

**Presidential Advisory Council on HIV/AIDS (PACHA)  
44th Meeting  
U.S. Department of Health and Human Services (HHS)  
Hubert Humphrey Building  
Washington, D.C.  
September 29 and 30, 2011**

**Council Members Present**

A. Cornelius Baker  
Praveen Basaviah  
Dawn Averitt Bridge, Co-Chair, Global Subcommittee  
Douglas Brooks, M.S.W., Incoming Co-Chair, Disparities Subcommittee  
Humberto Cruz, M.S.  
Kevin Robert Frost, Co-Chair, Global Subcommittee  
Patricia Garcia, M.D., M.P.H.  
Robert Greenwald, J.D., Co-Chair, Access to Care Subcommittee  
Kathie M. Hiers, Co-Chair, Disparities Subcommittee  
David Holtgrave, Ph.D., Co-Chair, Incidence Subcommittee  
Michael Horberg, M.D., M.A.S., Co-Chair, Access to Care Subcommittee  
Ejay Jack, M.S.W.  
Jack Jackson, J.D.  
Naina Khanna  
Douglas Michels, M.B.A.  
Mario Perez  
Rev. Vanessa D. Sharp, M.Div.  
Sandra Torres-Rivera  
Phill Wilson, Outgoing Co-Chair, Disparities Subcommittee

**Council Members Absent**

Helene D. Gayle, M.D., M.P.H., Outgoing PACHA Chair  
Rev. Dr. Calvin Otis Butts III, D. Min., M.Div.  
Ernest Darkoh-Ampem, M.D., M.P.H., M.B.A.  
Anita McBride  
Rosie Perez  
Malika Saada Saar, M.A., J.D.

**Staff Present**

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

**Presenters**

A. Cornelius Baker  
John L. Barnes, Executive Director, Funders Concerned About AIDS (FCAA)

Myron Cohen, M.D., M.P.H., Professor of Medicine, Microbiology, and Immunology, University of North Carolina School of Public Health

Jeffrey Crowley, M.P.H., Director, Office of National AIDS Policy (ONAP), The White House

Carlos del Rio, M.D., M.P.H., Professor and Chair, Rollins School of Public Health, Emory University Center for AIDS Research

John M. Douglas, Jr., M.D., Chief Medical Officer, National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases (STD), and Tuberculosis (TB) Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC), HHS

Margarita Figueroa-Gonzalez, M.D., M.P.H., Director, Division of Community-Based Programs, HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA), HHS

Andrew Forsyth, Ph.D., Senior Science Advisor, Office of HIV/AIDS Policy (OHAP), HHS

Donna Futterman, M.D., Professor of Clinical Pediatrics, Albert Einstein College of Medicine, and Director, Adolescent AIDS Program, Montefiore Medical Center

Miguel Gomez, Director, AIDS.gov, HHS

H. Irene Hall, Ph.D., FACE, Chief, HIV Incidence and Case Surveillance Branch, CDC, HHS

Michael N. Joyner, Director, Positive Action and Patient Advocacy, ViiV Healthcare

Bill Kapogiannis, M.D., FAAP, Program Director, Adolescent Medicine Trials Network for AIDS Intervention (AMTN), Pediatric, Adolescent, and Maternal AIDS Branch, National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH), HHS

Evelyn Kappeler, Acting Director, Office of Adolescent Health (OAH), HHS

Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, NCHHSTP, CDC, HHS

Israel Nieves-Rivera, Ex Officio Governmental Co-Chair, Urban Coalition for HIV/AIDS Prevention Services (UCHAPS); Director of HIV Policy and Manager, Program Collaboration and Service Integration for Viral Hepatitis, TB, STD, and HIV/AIDS, Population and Prevention, San Francisco Department of Health

Sade Powell, International Youth Leadership Council Member, Advocates for Youth

Julie Scofield, Executive Director, National Alliance of State and Territorial AIDS Directors (NASTAD)

Elizabeth Siegel, M.A., M.P.P., Public Health Analyst, Office of Public Health, Planning, and Innovation, Substance Abuse and Mental Health Services Administration (SAMHSA), HHS

Lawrence Stallworth II, Ohio Advocates Member, AIDS Taskforce of Greater Cleveland

Carole S. Treston, R.N., M.P.H., Executive Director, AIDS Alliance for Children, Youth, and Families

Deborah von Zinkernagel, M.S., B.S.N., Principal Deputy, Office of the Global AIDS Coordinator (OGAC), U.S. Department of State

## **DAY 1 MORNING SESSION**

### **Welcome**

PACHA Executive Director Christopher Bates welcomed everyone and then turned to a few procedural and/or administrative matters.

### **Swearing in of Newest PACHA Member**

Christopher Bates asked members to welcome the Reverend Vanessa D. Sharp, Chair of the Board of Directors of Sisterlove, Inc., in Atlanta, Georgia. OHAP Federal Advisory Committee Act liaison Olga Nelson proceeded to swear in Rev. Sharp.

### **PACHA Chair Resignation**

Mr. Bates announced that Helene Gayle has tendered her resignation as PACHA's Chair. Mr. Bates previously sent a note to members about that. During Jeffrey Crowley's remarks, there will be discussion of moving forward.

### **CDC/HRSA Advisory Committee Liaison**

Mr. Bates asked members to welcome Antigone Hodgins Dempsey as PACHA's liaison from the CDC/HRSA Advisory Committee (CHAC). PACHA's liaison to CHAC is PACHA member Douglas Brooks.

### **Disparities Subcommittee Co-Chair Change**

Phill Wilson has stepped down as Co-Chair of the Disparities Subcommittee. Subcommittee member Douglas Brooks is the new Co-Chair, serving with Kathie Hiers.

### **PACHA Charter Renewed and Posted**

The charter has been renewed and posted on PACHA's Web site. Postings that members expected to see earlier will be posted on that site early next week.

### **Release Forms for Documentary**

Mr. Bates noted that Kathie Hiers is being filmed for a documentary on HIV/AIDS in the South and has an announcement about release forms.

Ms. Hiers said the film crew wants to show the different levels of her work. They are filming the meeting today. If members do not mind appearing in the documentary, they should sign the release forms that have been provided. Release forms have also been made available to members of the public. If anyone objects to appearing in the film, do not sign the release form and "you will be edited out."

### **Remarks by Rev. Sharp**

Rev. Sharp expressed her pleasure at becoming part of the PACHA membership at this time. She considers this to be a high honor and a serious responsibility, particularly as she is a part of the faith-based community. As a minister, she has great concern about how some in the faith-based community have responded to HIV/AIDS issues. That being said, she hopes she will contribute to PACHA for the purposes intended and expects to learn a great deal.

Rev. Sharp noted that she has traveled a great deal over the past 15 years, with her work and her studies taking her to various local, national, and international fronts in the HIV/AIDS crisis. This has caused her to seek answers to problems, particularly how the church “has given excuses for not being more in the forefront of combating HIV/AIDS.” She has been to Africa to find answers that will help us move forward on solutions. She has learned of pioneers in Africa who have been in the HIV/AIDS trenches for more than 25 years addressing the crisis from a biblical perspective. She believes they are the model and the answer to many of the questions raised and concerns we have. In short, “it is about getting out in the community and addressing awareness and education in a way that doesn’t cause people to be so afraid.” We need “to make headway in ways that we haven’t.” She will continue to learn more about this as she continues her research in Nairobi, Kenya, for her doctorate.

## **Office of National AIDS Policy Update by Jeffrey Crowley, M.P.H., Director, ONAP, The White House**

Mr. Crowley welcomed Rev. Sharp to PACHA and thanked her for joining the Council. Mr. Crowley said Dr. Gayle was an important appointment, with extensive domestic and global experience. He appreciates the relationship he has had and continues to have with her. He and she try to talk every few weeks. She is an important source of counsel to him and to the President. Dr. Gayle is willing to make any contribution she can, given time constraints.

Options for appointing a new PACHA Chair are being explored. There are internal and external candidates. Also, the PACHA charter will be adjusted to create a Vice Chair position to assist the Chair. PACHA members will elect the Vice Chair. Mr. Crowley and Mr. Bates will keep members posted as they work out the logistics.

### ***PACHA Letter to the President***

Mr. Crowley noted that, in a bureaucracy, it is sometimes difficult to know how things move. David Holtgrave, Mr. Bates, and Mr. Crowley have discussed the fact that PACHA’s letter to the President is at The White House and is being reviewed by senior advisors. Mr. Crowley hopes a response will be developed in the near future. He stressed there is a process for everything, adding that “we will share the letter with the President.”

### ***Milestones***

Two days ago, ONAP was in Birmingham for the first of five meetings intended to be National HIV/AIDS Strategy implementation dialogues and visited Ms. Hiers and AIDS Alabama, as well as researchers at the University of Alabama at Birmingham, a leading AIDS research institution. Similarly, ONAP will be working with PACHA member Ejay Jack when its staff visits Des Moines as part of ONAP’s desire to pay attention to low-prevalence areas.

The meetings held so far have been highly successful in reviewing how best to utilize research for practical, on-the-ground solutions for States and localities, for example. “Much has to happen around State and local issues,” Mr. Crowley said, but “we have some solutions for tough situations.” A synthesis report will be forthcoming.

Mr. Crowley noted that on October 4, ONAP will be in Seattle for another implementation meeting, on workforce issues, and the next could be in Philadelphia on issues related to community infrastructure, which “is critical in a world of change.” Mr. Crowley said that “a lot of communities may have more community-based organizations than they can support.” It is “not for us to say how many is too many.” However, some cities have downsized, including Boston and Cleveland. Some community-based

organizations (CBOs) have become health centers, and some are working more closely with insurance companies.

These implementation meetings will also take up the concept of integration. This Administration has been trying to improve the coordination of Federal partners and wants also to review models of State and local integration. What integration models have proven successful? Where are they? Can we bring the private sector in as a partner? ONAP will focus in part on Des Moines, where there are successful models of State and local integration.

Mr. Crowley invited PACHA members who want to attend these localized implementation meetings to let him know. They are being recorded and, as he mentioned, a report or possibly a series of reports will be developed that ONAP hopes will then be used to move forward.

### ***The Budget***

Mr. Crowley's Office is working on the FY 2012 budget and beginning to look at the FY 2013 budget. These are difficult times, "but we don't have to throw our hands in the air." Rather, "we have to be smarter and work better around investments in HIV and how to have a big impact."

The biggest event on the horizon is that the world is coming to the United States next July for the International AIDS Society (IAS) annual conference. The White House is gearing up for this conference (which will take place in Washington, D.C.), and a planning process is in place at community and Federal levels, including involvement by OGAC, several HHS agencies, and Miguel Gomez at AIDS.gov. Mr. Crowley will reveal more when the time comes, but he can assure PACHA members that this event is "keeping us busy."

### ***Discussion/Comments/Questions and Answers***

As regards the status of the 12 Cities Project, Mr. Crowley said it is still a 3-year initiative, and the Administration intends to continue it. Mr. Crowley has heard a lot of interest in enlarging the project. Some have said 24 cities should be involved. Some are pulling together regional efforts. Sometimes it is thought that this is a big new source of money, but "it is not." Rather, "it is a source of innovation." Continuing, Mr. Crowley said that there is a provision in the President's FY 2012 budget that allows the Secretary of HHS to transfer 1 percent of her discretionary budget to this initiative. There have been consultations on what would be done with those funds, and "it has been advocated that we do one or two or three big things, taking to scale what we have done." Mr. Crowley noted that Dr. Holtgrave has worked with Baltimore in terms of this initiative, and Mario Perez has worked with Los Angeles. The Foundation for AIDS Research (amfAR) also is involved and is "pulling together lessons around some of the modeling."

Going forward, there may be some changes in the CDC's Funding Opportunity Announcement (FOA), and there may be a need to expand technical assistance (TA), but "we do not have the resources yet." First, Mr. Crowley stressed that "we need a budget and then we will dial on what makes the most sense." If "we get National Strategy implementation funds, the key will be trying to do something different. It is not clear yet. Federal leadership may decide that is not the direction to take. We will see." Ms. Hiers asked about a presentation to the Disparities Subcommittee yesterday by Andrew Forsyth of the Office of HIV/AIDS Policy (OHAP), during which he listed the sources of Federal funding that would be shifted. The AIDS Drug Assistance Program (ADAP) was on the list, which "seems curious, as there are many States with ADAP waiting lists." Ms. Hiers added that some have said these shifts would put more funds into the 12 Cities Project.

Mr. Crowley responded that he does not know about this in that context, “but this Administration is very committed to addressing the ADAP crisis.” To be clear, he “has not heard about taking money from ADAP for another purpose.” The CDC project underlying the 12 Cities Project began in high-prevalence jurisdictions, “and we don’t want to abandon that.” We “do need to figure out what we’re learning and give those tools to others.”

Jack Jackson noted he has been talking with Mr. Crowley about the need for funding for States to help them develop their own HIV/AIDS plans to implement the Strategy. His State, Arizona, is trying to develop its own plan, for example.

Dr. Holtgrave asked when ONAP plans to issue its report on the Strategy, to which Mr. Crowley replied that ONAP is working on that but is not very far along. The thinking in terms of timing is to let the operational plans at the agencies go through the calendar year before reporting out on progress. The report will be about what everyone is doing, including the States, localities, and the private sector. It is a struggle to figure out how to measure progress, Mr. Crowley added. If PACHA members have any ideas for this report, please send them to Mr. Crowley offline.

Humberto Cruz noted there is a conference today encompassing Federal Region II, which includes Puerto Rico and the Virgin Islands. New York State is presenting its HIV/AIDS strategic goals and objectives, what it has already achieved, and where it expects to be by 2014. One key goal, of course, is to reduce incidence in the State. This process New York State has followed could easily be used by other States. New York State is willing to share its process. Mr. Crowley noted that ONAP staff member and PACHA liaison James Albino is at that meeting.

Michael Horberg noted a recent public and private partners meeting at the White House. Mr. Crowley said that the Administration has long said such partnerships are important, but admits to struggling with how to have the greatest impact. Bringing large numbers of people to The White House is not the most successful approach, he has learned, so this time, the group was smaller, more concentrated, and included entities such as AIDS United. ONAP cosponsored the meeting along with The White House Office of Social Innovations and Civic Participation. Mr. Crowley now feels that the question is how to get more private sector support and work with private partners to leverage additional support. He invited PACHA members to provide input on that to him.

## **PACHA Letter to the President**

Turning to this agenda item, Mr. Bates noted that he was planning to move this letter down the line to various HHS agencies himself, but in talking with HHS leadership, he realized it was better for the Secretary to send copies to the various agencies for response. Mr. Bates is now tracking that on a nearly daily basis and will share information when he receives something back.

Dr. Holtgrave, who served as a coordinator of PACHA’s letters to the President and to the Secretary, thanked PACHA members for the time they spent on these letters over the summer. He thanked Mr. Bates and Mr. Crowley for their support, adding that they “were careful not to interfere with the content in any way but did increase the chances that these letters would be read at HHS and The White House.”

Dr. Holtgrave commented on the process. The last time the full Council met at the end of May, PACHA decided the letters were needed by July—fairly quickly, in short. It was understood that PACHA would need to have a conference call, allow public comment, and discuss and vote on these letters in public. Now, over the course of this winter, each PACHA Subcommittee could use the slides Dr. Holtgrave has

provided today to keep track of status and/or progress in the letters' action item areas within their respective purviews.

Dr. Holtgrave asked if this would be a useful way to keep track of the main items in the letters. He also asked if PACHA would like to follow up by asking the Secretary to attend a PACHA meeting, with PACHA's letter to the Secretary serving as a framework. Last, he asked what the optimal process would be for writing next year's letters. Does PACHA want to draft two separate letters again?

### ***Discussion/Comments/Questions and Answers***

Responding to Dr. Holtgrave's questions, Mr. Perez said it is important to track the status of these action items in the spirit of accountability. The Incidence Subcommittee, which he Co-Chairs with Dr. Holtgrave, will be viewing progress on the items within its purview and also progress based on past PACHA resolutions. PACHA needs to be consistent in all of this.

Phill Wilson said he is concerned that the sense of urgency that generated the letter has been lost. Just the process of moving the letter forward "is proceeding at a snail's pace when we are at a deciding moment in the history of the epidemic and can make huge changes that can save tons of lives."

Dr. Holtgrave agreed with the need for a sense of urgency. When he thinks about May, he is thinking about the next letter. The need for a response to the current letter is more urgent. Planning for the future should not take away from a sense of urgency now.

Mr. Wilson said one of the motivations for the letter was to have some sort of response by World AIDS Day this year. Will that happen? Even if it will not, getting a definitive answer to that question would be beneficial. PACHA must continue to be advocates on this. "It is our responsibility."

Mr. Crowley said he understands the sense of urgency. "To be honest, however, this is just how we respond to these things internally." In terms of PACHA's role, "you all can envision your role as being to hold us to account," but "from where we sit, you are advisory." The President will receive the letter. The Secretary has received the letter. "We will consider it." Now, "PACHA can say it wants a response in 3 weeks, but that is not feasible." We "cannot get to these questions until we have a budget for the year."

Mr. Cruz said he likes Dr. Holtgrave's slides of action items. Some of them will be easier to quantify than others. Setting up a process for measuring progress is one step, but the letter to the President has a larger purpose. On a yearly basis, PACHA should be responsible for or be a participant in outlining to the public what the Nation has been able to accomplish in meeting the Strategy's goals and objectives. "If we do this on an annual basis, we will have a detailed record to assess where there are gaps and tie this back to what impact certain decisions are having on our ability to meet the goals."

Many PACHA members nodded their heads in agreement with these statements.

### **Impromptu Updates From PACHA Members**

Douglas Brooks noted that at the last CHAC meeting, there was discussion of work coordination between the CDC and HRSA. Ms. Hodgins Dempsey added that when Mr. Brooks attended the meeting, "we were able to have an open dialogue on what CDC and HRSA would be working on together." She noted she is a person living with HIV/AIDS (PLWHA), and Mr. Bates noted that she is the new CHAC Co-Chair and is also working on disclosure and stigma.

Naina Khanna noted that since PACHA last met, the "30 for 30 Campaign" has been launched by women's groups around the country. This campaign has formulated a letter sent out widely, including to

The White House and PACHA members, asking for turning more gender analysis into policy and action. Meetings have been held with ONAP and with representatives from the National Institutes of Health (NIH), HRSA, and several other HHS agencies, as well as the HHS Office on Women's Health. Fairly robust discussion was held related to integrating sexual health with HIV for achieving the Strategy's goals around women. Also, in August, the group met with Kevin Fenton and others at the CDC.

Ms. Khanna said she wants to make sure the campaign's letter gets disseminated to all PACHA members today, and that a session on women is placed on the agenda for the next full Council meeting, adding that there are many biomedical advances that could benefit women.

Dr. Horberg noted that this agenda item has been envisioned and is one of PACHA's goals for its next meeting.

## **Subcommittee Reports**

### ***Access to Care Subcommittee***

Access to Care Subcommittee Co-Chairs Dr. Horberg and Robert Greenwald presented slides outlining the Subcommittee's work in recent months, achieved through monthly calls and a face-to-face meeting in August.

Issues considered included the "paradigm-shifting science" published last summer on HIV Prevention Trials Network (HPTN) 052 and the study's implications for access to care and funding. Also discussed was metrics, with specific attention to harmonization of metrics across platforms and reporting burden, a subtopic taken up by Subcommittee member Mr. Cruz. This is a real issue, Dr. Horberg said, adding that some clinics have a full-time position just to handle reporting, which is taking resources away from health care delivery.

Noted were resolutions PACHA has already passed, including the ADAP Increased Funding Resolution of 2010. Also noted was that emergency funding had been enacted for ADAP. Now, however, PACHA needs a fuller update from Mr. Bates on other funding called for in that resolution. The U.S. Preventive Services Task Force (USPSTF) HIV Testing Resolution called for an upgrading of HIV testing status, as a service graded C does not receive full funding for Medicare. The Subcommittee has been told that the task force has received the PACHA resolution, but it is unclear whether the resolution has been fully presented to task force members.

Mr. Bates said the testing resolution will be on the task force agenda in March. Dr. Horberg asked if it had been reviewed by the task force's reviewers, adding that his sense of the resolution is that PACHA would appreciate an accelerated time course on this, if possible. Mr. Bates said PACHA is in the position of advising, not dictating, that the task force move something on its agenda. Mr. Bates' Office has already made a clear statement that this was very important and that we want a response. "We almost didn't get the response we got," he added.

Dr. Horberg thanked Patricia Garcia and Sandra Torres-Rivera for developing the session on youth and HIV for the following day and also for working on a session on women and HIV, which the Subcommittee is recommending be a priority for the full Council's next meeting.

Mr. Greenwald noted the Subcommittee's support for implementation of the Affordable Care Act (ACA) for PLWHA. Important work is needed on an essential health package that meets the need of PLWHA for HIV care and broader health care. The Subcommittee met with John O'Brien of SAMHSA, the agency's ACA point person on the essential health package, on the importance of integration and coordination



among HRSA, the Centers for Medicare & Medicaid Services (CMS), and SAMHSA. The Subcommittee hopes to have Mr. O'Brien and others come to the next PACHA meeting to comment on regulations related to essential health benefits and other important topics, such as the need for close coordination across the relevant agencies.

In terms of HIV in operations research, it is important to recognize innovations in HIV care that could be applied more broadly in health care reform in general and certainly in the context of ACA. An organization that will be looking at this is the Patient-Centered Outcomes Research Institute (PCORI), and Capability Maturity Model Integration (CMMI) is involved as well. PCORI is interested in hearing from the community how HIV/AIDS entities have developed patient care and system collaborations that many would agree have been successful. CMMI is being used to look at Medicare and Medicaid innovations and how integration makes a difference. Dr. Horberg said there are clearly elements in HIV/AIDS care that can be easily translated so that all health care can be improved, so the Subcommittee will focus on those elements, hope to educate others, and also invite key people to give presentations.

The Subcommittee's priorities for 2012 are metrics, regulatory and reporting burdens, and ACA and mental/behavioral health; other priorities are ACA and the road to 2014, planning for Ryan White CARE Act reauthorization (Ryan White), women and HIV, and increasing access and linkage to care, with an emphasis on retention in care and ensuring an adequate HIV workforce. It will be important, Mr. Greenwald emphasized, to identify "game changers" and get them online as quickly as possible.

### ***Discussion/Comments/Questions and Answers***

Ms. Khanna said it is good that the Access to Care Subcommittee is thinking about broader contexts and the ACA. She asked about operations research and care navigation and peer-based models. Mr. Greenwald said the Subcommittee has not focused on this as much as it should. As it looks more at CMMI, he suspects that how these models can be translated will be examined.

Ms. Hodgins Dempsey said that when Mr. Crowley was talking about an innovation fund, most of the projects funded there are peer-based, are linking folks to care, and are seen as innovative. The Subcommittee could look further at that.

Mr. Brooks said he looks forward to a presentation by Mr. O'Brien. He asked if other agencies have similar point persons for ACA. Mr. Greenwald said he thinks they do, but Mr. O'Brien is particularly impressive in focusing on behavioral health.

Mr. Brooks said ACA provides a fair measure of hope to expand access, so how other agencies will be implementing this would be of interest. Mr. Greenwald responded that HRSA's HIV/AIDS Bureau (HAB) sits within HRSA in a way, some say, that does not give it direct input into HRSA's comments and recommendations. HAB tends to be part of HRSA's broad recommendation only. By contrast, Mr. O'Brien is at the highest level at SAMHSA, and being SAMHSA's point person for ACA is his sole responsibility. The Subcommittee is concerned about HAB's possibly low level of engagement in HRSA on issues relevant to the importance of ACA to the HIV/AIDS community.

Mr. Cruz said HAB's contribution is minimal. "Its hands are tied, and it has practically no power to make any meaningful recommendations." Also, reauthorization of Ryan White tends to become secretive at HRSA. "There is no way to know what is happening there as the result of exchanges of ideas and recommendations."

### ***Regulatory Burden***

Dr. Horberg asked Mr. Cruz to elaborate on what is happening with regulatory burden and HRSA. Mr. Cruz responded that early last spring, HRSA issued more than 300 new guidelines and monetary standards. The National Alliance of State and Territorial AIDS Directors (NASTAD) subsequently sent a letter to HRSA outlining how 13 of those needed to be reconsidered. As of today, there has been no official response. However, because HRSA's initial Webinar on these new guidelines was not able to cover all the issues, another Webinar was held recently. It was interesting, Mr. Cruz said, that when someone asked why the briefing covered only Parts A and B and not C and D, the answer was that Parts C and D sit in another part of the building.

Now he understands that the Government Accountability Office (GAO) has mandated a process of HRSA-related guideline review. This review targets a list of States, including New York State, and cities suspected "for some reason in connection with possible misuse and fraud," Mr. Cruz said, adding that "New York State has been reviewed every year with no findings, so that was insulting." In addition, earlier this week, Mr. Cruz attended a HRSA meeting on the new guidelines but came away "disheartened" because there seems to be no movement by the agency to engage in changes.

### ***Ryan White Think Tank Meeting***

Ms. Hiers said that a Ryan White think tank meeting will be held in a few weeks, in part to address the anxiety about how Ryan White will fit into the new landscape of ACA. The agenda is interesting from a community point of view and includes a few scenarios, ranging from full to partial ACA implementation. There will be an attempt to come to some kind of consensus before 2014. Ms. Hiers will report back on the meeting.

Mr. Perez said that some States are already grappling with the coexistence of Ryan White with ACA, California being one. There are certain effects the States are trying to avoid. He knows of lessons learned in California that he wants to share because he would like to see other States avoid the headaches. One thing that could be happening or is happening, depending on which part of the country you are in, "is a dramatic shift in costs from the State to local jurisdictions that could collapse many health departments across the country."

Mr. Cruz said the Access to Care Subcommittee is concerned about reauthorization looming "before we know what is happening with ACA." So the Subcommittee is thinking about having PACHA and/or the community ask for a delay in reauthorization "until we do know what is really going to happen with ACA."

A brief discussion among Mr. Brooks, Mr. Greenwald, and Kevin Frost indicated that the U.S. Department of Justice has asked the U.S. Supreme Court to rule on ACA, but it is not yet clear which case the Court will take up and on what parts of the law it will rule. Mr. Frost added that there is no guarantee that there will be greater clarity on this by summer.

Mr. Greenwald said he can make an analysis on this by Harvard available to members when it is complete.

### ***Global Subcommittee***

Global Subcommittee Co-Chair Dawn Averitt Bridge said the letters to the President and the Secretary show exceptional work and fortitude by Dr. Holtgrave and other PACHA members.

The Subcommittee worked in the spring on a high-level United Nations meeting. There was a lot of back and forth on that, but since then, the Subcommittee has had only one successful conference call and

many scheduling challenges. The Subcommittee did support Praveen Basaviah's work on the youth session that will be held tomorrow and also worked on public and private partnerships.

The Subcommittee has been feeling the need for an overall discussion on PACHA's legacy plans. The group also spends a lot of time grappling with how it can best support a largely domestically focused PACHA. Ms. Averitt Bridge noted that not all the Subcommittee's members are at this meeting, and that the Subcommittee has struggled with having a three-continent membership. Mr. Basaviah has been the most dogged member of that group. But, then again, he is younger....

The Subcommittee does not have any further updates at this time. It must get together and discuss how most effectively to continue to support the work of the rest of PACHA. Ms. Averitt Bridge then asked members for feedback on what they would benefit from hearing from the Subcommittee.

Global Subcommittee Co-Chair Kevin Frost said for those PACHA members who follow global issues on the Hill, "we did better than expected in the FY 2011 budget, and for FY 2012, I anticipate at a minimum that global health funding will remain flat." However, many are pessimistic about the Super Committee's capacity for compromise, and if that is the case, mandated cuts will be triggered that could be devastating to global health program funding.

There are some reasons for optimism, Mr. Frost added. For example, he is cautiously optimistic because he senses a growing momentum and enthusiasm for where evidence in prevention is taking us and what that could mean in the global arena "if we take advantage of this moment in time to change the trajectory of the epidemic." It may be that by World AIDS Day "we will see a very strong scale-up of treatment that could get us to having an effect." A number of groups are working on this global agenda, and Mr. Frost is hoping for real leadership in the months ahead.

### ***Discussion/Comments/Questions and Answers***

#### **Bringing PEPFAR Lessons Learned Abroad Home to the United States**

Dr. Horberg noted that the Access to Care Subcommittee has asked those involved in the 052 study to talk about its implications, including from a global perspective. He asked how the Subcommittee in particular and PACHA in general can bring to the domestic scene the lessons learned in the President's Emergency Plan for AIDS Relief (PEPFAR) related to HIV in the context of sexual health, program scale-up and peer navigation, and how to serve disenfranchised communities.

Mr. Frost responded that discussions about sexual health as it pertains to minorities in the global arena are increasing, principally related to men who have sex with men (MSM). MSM are finally being recognized as part of the underserved in the epidemic, for example. Also, the implications of HIV Prevention Trials Network (HPTN) 052 for global health are profound. Pre-exposure prophylaxis (PrEP) is also an important component.

Mr. Bates observed that reproductive and sexual health and the connection to HIV "is the synergy that gets created."

Mr. Basaviah noted that tomorrow, Miguel Gomez, Director of AIDS.gov, will speak about the use of new technologies, as PACHA needs to become more aware of how mobile technology is connecting rural patients and doctors abroad, but not as much as it could be here in the United States.

Rev. Sharp noted that she has worked with three hospitals and clinics in Kenya and that "the inroads they are making are very much improving conditions on the ground. " Many things "are being done there that you never hear about being done in the United States, including work with pregnant women

and their babies.” In addition, two universities, one operating in Botswana and another operating in Zululand, have established good programs homing in on all levels of HIV/AIDS related to women and children. In addition, a great deal of positive research has been conducted focusing on the impact on African men of having to deal with changes in masculinity. Also, there is a report about the impact of churches in cultures where development is 30–40 years behind other parts of the world in terms of their concern about HIV/AIDS.

In addressing MSM, Rev. Sharp continued, “we have to understand their culture and their mindset and address HIV/AIDS on their level.” For African women, “the issues have been there from the very beginning, more than we acknowledge in the United States for women here. Globally, we have good, published materials that could help us domestically.”

### ***Proposed Focus of PACHA’s World AIDS Day Statement***

Dr. Holtgrave proposed that PACHA’s World AIDS Day statement could be more focused on the global AIDS epidemic, which Mr. Frost and Ms. Averitt Bridge agreed was a good idea.

### ***Disparities Subcommittee***

Disparities Subcommittee Co-Chair Ms. Hiers said the Subcommittee had a very productive face-to-face meeting the previous day with some very interesting updates, the first from the Indian Health Service. Mr. Jackson is on the Subcommittee and helped arrange the briefing. Ms. Hiers came away impressed by all the testing initiatives of the Native American Indian tribes. It was striking how similar the challenges are for those who live on reservations and those who live in other, largely rural areas. These are both places where everyone knows everyone and everyone travels long distances for health care.

The second update was from the Office on Women’s Health, which reiterated the fact that there are no outcomes spelled out in the Strategy related to women. Ms. Hiers said she thinks PACHA will be hearing more about that in the future. Also, in terms of the Office of Minority Health, the Subcommittee learned something shocking, and that is the existence of prostitution rings on college campuses, where pimps are recruiting young women in their teens who then make their way through college doing sex work.

Ms. Hiers said the Subcommittee also received an update on the 12 Cities Project and CDC’s Enhanced Comprehensive HIV Prevention Planning (ECHPP) project, knowing that people confuse the two. Dr. Forsyth was very excited about the 12 Cities Project, which has accelerated. “We are beginning to see progress, particularly where strong leadership exists, such as in Baltimore and Los Angeles,” Ms. Hiers reported. She also will be promoting something that represents rural America. Ms. Hiers added that she is not certain the lessons learned in the 12 Cities Project will be applicable there.

The Subcommittee also discussed the U.S. Department of Housing and Urban Development (HUD) Housing Office for People with AIDS (HOPWA) reauthorization, which it continues to scrutinize. Ms. Hiers said HUD is committed to an implementation plan that removes it from cumulative AIDS counts, which is good “because when you use such counts, you are counting 600,000 deceased people and not accurately reflecting the epidemic today.” Ms. Hiers noted that more people with HIV/AIDS are living longer, “so a better way to distribute funding must be found.”

The Subcommittee also received a report on the “30 for 30 Campaign.” Mr. Brooks will have a separate report on that later.

Ms. Hiers then welcomed Mr. Brooks as the new Co-Chair of the Subcommittee, as Mr. Wilson has stepped down from that position.

Before addressing his stepping down as Co-Chair, Mr. Wilson said a clarification is needed because not one but two issues were raised in the briefing with the Office on Women's Health, the second one being that as a result of gender disparities on college campuses (a 5 females to 1 male ratio on some campuses), there is evidence of and concern about heightened levels of concurrency.

Mr. Wilson then welcomed Mr. Brooks as the new Co-Chair. It has been Mr. Wilson's pleasure to serve and to work with Ms. Hiers. She and Mr. Brooks will do a remarkable job. Mr. Wilson explained that he stepped down as Co-Chair in part because "we are at a decisive moment where it is increasingly important we take advantage of opportunities before us." He said he hopes "that none of us will be faced with the question of why, when we had a chance to dramatically change things, we did not." Therefore, personally, over the next few months, he will be considering the best use of his time in attempting to focus his energies more narrowly. He looks forward to continuing to serve on the Subcommittee.

Mr. Jack noted that all the presentations before the Disparities Subcommittee the day before touched on transgender health, which is very exciting, as there has not been much discussion on that. Transgender women are also being recognized and addressed.

### ***CHAC Report***

Mr. Brooks noted that PACHA had agreed at one of its meetings to look at disclosure and, knowing that CHAC was charged with recommendations in that area, appointed him to be the liaison with that committee. He reported that he made an agreement on PACHA's behalf that PACHA would not work further on disclosure until it had received a liaison from CHAC, so that PACHA and CHAC could work together. Now that Ms. Hodgins Dempsey is here, "we will be moving forward on disclosure."

### ***Incidence Subcommittee***

Incidence Subcommittee Co-Chair Dr. Holtgrave noted that the Subcommittee has been working on the following:

- Metrics and incidence, which will be addressed later today
- Prevention resources, following up on PACHA's January 28, 2011, resolution on the need for increased funding and ensuring that this was addressed in the letters to the President and the Secretary
- Finding out more from NIH representatives about different AIDS assays that are now available (This could be good, new technology for HIV testing, and a presentation on it could be scheduled at another PACHA meeting.)
- A whole set of activities, including mathematical modeling, that will build on ECHPP and the 12 Cities Project and "challenge us to know how to optimize the prevention benefits of all the resources we have available."

Dr. Holtgrave noted that some modeling can help us do that, as well as evidence-based decisionmaking, not modeling per se. The Subcommittee may bring more about all that to the full Council's attention in the future. In addition, Rosie Perez and Ms. Khanna have been representing PACHA at the working group on stigma and disclosure.

Incidence Subcommittee Co-Chair Mr. Perez said that as pertains to modeling, it is clear that a number of people in Government are looking at reach, effectiveness, and cost so that the best programs can move forward. Scientists, public health practitioners, and program designers could be encouraged to think more critically than ever before and to commit to share best practices. The Subcommittee is also

looking at the Nation's new incidence numbers from the CDC and continues to be concerned; although many populations seem to be stabilized, there has been a 21 percent increase in HIV incidence in the 13- to 29-year-old category, most alarmingly driven in part by a 40 percent rise in incidence among young gay black men. PACHA will hear more about this tomorrow afternoon. While Mr. Perez is glad we are doing a better job of measuring incidence, he is very much concerned about the trajectory of the disease among some groups in the United States.

### ***Discussion/Comments/Questions and Answers***

Cornelius Baker applauded the CDC for getting the data out on incidence. When the data were released, he recalls the Incidence Subcommittee's discussion with an NIH representative about how the CDC is refining the data and working to get real precision and accuracy in its reports. Mr. Perez characterized that discussion as very rich, adding that Mr. Baker pressed the representative on examining in depth the impact on women, transgendered people, and other communities not explicitly addressed in the CDC report. The Subcommittee wants the CDC to shed light on those other groups.

### **Subcommittee Sharing**

Access to Care Subcommittee member Dr. Garcia asked if there were a way for the Incidence Subcommittee to share more about what it learned, such as sharing the presentations.

It was noted that Subcommittee meetings are usually attended by science writers under contract to Social & Scientific Systems, Inc., NIH Office of AIDS Research (OAR) Support Contractor, and that these writers then write up meeting summaries. These summaries are not made public, but they could be made available to other Subcommittees as a matter of course.

Ms. Averitt Bridge noted that the Global Subcommittee has discussed from the beginning being able to share slides presented to its members, not just meeting summaries. "We have also talked about having a mechanism for sharing online."

Mr. Bates said his Office's exploration of how to share online has been put on hold. He noted that HHS has been going through "the migration process." Now that all the security items regarding its OS system are in place, he and Mr. Joppy can pick up that idea once again.

Ms. Averitt Bridge offered to help. Dr. Holtgrave agreed with the sharing concept. For one thing, sharing presentations and meeting summaries would help when it comes time for Co-Chairs and Mr. Bates to discuss priority agenda items for full Council meetings.

Noting that it was too early for the next series of presentations on public-private partnerships, Mr. Bates asked to begin the Public Comments session.

### **Public Comments**

**Virginia Fields**, President and Chief Executive Officer (CEO) of the National Black Leadership Commission on AIDS, Inc., said she is here today as a founding member and representative of the "30 for 30 Campaign."

Ms. Fields said we are now 30 years into the epidemic, and women living with HIV/AIDS represent nearly 30 percent of the epidemic nationally (more than 30 percent in some other parts of the world), yet women still do not play key leadership roles on policy with respect to HIV/AIDS, and many of the issues women have are not being addressed.

The Strategy is a real game changer, and Ms. Fields supports it, yet it missed an opportunity to address effectively the unique needs of women affected in the United States and the integration of sexual and reproductive health care with HIV care and prevention services.

Therefore, as a representative of the 30 for 30 Campaign, Ms. Fields is asking PACHA to make women a priority at its next full Council meeting; to establish a women and HIV/AIDS subcommittee or working group; and to acknowledge officially and address the lack of high-level Government leadership on women and HIV in the United States today.

Ms. Fields noted that a copy of her statement is available and that it includes the names of all the Campaign's founding members, including Ms. Hiers and Ms. Khanna. She looks forward to working with PACHA on this issue.

### ***Discussion***

A lengthy discussion ensued, primarily among PACHA members. Highlights included the following:

- Addressing the concept of a PACHA subgroup on women and HIV, Mr. Brooks asked if those topics could be covered by the Disparities Subcommittee.
- Ms. Fields responded that if PACHA's existing structure allows for what the Campaign wants to achieve, she is open to that.
- Dr. Garcia said PACHA's existing Subcommittee structure is coherent with the Strategy for the most part, but cross-cutting issues do exist, and some of them deserve the attention and resources of all the Subcommittees. Many PACHA members seemed to agree with Dr. Garcia's statement, and Mr. Bates said it was useful.
- Ms. Khanna suggested formation of a working group that crosses all Subcommittees that would review women's issues and possibly youth issues as well. PACHA has chosen areas of focus to be effective, but it would benefit members to have a more strategic picture.
- As a representative of African American women and children to this body, Rev. Sharp asked for a women's issues subgroup to be formed.
- Mr. Brooks said there is an essential need to focus on women and HIV. He added that those most disproportionately affected in the United States are black gay young men. "If we are going to form subgroups, maybe we need to restructure and have groups focused on subpopulations."
- Mr. Wilson said the question boils down to two things: PACHA needs to do a better job of communicating what it is doing, because women have been a major part of the Disparities Subcommittee's focus from day one, as have youth and MSM, and PACHA needs to do a better job of what it is doing, "for we have not been as effective as we need to be." This request is a reflection of that. Ms. Fields made it clear that the 30 for 30 Campaign is asking that women's needs be addressed. Mr. Wilson added that Ms. Fields' asking for it to be addressed at the highest level makes sense to him. He urged that the request be placed in the context that "ultimately, our vision is to address the vision of the Strategy and make sure no populations are left behind."
- Ms. Torres-Rivera asked if the Campaign has a specific set of recommendations on women to guide PACHA's work. Ms. Fields responded that the Campaign has had a series of meetings and put forth some very specific recommendations on data, surveillance, and metrics and how better information will better inform those concerned about gaps. Ms. Fields will make those recommendations available to PACHA members.
- In addition, the Campaign is asking that demonstration projects in one of the 12 cities focus on women, including transgender women.

- Mr. Bates noted that Ms. Khanna has a pertinent letter to distribute to members, and it will be distributed when he gets it.
- Mr. Baker said he opposes a subgroup. He added that it is important for PACHA to receive the Campaign’s recommendations as quickly as possible.
- Mr. Baker noted that the last Incidence Subcommittee meeting discussed young black gay men and how we have to address them. Members were concerned about the lack of information on women and transgendered people. “All this is our responsibility in Subcommittee,” he said, “as in we have to ask questions about the epidemic, with no silos.” Everyone “has responsibility for every American, and I don’t want to see us break out in little catchments.”
- In addition, Mr. Baker said he wants to hold people accountable, and if a particular Subcommittee “can’t do that, we need another Subcommittee or other members.” That is “the ethical approach we need to take.”
- Dr. Garcia said whether we call it a subcommittee or a working group, PACHA “does need to sanction a focus, a spotlight.” We “do have responsibilities on each of these Subcommittees, but as a group, we need to think in a focused way sometimes, as we will tomorrow, on youth.” Dr. Garcia added that she wants to see a focused effort created, because when everyone is responsible for everything, “nothing gets done.”
- Mr. Baker said he supports the concept of focused effort, but it has to be an issue-based effort. His concern is that creation of a subgroup on women “distorts perspective if it is not issue-focused.” If “we created a work group on women, that would distort the epidemic and would promote distortion of the data in that it would be thought we did this because women are the most disproportionately affected, when that is not true in a number of ways.”
- Ms. Averitt Bridge said this conversation is one that “many of us have been having for a very long time.” She noted that her focus has largely been on treatment, science, and research, adding that “we have this same conversation in scientific meetings around whether we should have science tracks and also in how we struggle with both segregation of and exceptionalism for women.”
- Ms. Averitt Bridge’s questions include what are the specific things we want to achieve? That query should be integrated into the work of the various Subcommittees, and when there is an item that is cross-cutting, “we identify it.” The “blanket of having a women’s subcommittee takes the responsibility off of everyone in the group to think strategically about what women need.” In short, “we have to pull it out by issue, and if that can be addressed in an existing Subcommittee, fine. If not, then we create a task force or whatever we want to call it.”
- Ms. Hiers said she appreciates this discussion. As she has said before, but she does believe it, the AIDS community is good at moving from one hot population to another. Young black MSM are undoubtedly the most affected population, but, also, “women are being dropped.” The fact is that in the Strategy there are no strategies related to women, and “that is not acceptable.”
- Mr. Greenwald linked to Ms. Averitt Bridge’s and Ms. Hiers’ statements in that he agrees with finding a way to coordinate across the Subcommittees. “We need to focus on the fact that the Strategy does not address women from any of the four perspectives and then lay out an agenda. As we did with disclosure, we would ask people from the various Subcommittees to do the work and put together a coordinated response.”
- Rev. Sharp said the real crux is treating each person with respect, dignity, and integrity. The bottom line for us and the Nation is to have that that one thing in mind. “Even if we all worked together, it still comes to that one thing, no matter the agenda or sexual connotation.”
- Ms. Khanna said there is a great deal of international precedent for incorporating gender analysis into an HIV response. In terms of this first national Strategy, there is a feeling in the



- Mr. Cruz said at the core of this is the difference between our epidemic and the global epidemic, i.e., a homosexual epidemic and a heterosexual epidemic. When one moves away from the United States, women are the centerpiece of the epidemic. Many of us have said all populations should be addressed. That means that “we can’t set aside women or MSM or youth or the aging or the mature.” Our responsibility is to address the epidemic in a generic way and to address how it affects populations, including migrants. The key here is to synthesize this discussion to focus on how subpopulations are addressed in the Strategy and how they are addressed in this PACHA. To create one group would cause a disservice to the other groups. Mr. Cruz’s recommendation is that PACHA has a responsibility as a group to look at each of the populations, including women, and “make sure we discuss and address those populations without leaving anyone out.”
- Mr. Jack agreed with this statement, adding that this is why he mentioned transgender populations and is pleased that the 30 for 30 Campaign has too, without his prodding. He added that it is very important to address all these populations. At the same time, it is “true that we drill down more on some than others. We have more data on some, for one thing.”

Mr. Bates asked if everyone had had an opportunity to weigh in.

Mr. Greenwald asked if we could make a decision.

Mr. Bates said he is not certain PACHA is ready to resolve this completely right now. However, he observed, there is a reason for all four Subcommittees to weigh in on this discussion, and, also, there may be very specific issues that will not be relegated to a Subcommittee but that a working group might focus on. Part of this will be driven by PACHA review of the 30 for 30 recommendations letter.

Mr. Greenwald noted that PACHA has time set aside on the topic of women and HIV for the next full Council meeting. His suggestion is to get a sense of the full Council on the concept of having members of each Subcommittee work together on preparing for this next meeting, with the focus on where the Strategy falls short on addressing women’s issues.

Mr. Bates suggested that this work entail not only the Strategy but also the 30 for 30 recommendations.

### ***Final Discussion***

Ms. Khanna suggested that a temporary task force be formed of members of each Subcommittee to work on planning for the women’s portion of the agenda for the next full Council meeting, with help from the 30 for 30 Campaign. Mr. Bates suggested instead that women weigh in at the Co-Chairs meeting, but there was objection to that, and the comment was made that each Subcommittee should decide who is interested in working on this.

Dr. Garcia noted that we can call this whatever we want to call it—task force or project or whatever—but it needs a leader and members from each Subcommittee. She asked if we can agree on that, and there seemed to be agreement.

Mr. Cruz suggested that PACHA make sure that population-focused efforts be the focus of future meetings, as well.

Ms. Averitt Bridge asked what kind of process PACHA followed to determine who should work on the youth presentations. Was it formal? The point is that a group would like to get together on how we get together and “how we do right by women in this country.” A first step is to decide how best to move forward at the next meeting, which may require no action other than to ask who wants to work on this. She also recommends that all PACHA Subcommittees go back and do a bit of analysis of the work PACHA is currently doing and how it affects the populations PACHA is tasked with. She would be willing to work on the development of the concept of how we do right by women for the next PACHA meeting, and would be happy to be part of a Co-Chairs’ call on how we do the other part of her recommendation.

It was noted that this discussion includes transgender women.

### ***Decision***

Mr. Bates said it seems that PACHA has made a decision on what to do. He asked for volunteers for the planning committee for the next meeting’s session on women.

Members of the planning committee will include Mr. Jack, Ms. Khanna, Ms. Hiers, Ms. Averitt Bridge, Ms. Torres-Rivera, Rev. Sharp, and Mr. Jackson. With those volunteers, Mr. Bates said, all the Subcommittees are covered. He added that others could also volunteer. Mr. Greenwald asked for all members to be informed of the first planning call.

### **Action Item**

Mr. Bates will inform all members of the first planning committee call.

## **Public Comments (Continued)**

**Carl Schmid**, Deputy Executive Director, the AIDS Institute, said that in its comments today, the AIDS Institute is focusing on the CDC’s 5-year HIV prevention FOA for health departments.

The AIDS Institute believes that the new direction outlined by the CDC will help decrease the overall number of new HIV infections in the United States and will achieve the goals of the Strategy by applying Federal funding where it is most urgently needed.

The AIDS Institute has historically supported the philosophy that the money should follow the epidemic. In 2009, the Institute conducted an analysis of how the CDC allocated its prevention dollars and found that there is a wide variation from State to State. The Institute found that funds were not distributed in a manner that would best reduce the number of new infections in the United States.

According to Mr. Schmid, the Institute is very pleased that the CDC has decided to rectify these past inequities and now will base the distribution of funds on the number of people with HIV. In an era of constrained Federal resources, it is even more important that funding be distributed so as to reduce HIV infections most efficiently and effectively. This philosophy is laid out in the Strategy, which calls for efforts to intensify HIV prevention in communities where HIV is most heavily concentrated and distribute funding to areas where it is most needed and where the most impact can occur.

Moving to a formula-based distribution of funds will undoubtedly create some redistribution. The CDC acknowledges the need to protect existing infrastructure by phasing in the changes over 5 years, limiting funding losses to no more than 25 percent in a year, and establishing a minimum award level. While this may be unpopular in the areas that will lose funding, it is the responsibility of the Federal Government

and the CDC to do what is best for the Nation overall in preventing HIV and reducing the number of new HIV infections.

The AIDS Institute acknowledges that distributing funds in a more equitable manner is just one component in improving our Nation's effort to reduce HIV infections. The Institute realizes that the total amount of funding that is available for HIV prevention is far from adequate and must be increased. If the overall level of funding is reduced in any way, the losses to the jurisdictions likely to receive reduced funding will be even greater.

The Institute also recognizes that the way the funds are allocated to various programs, interventions, and populations also is critical to decreasing the number of new HIV infections. The Institute believes that the CDC has done an excellent job of outlining and prioritizing prevention program elements in the funding announcement.

The CDC has the responsibility to ensure that its existing resources are distributed in the best possible manner to reduce the number of new HIV infections in the country, while being mindful of a challenging fiscal environment. The AIDS Institute believes that this funding announcement fulfills this mandate and encourages PACHA to lend its support as well.

## **Public–Private Partnerships**

In introducing this session, Mr. Baker noted the work of the Incidence Subcommittee related to prevention resources, including having the first speaker today, John L. Barnes, present to the group about the private sector and provide an overview of where private philanthropy stands with regard to HIV/AIDS. The second speaker will be Michael N. Joyner. Mr. Baker said there are many players in the private sector but none as significant as Mr. Joyner, his organization, and its predecessors.

Mr. Baker said this is but one in a series of conversations to be sponsored by the Subcommittee on how all sectors can contribute.

## **Presentation on U.S. and European Philanthropic Support To Address HIV/AIDS in 2010, by John L. Barnes, Executive Director, FCAA**

Each year, FCAA, a U.S.-based, 25-year-old group of funders that contribute to fight AIDS here and abroad, conducts a survey of its funders and releases a report on the findings.

Key findings of the 2010 report (not to be released to the public until November 10) are:

- Total disbursements in 2010 were \$459,020,191, down 7 percent from 2009 disbursements.
- Disbursements by the Bill & Melinda Gates Foundation (47 percent of all disbursements calculated by this group) decreased to \$215 million from \$244 million.
- Disbursements by all other funders decreased to \$244 million from \$249 million.
- The number of funders disbursing more than \$300,000 per year in 2010 (a total of 60 organizations) was the lowest on record since 2005.
- Twenty-seven percent of the funders providing a forecast for 2011 (not all did so) anticipate increased funding in 2011, including from the Gates Foundation.

The total giving by European-based philanthropies in 2010 was about \$153 million, according to a somewhat parallel survey and report conducted by the European HIV/AIDS Funders Group. All told, total philanthropic funding to HIV/AIDS in 2010 from both U.S.- and European-based organizations was \$612 million, down 7 percent from 2009.

In the United States, 42 funders represent 87 percent of all funding, according to the survey data, which are based on Form 999s and other sources. Totals given represent just the grant-making part of the giving organization's philanthropic budgets. Government funding is not included and is not necessarily going to domestic programs.

Mr. Barnes then showed a series of pie-chart slides depicting the geographic distribution of U.S. HIV/AIDS grants, the concentration of funders, and the regional distribution of domestic U.S. HIV/AIDS philanthropic funding in 2010. One slide (slide 5) shows the names of the 25 top funders in 2010, beginning with the Gates Foundation and ending with the H. van Amerigen Foundation.

Mr. Barnes then showed a series of slides illustrating private funding (2010) versus new infections (2009) that illustrates the gap in funding versus needs, particularly in the South (slide 9); the intended use of funds disbursed in the United States for domestic purposes, illustrating changes over the past 3 years (slide 10); and private funding by the top 46 U.S.-based philanthropic organizations (2010) versus estimated new infections (2009) by population type, which, Mr. Barnes said, shows greater alignment with need than public funding (slide 11). Slide 12 shows regional distribution of U.S.-based HIV/AIDS philanthropic funding in 2010 in terms of where it goes abroad (40 percent to Eastern and Southern Africa). Slides 13 and 14 follow up on that with breakdowns in terms of intended use and where money from the top 36 funders went relative to needs abroad.

Mr. Barnes sketched a profile of the European HIV/AIDS funders (<http://www.hivaidsfunder.org>), including that the top 10 accounted for 86 percent of all HIV/AIDS-related funder expenditures in 2010 (up from 83 percent in 2009) and that 38 percent of the funders (10 of 26) forecast increased funding in 2011. Slide 17 depicts where European money goes, and slide 18 lists the names of the top European Union HIV/AIDS funders in 2010, headed by the Wellcome Trust.

Mr. Barnes concluded by noting that both in the United States and in Europe, funding is highly concentrated among certain numbers of funders, which is seen as a vulnerability.

### ***Discussion/Comments/Questions and Answers***

Mr. Frost asked how the work of this group intersects with the work of GBCHealth, if it intersects at all. He noted that FCAA looks only at philanthropy from corporations, and GBCHealth looks at business practices. Further, aside from a handful of pharmaceutical companies, "there is not a single business that makes this list—private business—except for Levi Strauss and M.A.C. But what about Coca Cola, Chevron, and others in the Netherlands that make significant efforts in Africa? They are not here."

Mr. Barnes said that he understands Coca Cola "stopped making financial contributions." He also noted that the report covers 60 funders, adding that "just about every pharmaceutical company can be found in those ranks."

Dr. Horberg noted that Mr. Gates is the top funder, yet "here we all are working on our iPods, Macs, and so on." We "have to show support to the companies who support us and quit and penalize the companies that don't."

Mr. Barnes said it is possible there are companies and foundations that should be in this report but are not. FCAA will add them, if PACHA members want to draw his attention to them. "Let me know when the full report comes out."

Members interested in participating in the report release Webinar should go to <http://www.FCAAIDS.org>. The report can be downloaded from FCAA's Web site once it has been released. Mr. Barnes will mail hard copies to members, if needed.

Ms. Hiers said she uses this report every year in the South.

Ms. Torres-Rivera asked if Puerto Rico is considered to be a domestic country or an international country. Mr. Barnes said it is considered domestic and that, each year, FCAA spotlights certain areas. The spotlight this year is on Puerto Rico and the Virgin Islands. FCAA will also be at the Caribbean HIV/AIDS conference to try to focus on that region. In addition, FCAA is working on a funders' tour of the South in November.

### **Presentation by Michael N. Joyner, Director, Positive Action and Patient Advocacy, ViiV Healthcare**

Positive Action was founded in 1992 as the first pharmaceutical company program of its kind to support communities affected by HIV and AIDS. Today, Positive Action has programs focused on vulnerable and marginalized populations, prevention of mother-to-child transmission (PMTCT), HIV education at work, and community projects supported by local companies. The ViiV Web site shows all the grants. Mr. Joyner noted that ViiV is number 10 on the FCAA's top 10 list, but "it doesn't have Gates-like money."

A few of Positive Action's projects build capacity at the community level by helping to deliver greater and more meaningful involvement in the community by PLWHA; reaching marginalized populations; with the community, tackling stigma and discrimination and reducing violence against at-risk populations; and testing innovations in education, care, and treatment, as well as in capacity building.

Slide 4 depicts the reach of Positive Action around the world through its "Staying Alive" program in 32 countries, including Russia, where it is working on harm reduction.

Slide 5 depicts the Life with Dignity project, which is a collaboration between local community organizations, *Collectivo Sol*, the International HIV/AIDS Alliance, and ViiV's Positive Action program. Phase I in Mexico was so successful that ViiV decided to introduce the project to the same types of stigmatized populations in six other countries in Central America. ViiV hopes to continue this model elsewhere. Mr. Joyner said ViiV can even work with the Strategy on lessons learned and on linking to ViiV partners.

Slide 6 depicts other MSM-focused programs, including the new Global Forum on MSM and HIV to help with advocacy in Honduras and Morocco.

Slides 7 and 8 depict adolescent interventions, such as the Ubuntu Education Fund for Interventions for boys, and the ICRW/Pact Tanzania intervention for girls. Interventions for boys involve men and boys in the response, and the men's ceremony has embraced respecting girls, changing gender norms. A final report is due out soon on the ICRW/Pact Tanzania intervention, which mapped out safe zones for girls where previously there were none.

At present and for the foreseeable future, ViiV is focused on young people, Mr. Joyner emphasized, particularly youth-based efforts that build on the Body Shop's initial efforts, including the Staying Alive Foundation for prevention-focused programs and the HIV Young Leaders Fund for Youth Networks. ViiV is committed to 3 years of program funding of the HIV Young Leaders Fund and will soon be issuing requests for proposals.

Turning to the United States, Mr. Joyner noted the U.S. Southern Initiative, which is Positive Action's first domestic initiative, with a focus on adherence (slide 9). The Southern Initiative has awarded grants to several organizations in eight States specifically focused on reducing disparities in HIV/AIDS linkages to care and treatment among African Americans and Latinos in Alabama, Florida, Georgia, Louisiana, North Carolina, Mississippi, South Carolina, and Tennessee. Some of the organizations are in Phase I, and some are in Phase II. Mr. Joyner would like PACHA members to get to know the grantees listed on slide 11. Slides 12–15 briefly describe some of the grantees and their programs. Mr. Joyner said ViiV wants to grow this network of grantees and assess what has gone right and what has not.

Slide 16 graphically depicts centers of ViiV's network activity more or less across the South. Mr. Joyner said that many of these members, even those who did not receive grants, will participate in the IAS conference in Washington, D.C., next summer.

Beginning last year, ViiV made an \$80 million commitment to reduce mother-to-child transmission of HIV over the next 10 years in an effort also to prevent unwanted pregnancies and focus on children and their families (slides 18 and 19). This Positive Action for Children Fund aims to support and inform the global effort to alleviate the impact of HIV and AIDS on maternal and child health by supporting interventions that engage affected communities and to ensure that those communities can deliver projects that reach individuals at risk from or coping with HIV.

Slide 21 notes the existence of Positive Action at Work, which is a workplace program begun in pharmaceutical company factories and offices and is now on the ViiV Web site. Mr. Joyner invited PACHA members to look at this page on the Web site because it receives many hits. "Many are interested in these materials. There is not much out there."

### ***Discussion/Comments/Questions and Answers***

Responding to a query about how to get other organizations to do what ViiV does, Mr. Joyner said good information is available on the Web site. He added that ViiV does not take unsolicited grants for its international work but does for the Southern Initiative. Also, ViiV has new money for Positive Action, so it is looking for new opportunities.

Mr. Jack said that transgender individuals and sex worker populations often do not want to be recognized as such, and while it is good that some initiatives are reviewing that, expanding programs for these populations in the Southeast would be helpful.

Ms. Averitt Bridge asked what ViiV is considering in terms of sustaining its successful model programs and initiatives. Also, what is the public part of the partnership? Responding, Mr. Joyner noted that amfAR is participating in a program that works in 38 clinics across Kenya. It is a unique model, in that when you test positive, you become part of a "test positive" club and give feedback to the clinics, which helps increase adherence. Last year, he visited with some of the women involved, and they thought of this as their clinic. A threat to the sustainability of this project included a few issues with the Kenyan Government. "We had to get them in there to see how the program worked to help resolve some of the issues." In international projects, ViiV gets local governments involved from day one so that they will have success they can claim for themselves and want to continue. "It is not who gets the credit but who gets the services."

Mr. Cruz noted that he has lived for 30 years in the United States and is pleased that "finally, someone is talking about doing something in South and Central America, as they are many times forgotten." He noted that the Caribbean is second only to sub-Saharan Africa in its level of prevalence and incidence, yet "less than 1 percent of the funding goes there."

Mr. Cruz noted that Phases I and II of the Vida Digna program involve other organizations working with the target populations, including transgender individuals and sex workers, so how does ViiV make sure everyone's work is integrated to maximize limited funding? Mr. Joyner responded that it is important to have partners such as amfAR and the HIV/AIDS Alliance and also strong networks. The Alliance would be happy to share its model with anyone.

Ms. Khanna asked the presenters to predict the direction of private funding in the United States. Mr. Barnes responded that the annual survey does ask for projections, and from the responses he received, looking at top funders and specifically Mr. Gates, "we're optimistic the numbers will go up in 2011."

Mr. Baker asked how the presenting organizations are preparing their members for the future needs of communities in an environment where some may think that all the problems have been solved, but they have not. To the point, given the relative wealth of Europe but relative private sector complacency, what role does and will social services play? Mr. Barnes responded that on December 5, FCAA will hold its year-end gathering, and much of the discussion will be about those issues. "Our European sister organization is going through a difficult period now, and we are not sure it will continue to exist as a group. We are trying to help them continue." Further, "as mentioned in our report, nearly all the philanthropy from the European Community is from the United Kingdom. It is likely we will focus with grant makers there to ensure that they at least remain a coalition." The biggest challenge is that each year, "we lose funders." Twenty-two funders over the past 3 years are no longer funding HIV above \$300,000 per year. Others, like Coca Cola, have moved on to malaria and other diseases. In addition, the slowed economy has forced these funders "to make different decisions about their focus, and some are funding health care system infrastructure rather than specific diseases."

Mr. Perez asked if, among private partners, there is an effort to connect consumerism, capitalism, philanthropy, and conscientiousness in, for example, donating proceeds from consumer item sales to fight the epidemic. Mr. Barnes noted that the M.A.C. AIDS Fund does that, but FCAA does not get into those kinds of questions in its survey. In fact, "it is tough to get funders to answer the questions at all." However, for the 2010 survey, he will conduct a followup survey with the top 10.

Mr. Basaviah asked Mr. Barnes if he was aware of the foundations that are finally open to funding for-profit enterprises and whether there is a global resurgence in locally based foundations. Mr. Barnes asked Mr. Joyner to respond, because the funders who complete the FCAA report do not have detailed knowledge of the projects they fund, particularly when their funding amounts are on the wane. Mr. Barnes added that in the 2009 FCAA report, there is an appendix of foundations and philanthropic organization in other parts of the world. "We listed all those we found. UNAIDS has a real interest in that, and we're eager to work with them, if we can find the resources."

As for funding for-profits, Mr. Barnes said it is common to fund for-profits for research, but most for-profits would not be funded. Mr. Joyner added that ViiV only funds not-for-profits.

Mr. Joyner added that, within countries, "the strongest networks of HIV private funders are where local organizations are coalescing around them." In India, ViiV has received a number of proposals and has funded a growers' cooperative in Rajasthan. "We are seeing more groups active on the ground."

Mr. Cruz asked whether services targeted to intravenous drug users (IDU) and HIV were being funded by European foundations. Mr. Barnes responded that among European Commission funders, none are funding services for IDU as a basis of their funding. There is a funders' coalition focused on needle exchange, and amfAR is a member of it. Through its annual report, FCAA tries to review gaps between needs and funding. Mr. Barnes' slides show that U.S.-based private funding does focus on new infections

among IDU, more than any other population, including MSM. He added that “private funders often gravitate to what Government is not doing.”

Rev. Sharp asked Mr. Joyner if ViiV is working with nongovernmental organizations (NGOs) and others in more than the locations in Kenya he had already mentioned. Mr. Joyner responded that the one project he had mentioned involving amfAR addresses connecting clinics and patients.

Rev. Sharp said she visited the Mothers Project in Kenya, which she thinks is excellent, and wonders if ViiV is still looking for U.S.-based organizations, including in the South, to work in places such as Kenya and Ghana. Mr. Joyner said ViiV gets proposals every day from U.S.-based organizations working in Third World countries, including from physicians, although ViiV does not fund physician-based clinics.

Rev. Sharp mentioned that M.A.C. AIDS is involved in training women, leadership, and cohorts and sponsoring “blended” leadership conferences “with those of us who are positive, because politicians need to be aware in order to advocate for us.” HIV-positive men need to have that same opportunity. Mr. Barnes responded that something from the FCAA report he did not mention are sidebar examples of work being done by funders, including M.A.C. In addition, the funders’ guide to the Strategy will be released at the December meeting, and there will be discussion on what funders are doing to align their funding with the Strategy’s goals.

Concluding discussion, Mr. Baker said that what Mr. Barnes just said is very important.

## **Lunch**



## **AFTERNOON SESSION**

### **CDC Health Department FOA**

Incidence Subcommittee Co-Chair Mr. Perez and Subcommittee member Mr. Cruz introduced the next session, on the CDC health department FOA.

As mentioned earlier, the Subcommittee is interested in looking at all HIV/AIDS investments at the Federal level with an eye toward how they support the Strategy. It has become apparent that the CDC is an important funder in prevention. Some may be familiar with CDC FOA funds, but this program has gone through shifts recently. This session will therefore begin with an overview presentation from the CDC and then move on to hear from two individuals representing two different organizations—NASTAD and the Urban Coalition for HIV/AIDS Prevention Services (UCHAPS).

Mr. Perez said that we often think about prevention at the Federal level, but we need to look at multiple revenue streams across the landscape as well. Therefore, this will most likely be the first of many presentations in this area.

Mr. Cruz said that CDC FOA activity has a broad national impact. Before issuing a FOA, the CDC has many consultations; it was through this that he and others were able to make recommendations relevant to the Strategy. As a result, when the FOA was released, significant, drastic changes had been made in prevention resource allocation. After the presentations today, he hopes PACHA will have a lively discussion on what this means for the Nation, the States, and the cities.

### **Presentation on the CDC New Health Department FOA, by Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, NCHHSTP, CDC, HHS**

The guiding principles behind this FOA begin with the fact that the CDC's funded prevention programs have long been and will continue to be a central strategy for the CDC fight against HIV. The current effort allows, in this era of a national Strategy, for health departments across the country to take advantage of recent important findings related to prevention, including the HPTN 052 study results.

The Strategy specifically calls for the CDC to refocus its funded prevention programs for maximum effect on reducing new HIV infections and to address historic misalignment of HIV prevention resource allocations. Funding, the Strategy emphasizes, should follow the epidemic.

Other guiding principles are to focus on high-impact prevention, with an eye toward efficacy, cost, feasibility, scalability, and targeted populations. Ms. Margolies observed that recent scientific findings, including but not exclusively the HPTN 052 study results, provide "unprecedented numbers of effective tools for HIV prevention."

Before the FOA was published, partner/stakeholders engagement activities included:

- Meetings and conference calls with NASTAD and UCHAPS
- A 2010 high-performance leadership listening session
- Four regional conference calls and live meetings (Webinars) with health department representatives
- Final conference calls/live meetings with health department representatives, NASTAD, and UCHAPS
- A focus group of the Pacific Islands HIV/AIDS Community Action Network and a conference call with Pacific Island jurisdictions

- Creation of a health department FOA mailbox to facilitate recommendations
- Written recommendations from national partners.

Slide 7 shows the degree of alignment of the FOA with stakeholder feedback, including from the AIDS Institute, on issues ranging from counts of the use of living-with-HIV cases to gradual implementation.

FOA features include:

- An initial issue on June 30, 2011, involving \$359 million
- Matching resources to the epidemic, with funding distribution determined by unadjusted number of people diagnosed and reported to be living with HIV in 2008 (a better indicator)
- An increase in the number of eligible cities from 6 to 10 (Many southern States and several cities will receive increased funding.)
- A focus on interventions and strategies that will have the greatest impact on the epidemic while allowing flexibility
- Support for innovative programs by health departments
- Incorporation of the expanded testing initiative (as a separate category)
- Incorporation of learning from the ECHPP program
- Implementation of funding changes over a period of time (3 years under this initial announcement).

Key changes to the FOA in response to partner feedback included:

- A reissue on July 20, 2011, that incorporates changes
- An extended application deadline (an additional 15 days, to September 14, 2011)
- Phased-in implementation of the formula over 5 years, not 3 years
- A provision that no State will lose or gain more than 25 percent from its previous-year award
- Amendment of the range of floor funding from \$750,000 to \$1 million
- Amendment to include additional instruction for Category C (see health department categories below for details).

Three health department categories are included in the new FOA:

- Category A: HIV Prevention Programs for Health Departments
  - Required core program components: HIV testing, comprehensive prevention with positives, condom distribution, and policy initiatives
  - Required programmatic activities: jurisdictional HIV prevention planning, capacity building and TA, and program planning, monitoring and evaluation, and quality assurance
  - Recommended program components: evidence-based HIV prevention interventions, social marketing, media mobilization, and PrEP and post-exposure prophylaxis (PEP)
- Category B: Expanded HIV Testing for Disproportionately Affected Populations (36 eligible jurisdictions)
  - Required: HIV testing in health-care settings
  - Optional: HIV testing in non-health-care settings
  - Optional: Service integration
- Category C: Demonstration Projects To Implement and Evaluate Innovative, High-Impact HIV Prevention Activities (competitive and optional)

- Focus areas include: structural, biomedical, and behavioral interventions (or any combination thereof); innovative testing activities; enhanced linkages to and retention in care; advanced use of technology; and use of CD4, viral load, and other surveillance data to assess and reduce HIV transmission risk.

Ms. Margolies noted that some jurisdictions disproportionately affected are eligible for Category B funding. Of the optional components, the first one builds on a CDC pilot.

With regard to Category C, this is the first time the CDC has included money for demonstration projects (see slide 13 for details).

Next steps include application eligibility review, structured and technical reviews for Categories A and B, and objective reviews for Category C. The date for awards is January 2012.

Ms. Margolies noted that not all items were due at time of application submission, given the changes that have been made. Some items can come in within 6 months after an award (see slide 16 for details).

Concluding, Ms. Margolies said the CDC knows that health departments across the country already face difficult choices for making the best use of limited funds, so they will have access to extensive technical support from the CDC and its partners, as described in slide 17. NASTAD and UCHAPS have been funded to give some of this support.

### **Presentation on Achieving High-Impact HIV Prevention: CDC Funding Opportunity Announcement Issues for Consideration, by Julie M. Scofield, Executive Director, NASTAD**

Ms. Scofield said she will share some perspectives on the new FOA, address implementation challenges, look at some issues for further consideration, provide examples of what is happening in the field and the impacts of funding cuts, and then address next steps.

This is the first time the CDC has used a formula for distributing funding. As structured, this new FOA provides additional clarity and structurally changes the old cooperative agreement by creating the three categories of awards outlined by Ms. Margolies.

Category A's high-impact activities enable more nimble, higher impact, evidence-based interventions; increase HIV testing prioritization and emphasis on screening for other STDs; and increase foci on prevention with positives and policy barriers that impeded optimal service delivery. Some of these foci are the basic ones that have been funded since the mid to late 1980s; many of the optimal categories are reflected here.

Category B provides 36 jurisdictions with funding to expand HIV testing in clinical and nonclinical settings, with a slight increase in the number of those eligible.

Category C is brand new, competitive funding for innovative programs.

Implementation challenges include:

- HIV prevention is woefully underfunded in the United States—only 4 percent of overall Federal domestic HIV/AIDS investment.
- State and local resources for HIV/AIDS programs have declined, mostly for prevention.
- Federal operating agencies need to embrace the Strategy's call to achieve a more coordinated response with meaningful community engagement.

- New CDC incidence estimates among gay men of all races and ethnicities, particularly young black MSM, must be a call to action to increase our response in these communities.
- The ADAP crisis must be addressed.

### ***Key Message for PACHA***

A key take-home message for PACHA is “prevention is fighting over funding crumbs, so PACHA should take a look across the entire HIV/AIDS portfolio and ask if every other dollar is being used to better purpose.”

Issues to consider (slides 5, 6, and 7) include that Federal core funding for HIV prevention funding to health departments has been stagnant for over a decade; through expanded testing, “we have been un-leveling this playing field for core prevention for some time”; more analysis was needed before the FOA was released on what an optimal HIV prevention program looks like; and more time was needed for adequate planning for significant cuts or thoughtful scale-up of new dollars.

Additional issues include significant application challenges, given the unknown floor or ceiling amounts of funding for Categories A, B, and C and low-cost extension. Actual awards for the coming fiscal year could vary dramatically and will likely not be known for a long time, all making planning very difficult. Also, is the CDC going to align funding for CBOs with the new funding formula and new high-impact HIV prevention activities? These resources make a lot of difference in jurisdictions.

In addition, after a hard-fought battle, HIV prevention received an increased appropriation from Congress in FY 2011, but how do we continue to advocate for prevention when most jurisdictions are being cut under this FOA? Advocates will now have to tell congressional members “thanks for your vote before, and just to show our thanks, your jurisdiction is going to lose money next year.”

Last, the AIDS community has a long history of coming together to oppose dramatic reallocation of resources that could potentially lead to destabilization of programs, the last Ryan White reauthorization being a good example. So, “why are we not doing that for prevention?” Back with Ryan White, “we agreed to protect jurisdictions so they wouldn’t lose 5-10 percent. So why is it OK for them to lose 25 or 50 percent now? Our community should not square off and divide up in winners and losers.”

Ms. Scofield provided examples from the field of what would be the impact of funding cuts. The examples included Iowa, Hawaii, Maryland, Massachusetts, and Michigan (slides 8-12).

### ***Top-Line Requests***

Critical, top-line requests are:

- NASTAD supports the restoration of \$20 million to Category A and \$5 million to Category B. PACHA and the Prevention Justice Alliance are on record asking for the restoration of funds to Category A equal to amounts available in FY 2011.
- The impact of the new FOA needs to be well evaluated. Can the goals of the Strategy be met with so much reallocation of resources and dismantling of programs? What is the impact in communities?
- Progress on development of shared metrics and accountability is needed.

### ***Next Steps***

Next steps are:

- NASTAD is assessing how best to address the TA needs of jurisdictions as some of these jurisdictions implement dramatic cuts.
- NASTAD will continue to advocate for the restoration of core funding to Categories A and B and additional resources for HIV prevention programs overall.

Dr. Horberg quickly noted that PACHA has called for full prevention funding but not specifically as relates to the CDC. PACHA requested this in its letters to the President and to the Secretary, but not in its resolution.

**Presentation on UCHAPS Support for the CDC HIV Prevention Funding Opportunity Announcement for State and Local Health Departments, by Israel Nieves-Rivera, Ex Officio Governmental Co-Chair, UCHAPS; Director of HIV Policy and Manager, Program Collaboration and Service Integration for Viral Hepatitis, TB, STD, and HIV/AIDS, Population Health and Prevention, San Francisco Department of Public Health**

UCHAPS supports the CDC FOA based on the following principles/reasons:

- It is aligned with the Strategy.
- It increases transparency and ensures that resource allocations are based on the most recent HIV epidemiological data.
- It requires State and local distribution of funds commensurate with geographic area and populations disproportionately affected by HIV.
- It supports science-based public health interventions that can reduce new infections and achieve optimal health outcomes for PLWHA.
- It supports demonstration projects to address structural and system-level changes.

Slide 3 looks at all the ways the FOA is aligned with the Strategy. Slide 4 lists a number of old and new Federal initiatives and states that “all Federal initiatives are asking for the same thing, i.e., expand collaboration within and outside of health departments to implement targeted integrated services and programs that promote positive health outcomes for affected communities.”

“All money is part of the National Strategy,” Mr. Nieves-Rivera said. “That’s the way we look at it.”

Many health jurisdictions have been striving to achieve a coordinated response to HIV, Mr. Nieves-Rivera said, noting the boxes or silos on slide 5 representing HIV and STD prevention, HIV care and support services, surveillance, evaluation, research, primary care, and HIV treatment. These are the silos in which most health jurisdictions operate, “so we applaud the CDC for asking us to break them down.”

Slide 6 graphically depicts how the FOA aims to do this by supporting coordination to facilitate integrated services at the client level and achieve maximum impact. “The FOA provides for transparency in resource allocations, at long last, even if we don’t all agree with it,” Mr. Nieves-Rivera said. In addition, all three FOA categories are based on science, data, and a need.

Slide 8 depicts how the FOA ensures that the distribution of funds is commensurate with geographic and population burden of HIV disease. Current historical trends show that the highest areas of HIV diagnosis in the United States are the highest prevalence areas. Mr. Nieves-Rivera noted that HIV in metropolitan statistical areas (MSAs) with over 500,000 population in 40 States and 5 U.S. dependencies at the end of 2008 represented 79 percent of the estimated number of persons living with an HIV diagnosis and 77 percent of the estimated number of new diagnoses of HIV infection. AIDS in MSAs with over 500,000 population in all 50 States and 5 U.S. dependencies at the end of 2008 represented 84 percent of the estimated number of adults and adolescents living with an AIDS diagnosis and 84 percent of the

estimated cumulative number of AIDS diagnoses. Slides 9-13 graphically depict what this kind of information looks like on maps of the United States and select territories.

Science is important in terms of viral burden and where it is. Slide 14 depicts why the United States, including San Francisco in this case, “must also focus our efforts to reduce the viral burden of communities heavily impacted by HIV.” Slides 15 and 16 depict mean cervicovaginal lavage and new HIV infections, 2004–2008, in San Francisco and then, nationwide, major gaps in the implementation cascade—for example, out of the number known to be HIV-infected, how few (24 percent) are actually on antiretroviral therapy (ART).

Beginning his conclusion, Mr. Nieves-Rivera said the FOA addresses structural changes across the health impact pyramid “that we’ve been asking for forever” (slide 19). Last, all this “is not a fantasy exercise.” When members go back to their jurisdictions, they will need to have “bold and candid conversations, at all levels. You are going to have to make tough choices.” Jurisdictions will need to identify new models of service, such as testing services with and without pretest counseling, and cost will need to be minimized at all levels, such as reducing administrative burden. In addition, jurisdictions will need to maximize the use of their surveillance data.

“I come to you representing a public health office losing \$4 million over the next 5 years,” Mr. Nieves-Rivera said. “The money is being realigned to go to Alabama and elsewhere in this country. San Francisco is being funded appropriately to our current burden of disease and asks PACHA to look at this further in its discussion.”

For more information on the UCHAPS perspective, go to <http://www.uchaps.org>.

### ***Discussion/Comments/Questions and Answers***

Ms. Hiers said she wants to remind everyone that when the Strategy came out and there was talk of realignment of dollars, Mr. Crowley said this would be painful, and it has been. Although she supports the 12 Cities Project, for those not included in it, it is painful. The South and rural America have been in a lot of pain for many years, but the money should follow the epidemic, so moving to living cases is the right thing to do in all our distribution methodologies.

### ***More Money Needed***

When Ms. Hiers suggested realignment of funds related to Ryan White at the last PACHA meeting, she met with resistance. What she was trying to say is that “I don’t want to fight. There are people who need these resources.” Should the changes be more gradual? Yes, she agrees on that point, for this FOA is very quick and painful. In addition, she supports trying to replace the funds that people are losing from this core support, “as we are all dealing with less money to begin with.” Should more money be made available for all this? Yes.

Mr. Cruz called Ms. Hiers’ statement “beautiful.” Who would not support moving toward living cases? Meanwhile, Ms. Scofield identified issues for us to think about carefully. The original FOA proposal would have caused New York State to lose 80 percent of its funding in a 3-year period, which would have ruined infrastructure that could never be rebuilt. Also, in New York State, if you moved New York City out of the State, the rest of the State would still be within the top 10 in number of AIDS cases. The State has an epidemic. Meanwhile, Mr. Cruz is also concerned that this movement toward the CDC’s allocating resources to rural areas “is being matched by other Federal agencies, such as SAMHSA.”

Mr. Cruz noted that San Francisco has been able to do a lot to combat the epidemic, but it is a concentrated regional area. Some of the cities that receive money have had many achievements, “but it

was the State that made those achievements possible.” In terms of reducing costs, too, he does not have an ADAP waiting list in New York State despite funding cuts. As he mentioned earlier today, Federal Region II is creating a summary of what New York State and others in the Region have been able to accomplish and what they will be able to do in the next 3 years. “We will be documenting what we are able to do in the face of funding cuts.”

Dr. Holtgrave read PACHA’s past resolution regarding the prevention funding shortfall against need. He then said he is also concerned about core prevention service funding cuts of \$20 million. Even as it is clear there are unmet prevention needs in the United States, “where we’re letting ourselves as a Nation down is that a new litmus test is being created.” If one looks at “what is being cut in some jurisdictions, like front-line service delivery programs, one must ask if all the other money out there is being put to best use.” Today, Mr. Crowley mentioned the Secretary’s discretionary fund. Some Federal partners think that going for more than 1 percent of that “is too much to bear.” Well, “if we ask local jurisdictions for 50 percent cuts, maybe we should ask that of Federal agencies, as well.”

Dr. Holtgrave added that PACHA could do case studies on those who obtain more funding and those who obtain less, and then analyze this evidence for long-term impact. PACHA could also, in reviewing the Strategy, advocate asking for a reduction in incidence “before moving money around.” San Francisco is losing money, even though it is reducing incidence, but Dr. Holtgrave is not sure that will hold up elsewhere. In short, “those getting more need to reduce incidence more—do better—and that should be our goal in all the jurisdictions.”

### ***Underfunded Goals?***

Mr. Perez linked to Dr. Holtgrave’s last point, saying “We must make sure we don’t get set up to meet goals that are underfunded.”

Mr. Nieves-Rivera said it is important for PACHA to know that “we’re asking at the national, State, and local level for money to be placed where the epidemic is. In Florida, for example, it was finally recognized that where 50 percent of the cases are was not getting 50 percent of the money. We’re now asking everyone to follow that pattern. Every one.”

### ***Need for Implementation Analysis From the CDC***

Mr. Frost said he wants to underline what Ms. Hiers said, that “we’re all on the same team.” If we underscore some of the differences a bit, it is because we are all striving for the same thing. It would have been useful to have an analysis on what implementation ultimately means. Ms. Margolies responded that can be provided. Mr. Frost said what he would like is a thorough analysis from the CDC, because he knows the agency has done an analysis.

Mr. Frost said to Ms. Scofield that her statement about increased resources for testing “un-leveling” the playing field is not correct. He would like to see more thorough analysis of the effect of more testing in high-incidence environments.

Mr. Frost added that on the question of uniting around reallocation of resources, “there are times when we’ve all argued very strongly for something, including the formation of the NIH Office of AIDS Research.”

Last, addressing Mr. Nieves-Rivera, Mr. Frost said that while decreased viral loads can help decrease incidence in a place like San Francisco, there are other jurisdictions that do not see that decreased infection. While the association looks good in San Francisco, “you must remember that we’re talking about the test tube environment of a fairly small city.” Responding, Mr. Nieves-Rivera suggested that

Mr. Frost could check with his colleagues in Massachusetts who addressed this and also access to treatment and care. Mr. Frost responded that he thinks the data do not support the theory that when you decrease community viral loads you always decrease incidence.

Following up on Mr. Frost's statements, Mr. Baker said, "Let's presume that we can validate the 052 study results. Then the larger question becomes, what is the mix of resources one needs to get the Nation to maximum impact with that? Also, what is the relationship of funding sources other than the CDC to core public health infrastructure? Ms. Scofield has begun to show us what becomes unstable and what is foundational and needs to be looked at." In short, he agrees with Mr. Frost about seeing what the before and after would look like. It is helpful to look at levels of resources to levels of infection in the whole health infrastructure as well as in the epidemic itself.

Responding, Ms. Scofield said she appreciates what was just said and that Massachusetts will be the State to look at closely. Massachusetts feels it has made a difference in terms of access to health care, but now it will lose as much as 50 percent of its core funding over time and also in expanded testing, the result of which is "they don't think they'll be able to keep the number of infections down." Also, in terms of testing, it has been rather arbitrary to carve out testing from the core and then only allocate funds to a certain number of entities, then another certain number of entities, and so on.

### ***PACHA's Role?***

Mr. Brooks noted what Ms. Scofield said about how we are fighting over funding crumbs. In this environment, we will be lucky to get flat funding. Dr. Holtgrave asked if the money is being put to best use in the portfolios, which is a very important question to raise and one that this body should have a role in answering.

Mr. Brooks noted that the role PACHA could play would of course be a post-FOIA award role, perhaps a monitoring role. Mr. Cruz advocated coming back to the topic of PACHA's role at the next full Council meeting.

Ms. Averitt Bridge asked about access to care being a component of prevention and truly moving outside the siloed approach.

Responding to all the discussion so far, Mr. Perez concluded that very important questions were being asked. Responding for Center Director Kevin Fenton, who was no longer on the phone, Ms. Margolies said, "we recognize that what we did is very difficult and will be for many places. Given what we were asked to do in the Strategy, we put together the best FOIA we could. We will help States the best we can. If we are going to eliminate this epidemic, we must put the dollars where the people with HIV are."

## **Metrics Workgroup and Update**

### **Presentation on Developing Core Indicators, Streamlining Data Collection, and Reducing Federal Reporting Requirements for HIV/AIDS Program: An Update, by Andrew D. Forsyth, Ph.D., Senior Science Advisor, OHAP, HHS**

Dr. Forsyth showed a summary of Strategy targets for 2015 (slide 3):

- Reduce new infections
- Improve access to and outcomes of care
- Reduce HIV-related health disparities
- Achieve a more coordinated national response by
  - Ensuring coordinated programs



- Promoting equitable resource allocation
- Streamlining and standardizing data collection
- Evaluating programs and reallocating resources for maximum impact.

The last bullet and its sub-bullets are driving our work now, Dr. Forsyth said.

As Secretary Sebelius stated last January, common metrics are needed now to measure program outcomes in the 12 Cities Project for a number of reasons, including that such metrics will ultimately decrease costs.

As CDC Director Thomas R. Frieden noted last July when reporting on national HIV testing goals to Congress, Federal agencies have identified four common challenges and barriers to achieving the annual national HIV/AIDS testing goal, one of which is lack of standardized data collection systems and limitations associated with existing systems.

Given all this, the process Dr. Forsyth is engaged in is helping to develop a core set of federally funded HIV prevention, treatment, and care indicators.

Dr. Forsyth updated PACHA on work to date, including an indicators consultation on September 19 (slides 9 and 12) and a projected OHAP plan to finalize a core set of common indicators with a cross-agency indicators working group. That working group's goal is to provide recommendations for core indicators by December 15 to the HHS Office of the Secretary (OS) via the Office of the Assistant Secretary of Health (OASH) to streamline data collection and reduce reporting requirements (slide 10).

The current focus is on three types of indicators: process (short-range effects), outcome (moderate-range effects), and impact (longer range, cumulative effects over time). Dr. Forsyth's focus now is on outcome indicators, and Irene Hall's focus is on impact indicators, which she will discuss in the next presentation.

Important principles for developing cross-agency core indicators include finding the smallest set of core measures possible, using existing data/indicators to the extent possible, augmenting core indicators if and as needed, and, at the same time, reducing grantee burden (slide 15).

In his work, Dr. Forsyth is looking at five proposed core HIV/AIDS indicators for testing, late diagnosis, linkage to care, retention in care, and viral load suppression. He noted who has these already and who does not (slide 17) and key questions in developing core indicators, including: Are those he has identified the right ones? Who can or should collect these? Are they feasible to collect? How frequently should they be collected? What is missing? Dr. Forsyth said the consultation he mentioned earlier was important in identifying these questions.

When engaged in the consultation, "we saw a number of challenges on the table with regard to data streamlining," Dr. Forsyth said. Specifically, these challenges are:

- Absence of common data types, definitions, and policies (FOAs)
- Lack of interoperability of Federal data systems
- Legal mandates that constrain degrees of freedom
- How to strike an appropriate balance between organizational centralization and decentralization among Federal partners.

It is also, as slide 22 graphically illustrates, "a real challenge for grantees to provide data."

During the consultation, staff asked key questions regarding grantees providing data, including what would be acceptable target reductions, how best could these be achieved, and what barriers and challenges will need attention? Dr. Forsyth said the answers to these “will need to be negotiated.”

Slides 24 and 25 denote preliminary findings from the consultation, including the need to assess both population-based and program-level outcomes and the need for indicators in prevention as well as treatment and care. He noted that OGAC and PEPFAR program representatives were available to help the group address how to link specific Federal funding to program improvements. A report on all this will be coming out soon.

Next steps include:

- Finalizing the report and internal discussions
- Standardizing definitions and reporting frequencies (taking the focus beyond core indicators is a possibility)
- Holding regular Federal working group meetings related to indicators and requirements
- Consulting with experts, including PACHA, with regard to existing data
- Exploring information technology (IT) solutions for data collection and reporting.

Responding to a query by Mr. Cruz, Dr. Forsyth said incidence reduction is considered to be a long-term impact indicator.

### **Presentation on Evaluating the National HIV/AIDS Strategy with Surveillance Data, by H. Irene Hall, Ph.D., FACE, Chief, HIV Incidence and Case Surveillance Branch, CDC, HHS**

Dr. Hall began with an overview of the Strategy to lay the groundwork for showing how surveillance data will be useful in implementation evaluation.

The three major goals of the Strategy are to reduce new HIV infections; to increase access to care and improve the health outcomes of PLWHA; and to reduce HIV-related health disparities.

Specific goals for reducing new HIV infections are:

- To lower the annual number of new infections by 25 percent
- To reduce the HIV transmission rate by 30 percent
- To increase to 90 percent the percentage of PLWHA who know their serostatus.

Specific goals for increasing access to care and improving PLWHA health outcomes are:

- To increase the proportion of newly diagnosed patients linked to clinical care within 3 months of their HIV diagnosis to 85 percent
- To increase the proportion of Ryan White clients in continuous care to 80 percent
- To increase the percentage of Ryan White clients with permanent housing to 86 percent.

The second bullet point is measurable by surveillance overall and for Ryan White clients who have database linkages. The last bullet point is not measurable by surveillance.

Specific goals for reducing HIV-related health disparities are:

- To increase the proportion of HIV-diagnosed gay and bisexual men with undetectable viral load by 20 percent
- To increase the proportion of HIV-diagnosed blacks with undetectable viral load by 20 percent

- To increase the proportion of HIV-diagnosed Latinos with undetectable viral load by 20 percent.

On slide 7, Dr. Hall noted what is tracked in CDC surveillance activities. Entry into care and retention in care and viral suppression represent a new wave of surveillance. Slide 8 depicts the flow of HIV case surveillance information. The CDC now anticipates that by the end of 2011, all States will be included in estimates of HIV diagnoses. This has not always been the case. In terms of incidence surveillance, data from 25 States are what the CDC uses to come up with national incidence estimates.

Calling slide 11 very important, Dr. Hall noted that 30 States, the District of Columbia, and Puerto Rico allow collection of all values. This desirable situation has not been fully implemented elsewhere, so supplemental funds are available to States and territories willing to allow these values to be collected. Dr. Hall said she believes that 3 States have been added recently.

Slide 12 depicts the outcome of a CDC and HRSA consultation earlier this year. Importantly, the Department of Veterans Affairs (VA), CMS, HRSA, the CDC, SAMHSA, and NIH agreed jointly to consider and issue a report on strategies to encourage providers to collect and report standardized viral load and CD4 data from infected individuals within populations at greatest risk for HIV infection.

When one looks at HIV incidence levels estimates over time (slide 14, 2006-2009), one sees relative stability. When the CDC updates these estimates, it will be updating prior years as well as looking at trends over time.

Slide 15 depicts estimated AIDS diagnoses, deaths, PLWHA with an AIDS diagnosis, and PLWHA (diagnosed and undiagnosed) among adults and adolescents from 1981 to 2008. Dr. Hall said this year the CDC will provide new estimates of PLWHA.

Slide 16 shows annual transmission rates per 100 PLWHA 1977-2006, and “a dramatic decrease in this rate,” Dr. Hall emphasized.

Slide 17 is a graphic of the trend line in terms of those living with undiagnosed HIV, and while it has declined since the 1980s, about 20 percent of those living with HIV “don’t know it.”

Slide 18 reflects data on linkage to care and continuous care from 13 data reporting areas to show that the percentage of persons diagnosed in 2009 linked to care within 3 months was 82 percent, “just shy of the Strategy goal of 85 percent, although this is a limited sample,” Dr. Hall said. As for those in continuous care, 45 percent were found to be in this situation, against the Strategy goal of 80 percent. Variations on this can also be seen, Dr. Hall said, adding “we need more data.”

Slides 19 and 20 concern reducing HIV-related health disparities and measuring engagement in care. Data from 13 areas with mandatory laboratory reporting of HIV-related tests reported to national HIV surveillance show that viral suppression (less than 400 copies per mL) among PLWHA in care in 2009 was 77 percent among MSM, 65 percent among blacks/African Americans, 74 percent among Hispanics/Latinos, and 81 percent among whites. If viral suppression measurements of less than 200 copies per mL were applied, the percentages would change by about 6 percent, Dr. Hall said.

Concluding, Dr. Hall noted that of nine outcome measures in the Strategy, eight can be measured with surveillance data. However, there is a need to support and strengthen HIV surveillance activities. Specifically, there is a need to support existing surveillance methods to identify populations at greatest risk that need to be targeted for HIV prevention services. There is “room for improvement in the data we get, specifically around lab reporting policies and resources,” Dr. Hall emphasized.

### ***Discussion/Comments/Questions and Answers***

Dr. Horberg gave a note of caution about lists of only five metrics, as “they implicitly imply other measures as well.” He also said that to ease reporting burden, “you don’t have to report on some things.” He then asked about the role of public health, because “it is easy to say much falls under the rubric of public health.” Dr. Hall, he added, said we need all viral load data, “but we don’t.” Community viral load “is still a research tool.” As Mr. Frost pointed out earlier, it is not proven that community viral load is a cause and effect.

Further, according to Dr. Horberg, there is no public health mandate for the individual in terms of putting him/her into care, so there may be some need to change public health mandates. In addition, what is a visit? As we talk about changing economic priorities in health care, some patients are more stabilized than others, so we need to be more creative about what a visit is. With changes such as a more mobile population, much can be done through telemedicine and other ways to conduct a visit that will not be classically measured, such as through claims data.

Mr. Bates observed that a visit could be just an opportunity to see a doctor. “You may not be on antiretrovirals. You may just be getting a count of your T cells and nothing more.” Dr. Horberg responded that it is easy to say “office visit, but we have to be more careful about definitions in a more modern treatment era.”

Mr. Baker said it looks as if the indicators are more focused on diagnosis and care, so he is wondering about conversations related to a broader understanding of prevention, particularly population-based indicators that Dr. Forsyth’s working group may have recommended. Also, is there coordination with the lesbian, gay, bisexual, and transgender (LGBT) collection working group? There seems to be reticence in collecting sexual identify information. Last, how is the data collection effort being coordinated with STD and family planning systems?

Dr. Forsyth responded that his working group has not been around long enough to work out a plan for coordinating with the LGBT group or family planning providers, but he appreciates Mr. Baker’s comments. Dr. Hall said the CDC is collecting case report form information on sexual identify, and there is a working group at the CDC that is addressing improving the collection of this information. In terms of social determinants of health, the CDC can geographically code certain information, which allows for mapping of disease burden and a look at social determinants of health against census data.

Mr. Frost said he supports the minimalist approach Dr. Horberg was advocating.

Ms. Khanna asked about slides 18 and 20 of Dr. Hall’s presentation regarding linkage to care, continuous care, and measuring engagement in care, and about the implications of the HPTN 052 study for the relationship between care and prevention. How quickly will we be able to assess its impact?

Dr. Hall responded that the link to care definition is the people diagnosed in 2009. The continuous care and viral suppression definitions are among all PLWHA. “The way we look at these definitions has been pretty consistent across the board.” In terms of how quickly one is able to assess the impact of something, there is the lag connected to getting into care, some lag connected to reporting and getting the data into the surveillance system, and some lag in analysis.

Mr. Cruz counted up the lags and commented that it takes “more than a year” for the data to be available. In terms of viral load, local-level viral load “is an incredibly powerful tool, but not when you take that statewide.” While doing statewide viral load analysis in New York is a good generic indicator,

“it is not precise at this time.” Mr. Cruz added that STD has been demonstrated as an indicator for potential infection, and he would say it is “a critical element.”

### ***Resources for Surveillance***

Mr. Cruz then noted that the surveillance competitive agreement ends in 2013, and already there is discussion of how resources for surveillance will change and be distributed, which should be of concern to PACHA. PACHA should consider, systematically and at the national level, how we have used FOA resources to provide some level of support for surveillance. PACHA needs to make sure resources for surveillance for HIV/AIDS, hepatitis C, and STD are sustained to provide good answers for the Strategy.

Mr. Wilson said Dr. Horberg raised an important question, which is what is the difference between our job and our responsibility? While Mr. Wilson supports reducing administrative burden across the board, PACHA needs to be conscious of both its job and its responsibility. We could estimate that in order to formally track the effectiveness of the Strategy, the data we might need could be minimal. But he is fearful “that what we might think of as the floor might end up being the ceiling and eliminate our ability to get the data needed to end the epidemic.” In short, in talking about PACHA recommendations, “we have to consider the balance between PACHA’s job and its responsibility,” and he is not prepared to say today what he thinks that is.

Dr. Holtgrave said that was a great point to conclude the discussion.

### **Public Comment**

Mr. Bates asked if anyone in the room had signed up for public comments and wanted to deliver them on Day 1. Seeing no one respond, Mr. Bates noted that during the meeting tomorrow, the Disparities Subcommittee may introduce a resolution. He then asked for a confidential Executive Session to begin shortly.

### **Break**

### **Executive Session (Members Only)**

This session was closed to the public.

## **DAY 2 MORNING SESSION**

### **Remarks**

Mr. Bates welcomed everyone to Day 2 of PACHA's 44th full Council meeting. The agenda is very full. A large youth and HIV session is scheduled. It is exciting for PACHA to have the opportunity to discuss a population that does not always get addressed. The Co-Chairs of this initiative have arranged a great cross-section of speakers from Government and the community. They will address the experiences, opportunities, and some of the challenges related to HIV/AIDS facing adolescents and young adults.

### **Administrative Announcements**

The Federal Government is limiting the number of URLs it is using. As a result, the PACHA Web page will not continue as a standalone but, rather, will be folded into <http://www.AIDS.gov.web>. Mr. Bates is not sure precisely when the switch will take place.

Members who need reimbursements should seek out Charlene Edwards and her team from Social & Scientific Systems, Inc., to process paperwork. Members with travel challenges should do the same.

Dr. Horberg and Mr. Jack noted that over time, contact information for some members has changed, so they asked members to make corrections on the corrections sheets being handed around the table.

### **Youth and HIV**

#### ***Introduction***

Dr. Garcia and Mr. Basaviah introduced the beginning of the "Youth and HIV" session featuring 11 speakers.

Dr. Garcia said that today we are going to talk about an issue, not just a population, and that is how age affects HIV and AIDS. Youth demand and need our respect and attention. They have unique vulnerabilities across the board. A 15-year-old gay African American male's youth dictates a fair amount about how he thinks about the world and his choices, and it is the same with women. Age is the reason we are talking about this special population.

Dr. Garcia thanked all the PACHA Subcommittee members who gave their time to this matter and extended a special thank you to Mr. Basaviah.

Mr. Basaviah thanked all the speakers and Mr. Bates and Melvin Joppy, who worked hard to make this session happen. Mr. Basaviah also thanked a number of supporters from the youth and AIDS community for their assistance.

Mr. Basaviah noted that, 2 years ago, a special consultation was held at The White House regarding development of the Strategy. He was a facilitator, along with several other members of the youth and HIV community, and three recommendations were made related to access to care, prevention, and health disparities. Today, absent from the Strategy is a focus on young people. This session today "has been a long time in coming when it comes to the needs of young people and how to get recommendations regarding them back into the Strategy."

As Dr. Garcia said, Mr. Basaviah continued, when it comes to youth, everyone has particularities that are unique. If you are a homeless youth who has been kicked out of his parents' home, and you are now on

the Castro streets trying to sell yourself...imagine that. You think about the world a little differently. Youth who are incarcerated think about the world a little differently.

Today, PACHA is on a fact-finding mission to find out what the Government is doing to address these populations. There will be discussion and closing remarks by Carole Treston of the AIDS Alliance for Children, Youth, and Families.

**Presentation on Youth: A Special HIV Population, by Donna Futterman, M.D., Professor of Clinical Pediatrics, Albert Einstein College of Medicine, and Director, Adolescent AIDS Program, Montefiore Medical Center**

Dr. Futterman said it is strange to have been a youth advocate for so many years and realize that the first generation of youth we took care of is now in its early 40s. It is also a surprise in terms of HIV “because many did not expect us to live and thrive into a ripe old age.”

***Youth: A Special HIV Population***

- Thirty-five percent of new HIV infections are among youth, ages 13–29.
- Some 20,000 youth are infected each year, about 2 each hour, and more than 80 percent of them are youth of color.
- More than 85 percent of those infected were infected sexually, as opposed to perinatally.
- More than 50 percent of those who are infected have not been diagnosed.
- Among gay youth who are infected, 80 percent are not aware that they are infected, and the percentage may be greater.
- Growing numbers of those perinatally infected are reaching adolescence.

Dr. Futterman said our work must principally address youth of color and the following three major populations:

- Young men who have sex with men (YMSM), who account for more than 60 percent of new infections and rising. (This population is most affected, but “social forces constrain programs.”)
  - Young women, who account for 20 percent of new infections and have a low awareness of risk, both personally and from a partner.
- Those perinatally infected, a cohort of 7,000 in the United States with fewer than 100 new infections yearly. (This cohort has highly complex medical and psychosocial needs. Some were first identified in adolescence.)

Dr. Futterman said the first group above is a group for which there are no easy answers, although answers would be more available if there were better policies and campaigns regarding and against homophobia and stigma. In terms of women, “we don’t fully know where they were infected.” Many infected young men have had sex with young women. In terms of the perinatally infected, it is difficult to get exact numbers. The numbers above are from HRSA reports. Most perinatally infected persons are getting care in public health systems. Independence comes naturally to this group, and many of those dying in her clinic were perinatally infected. “We still need to maintain intensive services for them.”

***Youth Susceptibility to STDs/HIV***

Youth susceptibility can be broken down as follows:

- Behavioral vulnerability

- Adolescence is an age of experimentation, and 65 percent of adolescents have had sex by the 12th grade.
- There are homophobia and gender power imbalances in our society. (It is difficult to assert for condom use.)
- Youth are particularly susceptible to mental illness, substance use, and sexual abuse.
- Biological vulnerability of females
  - Young women’s cervixes are immature and more vulnerable to infection.
  - STDs, which increase transmission, are often asymptomatic.
  - Male-to-female transmission is efficient.
- Socioeconomic vulnerability
  - Youth populations in particular lack health care coverage and confidentiality assurances.
  - Youth populations lack adequate sex education (a huge issue). Needed is comprehensive sex education. Youth should not feel bad about having sex. It is part of their development.
  - Conflating factors include poverty, racial and ethnic discrimination, immigration status, and lack of stable housing.

Slide 5 depicts the estimated number of HIV/AIDS cases among adult and adolescent MSM by age group, 2001–2006 (33 States). Dr. Futterman pointed to the red line (13- to 24-year-old group), which is rising rapidly. Almost all of this increase (slide 6) is among non-Hispanic black males.

“This is a true public health disaster of horrendous proportions, and our response is not adequate.”

According to the Youth Risk Behavior Surveillance System (YRBSS), 5 percent of the youth population is LGBT, and 95 percent is straight. Among the HIV youth population, 74 percent are YMSM, 18 percent are young women, and 8 percent are “other” (slide 7).

Dr. Futterman said identifying as gay is “also a developmental process in reaching young MSM.” We “have to appeal to them on both behaviors and identity, and we’re just not doing it.” The only way to reach YMSM “is by being in touch with that generation as it moves ahead.”

Slide 8 shows the youth population versus HIV race and ethnicity, where it is clear that 65 percent of those with HIV are African American, even though African Americans are only 17 percent of the youth population. “It is very hard to say this,” Dr. Futterman commented, “but there is something going on that needs to be forthrightly addressed. If you remember nothing, THIS is the crisis we need to mobilize around.” The Strategy needs to bring youth into focus and reduce new HIV infections, increase access to care, improve health outcomes, reduce HIV-related disparities, and provide a coordinated national response.

At present, HIV testing and linkage to care is the best strategy yet, and it needs to be routine and targeted. Dr. Futterman noted that she works in the Bronx, and the pediatric emergency department of her own hospital does not offer HIV testing. “What kind of scale-up is this?,” she asked. Dr. Futterman said she is ashamed of her hospital because “this is primarily a medical problem, and we can’t shove it to the CBOs.” Repeated testing is also needed. Of all the positive youth coming into her clinic, she has had four who previously tested negative. In addition, “we don’t have effective prevention, because we are being constrained, and we are not giving accurate personalized and relevant messages to young people. Unless we do that, we won’t reach these kids. Coca Cola invests millions each year to update their marketing. We will not reach young people unless we do something similar.”



In terms of increasing access and improving health outcomes (slide 11), “we need to keep adolescent programs and ensure that services are accessible by youth.” Even in this era of cutbacks, because adolescent care is known to improve retention and outcomes, comprehensive age-appropriate medical and mental health HIV services must be available, “for adolescents will only grow and age and get much sicker than they are now unless we catch them now.” Yet many providers “don’t know what this is about or care.” Also, transition programs are important, including for adherence.

Reducing HIV-related disparities (slide 12) entails:

- Leading with science and not fear in terms of youth sexuality
- Implementing comprehensive sex education with LGBT information
- Addressing stigma, homophobia, and transphobia
- Addressing the development needs of perinatally and sexually infected youth
- As stated before, ensuring that youth care continues to be funded even in an era of funding cutbacks and health care reform.

Last, in terms of the Strategy and a coordinated national response (slide 13):

- Youth need to be represented on PACHA. (Youth expertise is needed to address cross-cutting challenges of youth and HIV.)
- Youth need to be addressed in working groups that are addressing scalability, outcomes, and Federal agency coordination.
- There needs to be a public commitment to HIV youth programs and campaigns.

Dr. Futterman said she hopes PACHA can ask the President to use his bully pulpit and his campaigns to address the needs of HIV youth.

To-do list (slide 14):

- Put youth on the map at PACHA.
- Make HIV real for this and future generations.
- Bridge the gap between effective research and scalable programs.
- Ensure that the Strategy expands focus to reverse the devastating impact of HIV among youth of color.

Dr. Futterman noted that she and others have been at this for a long time and cannot possibly maintain a fever pitch of emotion, but when she sees the statistics, “I want to scream and cry.” How “do we communicate this urgency? Our kids are dying. The number of youth we are potentially losing is truly astounding. We need to pick this up in a different way. We should be in a mop-up phase in this epidemic, not in an all-out phase once again.”

**Presentation on NIH Research To Address HIV/AIDS and American Youth by Bill G. Kapogiannis, M.D., FAAP, Program Director, Adolescent Medicine Trials Network for HIV/AIDS Intervention, Pediatric, Adolescent, and Maternal AIDS Branch, NICHD, NIH, HHS**

Dr. Kapogiannis addressed:

- NIH research resources targeted to HIV/AIDS in youth
- What NIH is doing to address the needs of youth affected by HIV
- Youth engagement in planning and implementation

- Intra- and interagency collaborations
- Challenges and remedies
- Future directions for HIV/AIDS research activities.

Of the \$147.2 million NIH provided in support of HIV/AIDS research among adolescent and young adult populations in 2010, roughly one-third principally involved NICHD support. Approximately half of that support funded the Adolescent Medicine Trials Network for HIV/AIDS Intervention (ATN) (slides 10 and 11).

Research focused on youth with perinatal HIV infection is being conducted under the Pediatric HIV/AIDS Cohort Study Adolescent Master Protocol, which evaluates effects of perinatally acquired HIV infection and its treatment in preadolescents and adolescents growing up with HIV and also in three groups within the Clinical Trials Network investigating drugs, nonvaccine prevention interventions, and microbicides (see slide 13).

ATN is the only domestic research network devoted entirely to HIV-infected and at-risk youth ages 12-24. Its mission is to study treatment, adherence, and clinical management of HIV-infected youth and to study primary prevention, including HIV vaccines and topical as well as oral agents to prevent transmission in at-risk young men and women (slide 15).

Specific research examples include therapeutics research into medication management and strategy trials for HIV and complications; behavioral research involving adjustment to new diagnosis, adherence, secondary prevention, depression, and substance use; and community prevention research involving identification and linkage to care of youth who were previously unaware of their infection, including structural interventions (slide 16).

Slide 17 delves more specifically into the ATN's community prevention agenda and its Connect-to-Protect C2P Program. Slide 18 indicates how youth are engaged in research planning and implementation through participation in the ATN community advisory board (CAB).

Dr. Kapogiannis then displayed a graphic indicating the complexity of youth linkage to and engagement in the care continuum, emphasizing that youth can and do go back and forth between crisis management, patient education/orientation, and clinical care.

Showing another graphic of an integrated model of transitions in HIV-related prevention, diagnosis, and treatment (slide 21), Dr. Kapogiannis noted in particular that to impact a zero risk of transmission, one has to impact "all the other domains on this slide" and that the transition toward adult treatment is a time when risk can go up again.

In terms of intra- and interagency collaborations, a working group of the OAR Advisory Council is devoted to HIV-infected adolescents and young adults and special consideration. Dr. Kapogiannis heads this working group. He noted that the Advisory Council convened a special meeting last November focused on the unique considerations in working with vulnerable youth populations. In addition, there is a new collaboration between NICHD, ATN, and the CDC on HIV pre-exposure prophylaxis (PrEP) for youth based on new PrEP findings (slide 22).

In addition, ATN is collaborating with the CDC involving specific objectives for SMILE in CARING for YOUTH (slides 23 and 24) meant to address specific challenges in identifying recently infected youth in the United States and facilitate practical and meaningful linkage to care. While the collaboration assisted in identifying 1,300 newly infected young people over 2 years, the program faces challenges, including fragmentation of linkage-to-care activities. This kind of problem is now being addressed.

Finally, Dr. Kapogiannis noted several future directions for HIV/AIDS research and activities in parallel with the Strategy (slides 25 and 26).

### ***Discussion/Comments/Questions and Answers***

#### ***Where Is Routine Testing?***

Douglas Michels said he has come away feeling like we are failing our youth. We must engage the provider community and get them engaged in promoting prevention and scaling up testing. There have been recommendations for routine testing since 2006, but that is not happening, so how can we change that?

Dr. Futterman responded that we have to change our thinking on this. HIV testing must become screening, which means disentangling it from prevention. New York just went a long way on this, becoming the first State to mandate HIV testing. It is the first time her own hospital's leadership realized they had to do something. The new law is still inadequate, as the health department insists on a written signature, so we are still stuck in barriers that prevent testing from moving to the next levels. In short, routine testing is not the strategy but rather making this a screening and moving more resources into engagement and linkage.

Continuing, Dr. Futterman said, "There will never be enough counselors to do this work, even though it is my life's work, so we need to do it more quickly and smarter. And we need prevention. We need a paradigm shift on prevention, but we don't have unity in our community around this."

#### ***NIH and Prevention***

Mr. Michels said he agrees. He noted the youth and HIV research funding levels at NIH, then asked, "And what are we spending on prevention in youth?" Is it "time to re-evaluate reallocation of resources?" In his company, he added, "if I saw this, that is what I would do."

It was noted that, at NIH, there is a substantial component of relevant research at the National Institute of Mental Health (NIMH) and other Institutes that focuses on prevention and behavior science. Dr. Kapogiannis also noted the new collaboration on PrEP that he mentioned in his slides.

Ms. Hodgins Dempsey said because we must do something about the exponential increase in infected MSM, why not use PrEP and the results of the 052 study at the same time?

Dr. Kapogiannis said that is a very good idea and worthy of further study, particularly 052. In fact, this is under discussion at NIH.

#### ***Care as a Prevention and Care Strategy***

Dr. Futterman said getting youth into care is a prevention and care strategy. A major, urgent, real targeting of those most at risk "is more than called for." She is very wary of continued reliance on pilot programs.

Ms. Hiers said she leans toward testing and counseling. Does anyone have ideas around the national response that could help providers if the counseling piece was eliminated?

Responding, Dr. Futterman said the response should be to use existing resources, as in: use the power and skills of medical providers. "We've mystified providers away from thinking that they actually do know what to do. ER knows how to handle a bullet in the head. Diagnosis gives you the power to do

something about it, which is the most rewarding thing a provider could do. We have free tools over the Internet. I say 'get over it.' Why is this still a problem in HIV/AIDS?"

Mr. Greenwald applauded Dr. Futterman's statements. Mr. Cruz said he has nothing bad to say about her. However, New York State is not mandating HIV testing. It is offering it.

Continuing, Mr. Cruz thanked Dr. Futterman for her great summary of the dynamics that cause HIV in youth populations. Among those, sex education is not happening. Also, we have a dichotomy in this country about what should be done. The same dynamic comes into play when you try to change HIV testing. In 1996, New York State issued a report entitled "Illusions of Immortality," which continues to be relevant today. If he were publishing it today, he would add a piece on how, in our promotional world, youth think "getting HIV is not a big deal anymore."

Ms. Khanna said when we think about sustainability, we need to move away from pilot programs. Now we have the opportunity in health care reform, but how is it going to work for young people at risk? How can we foster a sense of trust in interacting with health care systems, particularly for young, black MSM and women?

### ***Leadership Summit Needed***

Mr. Brooks asked, if you were the Secretary, what is the one thing you would do for young black men? Responding, Dr. Futterman said a leadership summit is a first step, bringing together leaders from industry, culture, churches, communities, and the medical world. She went on to note that every 5 years, it is a new generation. You could say that you had a great program at your high school, but those kids are not there now.

Mr. Wilson asked if the issue around testing and counseling is not about abandoning counseling but, rather, redefining it. Kids assume HIV is part of their physical exam and that if they were positive, someone would tell them. So we need to keep that conversation.

Rev. Sharp agreed that simplicity is good. Once we advertise and communicate, that is when we will get results.

### **Presentation on CDC Efforts To Address HIV/AIDS and Youth, by John M. Douglas, Jr., M.D., Chief Medical Officer, NCHHSTP, CDC, HHS**

Dr. Douglas noted all of CDC's efforts to address HIV/AIDS among youth (slide 2), and that the Division of Adolescent and School Health (DASH) is the epicenter of CDC's increasing interest in sexual health.

### ***DASH***

The guidance DASH provides is guidance to adolescent and school health programs to prevent HIV/STDs/teen pregnancy, and it is primarily about how to evaluate curricula. DASH program support, such as funding and TA, is program support to education agencies.

Specific DASH activities include conducting the YRBSS, the School Health Policies and Practices Study (SHPPS)/Profiles. YRBSS and SHPPS/Profiles provide information complementary to one another (see slide 4).

Key indicators such as these studies and surveys help if and when we think about driving policies, Dr. Douglas said, for through YRBSS and SHPPS/Profiles, CDC and others can look at what schools and States are doing, including the percentage of schools addressing key topics in prevention.

Slide 5 shows how many YRBSS sites ask questions on sexual identity and sex of sexual contacts only or both. The number of sites measuring these things fluctuates, but as of 2007, seemed to be on the rise. Dr. Douglas explained that States have to accept these questions' being asked. While there is progress here, generally speaking in terms of numbers, "the glass is not completely full."

### ***Health of Lesbian, Gay, and Bisexual (LGB) Youth***

Data from seven States and six cities relevant to the health of LGB youth were released in a CDC *Morbidity and Mortality Weekly Report (MMWR)* last June during the U.S. Department of Education's LGBT Youth Summit. It was the first population-based data collection on health risk behavior of sexual minority youth—and an important step, Dr. Douglas said. It documented increased health risk behaviors in the areas of injury, violence, suicide, tobacco use, alcohol/drug use, sexual behaviors, diet, and physical activities (slide 6).

Dr. Douglas noted DASH Guidance for school health education (slide 7). He went on to emphasize DASH's programmatic activities (slide 8). These activities provide:

- Support for HIV prevention education in 49 State education agencies and 16 local education agencies to
  - Build the capacity of schools and other institutions to promote sexual health among youth
  - Foster delivery of high-quality, evidence-based sexual health education
  - Increase youth access to contraceptives and sexual health services
  - Establish supportive environments for LGBT youth
  - Enhance youth resilience through positive youth development and family education.
- Funding for NGOs to support programs in areas with the highest HIV/STD/teen pregnancy burden, with 13 NGOs to be funded 2011-16.

Dr. Douglas said that at State and local levels, these are bully pulpit efforts. "We don't mandate at the Federal level what gets taught, not even States do, in terms of sex education and sexual health."

### ***DASH Challenges***

Slide 9 addresses DASH challenges and possible responses. First, "it is very difficult to deal with a decentralized education system increasingly focused on test results. This marginalizes other things, including health promotion," Dr. Douglas said. In addition, funding for school health programs is fragmented and inadequate. "There are real gaps between the need to implement evidence-based interventions with fidelity and program capacity to deliver them on the ground. There are many questions about tailoring interventions to different settings." Last, there is a need for balance, ensuring that all students are educated about HIV/STD but also targeting high-risk adolescents. "This is tough and a real challenge for DASH," Dr. Douglas emphasized.

In alignment with the Strategy, CDC's Division of HIV/AIDS Prevention (DHAP) focuses on reducing racial/ethnic disparities and on populations most at risk, such as MSM. While youth are important in both, youth are not focused on as a primary target and, overall, most youth-focused programs are conducted by DASH (slide 10). However, DHAP has a few specific youth-focused activities, including testing events by health departments and CBOs and release of a YMSM of Color and YTG of Color FOA, the goal of which is to reach 90,000 with testing, identify and link 3,500 new positives to care and prevention, and deliver behavioral change HIV prevention and condom distribution programs for those at high risk. Dr. Douglas said this is a really important program that has been expanded but that it also "demonstrates the scalability problem we're talking about" (slide 11).

CDC Division of STD Prevention (DSTDP) activities focus to a great degree on youth, because nearly 50 percent of all STDs are estimated to occur in youth. Dr. Douglas focused on the DSTDP priority activity of HPV vaccine implementation and monitoring, noting that use of the vaccine in the United States "is going flat by contrast to Australia, Canada, and the U.K., where the vaccine is offered in schools." DSTDP activities also include monitoring bacterial sexually transmitted infections (STIs) in YMSM, both as a marker and as a biologic enhancer. Last, in terms of behavioral interventions, the division's Project CONNECT in Los Angeles resulted in substantial testing there, and Get Yourself Tested (GYT) "is probably one of the most successful social marker programs we've ever been involved in" (slide 12).

Slide 13 shows the percentage of CDC HIV prevention resources that are targeted for youth:

- DASH: 100 percent
- DHAP: No precise data
  - 20 percent reported HIV cases in 2009 in youth.
- DSTDP: No precise data
  - But, roughly, "the programmatic work is following the epidemic."

### ***Sexual Health as a Framework***

The CDC Sexual Health Initiative Consultation in April 2010 (slide 14) received strong endorsement by attendees who applauded sexual health as a broad, contextual, positive, inclusive, and empowering framework. Key recommendations included:

- Developing a CDC definition of sexual health and a white paper, as well as key objectives and national sexual health indicators
- Communications research to find the right metaphors, tone, and messages for greatest acceptance
- Consideration of a national coalition of partners, including faith-based organizations
- Working with programs and providers to determine how such a framework could enhance their work.

What is the value added of a sexual health focus? Such an approach (slide 15):

- Shifts the focus from a disease focus to a more positive health-based approach (helping to normalize the conversation, the most important part of what we are trying to do here).
- Helps enhance the efficiency and effectiveness of prevention messaging and services by bundling message and services.

In slide 17, Dr. Douglas concluded by noting CDC efforts to address sexual health, including work on a white paper, pulling together review of intervention evidence and transnational approaches, assessing communication frameworks and messages, and as of today, the launch of a new National Coalition to Enhance STD/HIV Prevention Through Promotion of a Holistic Approach to Health and Wellness.

### **Presentation on Ryan White Programs and Youth, by Margarita Figueroa-Gonzalez, M.D., M.P.H., Director, Division of Community-Based Programs, HIV/AIDS Bureau (HAB), HRSA, HHS**

Dr. Figueroa-Gonzalez noted HAB's vision and mission, then briefly characterized Parts A, B, C, and D of Ryan White programs, as well as Part F. She said that HAB is ensuring quality of care through continuous clinical quality improvement, HIVQUAL-US (a systematic strategy for building capacity to improve HIV care quality), and the National Quality Center.

Ryan White funds primary health care, including medications and support services, provider training, TA, and demonstration projects. Dr. Figueroa-Gonzalez detailed what this funding pays for in slides 7-9. More than 529,000 uninsured and underinsured persons affected by HIV/AIDS are served annually each year as clients of Ryan White programs. Seventy-three percent are racial minorities, and 33 percent are women. Youth ages 13-24 comprise about 7 percent of Ryan White clients.

Dr. Figueroa-Gonzalez went on to provide specific information about Parts C and D (slides 12-14) and then specific information about Part D youth programs (slide 15), under which:

- Seventeen grantees are funded to provide services for HIV-infected youth.
- The goals are to identify HIV-positive youth, enroll them into care, and retain them in care.
- Sixteen sites are in large cities.
- One program is located in Harlingen, Texas.

Slide 16 introduces specifics about Part F (Special Projects of National Significance [SPNS]), and slide 17 notes a SPNS initiative of interest that is identifying, linking, engaging, and retaining YMSM of color in HIV care. Slide 18 details this particular initiative as:

- Employing innovative service models designed to reach HIV-infected YMSM not engaged in clinical care and link them to appropriate clinical, supportive, and preventive services
- Supporting innovative outreach to assist HIV-infected individuals in learning their HIV status
- Linking HIV-infected persons to primary care services
- Providing prevention with positives.

Outreach methods employed with YMSM include (slides 19 and 20):

- Venue-based outreach
- HIV testing vans
- Youth-focused materials
- Chat rooms and social network sites
- Community drop-in centers
- Social and sexual networks
- Community-wide HIV testing initiatives
- Use of peer or near-peer outreach works
- Health care and youth-focused service system “in reach,” networking with health care providers.

Treatment interventions and services (slides 21-23):

- Are aware of and embrace youth culture.
- Create youth-friendly physical site and staff.
- Offer separate youth-designated waiting rooms.
- Use multidisciplinary staffing model.
- Employ clinicians expert in treatment of adolescent medicine and HIV.
- Create one-stop clinical and psychosocial support services.
- Provide transportation and accompany clients to their first medical appointment.
- Meet clients where they feel comfortable, emphasizing privacy and respect, and maintain consistent contact.
- Use motivational interviewing to engage clients.
- Effectively and creatively address treatment adherence and medication education.

- Use peers or near-peers as system navigators.
- Decrease wait time for appointments.
- Use flexible scheduling with an expectation that some appointments will be missed and need to be rescheduled.
- Address legal issues faced by HIV-positive youth.
- Anticipate and address loss to followup.

Lessons learned about youth (slide 24):

- That YMSM in particular struggle for daily survival.
- That they welcome a friendly, safe, youth-centered space, with separate youth waiting rooms.
- That a youth-centered model differs from an adult model.

When engaging youth in planning and program implementation, HAB employs (slide 25):

- Peer counselors/patient navigators
- Peer educators
- The Consumer Advisory Group
- Quality management activities (Cross Part Collaborative).

### **Challenges**

Challenges in HAB's Ryan White work across the board, including with youth (slide 26), include:

- Increased demand for services with few new or declining resources
- Rising costs of care and growing prevalence of HIV
- Expanding access to medication at the lowest possible price
- Prioritizing core medical services.

Other critical elements in designing programs for YMSM of color (slide 27):

- Establish strong care teams with clear roles and responsibilities among team members.
- Ensure training in adolescent development, motivational interviewing, and mental health and addiction screening.
- Be aware of youth culture.
- Adopt new technologies, such as texting.
- Assign experienced social workers to YMSM of color.
- Develop community resources.

Dr. Figueroa-Gonzalez noted that she has copies of an evaluation of the YMSM of Color Initiative. It was published last August in *AIDS Patient Care and STDs* (slide 28).

Continuing challenges in working with HIV-positive youth include (slide 29):

- Persistent stigma
- Cultural competency within the health care system
- Complex disease management issues
- Comorbidities (mental illness and substance abuse).



## **Presentation on Emerging Opportunities for Youth: Integrating Behavioral Health and HIV-Related Care, by Elizabeth Siegel, M.A., M.P.P., Public Health Analyst, Office of Policy, Planning, and Innovation, SAMHSA, HHS**

Ms. Siegel began by noting SAMHSA's strategic initiatives plan for 2011-2014. She emphasized #1, which is prevention of substance abuse and mental illness at the community level with a focus on the Nation's high-risk youth, and #5, which deals with health reform.

The centerpiece of health reform is integrated, coordinated care. SAMHSA, Ms. Siegel said, considers this to be a "two-way street." Slide 4 focuses on the synergy between health reform and SAMHSA's strategic objectives, including:

- To increase access to appropriate high-quality prevention, treatment, and recovery services;
- To reduce disparities that currently exist between the availability of services for mental and substance use disorders compared with the availability of services for other medical conditions; and
- As noted, to support integrated, coordinated care, especially for people with behavioral health and co-occurring health conditions, such as HIV/AIDS (see also <http://www.samhsa.gov/HealthReform>).

Slide 5 shows that much of SAMHSA's HIV/AIDS funding is related to the Minority AIDS Initiative (MAI).

Slide 6 shows SAMHSA's three centers—the Center for Mental Health Services (CMHS), the Center for Substance Abuse Treatment (CSAT), and the Center for Substance Abuse Prevention (CSAP)—and the age of program participants compared to new HIV infections. The graph on the slide is intended to show that, overall, some 30 percent of all SAMHSA program participants are youth (ages 13-24). Some 41 percent of all CSAP program participants are youth (ages 13-24), while 25 percent of all CSAT participants are youth (13-24). Only 5 percent of CMHS program participants are youth.

One reason SAMHSA can capture that many youth, Ms. Siegel said, is that the agency is actively engaging youth in HIV/AIDS-specific programs. Specifically (slide 7), youth are a MAI-targeted population who act as peer educators and are instrumental in recruitment. In addition, in FY2010, 5-year Capacity Building Initiative (CBI) grants were introduced that aimed at preventing substance abuse and HIV/AIDS transmission among youth ages 18-24 by involving colleges, universities, and CBOs.

### ***Key Challenges***

Key challenges (slide 8) are retention, although incentives help; engaging families and parents, although HIV status, sex, and drugs can be tough topics for family discussion; and stigma, which may affect teens' willingness to participate. Stigma, Ms. Siegel added, can come from many different directions.

SAMHSA is looking forward to (slide 9):

- Continuing to offer high-quality TA to ensure effective use of funds
- Continuing its focus on high-risk populations and communities most impacted by HIV/AIDS
- Further developing integrated systems of care.

### ***Discussion/Comments/Questions and Answers***

Mr. Perez asked Dr. Douglas about the concept of having a cross-disciplinary effort that concentrates on the needs of black YMSM "rather than rely on school boards to shape what we haven't been able to shape across the board for all students in 20 years."

Responding, Dr. Douglas said that model sounds interesting. He added that funding is tailored in part to morbidity in the epidemic, but he would be reluctant to give up on education agencies. Some are progressive, and some are less so. Not to fund or to fail to encourage the latter to deal effectively with their youth is something he would be reluctant to do. The kids who end up being at risk, like those he works with in Atlanta as a doctor, “are never from Atlanta.” If “we focus on big cities and not the Savannahs and so on, we reduce our chances of reaching those youth through the pipeline.” Further, using the Strategy to better coordinate efforts across agencies is important “because it is hard to make Government work across agency lines.”

Rev. Sharp said she has worked with at-risk youth for some time and with the realities of Georgia school systems and their lack of structure, particularly for middle-school children. Corporations are investing more in the prison systems than in the school systems, and it affects us. Black colleges have a high rate of HIV/AIDS infection. So, she asked Dr. Douglas, how do you take all that into consideration?

Responding, Dr. Douglas noted that he has kids in Atlanta schools too. He would like to respond to the image of prisons. He said that “this is a major way this country chooses to spend funds. Our sentencing guidelines have wreaked havoc on minority communities. A rapid rethinking of this unaffordable path is needed.” Someone, he added, mentioned rehabilitation. “What a novel idea! If we could create parity in sentencing, encourage rehabilitation, and restore health to impacted communities, that would be a big first step that could be addressed across Government, including the Justice Department.”

Dr. Holtgrave asked about block grants and what they are buying. Specifically, do we have more data on the use of block grant money at SAMHSA? Dr. Holtgrave also asked Dr. Douglas about DASH’s budget and whether it is too high or too low.

Responding for SAMHSA, Ms. Siegel said she does not have that information, but the block grants do buy services, and some States are using the 5 percent set-asides for early HIV intervention services.

Responding for DASH, Dr. Douglas said he does not know the answer to the question about DASH’s budget, as it just joined his Center. He does know that the allocation used is driven in part by the HIV reported numbers formula and that has been driven in part by DASH’s ability to work with the 12 Cities Project.

Ms. Hiers thanked Dr. Douglas for mentioning the “Macon, Georgias, and other smaller cities of the South.” She asked Ms. Siegel about whether SAMHSA is moving away from using cumulative AIDS cases. Responding, Ms. Siegel said she will get the answer to that question and will also get information about the agency’s total dollar amounts for youth and HIV programming. She added that SAMHSA’s programs “are very different.”

Mr. Greenwald asked Ms. Siegel about efforts to ensure that, as ACA is implemented, there is integration between HIV and behavioral health. In looking at the agency’s strategic initiatives (Ms. Siegel’s slide 2), he could not make out whether any one of them relates to HIV/AIDS.

Responding, Ms. Siegel said the strategic initiatives were crafted to help the agency align the areas it wants to work in, not content areas like HIV/AIDS. She will try to get more information for PACHA on how the initiatives were crafted.

Mr. Jack said that DASH is holistic, and “we need comprehensive education about HIV/AIDS and STDs.” When he has to teach 40 women “where their uterus is, we have to have these funds and target them.” We “are not giving youth the education they need, and we need to do it in a sex-positive and prevention way.” Also, “these youth want love and care.”

Mr. Jack said he has two questions from the audience for Dr. Figueroa-Gonzalez: What funding amounts were invested in MSM from 2004 to 2009, and at how many sites? Responding, Dr. Figueroa-Gonzalez said there were eight sites: four CBOs, two universities, and two departments of health. She does not have the dollar amount at hand, but average awards were \$300,000 per year for 5 years.

Mr. Baker said organizational grants that are small amounts and not integrated are not providing centers of excellence for us, so we have to look at large-scale investment in organizations over a 5-year period with a single application and think about what that kind of investment will do. His question outside of that is, in correlation with policies and disease prevalence, how well are we communicating to the public and elected officials?

Responding to the question, Dr. Douglas said, “Not well enough.” Looking just at what Georgia and New York are doing “is a lot more difficult than we’d like, so DASH is putting money into an every-2-years study to get trend data that can be matched with infection, morbidity, and so on that theoretically could be influenced by school programs.”

Mr. Baker said policymakers cannot respond without data, and Dr. Douglas replied that if the YRBSS was conducted every other year, that would be useful, as it is “being used very effectively on State-based levels where it is conducted now.”

### **Presentation on PEPFAR’s Work With Youth, by Deborah von Zinkernagel, M.S., B.S.N., Principal Deputy Global AIDS Coordinator, OGAC**

Ms. von Zinkernagel said the good news is that, globally, new infections have dropped from 16,000 per day to 7,000. For example, in 16 countries, HIV prevalence trends among 15- to 24-year-old pregnant women showed a decline, with 12 countries showing a decrease of 25 percent or more. In Kenya, the prevalence rate dropped from 14.2 percent in 2000 to 5.4 percent in urban areas and from 9.2 percent to 3.6 percent in rural areas in the same period. Ethiopia’s decrease is even more astounding—a 47 percent drop in urban areas and a 29 percent drop in rural areas (slide 3). In both Kenya and Ethiopia, PEPFAR is the largest contributor to the national AIDS response.

The impact is great when you put care and treatment and prevention together, Ms. von Zinkernagel added, going on to note an even broader swath of prevalence and incidence percentage drops on slides 4 and 5, with the exception of Uganda.

### ***PEPFAR’s Work With Youth***

Slides 7-10 detail PEPFAR’s programs involving youth and the results. Highlights include:

- In 2010, PEPFAR supported 257,694 children on ART, 8 percent of all PEPFAR treatment clients.
- PEPFAR convened a public-private partnership to bring together U.S. Government (USG), drug industry, and non-governmental -organization representatives to find solutions to inadequate pediatric formulations and access.
- PEPFAR prevention of mother-to-child transmission (PMTCT) programs save babies and mothers. Here the USG is leading the global effort, preventing an estimated 114,000 infant HIV infections in 2010.
- PEPFAR is committed to the global goal of 90 percent PMTCT reduction by 2015.
- Recent external review identified PEPFAR as the largest global funder of programs for HIV-affected orphans, vulnerable children, and youth.

- Key activities strengthen support systems for youth by strengthening families as primary caregivers, supporting the capacity of communities to create protective and caring environments, and building capacity of social service systems to protect the most vulnerable.

Working directly with young people, PEPFAR funds programs to provide technical/vocational training and psychosocial support through youth clubs, support groups, and mentoring. Ms. von Zinkernagel stressed that youth participation in decisionmaking is seen as increasingly important.

### ***Prevention for Youth***

Sharp declines in new HIV infections among youth over the past decade have been key drivers in the global drop in new infections. PEPFAR programs address youth with combination prevention—a range of interventions delivered in the variety of settings young people frequent. HIV-Free Generation, for example, is a public-private partnership targeting prevention to teens through media, games, and music, and “Shuga” is a TV drama coordinated with a youth-focused prevention campaign (slide 12).

In August, PEPFAR released its new Guidance for the Prevention of Sexually Transmitted HIV Infections, which moves the program in prevention to an evidence-based orientation.

The vision of evidence-based combination prevention “is very important,” Ms. von Zinkernagel said. Implementation details (slide 14) include:

- Mapping prevention needs and targeting activities through “4 Knows” data: know your epidemic, context, response, and costs.
- Scaling up high-impact, evidence-based interventions.
- Addressing structural factors.

Elements in the prevention package break down into biomedical, behavioral, and structural. More detail can be found at <http://www.pepfar.gov>, including about normative guidance around PrEP as prevention. PEPFAR does not yet have that guidance. The World Health Organization (WHO) will be providing it.

Ms. von Zinkernagel noted slide 15’s graphic that shows how a country prevention portfolio is tailored to the needs of key populations, including foundational programs for youth.

Ms. von Zinkernagel stressed that the guidance provided in the global HIV strategy reviews the evidence base for interventions focused on youth. When it comes to program implementation (slide 16), PEPFAR has a strategic goal of providing “100 percent of youth in PEPFAR prevention programs with comprehensive and correct knowledge of ways HIV is transmitted and ways to protect themselves.” Further, it is advised that:

- In schools, programs should be curriculum-based.
- In clinical settings, service providers should be trained and actions taken to make facilities more youth-friendly, coupled with activities in the community that link or refer young people to health services.
- Rigorous evaluation needs to be integrated into programming.

Key areas of focus for PEPFAR youth programming (slide 17) include:

- Education programs in and out of school with components on preventing STIs, including HIV, linked to education on pregnancy prevention
- Providing information and skills building necessary to help youth prepare to make their eventual transition to sexual activity safer and healthier

- Working with parents and guardians to help improve connectedness to and communication with youth
- Expanding access to community-level prevention programs, including peer outreach and curriculum-based programs for out-of-school youth
- Supporting targeted interpersonal communication, supplemented by youth-oriented, mass-media programs that encourage youth to think critically about HIV prevention and to influence attitudes, behaviors, and norms to promote healthy choices.

Prevention efforts focused on sexually active youth (slide 18) include:

- Tailoring programming for those most at risk based on patterns of behavior and their needs
- Encouraging development of skills and norms to promote secondary abstinence, mutual monogamy, and partner reduction
- Supporting programming to engage influential adults within the community to create an environment conducive to adoption of safer sex behaviors
- Encouraging sexually active youth to learn their HIV status and provide or refer them to confidential youth testing and counseling as well as linkages to care for those who test positive.

Slide 19 provides more information about “Shuga,” including focal points of an evaluation conducted by Johns Hopkins University researchers on the impact of the action-packed, hard-hitting drama. Interestingly, among Nairobi youth surveyed for the evaluation, 64 percent were aware of the program, and 60 percent had watched it. The evaluation also found statistically significant intention for behavior changes, including decreases in multiple partners.

PEPFAR has a special focus on young women and girls, because, in Africa, young women experience HIV infection at rates three times that of men of the same age (slide 22).

Ms. von Zinkernagel noted elements of PEPFAR’s gender strategy, which include increasing gender equity in HIV/AIDS programs and services (slide 23). When it comes to young women and girls, PEPFAR supports high-impact combination prevention (slide 24) and has decided also to confront gender-based violence as a driver of the HIV epidemic, with challenge grants in 30 countries developing strategies around gender-based violence (slide 25). Ms. von Zinkernagel offered to tell PACHA more about that in the future, if members would like.

PEPFAR looks forward to ramping up its current Together for Girls public and private partnership efforts (slide 26) to contribute core strengths:

- To conduct national surveys to document the magnitude of sexual violence against girls
- To support country plans of action with interventions tailored to address sexual violence
- To launch public awareness campaigns to draw attention globally and locally to the problem of sexual violence against girls.

Key partners in the Together for Girls efforts are the Secretary of State’s Office of Global Women’s Issues (S/GWI), PEPFAR, CDC, the Nduna Foundation, and others.

Supporting girls as they move toward adulthood, PEPFAR has acknowledged that HIV prevalence among adolescent girls is three times higher than among boys of the same age (15-24) globally (slide 27). PEPFAR programs to strengthen girls’ ability to thrive include not only the Together for Girls initiative but GoGirls!, which addresses girls’ vulnerability through communities, schools, and empowerment

programs, and the Guided by Voices (GBV) Program Initiative, which is scaling up programs to address GBV in three countries—the Democratic Republic of the Congo, Mozambique, and Tanzania.

Concluding, Ms. von Zinkernagel said a great deal of information can be found on the PEPFAR Web site (<http://www.PEPFAR.gov>).

### **Presentation by Miguel Gomez, Director, AIDS.gov, HHS**

Mr. Gomez has slides but he will speak extemporaneously, in part because he has to help the Secretary launch a new mobile initiative shortly. One of his favorite quotes is on the backside of his slides, modified from Danah Boyd, to the effect that “social network sites have changed our lives because they have made this rapid shift in public life visible.” So, “we should learn from what teens are experiencing. They are learning to navigate networked public, and it is in our interest to help them.”

Mr. Gomez added that “we have to understand and respect this new public life. It is about new media, and we need to understand what that means, which is conversation. We have to work with youth where the public health community is not.”

Mr. Gomez took the opportunity quickly to announce that PACHA members with Web sites may arrange to have a direct link to the site Mr. Gomez directs—<http://www.AIDS.gov>. Just contact Mr. Gomez. He also suggested that members might want to establish a link to the Strategy.

Mr. Gomez asked members to look at his slide featuring a baby. There, he has noted that “a digital native is a person born into the digital age (after 1980) who has access to networked digital technologies and strong computer skills and knowledge. As social media use has grown in the United States, so has students’ appreciation of the First Amendment, and they believe what is online 60 percent of the time.”

Is our information where youth’s information is? Often, Mr. Gomez said, the answer is no. He asked members to view his slide entitled “Teen Gadget Ownership.” This shows that most teens own “all the gadgets,” and they use them to go online, most often using a desktop or a laptop.

What is the typical number of texts sent by teens per day? Mr. Gomez said the mean by all girls is more than 120. Teens and adults want texting messages that are clear. These messages could be reminders, for example, about adherence, Mr. Gomez noted.

Mr. Gomez said that the “2010 Trust Barometer” has some things to say about what we need to realize. First, “we have reached an important juncture, where the lack of trust in established institutions and figures of authority has motivated people to trust their peers as the best sources of information.” Translation? They will trust a peer like them. But they still want to hear from an authority figure, as in this quote from the “2010 Trust Barometer”: “...Informed publics value guidance from credentialed experts....”

Mr. Gomez said that no longer can we say that youth and adults will not trust Government; rather, “it is how we present things.” The Strategy talks about using new technologies, but “we don’t know how to make that real. So it is our obligation to learn, including from global partners.”

Concluding, Mr. Gomez said, “if we do not as a community understand and use new technologies, we are not where people are making decisions. We should look at how new technologies are being used in other countries to tackle the epidemic. Gaming is a great opportunity, for example, but we have to think carefully about it.” Mr. Gomez added that he is sure someone from PEPFAR could provide more information on this.

## **Presentation on Addressing HIV/AIDS Prevention Among Adolescents, by Evelyn Kappeler, Acting Director, OAH, HHS**

OAH is a new organization within the Secretary's Office established by the Consolidated Appropriations Act of 2010 and responsible for:

- Coordinating adolescent health programs and initiatives across HHS
- Implementing and administering a new grant program to support evidence-based teen pregnancy prevention approaches
- Implementing the Pregnancy Assistance Fund as established by ACA.

Of the OAH initiatives, the Teen Pregnancy Prevention Initiative takes a two-tier approach: first, replication of evidence-based programs (funded at \$75 million), and second, research and demonstration projects (funded at \$25 million) (slide 3).

Ms. Kappeler quoted the Community Ideas consultation of April 2010 to note that many advocate that HIV/AIDS prevention among adolescents include comprehensive, evidence-based sexuality education.

Ms. Kappeler then detailed HHS evidence-based teen pregnancy prevention programs and identification of 28 evidence-based program models that have or will serve as the basis of a funding announcement. All the interventions enhance protective factors and positive health behaviors related to prevention of unintended pregnancy, STIs, and HIV/AIDS; 18 of the interventions include content on condoms; and 4 include content on condoms and other types of contraception (slide 5).

Slide 6 details the OAH grantees' replication of evidence-based programs side of things, including that 75 grantees have been funded to replicate evidence-based programs to prevent teen pregnancy to the tune of \$400,000 to \$4 million per year from September 2010 through August 2015.

Examples of Teen Pregnancy Prevention (TPP) programs addressing HIV/AIDS prevention among adolescents include Becoming a Responsible Teen (BART) and Be Proud! Be Responsible! (see slide 7).

Examples of TPP grantees implementing strong HIV/AIDS prevention programs are the University of Nevada at Las Vegas, which is involved in BART for African American youth ages 14-18 in Clark County, Nevada, and Le Bonheur Community Health and Well-Being, which is involved in Be Proud! Be Responsible! for African American youth in North Memphis (see slide 8).

### ***A New National Resource Center for HIV/AIDS Prevention Among Teens***

Additional work involves the National Resource Center for HIV/AIDS Prevention among adolescents to be established and operating in FY2011 with \$200,000 from MAI. The purpose of the Center will be to provide information, resources and training, and TA to promote HIV/AIDS prevention (see slide 9). It is hoped that a strategy can be developed to manage and market this Center, Ms. Kappeler said.

Noting that a cooperative agreement regarding this Center had been awarded to the University of Medicine & Dentistry of New Jersey (UMDNJ) through a competitive process (\$200,000 for up to 3 years—"a modest amount of money"), Ms. Kappeler said that UMDNJ will develop and implement a strategy to manage, maintain, market, and evaluate the Center (slide 10).

Providing more details extemporaneously, Ms. Kappeler said there is a need to plan and pilot this Center, an intense need for TA, a need to examine the meaning of implementing with fidelity, and that evaluation has been embedded in this program—in fact, several layers of evaluation "that meet the same standard as evidence review."

Ms. Kappeler invited members to visit <http://www.hhs.gov/ash/oah> to learn more, adding that a new site will be launched this week.

### ***Discussion/Comments/Questions and Answers***

Dr. Horberg said he does not think about the African American population in Nevada as being a very large population, adding that “we have to go to communities where there will be an impact.”

Responding, Ms. Kappeler said there was intense interest in this funding, with over 1,000 applications received in a competitive process and little time to provide guidance to potential grantees. “The fit is not always as close as we would like.”

Mr. Wilson asked Ms. von Zinkernagel about Uganda. Not that long ago, he noted, there was “the miracle of Uganda,” but much of what was said to be going on in Uganda “was not what was going on there.” So, what happened? Responding, Ms. von Zinkernagel said this question is fair and good and people across Uganda are still struggling with the answer. Initially, she explained, there was a rallying around, a real public awareness of the dangers of HIV/AIDS. There were questions about the impact of an abstinence before marriage strategy there, but general awareness did impact behavior. Over time, however, that general awareness level fell. Now, some CBOs and civil society groups are speaking out again, calling for more emphasis on the epidemic. OGAC is hoping the Government sector will be re-energized and respond with an emphasis on treatment as well as prevention.

### **Presentation by Lawrence Stallworth II, Ohio Advocates Member, AIDS Taskforce of Greater Cleveland**

Mr. Stallworth thanked the full Council for inviting him to tell his story.

“In the spring of 2009 at the age of 17, I became unusually sick and was hospitalized. Three days into my 5-day stay, I was told that along with contracting a bacterial infection, I was HIV-positive. Seeing as how that was by far the last thing I expected to hear out of the doctor’s mouth, I burst into tears. I felt scared, hurt, alone, and sad. It was like my world came crashing down on me. I told my aunt first, as she has been my biggest support in my life. My parents came next. My mother was there for me when I needed her. My father, with whom I’ve had a strained relationship, especially since my difficult coming out process, didn’t know how to be there for me.

“Within a few months after my hospitalization and returning to high school, I told some trusted teachers about what had happened to me. Unbeknownst to me, a staff meeting was held to talk about a student who was HIV-positive and what should be done about him. The fact that they were talking about how to ‘deal with me’ was devastating. Right after that meeting, I was refused service by the Cosmetology Department teacher at my school. She said, and I quote, ‘We don’t teach Universal Precaution down here, Lawrence, and I can’t subject the students to that kind of risk.’ It was my first encounter with being betrayed by trusted adults, and it still hurts me to this day.

“After graduating high school, I was introduced to a community I was unaware of. I heard from friends about a place where young gay people could find acceptance and friendship in a safe space. This place is called the Beyond Identities Community Center (BICC), a program of the AIDS Taskforce of Greater Cleveland. Here I found a community of young people just like me. It gave me a reason and an outlet to find my voice. After graduating from BICC’s Mpowerment Program, I applied to the Ohio Advocates Youth Leadership Council, a joint program of the AIDS Taskforce of Greater Cleveland and Advocates For Youth. Ohio Advocates gives me the tools to become a stronger advocate and the opportunities to speak to my peers and policymakers about the issues that are important to me.



“Transitioning into young adulthood, and thanks to the education and training I received through the AIDS Taskforce of Greater Cleveland’s programs, I was hired as a community educator for the AIDS Clinical Trials Unit of Case Western Reserve University Hospitals of Cleveland. I loved this job and learned so much about prevention research and community engagement. Unfortunately, it did not provide medical benefits, and I earned too much to qualify for State benefits. I was forced to choose between a meaningful job and potential career and access to my life-saving medications. Because of this, I chose to resign from my position to remain eligible for Government assistance to pay for the \$2,400 monthly cost of my medications. Effectively, I am now back to square one.

“Based on my personal experiences, I would like to leave this Council with a few recommendations. First, I believe it is important for youth to be represented on future PACHAs. The youth are ‘now.’ As a young person directly impacted by broad policies, I can speak to the realities of the everyday practice of these decisions. Young people have a right to influence the policies that affect them and are in the best position to recommend what is needed to assist them. It is also my recommendation that this Council have representation from providers that directly serve youth, such as pediatricians and social workers. Cleveland Clinic sees me as a human being.

“Second, I recommend participation by the U.S. Department of Education in the implementation of the Strategy. As you heard from my experience in high school, it is apparent that school administrators, staff, and faculty need access to training and education about HIV. I was discriminated against with no regard for the confidentiality of my situation. I also believe it is important for the U.S. Department of Education to help shape and implement evidence-based, LGBTQ-inclusive, comprehensive sexual health education in the Nation’s public schools. It is apparent to me that teens are still not receiving the information they need. For example, I spoke on a panel 2 days ago at a local high school in the Greater Cleveland area and was shocked by a few of the questions from the students during the post-presentation Q&A session. The first student asked, ‘Isn’t the difference between HIV and AIDS that HIV can be cured and AIDS can’t?’ The second question was ‘Can’t you only get HIV from gay sex?’ These were juniors and seniors in high school, and if that doesn’t scream ‘More education is needed,’ then I don’t know what does.

“Finally, I recommend that this Council promote a nationwide HIV anti-stigma campaign specifically for young people and more specifically for young people of color. Recently, the CDC reported that young black MSM are particularly affected by new HIV infections. HIV and AIDS have been around for over 30 years, but the stigma I face today and the stigma that other members of my community face not only from their families but from their friends, churches, and trusted adults, is a clear barrier to open conversation and education about HIV/AIDS prevention and treatment. I also believe it is vital to have community support for local programs, such as the BICC in Cleveland, that prove effective in relating to young LGBTQ individuals, especially young MSM of color, in order to prevent HIV transmission. I’ve also found it to be a safe space for those of us who are young and HIV-positive.

“The stigma and discrimination I faced when I was in high school could have been enough to keep me from fulfilling my full potential. As a young person, I am a testament to the resiliency of youth. This is partly because this is just who I am, but also because of the support of my community. Since being diagnosed 2 years, 5 months, and 26 days ago, I have taken the opportunity to speak publicly about HIV. I have spoken at the Rock and Roll Hall of Fame for World AIDS Day 2010 and served as a panelist for several high school and college presentations. I was featured in an award-winning local public service announcement (PSA) and have conducted several workshops on HIV 101, treatment, research, and prevention. I have visited my local, State, and Federal legislative offices and advocated for comprehensive sexual health education and HIV/AIDS care and services funding support, encouraging

other young people to do the same. I am the youngest elected president of my tenant council organization and a State bowling champion. Looking to the future, I will begin nursing school within the next year, become a professional bowler in 5, and one day I will run for public office.

“The decisions made by this Council and other policymakers directly affect my future and my peers’ future. A phrase by which I live and which still stands true for me today goes as simply as this: ‘Decisions are made by those who show up.’

“Well, I’m here.

“Thank you for giving me the opportunity to be here and share my story with you today.”

### **Presentation by Sade Powell, International Youth Leadership Council Member, Advocates for Youth**

“Thank you for inviting me to speak. I am originally from New York. Now I’m attending George Washington University in Washington, D.C.

“HIV was normalized in my household. Even before I knew what it was and what I was doing, I was a sexual and reproductive health rights activist. Reflecting on my childhood, I remember conversations involving words like protection, highest infection rates, free testing, and black community. A memory that strongly stands out is when I was a 7-year-old, rummaging through my mother’s stuff. Somehow in the midst of my exploration, I always ended up at the same drawer in her nightstand. It was filled with condoms and lubricants. At this age, I had somewhat of an idea what I had encountered, but I didn’t understand everything.

“I began to understand the day my brother and I got a rare opportunity, especially for 8- and 9-year-olds, to ride a Housing Works float with my mom and her colleagues in the annual African American Day parade in New York City. Housing Works is a nonprofit organization with the mission of ending both homelessness and AIDS through direct service and advocacy. As I sat on the edge of the float with my oversized yellow shirt that read in bold black letters ‘SAFE SEX,’ I dug my hands deep into the container of condoms and safer sex information and threw them out into the crowd.

“Some time later, some float rides later, and some getting used to rummaging through that drawer later, I learned what was my mother’s driving force behind her involvement in THIS work...and this too would become mine.

“Growing up, my mother was a Daddy’s girl. My grandmother was a Jehovah’s Witness, and my grandfather was a devoted father and Black Panther. For a black man living in Brownsville, Brooklyn, that was a rarity. But as his ‘fro grew, so did his addiction to drugs. For 30 years of my mother’s life, she would have to battle the pain of searching for her homeless, doped-up father, who was later infected with HIV, as well as her own drug addiction.

“It wasn’t until the day her father died that my mother told me he had been in the hospital and passed away from an AIDS-related illness. But as I stared into her eyes to search for the full truth, I saw a look of absence I had never seen before that was suddenly replaced by an even stronger, burning passion. For the next few weeks, Luther Vandross’ ‘Dance with My Father’ would fill the silence in my home and the emptiness in my mother’s heart until her next project. It was then, when I was 10, that Granddaddy Frank became my inspiration, and so did my mother.

“Fast-forwarding to middle school, I can recall what little sex education I received as a 7th- and 8th-grader. Each year, we would get notice that regular class was to be suspended because Mt. Sinai’s

Adolescent Clinic would be coming to talk with us about sexual and reproductive health. The teacher would pass out forms for our parents/guardians to sign to opt-in to the only sex education that we would receive for the school year. I only received four classes and probably a total of 12 hours of sex education, which ultimately fell short of New York City's sex education mandate.

"My friends and I discovered that most parents sign this kind of document to sort of release themselves of the responsibility for having the typical 'birds and the bees' talk with their children. Clearly, my mother signed it, but even she, who was fairly liberal, failed to discuss some of the things I learned in these classes. Surprisingly, many of the kids' parents who seemed very liberal didn't sign it, and to be honest, these were the kids desperately in need of this information, primarily because they were also the kids involved in a lot of the sexual activity going on during school.

"In high school, I found myself in a whole bunch of mess, and before I knew it, I was at Planned Parenthood signing up for emergency Medicaid to carry out an abortion. Later, I realized that the same act that got me pregnant also put me at risk for HIV and other STDs. A part of me always felt that if I had adequate comprehensive sex education, and if I had had more of an open and trusting relationship with my mom, I would have made healthier decisions regarding my sexual health.

"However, what I want through compelled me to help others, so I joined YWCHAC, formerly known as the Young Women of Color HIV/AIDS Coalition, in the summer before my sophomore year of high school. As part of the outreach, we would host safer sex education parties and health summits in communities where HIV/AIDS rates were high and lobby City Council members about the importance of implementing HIV/AIDS education in public schools. Being involved in this program and this work has helped bring my mother and me closer together by allowing us to bond over similar passions while simultaneously opening that door for us to have a different type of dialogue—one around sexual health, one I think every child should have with his or her parents. We now have in-depth conversations about sex, contraceptives, the male and female reproductive systems, and even the socioeconomic, political, and cultural factors in which this disease is imbedded.

"Due to this work, to my surprise, I became THAT girl. Almost all of the networking I did among my peers was founded on the advocacy work that I did. This was also when I realized the extent of misinformation that was circulating among my peers. For example, they did not know what STD stood for, didn't understand that HIV was the precursor to AIDS, and thought douching to flush out sperm after having unsafe sex would help prevent pregnancy. In school, my peers—black, white, it didn't matter—all approached me and asked about STD symptoms, nearby clinics, free testing, and even for condoms, in spite of the 'safe place' my school tried to establish for condom availability, which was located in the basement where no one would notice. While it is great to have condoms available on campus, the location was not ideal and only served further to stigmatize safer sex. Teachers were also left off the hook so that they did not have to deal with providing a safe place or to be the adult that we students needed to come to for information and support. My peers and I wanted adults we could speak to.

"In my high school, it was required that sophomores take health class, which was supposed to cover sexual health, substance abuse, and mental health. However, the class was lackluster because it was taught by the gym teacher, who had little to no knowledge in these areas. When it came time to discuss sexual health and STDs, my gym teacher just showed us a movie about a gay man coming to terms with his sexuality and having HIV. He also went as far as to state that one could tell when someone had HIV because they would have lesions and most likely are the homeless people we encountered every day. My friends looked at me to agree with his statements, and while I was embarrassed for him, I respectfully objected. He allowed me to take over for the rest of the class.

"I am proof that if relationships are built and maintained between young people, their parents, teachers, and community leaders, then it is possible for youth to effectively combat the HIV crisis. It is vital that in combating this disease, adults, including parents, learn to build youth-adult partnerships and ensure that comprehensive sex education is prioritized so that youth have the correct information to make healthy decisions regarding our bodies. With your leadership, I hope that, one day, we will have a national campaign focused on young people and HIV, meeting them where they're at, and including resources for events such as spoken word, parties, workshops, festivals, and other forms of outreach.

"Above all, we need leadership from the top. If the First Lady can talk about physical fitness and build a garden at The White House, and the President can talk about the significance of fatherhood, I think the First Family should talk about the importance of sexual health. They are the parents of two young daughters who are nearing the age when HIV infection rates are high in young women of color. It can't just be normalized in my house. We need the First Family to be role models too.

"Thank you for giving me the opportunity to be here and share my story with you today."

### ***Discussion/Comments/Questions and Answers***

Ms. Hiers congratulated Mr. Stallworth and Ms. Powell. She asked them if they would like to move to Alabama because she respects and admires them very much.

Ms. Khanna thanked Mr. Stallworth and Ms. Powell for their inspiring words and wisdom. She noted that both she and Mr. Wilson are involved in planning for the International AIDS Society conference this next July, so she would like to know that if these young people had one wish for what this conference could accomplish for youth in the United States, what would it be?

Responding, Mr. Stallworth said, "Bring us to the table because decisions are being made about us, not with us. Give us an active role. We can handle it." Ms. Powell added, "We need your support in supporting youth organizations so that they are allowed to go into schools to provide comprehensive sex education. Throughout New York City, we are getting sex ed from gym teachers who are not qualified. We find out everything from each other. We don't have that relationship with adults." She added that youth and adult partnerships are vital in fighting this epidemic. "I love being THAT girl, but I should not have to stand alone being that girl."

Mr. Cruz added his accolades, telling both Mr. Stallworth and Ms. Powell that they are incredible. He said it was shocking that Mr. Stallworth had to give up his job in order to get good health care. He asked Mr. Stallworth to say more about that.

Mr. Stallworth said he received a letter from the State saying that he was making too much money and could not keep his current health care. He had gotten the job a year prior. He was young (he just turned 20 a few weeks ago), so "I was young, I'm smart, and I knew I would get another job in this field. I was not willing to give up the care. I shouldn't have to choose. It would be great if policymakers could fix that."

Ms. Powell said that when she hears a story like that, she wonders about what if he had a family or kids? "It is sad, because that is the reality for too many. That's the point of having to make that kind of decision." Mr. Stallworth added that it makes no sense to him why there are ADAP waiting lists. Ryan White started out with "\$50 million, but has been flat-funded for some years now." In Cleveland, "you see infection rates go up but still a program is flat-funded. When you have programs that reduce viral load, I don't understand that. People's lives should not be played with."

Mr. Brooks said he wishes he could tell the two young people in front of him how beautiful they are. He hates that Mr. Stallworth became infected. He wants to make a promise, and that is: “This is not just a forum where you have shared your stories and then they will be forgotten.” Rather, “you and your testimony today, I promise you, have made a difference.”

Rev. Sharp said that as a mother and as an advocate, she feels these stories. “It doesn’t get easier, but you have people who support you where you are.” She asked Mr. Stallworth about the anti-stigma campaign he mentioned and what it would look like, for him.

Mr. Stallworth replied that it would involve sitting down with young people, talking in plain words about what is actually going on. Examples from the black community include being stigmatized for being black, being positive, and being a man. “How can we ever expect to reach the people we need to?”

Rev. Sharp agreed, adding that she is trying to get the churches to talk about sex. As matters stand for the most part now, “we are giving people permission to seek outside information and not, in our churches, providing the structure that would enable our youth to know more about safe sex because of fear.” We “are falling behind, and I apologize for the church. I will help.”

Ms. Powell observed that the main reason such huge stigma exists around HIV, MSM, and sexuality in the black community is “because we’re not having these conversations, parents aren’t. For many it is not normal to sit down around the dinner table and discuss how your day was. Even my mother, who was involved in this work, would always just say, ‘you’d better not get pregnant,’ so when I did, I didn’t know what to do. I didn’t know who to go to in order to find out about clinics or free anything. That’s scary. My boyfriend at that time and I, we just worked our way through our friends. Planned Parenthood? I didn’t even know what that was. I could’ve picked up birth control from them in the shopping district of SoHo. This is something that needs to be normalized. If we can talk about what’s going on in the Middle East, we can talk about sex.”

Mr. Basaviah asked what media young people are using. Mr. Stallworth responded that there is a number you can text that will tell you where testing clinics are. “I’d rather text than talk. I’m more likely to retain the information and follow through. But the message needs to be plain-spoken.” Ms. Powell said that it may be far-fetched, but there needs to be a company that provides you with monthly text messages about where you can go to get information. Right now, she gets random messages about free pizza, when she would prefer to know about other places to go in D.C., and she has been here for months.

Mr. Wilson observed that Mr. Stallworth is one of the people in the new incidence data released by the CDC—one of the young gay black men. He asked Mr. Stallworth what would have prevented him from getting HIV. Responding, Mr. Stallworth said, “If my father had been more forthcoming and relatable....” He explained that he was going through an awkward time at the time and that he likes men, not girls. “If my father had just talked to me and helped me find people to talk to....I had to do a lot of research on my own, like what I need to know and how to take care of myself. If parents can get involved right at the beginning....” But when Dad said, “‘I ain’t going to raise a fag in my house,’ well...and then he says, ‘because you went out and did this, this is why you have HIV, and I don’t.’ ”

### **Summary Remarks, by Carole S. Treston, R.N., M.P.H., Executive Director, AIDS Alliance for Children, Youth, and Families**

Concluding discussion, Ms. Treston provided summary remarks on the Youth and HIV session. She began by saying she hopes Lawrence and Sade feel the love and respect of PACHA and everyone in the room.

She thanked Mr. Basaviah and members of PACHA for sponsoring this session. She thanked her Federal partners here today (including the U.S. Department of Education, which was absent).

Continuing, Ms. Treston said it was a year ago nearly to this day that youth issues were on the agenda at a PACHA meeting, and youth spoke powerfully about their experiences. Before that, in December 2009, as a lead-up to development of the Strategy, ONAP convened a White House meeting on youth. More than 30 youth living with HIV and HIV adolescent experts and providers from around the country came together at that meeting, then worked over the next few months to come up with expert recommendations on how to address the HIV crisis among youth, in particular, among youth of color.

Ms. Treston said she has before her a list of detailed, thoughtful, innovative approaches and strategies that are solutions. “We know how to tackle this problem.” Everyone in this room knows how to do that. But the question is, do we have the will, the collective will, and the resources to invest in this most at-risk and underserved population, specifically, young MSM of color.

Ms. Treston said she would venture to say that the social and sexual networks these young people travel in are much more interconnected and integrated than “any of us can imagine.” The “silos that we plan in have separate silos for young MSM, separate silos for prevention and care for young women of color, and so on.” These “are artificial silos that happen on the national and administrative level but that may not reflect the real experiences of young people. As others have pointed out, the fluidity and changing nature of sexual identify and preference is part of adolescence, and in those expanding circles of young MSM are young people who move in and out—young men who have sex with young women and young women who have sex with gay guys, and it is all much less definable than the adult experience.”

So, Ms. Treston asked, who is going to invest in this population of young MSM, young women of color, and all their expanding and contracting social and sexual networks? Before tackling that, Ms. Treston said she will summarize and articulate the requests of the small group that met to plan this session. That group has thought a great deal about what is reasonable to ask of PACHA and what is really part of the greater struggle and perhaps not under PACHA’s direct control.

First, the next available seat on PACHA needs to be filled by someone with broad expertise in youth and adolescent HIV, someone “who can cover the intersections and integrate the world of prevention, care and treatment, research and public health, and scale-up.”

Second, as the President’s Advisory Council—“that is the title of this body, right?”—PACHA is being asked to ask—or advise—the President and First Lady “to step up to the plate and lead a social marketing campaign, a PSA, to give some visibility and attention to the toll of HIV on the African American community. The youth at the ONAP meeting had a specific plan, and now they ask that as an African American man and father, the President---and his wife and mother of his daughters—step up and shine a light on the impact HIV can have on young people, particularly young African American men and women, and provide a role model around this and HIV’s impact on families. It is hoped that the President will follow through and that his follow-through will carry through into his second term. “Even if “things don’t turn out that way,” President Obama will still have a big voice and big influence. His visibility is important, “and our young people need it and have asked for it.”

The third request deals with metrics on youth. Ms. Treston said she understands how difficult it is to collect and analyze data, especially across agencies and funding sources, but “that coordination was to be one of the hallmarks of the Strategy.” It will be a difficult task with such a mobile population, as every few years, youth move out of the youth population as they age. “But the ability of some to present data on youth resources today was appalling. Agencies can’t identify the resources or programming targeting

youth. So we would ask that PACHA make it a priority to champion the inclusion of youth metrics and the ability to measure and track appropriate accountability for the appropriate resources targeting this most impacted population.”

Last in the realm of what is possible and feasible to ask of PACHA, when the Strategy was released, “we raised the big question about the inclusion of youth as a target population and the need for the Department of Education to be part of the implementation plans, and we were told that this Strategy, like any strategy, was a ‘living, breathing entity and would be responsive to new developments and changes in the environment.’” So Ms. Treston’s question now is, “How does that happen?” Now that we have revised incidence data showing the rapid increase in HIV infection among young MSM of color, how do we ensure that changes and new development “are accounted for in a very real way?”

Now to the questions or requests over which PACHA may not have jurisdiction or be able to tackle because they are part of bigger societal challenges and are related to the will and prioritization of young people:

First, Ms. Treston said, “we need a better investment of resources in young people with HIV and in the programs that serve them.” No wonder, she added, that we are failing to reach them, for today, “we heard reports that the new CDC FOA for young men is approximately \$11 million per year, and we heard about the Ryan White SPNS projects that ended in 2009 after expenditure of an average \$300,000/project at eight sites, or just a little more than \$2 million per year.” In addition, “of the \$3 billion invested in HIV/AIDS research at NIH, \$150 million is in adolescent-specific research, and \$6 million in the coordination project on youth between the CDC and NIH.”

Add that all up, Ms. Treston said, and “it doesn’t seem like enough.” We “need more resources and more coordination across agencies of these resources. Two of the most important sources of funding for HIV programming for youth and young people—the CDC’s DASH and the Ryan White Part D programs—have been flat-funded for years, and it has been an uphill battle to maintain that !”

Concluding, Ms. Treston said we need to think about scaling up what works. “This constant churning out of pilot projects is not an effective strategy, as Mr. Baker has pointed out.” In her opinion, Ms. Treston said, “funding something for just \$300,000 for a few years and then ending that and starting something else—another pilot over here, somewhere else—is not an effective strategy.” For those of us in the field, Ms. Treston said, this constant churning, this constant spending months writing a proposal for a unique, innovative strategy and then spending the first year of funding developing it, “doesn’t seem the best way forward.” There needs to be “an effort to think about scaling up successes, a more efficient way to utilize resources to sustain better outcomes for those most in need and most at risk.”

## **Last Remarks**

Mr. Baker said that the OAH presentation was too short and that he is a little disturbed that most of the current setup of the Office seems devoted primarily to pregnancy prevention. “I want to know a lot more.” He said he also recognizes some of the political compromises “that got us to where we are now.” For example, “some of us were for abstinence but not until marriage.” It “would be a travesty if we moved from that to a pregnancy prevention paradigm.” Last, “how do we resolve Mr. Stallworth’s issues, including the need to have helping parents?”

Mr. Bates said that this session was “probably one of the most powerful sessions we have ever had.”

## **Lunch**

## **AFTERNOON SESSION**

### **HPTN 052**

#### ***Introduction***

Dr. Horberg said that the next two presentations “follow everything else we’ve been doing in this meeting perfectly, because we’ve been talking about how to change the epidemic domestically and internationally and how we advise the leadership and Executive Branch of the Federal Government to attain those goals.” In his humble opinion, the results of the HPTN 052 study “is the game changer” because he is a firm believer in science-based medicine.

First, in this session on HPTN 052, PACHA will hear about the science and hope to have a good discussion of its implementation in both the domestic and international arenas. A relevant handout on the research and its implications was made available to members today by the Center for Global Health Policy and the HIV Medicine Association (HIVMA).

The first speaker is Myron Cohen, who led the HPTN 052 research and has been leading other such research for 30 years.

#### **Presentation on HIV Treatment as Prevention, by Myron S. Cohen, M.D., Professor of Medicine, Microbiology, and Immunology, University of North Carolina School of Public Health**

Dr. Cohen noted four HIV prevention opportunities (slide 2), the first of which is behavioral and/or structural for the unexposed and the fourth of which is treatment of HIV and reduced infectivity for the infected, with vaccines and PrEP in between. Ideally, he said, “We would like to keep those who have been exposed negative.” With that as an ideal, across the board of prevention opportunities, he has concerns about behavioral and structural intervention, thinks we are making incredible progress with vaccines (for the exposed), and realizes that post-exposure prophylaxis has been routinized, but, in the end, “we are left with the big gorilla, which is when we treat, do we render those who have been infected less contagious?” The 052 study is very much about this. With caveats, it is a success in this regard, and “it has taken us a long time to reach this point.”

In preparing to examine the use of antiviral treatment as prevention through the 052 study, researchers wanted to know more about agents and suppression (slide 3), and in the study itself, more about the possible magnitude and durability of the benefit as well as whether earlier therapy is better (slide 4).

Those goals can be considered against the backdrop of key questions in general about treatment as prevention, which include:

- How effective are ART drugs in preventing HIV transmission?
- What do we tell couples and infected persons? (Every transmission event involves a discordant couple.)
- Can we expect reduced population HIV incidence from ART?
- What are barriers to “treatment as prevention”?

#### ***The Study Design and Enrollment***

Slide 6 depicts the HPTN 052 study design and its two arms. Dr. Cohen noted it took a long time to get to this point, as he started working in 1987 on the biology underlying it, and when the time finally came for the study, he had to get a large stock of drugs (six companies contributed).



Over several slides beginning with slide 8, Dr. Cohen detailed enrollment for the study, including oversampling Africa. Thirteen sites in all were involved, five in Africa. “We had wanted to enroll MSM and couples in the United States, but it proved difficult. The study does not have a lot to say about MSM. It ended up being primarily focused on heterosexual transmission, and that was not by design.”

Dr. Cohen noted that he and his colleagues had intended to continue the study through 2015, but when earlier results were available, the Data Safety Monitoring Board (DSMB) recommended, in early April of this year, that these data be announced as soon as possible (slide 13). Dr. Cohen noted that while the study continues to follow enrolled couples, all HIV-infected participants are now being offered ART.

### **Early Findings**

Part of the reason for the early public release of findings from the study lies in slide 14, which shows there was evidence that, despite safer sex counseling and condoms, some of the couples in the study had had unprotected sex outside the relationship that led to some “unlinked” transmission events involving individuals who were not receiving ART as part of the study. When Dr. Cohen and his colleagues looked further into the implications of this, they found that despite this, overall, ART was having a good effect—incidence was virtually nonexistent or very low—in both the immediate and delayed study arm—a very good thing (slides 15 and 16).

Further examination of early data and analyses (slides 18 and 19) “reinforced our belief that this intervention is near perfect...as long as you are adherent.”

Mr. Frost noted that more females transmitted to males in this study and that more females were enrolled as index, so why? Responding, Dr. Cohen said antenatal clinics are a good source of recruitment.

Back to the presentation, Dr. Cohen showed the next slide (slide 20) on consistent use of ART. This, he added, is very important. “We were only testing one variable: were people suppressed and if they were, could they transmit? We had to have suppression all the time in the immediate arm. See also the rising level of suppression in the delayed arm.”

With presentation of the slides noted on slide 21 by Beatriz Grinsztejn at the Sixth IAS Conference in Rome on July 18, 2011, “we announced we had answered the magnitude question.” Also, for couples in a stable relationship, there is “altruistic adherence, and this plays a role in implementation.”

Dr. Cohen showed a number of slides pertaining to duration and clinical results beginning with slide 22.

On August 11, 2011, the research team published “ART STOPS HIV Transmission” in *The New England Journal of Medicine (NEJM)*. Another paper is due out soon in the *International Journal of Infectious Disease*, and a few others will follow.

### **What Is Next?**

In terms of what is next, Dr. Cohen reiterated that on April 29, one day after the DSMB recommendation, “we decided to offer ART to everyone in the study at higher CD4 counts than recommended.” By that time, all but 150 couples had gone on therapy. The study continues with more examination of durability of prevention, whether delayed therapy suffered adverse clinical outcomes, and whether these results could apply to all heterosexual couples. In all the committees he sits on, if the infected person in the relationship is suppressed, regardless of the nature of the relationship, they are suppressed, but there is a debate on whether we should focus on discordant couples or someone more

promiscuous. In terms of MSM, WHO will be discussing this soon and “what we are going to do about it.” The HPTN 052 study “doesn’t really address this.”

Dr. Cohen noted that as soon as early study results were released in April/May, everyone started talking about how this is the end of the epidemic. However, Dr. Cohen said he has to be a voice of caution about policy.

Slide 28 shows the results of an article Dr. Cohen co-authored to summarize existing models on ART for prevention, and” it is sobering about the thesis that if we treat everyone, we will get rid of the epidemic.”

Slide 29 cites two other published studies Dr. Cohen has hesitations about because they lack true assessment of HIV prevalence; the number of people “suppressed” on ART (they were really suppressed, but in the real world, that is difficult to accomplish); and most of these studies do not measure incidence.

### ***The Horse Is Out of the Barn, but Combination Prevention Trial Results Are Needed***

Because the horse is out of the barn on treatment as prevention (slide 31), “we need to understand the limits and benefits of ART as prevention.” As shown on this slide, other studies are being conducted, including on the limits of getting people into care and keeping them there. Noting the combination prevention trials in Botswana and POPART (South Africa), Dr. Cohen said, “if we do everything we know to do, we’ll see a big reduction from these studies, and it will take only 4 years.” Here, “biologists are pushing the limits of combination prevention in the hardest hit communities.”

Beginning his conclusion, Dr. Cohen said he is optimistic about testing and treating as prevention, but there are limitations. As shown on slide 33, one can see in multiple studies the effect of the newly, acutely infected on the epidemic, i.e., these folks are driving the epidemic, and “if we don’t reach them, that stymies us.” In terms of test, link, and treat, slide 34 shows the reality in the United States. “We have these numbers of infected and then we have these other numbers of those who are durably suppressed. That’s a problem. We have to fix this situation so people being linked to therapy will improve their health and their partners’ health.”

Showing his last slide, regarding clinical trial evidence for preventing sexual HIV transmission (slide 35), Dr. Cohen said this is an exciting time for the HIV prevention world. “Game changing is inappropriate,” he added, “but we do have more tools, and if they are used properly, good, exciting things can be done.”

### **Presentation on Antiretrovirals for the Prevention of HIV Infection: Where Are We in 2011?, by Carlos del Rio, M.D., Professor and Chair, Rollins School of Public Health, Emory University Center for AIDS Research**

Dr. del Rio said that, mainly, “we’re now seeing prevention going biological, and it is changing the way we’re approaching prevention because, up to this point, we have relied on behavioral interventions.”

A number of randomized clinical trials have shown that biologics can have an effect on incidence (slide 4), including HPTN 052 and, more recently, the ongoing HPTN 065 study.

It has been known for some time that suppressing HIV viral load in individuals reduces perinatal transmission (slide 6).

Dr. del Rio noted the pre-exposure chemoprophylaxis (PrEP) study in MSM that showed a 44 percent reduction in HIV incidence for some, but “that was a bit disappointing.” If you were adherent, this

percentage went as high as 73 percent in this study, but one thing the study showed was that you had to take the pill, so “behavior still plays a major role.”

Dr. del Rio noted challenges for PrEP in the aftermath of that study’s findings (slide 8), then moved on to mention ART for prevention and discordant couples studies that predated 052 (slides 9 and 10).

Dr. del Rio provided slides regarding HPTN 052 but did not dwell on them due to Dr. Cohen’s presentation and moved quickly to testing and transmission (slide 15). It is important to expand testing to as many as possible, he emphasized, because people who know their status are less likely to engage in high-risk behavior, and those who are found to be HIV-infected can then be treated, reducing their viral load. However, “we need to do a much better job of testing, followed by linkage to prevention services. To have 25 percent who don’t know their status is unacceptable now.”

Dr. del Rio also emphasized that couples counseling and testing is more important than ever for a number of reasons having to do with discordant couples, principally that there are findings of high levels of unprotected sex (slide 16), and it is not always for the reasons one might consider. For example, Dr. del Rio noted, if one has a stable partner, one is more likely to have unprotected sex with that partner.

Looking quickly at decreases in community viral load and a study that found an association between those decreases and reductions in new infections in San Francisco, Dr. del Rio commented that the highest viral load levels found in the community were among homeless individuals, which begs for a focus on other determinants of health as well.

Turning to the HPTN 065 trial (Testing, Linkage to Care, Plus Treatment) (slide 24), Dr. del Rio said “the whole system is working better in this trial because people are being forced to work together.” In fact, “the outcome of this may be that the whole machine is working better.” The study is not without controversy, as a *POZ* article recently made clear by questioning how much we can force testing and starting therapy. Dr. del Rio added that his biggest regret is that stigma still plays such a major role in transmission. “We can’t do a lot of what we’d like to because stigma is out there.”

Dr. del Rio noted that Bruce D. Walker and Nesli Basqoz advocated back in 1998 that HIV infection should be treated like other infections, “by treating it” (slide 26), and “we may need, indeed, to do that.” The problem is, it is just not getting tested, and into care and therapy. Rather, from data that Gardner et al. and he and others have gathered over the years, while over a million people are infected in the United States, maybe 20 percent are not suppressed “for a number of reasons” (slide 28). Simply put, there are major gaps in the implementation cascade, as the well-known graph on slide 28 shows. However, where are we going to get the resources to get more people into care and into therapy? These are big issues to think about.

Treatment clearly is prevention, Dr. del Rio said. The 052 data show that. But not all prevention is treatment. For example, even food security is prevention. But it is not treatment.

Beginning his conclusion, Dr. del Rio said HPTN 052 “is the best news we’ve had in a long time. It is a major opportunity to address the epidemic here and abroad. Early therapy offers benefits to the individual and to society. But the epidemic in the United States has changed dramatically, and most new infections are among young African American MSM.” So, “how do we find them?” In addition, “How do we get them tested and linked to care and prevention services?” Dr. del Rio’s basic conclusion on this is that behavioral issues will still need to be addressed, and “we also need to figure out how to make 052 operational” (slide 36).

Policy implications (slide 37) include:

- The need to scale up HIV testing, including couples testing
- The need to prioritize diagnosing HIV infection at a higher CD4 count (the current median count at diagnosis in the United States is 317 cells/uL)
- The paramount need for case management at the time of diagnosis to endure linkage to care
- The need for HHS treatment guidelines to reflect study findings and CDC guidance for “when to start” considered less important
- The need for there to be no problems (such as ADAP waiting lists) to ensure availability of ART for those who need it
- The need to prioritize engagement and retention into care in all HIV clinical settings
- The need for mental health and substance abuse treatment to be part of comprehensive HIV care.

In the end, Dr. del Rio said, “we have a unique opportunity to change the epidemic. The biggest mistake would be not to do something in response to these recent studies.”

### ***Discussion/Comments/Questions and Answers***

Dr. Holtgrave asked about the “need ART” category in the major gaps in the implementation cascade bar graph on Dr. Cohen’s slide 28. Dr. Cohen noted that the left-most column is the denominator, and whether one is asking about “need ART or on ART, what’s the difference, because if you want to impact the epidemic, you need these percentages to be around 50 percent, and we’re nowhere close to that.”

### ***What Are We Struggling About?***

Continuing, Dr. Cohen said these are HHS criteria, of course, but a fair number of people who need ART are not getting it, don’t want it, or have not been prescribed it, and that’s an issue with certain populations. What, he then asked rhetorically, are the things that have changed his perception of the epidemic? He increasingly believes, “and we’re having trouble with this, is that we’re creating confusion in this highly stigmatized disease with the rationing of pills, which for rich countries, makes no sense.” To the point, “I’m lobbying you about the rationing of pills and the confusion about whether you can get them or not because this is not smart policy. If there is one thing President Obama could do, it would be to recommend proper treatment and make sure the pills are available. What are we struggling about?”

Responding to a query by Mr. Frost on the difference between O52 and PrEP in terms of drug levels measurement, Dr. Cohen said the problem with this is the way the PrEP studies are done. One study found that if you find drug in the blood, you are less likely to have a transmission, but that is a single parameter surrogate. “We don’t really know how PrEP works. The trials don’t necessarily agree with one another.”

Responding, Dr. del Rio noted that in terms of presence of drug, “the phase we’re beginning to see in terms of penetration into female genital secretions might be very important. Dr. Cohen added that tenofovir concentrates in the rectum better than in the vagina. Is tenofovir not working so well in women because of a lack of adherence, or does the drug not work that way? In short, “PrEP is very important, but very convoluted.”

Mr. Frost said that while he is nitpicking, “the resistance events have happened.” Meanwhile, what are Dr. Cohen’s reservations about O52? Responding, Dr. Cohen said that “we did a study to understand the magnitude of the findings, but we didn’t have the subjects in terms of MSM.” Meanwhile, he is 100 percent certain there is something better. “I’d like the magnitude to be 100 percent.”

Mr. Frost asked if there is a biological difference in MSM, to which Dr. Cohen responded that acquisition is not about MSM, it's about anal intercourse, and it is not well understood in terms of transmission. The biology IS different there. A transmission even involving men and women usually does not involve that many different viruses, but in anal sex among homosexuals, many more of the viruses are different.

Mr. Baker said that in terms of the U.S. epidemic, he thinks that the panel has given PACHA conflicting information. One of the challenges of PrEP was that efficacy rates were different in different parts of the world. In the United States, these rates were very high, involving mostly white gay men with good adherence. It is true that PrEP might not be as efficacious with other populations. But if you are young and positive and not in a couple relationship but having sex, should you use this as a method to help prevent transmission? "If we want to change the course of our epidemic using these data, how would you apply it? Also, given the lack of data on anal sex, what would you do for the young, black MSM?"

Dr. Cohen responded that he believes that ART probably has tremendous benefit for MSM discordant couples. "When you weigh the treatment and prevention benefit, we need to use these agents more, and to make it simpler." So, "there is a benefit to you and your partner, but we don't know the 20 years side effects of these agents." He does believe that using the ART available today much earlier and more aggressively in the United States "is to everyone's advantage, and that would be the hallmark of change in the United States." Meanwhile, PrEP is a little more special. "What are you bridging people to? We need a profound strategy."

Dr. del Rio said when you tell folks that ART may decrease transmission to their loved ones, they look at it in a different way that may influence decisionmaking. In terms of starting early and toxicity, "we're starting people on drugs they will have to take for life, unfortunately. The effect of taking that amount of drugs over your life if you start early is not known, but the number of extra years may be fairly minimal."

Dr. Cohen added that "we're thinking we can cure this infection, and that affects my thinking. I'm thinking this is a lifelong therapy."

Mr. Frost said he wants to echo what Dr. Cohen said. "We think we're going to cure this disease, we have obstacles to overcome, but our mindset has changed."

Dr. Garcia noted the major discussion this morning about youth and asked if Drs. Cohen and del Rio could address the mucosal immunity of younger people. Responding, Dr. Cohen said that there is no explanation for differences between what young women in Africa and America could benefit from. Dr. del Rio agreed.

Dr. Holtgrave said that it seems there is an approximate 180,000 care gap in the United States, based on the gaps graph and the data and the analysis behind it, and he asked if Drs. Cohen and del Rio agree. Responding, Dr. Cohen noted that is a rhetorical question, as Dr. Holtgrave is the world's expert on this. Meanwhile, "we've had fights over this model, but I'd rather hear your opinion." Dr. del Rio said, yes, the issue is many people are needed in care, but we're not sure how many exactly, "so I defer to Dr. Holtgrave." Together, Drs. Cohen and del Rio agreed, however, that "we haven't impacted the epidemic at all in the past 10-15 years."

Mr. Cruz asked, "What are the questions now for PACHA and for New York State?" One of them is how do we use limited resources to tackle this, as there is a cost to applying the O52 findings and providing medication at a higher CD4 count. If resources will not increase, prioritization is needed. This is what Mr. Cruz is grappling with at his level.

Dr. Cohen responded that the system receives 50,000 cases every year, so either you pay now or you pay later. Health economists are working on this. Dr. del Rio said one thing we need to take a hard look at is where the money is being placed. “We need to look at where money is being spent for prevention. We need to reevaluate the old portfolio, and some people aren’t going to be happy with the answers. The resources are not available now or infinitely. If we don’t apply some principles now, we will pay later.” We “need to agree that 50,000 or whatever that number is exactly is too high for a country like the United States, higher than any other developed country.”

Dr. Horberg asked what the guidelines should be for starting therapy. Dr. Cohen responded that WHO is planning to change these guidelines and will release them at the IAS conference in Washington, D.C., next year. “The highest concern is that people be treated before they fall below the level that threatens their health. Further, that benefits interfering with transmission.” In addition, “I think they are right. Let’s focus on those who need to be treated and get them treated because everyone has a sexual relationship.”

Responding, Dr. del Rio said, “We need to do a better job of finding those who are infected. We need to go out and find those with acute infections and their sex partners. Sitting around waiting for someone to show up at a clinic doesn’t work.”

Rev. Sharp responded that, even as you address that, in trying to educate folks, they should know that “when I found treatment for example, I found it couldn’t be given unless I had a certain count. That was a deterrent. Oh, no, it was the ‘no’ medicine for me.”

Dr. Cohen said, yes, you get the stigma and the paperwork without any benefit to your health. He totally understands. Rev. Sharp said couples are different. Dr. Cohen replied that the efficacy of transmission in discordant couples is lower. “We saw behaviors in couples where adherence to the pills was greater than what you see in general practice. We think the partner was helping. We think there is altruism in a couple.” Dr. del Rio agreed that he is seeing this in his practice.

Mr. Frost said when to start to treat is a policy question, so he agrees with the rationale of trying to intervene at the point where people’s health seems to be at risk. “That is based on what we know.” But “if I were to ask you what you would do if you found out you were HIV-positive, what would you do?” Both Dr. Cohen and Dr. del Rio agreed they would take pills—start therapy—“if we had access to pills that are well tolerated and highly effective.”

Dr. Cohen added that he was not in that camp until the 052 study. “Most of the transmissions occur in those with high CD4 counts in the 052 study.”

Mr. Frost said that is important, and “we need to acknowledge a growing body of data around that.”

Ms. Khanna asked whether HIV criminalization is relevant to this conversation. Dr. Cohen responded that he is on the WHO committee that had a meeting on this, and the committee is coming out with strong documentation on misconceptions about HIV criminalization. This may be on WHO’s Web site already. He added that Harvard health economists are doing a regional analysis that takes into consideration, as we analyze the relevant data, what we’re trying to embrace and how much benefit could be realized. “It is difficult not to believe that earlier treatment will have a significant, daily benefit.”

## **Clarification**

In helping to end the HPTN 052 discussion, Mr. Bates said that earlier today, the presenter from NIH, Dr. Kapogiannis, heard some responses and wanted to correct some figures he heard.

Dr. Kapogiannis noted that the NIH budget is \$30 billion overall, 10 percent of which goes to HIV/AIDS funding. The \$150 million he depicted for HIV and youth is most easily quantifiable “after the research is done.” Part of the entire HIV/AIDS budget is devoted to fund basic HIV/AIDS science, such as Dr. Cohen et al.’s 052 study. Populations ages 18-24 do benefit from studies such as these.

## **Update from the Prevention Conference and Black MSM**

Mr. Wilson said he will focus his update on a session at the Prevention Conference devoted to looking at the new incidence data. Over a 3-year trending period, HIV rates have been fairly stable across the United States with the exception of one population—MSM, primarily young black MSM, who have experienced a 48 percent increase in incidence over that 3-year period. This, Mr. Wilson continued, is against a possible backdrop of 46 percent prevalence. In those data, more than 70 percent identified did not know they were positive, much less at risk of infection.

For many of us, these data are very alarming but also reinforce what we have known for some time, Mr. Wilson said, adding that “we will not drive this epidemic down until we address those most at risk, and this includes black women as well. We need to build a capacity among young black MSM to respond in an appropriate manner, for themselves.”

The other important thing Mr. Wilson wants to mention is the knee-jerk reactions some have to these data, as in “why aren’t they changing their behavior?” This is blaming people for their infection, and when you look at behavior, “black MSM are not engaging in riskier behavior than white MSM, yet their risk is much higher.”

Mr. Wilson noted that he is a civil rights baby. He remembers his parents telling him he could not take his lead from others’ behaviors. The point was that when he got to school, other students in his school were not going to be black. His mother told him to remember “you have to be twice as good to get half as far.” Mr. Wilson’s point today is that MSM who are black need to be more vigilant to be as safe as others, but “how can we create an environment where they do not have to be twice as good and where there is sufficient structure for them to protect themselves?” We “must confront structural and social determinants of health. We continue to see incarceration, rising unemployment, and lower college enrollment in the black community. If we are going to be successful, we need to address this. AIDS does not happen in a vacuum. This requires dealing with the whole person.”

Mr. Wilson said he was also alarmed at the lack of mass reaction to these latest data. There was no uprising in the LGBT media. The major organizations did not stand up indignant nor did the black community. What this said to him is, “These men don’t matter.” And “that is outrageous.” Until “we own that they do matter, it will be difficult to build systems that respond to the epidemic in that population.” Mr. Wilson noted that he has often said we are “at a deciding moment, for there are so many things we know and can do. So much of what we’ve heard, including today, speaks to that.”

Mr. Wilson went on to note that we can diagnose earlier, we understand how to prevent exposure, and treatments today are better than ever, yet in the post-ART age, health disparities are wider than they have ever been. With PrEP, we understand the theory about treatment as prevention, and with treatment, we can prevent transmission, so “the question is, are we going to use those tools?”

Concluding, Mr. Wilson said that “when we look at what is happening among young black MSM, it is absolutely shameful.”

## **Disparities Subcommittee Resolution**

Mr. Wilson thanked Mr. Brooks for bringing to the floor the Disparities Subcommittee resolution for full Council consideration. Mr. Brooks noted that he had already received some feedback.

### ***Discussion/Comments/Questions and Answers***

The full Council discussed the resolution before them.

Aside from some language refinements, issues discussed included whether to use language exclusive to one population or use language in the order of “minority needs” and whether specifically to list HHS agencies that should play a role or whether the resolution should primarily address the Secretary.

Mr. Greenwald kept track of changes discussed, helping to write new language when needed and agreed to as regarded, for example, social determinants of health, an NIH research plan, and insertion of timelines and dates.

Toward the end of discussion, Mr. Greenwald checked with Mr. Bates on whether this process was acceptable in moving toward a vote today. Mr. Bates sanctioned the process and noted that 14 PACHA members were still present and that a quorum is 13. Mr. Brooks asked that when the resolution is adopted and sent to the Secretary, a response be requested as an urgent matter.

Following last, brief discussion of transgender populations and data issues, Mr. Wilson suggested that both these questions be taken back to the Subcommittee and dealt with apart from the resolution on the floor.

### ***Resolution Adopted***

Dr. Holtgrave moved for approval of the resolution with modifications. This was seconded by several members. Mr. Bates asked all in favor to so indicate by voice vote, a voice vote was taken, and Mr. Bates stated that the motion had been approved. Mr. Brooks will send the resolution to Mr. Bates for proper formatting, and members will receive a copy when it goes to the Secretary, possibly as early as next week.

## **Presidential Advisory Council on HIV/AIDS Disparities Subcommittee Adopted Motion [No title]**

WHEREAS, the Centers for Disease Control and Prevention (CDC) HIV surveillance report, released on August 3, 2011, underscored the significant health disparities that exist for Black gay and other men who have sex with men (BMSM) in general and young Black gay and other men who have sex with men (YBMSM) in particular, showing that while the overall number of new HIV infections in the United States has remained fairly stable from 2006–2009, there continues to be an increase in new infections among BMSM; most alarming was the 48 percent growth of new HIV infections among YBMSM, ages 13-29, with a statistically significant estimated annual increase of 12.2 percent and,

WHEREAS, the CDC reported in the *Annals of Internal Medicine* on August 1, 2011, that rates of primary and secondary syphilis, an indicator of elevated risk for HIV transmission and acquisition, disproportionately increased in recent years among Black and Hispanic young men who have sex with men, and,



WHEREAS, a study presented at the National Medical Association 12th Annual Colloquium on March 31, 2011, reported that social stigmatization is still the largest barrier keeping African American frontline physicians from routinely testing their patients for HIV, and,

WHEREAS, a study published in the *American Journal of Public Health* in December 2010 reported on the disproportionately pervasive trauma exposure histories and post-traumatic-stress disorder risk in a large survey of sexual minorities, including MSM, and,

WHEREAS, a September 2011 special supplement to *Public Health Reports* underscores a need to address social determinants of health (SDH)—the underlying economic and social conditions that influence the health of individuals and communities as a whole.

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS calls on the Secretary of Health and Human Services to convene a high-level summit (including Government and non-Government stakeholders) on the HIV epidemic and its impact on YBMSM and to create a Department-wide task force charged with developing a comprehensive plan to address all aspects of the epidemic among YBMSM.

We also call on the Secretary to ensure the following: (1) that HIV prevention, care, and treatment funding distribution methodologies are aligned with the epidemic in ways that adequately support the needs of populations disproportionately impacted by HIV, including YBMSM; and (2) that knowledge gained from studies of social determinants of health are integrated into all interventions that might help to reduce inequalities in health.

We further call on the National Institutes of Health to develop and issue a high-priority research plan, by March 31, 2012, that addresses HIV among YBMSM, including evaluating the potential benefits of biomedical interventions (such as PrEP and treatment as prevention) and the use of novel technologies and other strategies to engage YBMSM in care and treatment and combination prevention strategies.

We call on the Health Resources and Services Administration and the Centers for Medicare & Medicaid Services to require all physicians practicing at publicly funded institutions or receiving public reimbursement for the delivery of health care services to undergo continuing medical education (and where available certification) in HIV testing, care, and treatment.

In conclusion, the National HIV/AIDS Strategy envisions a Nation where HIV infections are rare and all those in need of care are granted it without exception. Providing prevention, care, and treatment and all social services that are culturally structured and of high quality to Black MSM at all stages of life is a key milestone to ending the HIV epidemic in the United States.

## **Public Comment**

**Tinselya Simms-Hall** from the Women’s Collective said she attended yesterday’s meeting and heard the conversation about the 30 for 30 Campaign. While the dialogue was great, she heard a sentiment that “we need to be careful of, and that was that until certain groups have certain numbers, they are not worth increased attention.” Mr. Wilson said he was in a place where there was no reaction to the new numbers. “We should have been in an uproar when this group first appeared vulnerable. We do not want to tell people they are not worth attention until they get sick and die because that kind of thing has been said. All are worth the attention that should be given to them.”

Ms. Simms-Hall then noted that the D.C. Community Coalition for AIDS 2012 presented a policy platform for the District of Columbia to the D.C. Mayor’s Commission earlier this week. This is an effort to get a comprehensive plan for D.C. similar to the National Strategy. It also takes matters to another level by addressing possible gaps in the national Strategy.

Ms. Simms-Hall asked for PACHA's support of this policy platform, copies of which she made available to members.

Mr. Bates commented that this coalition is doing what it is supposed to do. All States need to develop State plans, and this D.C. effort is moving forward properly.

**Deborah Fraser**, a consumer, said "I represent the people all this lovely talk is aimed at. We continually face the issue of finding enough money to test and treat everyone. I really suggest that the necessary resources could come from redundant studies and counseling. Who is researching the research, anyway? I have been in a pilot, and I know the money is there. Second, treatment as prevention. This is a radical thought? For a consumer, this is such a no brainer. When you get HIV, take meds. That is not a radical idea. You need to talk to community people more often."

Last, there was an NIH person here, and "I wanted to ask about linkages to care because wherever that sits, it is defined differently, and I did not hear good definitions from this group. It needs to be more than a 'you have three medical visits' kind of thing." There "should be something like a peer model, where you get in there and you have a relationship with a case manager or a provider. Many in our population do not have a good history of developing a good relationship with their provider. You have somebody in care when they keep coming back."

### ***Discussion/Comments/Questions and Answers***

Mr. Jackson asked if PACHA could get a briefing on the dialogues across the country on the Strategy, to which Mr. Bates replied that he would reach out to James Albino at ONAP on that.

Ms. Torres-Rivera thanked Mr. Baker for clarifying the position of some members as to why they are not at some of the meetings. She asked, also, about receiving information about when the different Subcommittees meet so that others can participate.

Mr. Bates said Mr. Joppy has been trying to let everyone know when the Subcommittees are meeting. Everyone will be copied on those announcements.

Mr. Joppy noted that he does not need to know that you are not part of that particular Subcommittee or whether or not you will be participating.

Dr. Holtgrave asked if PACHA is done with the public session because, if so, PACHA could talk about work flow.

Mr. Bates said that in terms of the next full Council meeting, since PACHA wants the Secretary to come, he will explore with her Office what is possible when, and then we can decide whether we wait or go ahead without her and so on. This also has to do, he added, with whether the next meeting is held in Washington, D.C., or away.

### **Executive Session (PACHA Members Only)**

After the Executive Session, Mr. Bates adjourned the 44th meeting of the full Council.