

Presidential Advisory Council on HIV/AIDS

(PACHA)

Conference Call

June 29, 2010

4:00 p.m.–5:00 p.m.

Council Members—Present

Helene D. Gayle, M.D., M.P.H., PACHA Chair
Dawn Averitt Bridge
Douglas Brooks, M.S.W.
Humberto Cruz, M.S.
Ernest Darkoh-Ampem, M.D., M.P.H., M.B.A.
Kevin Robert Frost
Patricia Garcia, M.D., M.P.H.
Robert Greenwald, J.D.
Kathie M. Hiers
David R. Holtgrave, Ph.D.
Michael Horberg, M.D., M.A.S., FACP, AAHIVS
Ejay L. Jack, M.S.W.
Naina Khanna
Jim Kim, M.D., Ph.D.
Anita McBride
Douglas A. Michels, M.B.A.
Mario J. Perez
Phill Wilson, B.F.A.

Council Members—Absent

Antonio Cornelius Baker
Praveen Basaviah, B.A.
Rev. Dr. Calvin Otis Butts, III, D. Min., M.Div.
Jack C. Jackson, Jr., J.D.
Rosie Perez
Malika Saada Saar, M.A., J.D.
Sandra Torres Rivera

Ex Officio Government Members

Centers for Disease Control and Prevention

Kevin Fenton, M.D., Ph.D., FFPH

Director

National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Disease (STD), and Tuberculosis (TB) Prevention

Centers for Medicare & Medicaid Services

Effie George (for Barbara Edwards, M.P.P.)

Director

Disabled and Elderly Health Programs Group

Center for Medicaid and State Operations

Health Resources and Services Administration (HRSA)

RADM Deborah Parham Hopson, Ph.D., R.N., FAAN

Associate Administrator

HIV/AIDS Bureau (HAB)

National Institutes of Health (NIH)

Jack Whitescarver, Ph.D.

NIH Associate Director for AIDS Research

Director

Office of AIDS Research

Office of the U.S. Global AIDS Coordinator

Ann Gavaghan, M.P.H.

Chief of Staff

Substance Abuse and Mental Health Services Administration

Beverly Watts Davis, M.A.

Director

Center for Substance Abuse Prevention

U.S. Department of Housing and Urban Development

David Vos

Director

Office of HIV/AIDS Housing

Additional Federal Staff

James Albino, The White House

Laura Cheever, HRSA

Jeff Crowley, The White House

Miguel Gomez, Office of HIV/AIDS Policy (OHAP)

Rosie Henson, Office of Public Health and Science
Greg Millett, The White House
Doug Morgan, HRSA
Ron Valdiserri, OHAP

PACHA Staff

Christopher Bates, M.P.A., Director, Office of AIDS Policy, and Executive Director, PACHA, U.S. Department of Health and Human Services (HHS)
Melvin Joppy, Committee Manager, PACHA, OHAP, HHS

Presenter

RADM Deborah Parham Hopson, Ph.D., R.N., FAAN, Associate Administrator, HAB, HRSA, HHS

Remarks by Helene D. Gayle, M.D., M.P.H.

PACHA Chair Dr. Helene D. Gayle welcomed participants to the conference call of the full Council.

Conference Call Agenda

A major purpose of this conference call is to give PACHA members an opportunity to review, discuss, and vote on a draft resolution from PACHA's Access to Care Subcommittee regarding the AIDS Drug Assistance Program (ADAP). First, RADM Deborah Parham Hopson will give an overview briefing on the ADAP situation, and then Access to Care Subcommittee Co-Chairs Mr. Robert Greenwald and Dr. Michael Horberg will introduce and explain the draft resolution.

A brief Public Comments period will follow PACHA member discussion and precede the vote.

Update on ADAP, by HAB/HRSA Associate Administrator RADM Deborah Parham Hopson

RADM Parham Hopson began by noting that like others on this call, HAB, HRSA, and HHS are very committed to helping people living with HIV/AIDS (PLWHA) gain access to care and treatment.

As of today, 11 States have a total of 1,924 PLWHA on waiting lists for access to ADAPs. This is an increase of 269 people on waiting lists in the past week, and an increase of 730 during the month of June. RADM Parham Hopson said she has never before seen such a rapid increase in ADAP demand in her 8-year tenure at HAB.

Increased Demand Factors

RADM Parham Hopson said many factors lie behind this increased demand and the actual and projected ADAP shortfall within States. These factors include, but are not limited to: increased HIV testing and linkage to care efforts for HIV-positive people; access to medications; retention-in-care efforts that have encouraged those already in ADAP to remain; and the economic downturn, which has resulted in an increase in the number of unemployed and underinsured or

uninsured individuals, loss of State general revenue devoted to ADAP activities, and cutbacks in State-funded programs.

What HRSA Is Doing

HRSA has been working closely with the States to ensure that those on waiting lists have access to HIV-related medications through pharmaceutical manufacturers' patient assistance programs. On April 5, HRSA awarded \$1.14 billion in Ryan White CARE Act Part B funds to all the States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and Pacific Island Territories—70 percent of which was directed to ADAP.

In addition, on April 12, HRSA released another \$41.7 million in Part B ADAP supplemental grants to 25 eligible States, Puerto Rico, and the U.S. Virgin Islands.

By August 1, HRSA expects to award about \$17.5 million in new Part B supplemental grant funds, which States may use to support their ADAPs. States also may allocate a portion of their Part B base funding for ADAP services.

HRSA/HAB is in weekly contact with the ADAP directors in States with waiting lists and those States with other cost-containment measures in place. HRSA is providing technical assistance to enable these State programs to ensure that individuals on ADAP waiting lists have access to alternative resources for HIV/AIDS prescription drugs, as mentioned earlier. HRSA also is providing technical assistance to help States assess their current drug purchasing methods to identify additional cost-saving opportunities and improve methods used to forecast ADAP utilization.

Concluding, RADM Parham Hopson said, "We all recognize the need to continue to improve access to critical HIV/AIDS prescription drugs," and "we are working to prevent and ultimately eliminate the need for ADAP waiting lists."

Remarks from Access to Care Subcommittee Co-Chairs Robert Greenwald and Michael Horberg

Mr. Greenwald introduced the Access to Care Subcommittee's draft "Resolution Regarding Timely Access to Life-Saving Care and Treatment" as unanimously endorsed by Subcommittee members and provided to PACHA members for this meeting.

Draft Resolution

The draft resolution, beginning with background, reads as follows:

Presidential Advisory Council on HIV/AIDS Access to Care Subcommittee Draft Motion

The Patient Protection and Affordable Care Act of 2010 will greatly improve access to affordable, high quality health care for many people living with HIV and AIDS. Key reforms in the new law include elimination of the Medicaid disability requirement, which will provide access to Medicaid to individuals and families with income below 133% of the federal poverty level beginning in 2014. The Act also provides for counting ADAP contributions toward Medicare Part D's true out of pocket spending limit ("TrOOP") starting in 2011 and eliminating the Medicare Part D "donut hole" by 2020. In addition, the Act contains provisions that will increase access to private health insurance by eliminating pre-existing condition exclusions, ending the practice of charging higher premiums based on gender or health status, increasing affordability through subsidies for people with income up to 400% of the federal poverty level, and increasing portability.

However, many of these and other important reforms do not go into effect until 2014 or beyond. While health care reform will significantly improve access to care, people living with HIV and AIDS will likely continue to face challenges even after implementation. In the meantime, people living with HIV and AIDS confront significant barriers to access to care and treatment right now. For instance, current practices in the private insurance sector often preclude individuals from purchasing private health insurance. Medicaid remains largely out of reach other than to those disabled with AIDS. Medicare Part D co-payment obligations continue to limit access to drugs for many Part D beneficiaries. And, the increased demand for Ryan White Program services and ADAP benefits is contributing to growing wait lists, leaving many people unable to access care, treatment and essential support services.

Individual and public health goals demand that the federal government, in partnership with state governments, do all that it can to address the significant gaps in access to care and treatment that will exist until health care reform is fully implemented in 2014 and beyond. Uninsured, low-income people living with HIV and AIDS cannot wait until 2014 for access to Medicaid. Similarly, ADAP wait lists and cost containment measures, including restrictive income eligibility requirements and drug formularies, must be eliminated. The Centers for Medicare and Medicaid Services and Health Resources Services Administration must have the financial resources and programmatic tools necessary to adequately identify and meet existing and ongoing need for care and treatment.

WHEREAS people living with HIV in the United States experience multiple barriers to care and treatment leading to unnecessary and greater morbidity and mortality;

WHEREAS there is increasing evidence that earlier care and treatment helps improve HIV-related survival and prevent the spread of HIV infection;

WHEREAS the Patient Protection and Affordable Care Act of 2010 will greatly improve access to care and treatment for low-income uninsured people living with HIV and AIDS when the Medicaid expansion goes into effect in 2014;

WHEREAS from now until 2014 an increasing number of people living with HIV and AIDS will lack access to care, life saving medications and essential support services;

WHEREAS emergency and ongoing adequate federal Ryan White Program funding, including AIDS Drug Assistance Program (ADAP) funding, will eliminate growing waiting lists and other recently implemented access restrictions, and will allow states to provide life saving care, treatment and support services to people living with HIV; and

WHEREAS the Early Treatment for HIV Act, with its enhanced federal medical assistance percentage (FMAP), will support federal-state partnerships in efforts to extend Medicaid coverage to pre-disabled, low-income, uninsured people living with HIV;

BE IT RESOLVED that the President's Advisory Council on HIV/AIDS recommends that the President and the Secretary of Health and Human Services work closely with Congress to:

1. Provide adequate emergency federal ADAP funding in FY2010 (\$126,000,000) to eliminate wait lists, reverse cost containment measures, and meet anticipated increased demand for live-saving treatment in FY 2010.
2. Provide adequate federal Ryan White Program funding in FY2011 and beyond to meet growing demand for Ryan White Program provided care, treatment and essential support services.
3. Provide states with the ability to immediately expand access to Medicaid for people living with HIV and AIDS through the enactment of the Early Treatment for HIV Act.

Briefing by Mr. Greenwald

Briefing members on the draft resolution, Mr. Greenwald emphasized that:

- The resolution's call for emergency Federal ADAP funding in FY 2010 through March 31, 2011, would, if enacted, allow for elimination of waiting lists and would reverse access restrictions, such as lowered financial eligibility criteria and removal of drugs from ADAP formularies.
- The resolution would not provide any funding that would allow States to expand their ADAPs in any way.
- The resolution's call for adequate Federal Ryan White Program funding in FY 2011 and beyond across the various parts of the program is critical because it is estimated that between 2002 and 2007, the number of PLWHA in the United States increased by

30 percent, and Ryan White Program funding adjusted for inflation decreased by about 5 percent.

- Although Secretary Kathleen Sebelius has offered States the opportunity to increase Medicaid access immediately to all people with incomes at or below 133 percent of the poverty level, and Subcommittee members support this, it is highly unlikely that many States will be able to take advantage of this offer.
- Subcommittee members therefore thought it important to allow States to expand such access only to PLWHA, which perhaps is more fiscally realistic, through enactment of the Early Treatment for HIV Act (ETHA), particularly since ETHA includes an enhanced Federal contribution ranging from 65 to 81 percent of the cost of Medicaid base care.
- If enacted in States, ETHA would greatly relieve pressure on Ryan White programs, including ADAP.
- With ETHA, many current Ryan White and ADAP beneficiaries would be eligible for comprehensive Medicaid base care and treatment, and Ryan White programs would increasingly be able to provide wraparound benefits that would fill gaps in Medicaid programs as well as serve those who remain ineligible for Medicaid.
- On a practical level, States with a history of generous Medicaid access could reap an immediate benefit, because ETHA enhances the Federal/State Medicaid financing partnership.
- States with a history of less generous Medicaid programs would benefit as well; for example, the Alabama legislature just voted to increase its ADAP funding by \$5 million, but with ETHA, that appropriation could allow some \$20 million in Federal Medicaid dollars, which may be a better approach.

Mr. Greenwald noted that the Subcommittee discussed at length various other options than those presented and unanimously agreed that a resolution addressing only emergency ADAP supplemental funding was wholly inadequate. It was clear to the Subcommittee that the resolution should also provide guidance for addressing unmet care and treatment needs beyond HIV medications and beyond 2011.

The Subcommittee agreed to restrict its recommendations to HIV-specific guidance, although members understand the importance of broader, non-HIV specific action. For example, “we know that without active support” from Congress in extending enhanced Medicaid matching funds for State Medicaid programs, “many States will be forced to implement very dramatic cuts to discretionary care and treatment programs.” At the same time, however, the Subcommittee concluded that the expertise and role of PACHA “was best suited...for now...to HIV-specific solutions.”

Timing

The President’s proposed FY 2011 budget already is being considered by decisionmakers behind the scenes, and the National HIV/AIDS Strategy is about to be released, so the timing of this resolution “is perfect” for reaching budget decisionmakers as well for providing concrete

recommendations to address one of the Strategy’s principal goals—increasing the number of people in care.

Concluding, Mr. Greenwald said the Subcommittee understands that some parts of the resolution will be difficult for the Administration and Congress, particularly given the current fiscal environment. Mr. Greenwald noted, however, that both the Secretary and the President are on record in support of Ryan White programs and ETHA. In the end, given that PACHA advises the Secretary and the President on HIV and AIDS, “we feel it is our duty and obligation to advise them through this resolution of the great promise these programs, if fully implemented, will provide in addressing the care and treatment needs of hundreds of thousands of low-income people living with HIV and AIDS in this country.”

Co-Chair Support

Dr. Horberg reiterated the Subcommittee’s full support of the resolution. He noted that many of his patients benefit from ADAP. His clinician colleagues also support ADAP because ADAP access is critical to achieving successful patient outcomes.

PACHA Member Discussion

Access to Care Subcommittee member Humberto Cruz noted his background in running ADAPs and as a member of the National Alliance of State and Territorial AIDS Directors (NASTAD). For many years, his department (the New York State Department of Health) and others have been demanding more resources to meet the increasing needs of both those who are living longer and those new to testing and testing positive. Economic circumstances have had a considerable effect. In the past year alone, New York State has experienced a 23 percent increase in ADAP demand. It is clear that New York and other States need emergency funds; therefore, Mr. Cruz supports the resolution, including its call for enactment of ETHA.

However, Mr. Cruz said that the emergency funds should not be subject to unobligated funds penalties and should be treated as “new money” as pertains to the 5 percent for emergency funding.

Call for Further PACHA Member Questions/Comments

Dr. Gayle thanked Mr. Cruz for his comments and asked if there were any further PACHA member comments or questions.

Douglas Brooks asked if PACHA members would be asked to vote on the draft resolution as it currently stands. Dr. Gayle responded in the affirmative. Mr. Greenwald added, “We completely concur with Mr. Cruz’s comments, and we will want to address them as we move toward implementation of the emergency supplemental.”

Hearing no further PACHA member comments or questions, Dr. Gayle asked for public comments. She asked commentators to give their names and affiliations and state whether

they concur with the draft resolution. Commentators also were invited to raise specific discussion points or objections.

Public Comments

Carl Schmid, Deputy Executive Director, The AIDS Institute, said The AIDS Institute supports the draft resolution's call for emergency funding, as the ADAP crisis grows worse every day. In February, when PACHA first met, there was an ADAP waiting list of 362 people. In April, that list had grown to 938 people. As of June 24, the waiting list stood at a historical record of 1,840 people in 10 States and now also the State of Florida. RADM Parham Hopson provided an update today. In short, in just 4 months, the list has grown by more than 500 percent, and other States will soon institute waiting lists.

The AIDS Institute supports the draft resolution's recognition that ADAP and the entire Ryan White Program need additional funding not only now but also in coming years until the provisions of the Patient Protection and Affordable Care Act are fully implemented in 2014.

Swift action is needed, and the response must be great enough to address the current situation and that of the coming months until the States receive their 2011 funding, provided that there are adequate increases in appropriations. The response must address not just waiting lists but other cost-containment measures, such as reduced eligibility, reduced formularies, and other limitations that reduce access to medications. If the response is not adequate, "we know we're just going to be back to the same place again."

Others scheduled to provide public comments during the call were:

- Doreen Keeler-Tollerson, Louisiana AIDS Advocacy Network
- Dennis Levy, Black and Latino AIDS Coalition
- Ann Lefert, NASTAD
- Damon Humes, Men of Color Health Awareness Center
- Anthony Roberts, National Youth Caucus
- Andrea Weddle, HIV Medicine Association
- Jenny Collier, Ryan White Medical Providers Coalition

End of Public Comments

Hearing no further public comments (due to technical difficulties), Dr. Gayle requested a roll call vote on the draft resolution.

Roll Call Vote

Christopher Bates conducted a roll call of PACHA members for the purpose of receiving their verbal votes on the draft resolution. At the end of the first roll call vote, Dr. Gayle stated that "we have the number of votes to pass it, but we still will go ahead and solicit input from people who were not able to be heard or who were not on the call." At the end of the second roll call vote (necessitated by technical difficulties), Mr. Bates stated that well over a quorum of members had voted, all in support.

Action Items

Action Item: Mr. Bates will send all PACHA members an e-mail to obtain confirmation of passage of the draft resolution.

Action Item: Mr. Bates will ensure that public comments received in writing are placed in the public record and on the PACHA Web site.

Adjournment

The call operator ended the call at 4:49 p.m.