of PEPFAR, and that you direct the Department of Health and Human Services' Office of Legislative Affairs to work in collaboration with the White House Office of National AIDS Policy (ONAP), and the Office of the U.S. Global AIDS Coordinator to advance Congressional reauthorization of PEPFAR, and that reauthorization include no riders creating additional restrictions on programs supported by PEPFAR beyond current law, particularly those that would serve to limit support for sexual and reproductive health services and the human rights of LGBTQ populations. We urge further that they work to support appropriation of funding for PEPFAR at current or higher levels when a FY24 budget is passed.

<sup>&</sup>lt;sup>1</sup> https://www.kff.org/policy-watch/pepfar-reauthorization-2023-key-issues/#:~:text=This%20year%2C%20Congress%20will%20consider,would%20be%20PEPFAR's%20fourth%20reauthorization.

We are deeply concerned also, that the U.S. House of Representatives is proposing drastic cuts to the domestic federal HIV portfolio. The House Labor and Health and Human Services, Education (LHHS) appropriations subcommittee has proposed removing \$767M in HIV funding for fiscal year 2024, including funding for the Ending the HIV Epidemic initiative (EHE). The EHE initiative, created by President Trump in 2019, has also garnered bipartisan support, but its demise will severely limit any progress toward ending the HIV epidemic in the U.S. and the goals stated in our National HIV/AIDS Strategy (NHAS). We are especially concerned that the proposed cuts include drastic reductions in the Minority AIDS Initiative (MAI). Yet the latest data from the Centers for Disease Control and Prevention (CDC) show that significant progress is being made in our country. New HIV infections were 12% lower in 2021 than in 2017, with a 34% decrease in new infections among youth ages 13-24. <sup>2</sup> In addition, by 2021, lifesaving HIV viral suppression rates have risen to 66% among people living with HIV in the U.S. <sup>3</sup>

PACHA urges you to use your influence as Secretary to address these drastic cuts to the federal domestic HIV portfolio, and that you direct the Department of Health and Human Services' Office of Legislative affairs to work in collaboration with the White House Office of National AIDS Policy (ONAP), and the departments and agencies in the federal interagency working group on HIV to urge Congressional support for maintaining current funding levels for the federal HIV portfolio, and that they work to advance the original FY2024 budget requested by President Biden for addressing the U.S. HIV epidemic. Further, we request that you, your HHS Office on Legislative Affairs, and the federal interagency working group on HIV work to prevent any riders to HIV funding that would restrict sexual and reproductive health programs supported by federal HIV funds or that would limit rights and access to health care for LGBTQ people.

Our global and domestic progress must not be stopped by political forces in Congress. We urge your immediate attention to help address these grave concerns of PACHA and our constituents.

Thank you for your leadership.

Sincerely,

John Sapero PACHA Co-chair Pro Tem Ada Stewart, RPh, MD, FAAFP, AAHIVS, HMDC PACHA Co-chair Pro Tem

<sup>&</sup>lt;sup>2</sup> https://www.cdc.gov/nchhstp/newsroom/hiv-resources.html

<sup>&</sup>lt;sup>3</sup> https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-28-no-4/index.html