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AIDS at 30: Where we Are Today and What's Ahead Kaiser Family Foundation June 21, 2011

JEN KATES: –Good afternoon everyone. Welcome. I'd like to welcome you all here on behalf of the Kaiser Family Foundation. I'm Jen Kates. I'm obviously not Drew Altman. Drew could not be with us today because his father is very ill and he's with him now but Drew very much wanted to be here because of his commitment to and passion for addressing this epidemic, which for him began in the 1980s when he was at the Robert Wood Johnson Foundation and a mission he brought with him to Kaiser and made part of our institution's mission. We've had strong board support for that as well as by senior leadership from Diane Rowland and many of us staff at the Foundation have play a role and are very committed to this.

Since Drew's not here, I just want to say on a more personal note, all of us have our deciding moments, those everyday opportunities when you take a stand against HIV or you are greater than the disease. Mine was more than 20 years ago

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at a moment when I decided to commit my career to fighting HIV and change my life going forward. I want to publicly thank Drew for his deciding moment to fighting HIV part of KFF's mission because it's really a firm part of what we do. It's in our policy work, in our survey research and polling, which you'll be hearing about today, and the policy work not just on HIV but across the foundation on Medicaid, on Medicare, on women's health and disparities, in our journalism work at Kaiser Health News and of course most visibly in our big media campaigns and partnerships, which run across the U.S. and internationally including Greater than AIDS. We'll spotlight Greater than AIDS today when we talk about the impact of the epidemic in Black America.

In other words our work in HIV cuts across our entire organization and will remain a priority for Kaiser as long as there is an epidemic. I know that I'm speaking Drew's words because he actually wrote that specific line when he thought he was coming and I thought it was important to say it.

Today's event recognizes the 30-year mark of the epidemic, which still seems unbelievable to me. We'll be presenting two new surveys. First, we'll hear about our new national survey on HIV/AIDS, which we have done seven times before. So we have a really unique repository of trend data on what Americans think about the epidemic. We also will be hearing about a new Washington, D.C. survey we did with our

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partners, *The Washington Post*. It's our 22nd joint survey project with *The Post*, our first one beginning in 1995 and given that D.C. is one of the epicenters of HIV in the U.S. and we all are here, we felt strongly at the Foundation and *The Post* too that we wanted to gauge views on the epidemic here in our nation's capitol.

We'll also hear from our good friend and true leader in the fight against HIV, the Director of the White House Office of National AIDS Policy, Jeff Crowley, who as we all know, is instrumental in developing the first ever comprehensive national strategy on HIV for the U.S. Then we want to focus in on the impact of HIV in Black America. We'll spotlight the Greater than AIDS campaign, which we developed and operate with Phil Wilson and the Black AIDS Institute and many partners across the country, several of whom are here. That will lead into our distinguished panel, which will be introduced to you later on. We'll end the evening with a reception downstairs. Everyone can visit together more informally.

Before I wrap this up, since we're here at the 30th year mark and of course through the magic of our video production unit headed by Jackie Judd, who's here, and the hard work of Francis Ying and Renato Perez, we have a short video that remembers some of the key highlights and moments in the last 30 years and it's available to everyone here and beyond on the Web if you're interested. So we'll watch that.

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[VIDEO 00:04:00-00:08:13]

JEN KATES: So clearly tremendous progress has been made, much of it scientific but of course we know much of the progress is due to everyone here and the community that fights tirelessly on this epidemic. There are many opportunities that we all know are right here. The national strategy itself, which talks about focusing resources where the need is greatest, where the hardest hit places are in the country, that's a step forward and an important direction. The new 052 trial results that we're all still pretty excited about, the return of the International AIDS Conference next summer for the first time in more than 20 years because of the lifting of the travel ban, and we still face some real challenges and I'm sure many of them will come up today but we're hoping that today will also be a constructive and engaging conversation, ways that we can really try to make a difference. So with that, let's hear about our survey results. I'm going to turn this over to my colleague, Dr. Mollyann Brodie, who's our Senior Vice President at Kaiser and Director of our Public Opinion and Survey Research Program and Jon Cohen who's the Director of Polling and the Polling Editor at *The Washington Post*.

MOLLYANN BRODIE: Thanks Jen. Good afternoon everyone. As Jen said, what I'm going to talk about today is the eighth survey in our series that we started in 1995. the goal of the series and the surveys are to better understand the evolution

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of public opinion towards HIV and national efforts to prevent and treat it. So what I'm going to do is first show you long, broad-term national trends that we've seen over the decades and then I want to take a deeper look at the views and experiences of Black Americans, certainly one of the communities that have been severely and disproportionately affected by the epidemic. Then we'll take a quick look at the trends and reporting on HIV on reporting of people's testing.

There's a lot more. Everything I'm going to talk about today is in the reports that are in your packet and I have to say there's a lot more data in your packets. So I'm going to sort of do the highlight reel. I do want to first thank Liz Haml, Claudia Deane, and Bianca DiJulio for their extraordinary work on this project and on this survey series over time.

So let's just start with national views. So first off, let's think about the visibility of HIV in the public sphere. It's perhaps not surprising, 30 years into the epidemic, that there's a declining sense of national urgency and declining visibility of HIV. You can note here how few now name HIV as an urgent problem facing the nation, seven percent, you can see that bottom of that blue line. It's fallen from a high of 68-percent in 1987. Fewer and fewer are now telling us that they are hearing or seeing about HIV suggesting that the visibility and the prominence of the epidemic in news coverage is declining as well.

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So notice here that in 2004, 34 percent told us that they had seen or heard a lot about HIV. That's down to 13 percent today. Now along with this decline in visibility and a declining sense of urgency, we also see a decline in the share saying that the U.S. is losing ground in the epidemic. That's the orange line. It's down to 18-percent today. Alternatively and on the other hand, we're seeing some slow increases in about 40-to-50 percent of Americans think the country is making progress towards the disease. Now certainly after watching that video and being reminded of some of the key events over the last 30 years, it's hard to disagree with the public on this point but I guess the question and something that's probably worth talking about later in our discussion is, "what's the pace and the direction of that progress as we move forward?"

Certainly these changes and advancements in treatments over time have contributed to the sense of progress and you can see that here. Now 30 years into the epidemic, the vast majority of people believe that people with HIV can lead healthy and productive lives. About half also see HIV as a manageable chronic disease but what that means is the other half still see HIV as something different than diabetes or having high blood pressure.

On another long-term trend that I think is important to note, especially considering the long-term economic challenges

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the country has been facing, is you see here that half of Americans still support increased spending for HIV and AIDS. That's the blue line. Only one in 10 or less say that the federal government spends too much in this area. That's the orange line. I guess what this suggests to me is that perhaps a heightened sense of urgency among the public is not necessarily a precondition to the sense that resources can help.

Now one last point on this issue about visibility and the epidemic. The survey found that three-quarters of Americans could not name a single individual who stands out as a national leader in the fight against HIV. No person who was mentioned made it into double digits. As you see here, most Americans say that there has not been enough action on HIV from a variety of groups and institutions starting with Congress and including corporate America, religious leaders, pharmaceutical companies. While I think for many of you here who've worked so tirelessly on the issue, it's unfortunate that the public isn't necessarily hearing about the work that's being done but what I think we need to take away from this is it's yet another indication that the visibility of actions and efforts on behalf of trying to address this epidemic are just not going seen.

Now what else have we seen about the public over these last years? This is their level of knowledge about HIV and we all know how important knowledge is to ultimate behavior change

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and to people's attitudes. What we saw early in the epidemic is it was a steep learning curve but since 1990, misperceptions about transmission have stubbornly persisted across the public. Currently about one in three think that HIV can be transmitted either by sharing a drinking glass, touching a toilet seat or swimming in a pool with someone who's HIV-positive.

Furthermore, about half still don't realize that there are drugs that a pregnant woman can take to reduce the risk of transmission to her baby. One in five don't realize that there's no cure for AIDS at present. One in four believe that Magic Johnson has been cured and another one in four believe that there actually is already an AIDS vaccine. Now certainly these misperceptions can have serious consequences for individuals but they also have serious consequences for people's broader attitudes.

One of the things we've been looking at is people's attitudes and comfort around people who have HIV. What we find is that many Americans still hold attitudes that may stigmatize people with the virus, but these reports in these attitudes have declined in recent years but perhaps not nearly as fast or as far as people think is needed and certainly is needed. So if you look at the blue line, in 1997, 32 percent of the American public told us that they would be very comfortable working around someone who has HIV or AIDS. That's risen to 49 percent today but what this means on the flipside is that still

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today, 30 years after the epidemic started, in 2011 substantial shares say they'd be uncomfortable having food prepared by someone who is HIV-positive, having an HIV-positive roommate, having a child in a class with an HIV-positive teacher, and working with someone who's HIV-positive. Now the persistent misperceptions that I just showed you on knowledge related to the disease are important because our research has shown that those misperceptions are related to holding these potentially stigmatizing attitudes. That is, people who know less are considerably more uncomfortable than people who know more.

Now there have also been some real declines since the early years of epidemic in the share expressing the views that AIDS is a punishment or that it's people's own fault if they contract the disease, but these extremely negative attitudes are still held by a significant share of the population, 29 percent and 16 percent respectively. But it is certainly many fewer than in 1987 and perhaps most notably in looking at these long-term trends that we've measured, is that after nearly a decade of decline, the share of Americans who say they are personally very concerned about being infected has ticked up for the first time this year. That was largely driven by young people where almost a quarter now report being very concerned about the epidemic.

Now I certainly don't need to tell anybody in this audience that HIV has placed a disproportionate burden on Black

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Americans. I know we're going to have a lively and informative discussion about that in just a few minutes. so I'm just going to take a few slides to talk about the views and experiences of Black Americans towards HIV. So first of all you notice here that Black Americans, and particularly young Blacks, express much higher levels of concern about HIV than Whites. They're four times as likely as Whites to say that they're very concerned about becoming infected with HIV and Black parents are three times as likely as White parents to worry about their children becoming infected. For young Black adults under 30, worry is considerably more ubiquitous. Half, 51 percent say that they are very concerned about becoming infected and another 15 percent are somewhat worried.

Now HIV has personally touched a large swath of the American public. Four in 10 tell us that they know someone or have a close family member or friend that has HIV or has died of AIDS but this rises to almost six in 10 among Blacks and Blacks are more than twice as likely as Whites to say it's a close friend or family member who is living with or has died from AIDS. That's that 41 percent in the dark blue in your second bar versus the 17 percent in the dark blue at the end. Perhaps as a result of these more close personal ties to HIV, Blacks are almost three times as likely to see HIV as an increasingly urgent problem for their community. That's the 35 percent in the blue line versus the 12 percent in the orange

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line at the end of that trend. But there's also something else to note about this chart and that's at a time when HIV continues to place it to disproportionate burden on the Black community, many key measures of concern and visibility in these surveys are not necessarily increasing for Blacks. They're flat or turning downward over time. For example here, you see the share of Blacks saying HIV is a more urgent problem for their community than it was a few years ago, fell from a high of 49 percent in 2006 to 35 percent today. Similarly the decline in visibility of the epidemic that we saw before for the nation overall is also reflected in the views and experiences of Blacks. While 62 percent of Blacks told us that they had seen, heard or read a lot about the problem of AIDS in 2004, now just 26 percent say the same. These are all important starting points for our discussion coming later.

Now lastly, let's just take a look at the reported testing rates and the one thing that you can't help but take away from these charts is how incredibly flat they are. Reported testing rates have been flat since 1997 including among some of the key groups at higher risk. Note here that about half of those ages 18 to 64 say that they have ever been tested and one in five say they were tested in the past year. These are shares that have been completely stagnant over time. Note here that while we note that Blacks are more likely to report being tested than Whites, that's the blue line versus

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the orange line, their reported testing rates have also been roughly the same since '97. This is true again for younger adults. There's a persistent and stagnant reported testing rate for young adults and for young Blacks as well.

Now as I think all of you probably know and was certainly mentioned in the video, in 2006 the CDC began recommending routine HIV testing in health care settings for anyone between the ages of 13 and 64. Now clearly data I just showed you indicate that this hasn't necessarily happened but it's a potentially positive first step. We do see a small increase in the share saying their doctor suggested they get tested. It increased from 19 percent in 2009 to 29 percent today. We also see that almost seven in 10 Blacks, about half of Latinos and four in 10 Whites report that they have talked with a health care provider about HIV. I'll also note that many, particularly young adults, report talking to their partners about HIV. So at least some of these very important conversations seem to be happening.

Now in this eighth survey, we also found what I think won't come as much of a surprise and that's that the media, which includes broadly radio, television, newspapers, and online sources, is the top information source on HIV across all racial and ethnic groups and across older and younger Americans but what might be more of a surprise is that substantial shares of the public and majorities of Blacks and Latinos say that

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they want to have more information on HIV-related topics including prevention and testing. this means that there is a receptive audience out there for people who are still interested in educating and increasing awareness and opportunities around helping people make better choices and know about testing and how to talk to partners and how to prevent the spread of HIV.

I want to just quickly do the four takeaways that I think are really a way that we need to start our broader discussion and really the things that I hope you take away from this particular iteration of the survey. So certainly we saw that visibility about the epidemic and the public sense of urgency is down, but one of the things that has ticked up is the personal concern about the disease and about getting infected, especially among young people. I think that does mean that there is an audience out there for all of the activities and the efforts that many of you are involved in.

I think it is impossible not be struck by the extent to which this disease's impacts are so disproportionately felt in the Black community. We saw that Blacks are much more likely to know someone touched by AIDS. They express more worry about it. They view it as the nation's most urgent problem. Still many of the key measures of concern are either flat or trending down when we might hope that they would be going in a different

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direction given the disproportionate burden that is still happening in the Black community.

I think the stagnant rates of testing are also of concern. It is something that should be discussed and thought hard about. It was certainly encouraging to see that doctors seem to be talking more about getting a test but yet we're not seeing that reflected in actual changes in reported behavior. Finally I do think it's worth noting that 30 years into the epidemic, substantial shares of the public continue to express discomfort at the idea of interacting in various situations with people who are HIV-positive. This expressed discomfort is linked to knowledge about transmission and so it's also disconcerting that a third of Americans continue to be misinformed about some of these basic facts. So I'm going to stop here and let Jon talk to you about our recent survey in the District that also tackles some of these topics and then afterwards, we'll have time to take your questions and see what you think of all this data. Thank you [applause].

JON COHEN: Thank you very much. A lot of what Molly talked about were trends over time. We don't have that luxury with this survey of Washington, D.C., this is the first time we've asked many of these questions of our local community. So a lot of the comparisons I'll be making are between this survey and the national data that Molly just said, just talked about but it's really interesting to look at some of the similarities

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and differences between residents of Washington, D.C. and national opinion on these essential issues.

I would like to thank the Kaiser Family Foundation for partnering with us on this survey. As Jen mentions, it's the 22nd in the partnership that also started in 1995 much like some of your national trends on the HIV work. We did a recent recession survey just this spring and so this is the second this year and it's a tremendous thing for *The Washington Post* to be able to present these great polls. So we appreciate the Kaiser Family Foundation's support in doing that. The first slide just shows the stark differences between the public perception of HIV/AIDS in the district compared to national opinion. The seven-percent you see on the left of U.S. adults nationally saying that HIV/AIDS is the single most urgent national health problem that compares to 36 percent of district residents who say HIV/AIDS is the most pressing health care issue facing the district. That's a dramatic difference. The 36 percent compares to about where the U.S. public opinion was in the mid 90s I believe if we remember back to Molly's slide.

We called about 1,300 of you, those in the audience who live in Washington, D.C., may have called you on your landline telephone at home during dinner or on your cell phone and we appreciate your participation in this poll. We did do a slight oversample of African Americans for a total of 812 Black respondents in this survey so we're able to break apart African

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Americans into age groups and income groups much the way that Molly and her team have done with the national data.

In terms of how serious a problem District residents perceive HIV to be in this community, fully 39 percent call it a very serious problem. A total of 59 percent call it a serious one. Concern varies a lot by race. Molly mentioned the disproportionate impact that HIV/AIDS has had on the Black community and that's certainly noted by residents. If you look at the top line, African Americans under 40 years old, 63 percent say HIV/AIDS is a very serious problem in their community that compares with just 23 percent of Whites aged 40 and up. These differences extend to whether or not people, they themselves, know someone who has AIDS. Fifty-eight percent of all D.C. residents know someone who has AIDS or has died of AIDS or has tested positive for HIV. That compares with 41 percent of all adults nationally in the poll that Molly just talked about.

There's a big difference between African Americans here in the city, 65 percent of whom say they know someone who has AIDS or died of AIDS or has tested positive for HIV compared with 54-percent of White adults here. Those are both high, or both among African Americans and Whites are higher than national numbers so that by about the same margin although slightly higher among Whites than African Americans. Molly talked about the level of comfort that people have dealing with

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people who have HIV. Fifty-five percent of all adults in D.C. say they would be very comfortable working with someone who has HIV or AIDS. That's slightly higher than the 49 percent we saw nationally. There's a big gap here between White and Black adults, 71 percent of White adults in the District told us in the survey that they're very comfortable working with someone who has HIV or AIDS compared to 47 percent of Black adults. Interestingly, there's little racial difference on this question nationally. There's this large gap in D.C., not sure I can answer why but further study is necessary on that question.

Despite the big differences between D.C. and the nation, there's little difference when it comes to concern, 17 percent of all District adult residents are very concerned about contracting HIV very similar to the 18 percent nationally. There is over, as we saw before, big differences on this question by race, 29 percent are concerned that they themselves will be infected with HIV. It's 44 percent among Black adults, 11 percent among Whites. I should note Molly also mentioned how likely people are to discuss HIV/AIDS with their friends and family. Here we have a big difference by race, about half of African American adults in the city say that they discuss, at least sometimes, HIV/AIDS with friends and family. That's about double the proportion among Whites.

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One of the things that Molly ended with is the problem with continued misperceptions in this area and we see that in D.C. as well. If you look at the top line, whether a pregnant woman who has HIV can take certain drugs to reduce the risk of her baby being born infected, 47 percent nationally gave an incorrect answer, that's just 31 percent in D.C. where in some cases, knowledge is a lot higher. But when it comes to those two questions about whether Magic Johnson himself been cured of AIDS and whether there's a vaccine available to prevent people from becoming infected with HIV, there's virtually no difference between national adult misperceptions and the misperceptions of adults here in Washington, D.C. So I'm going to end the brief comparative note on that question. I just want to point out this is part of the larger survey that we did with our partners on life here in the District that we've been reporting all week. Darryl Fears, *Washington Post* national reporter who will be leading the panel discussion later, wrote the article that appears in the pages of *The Washington Post* today on HIV and I look forward to your questions [applause].

JEN KATES: We actually do have time for questions. So please take this opportunity. I'm still struck by seeing the differences between D.C. and the national findings. It's really striking. So any questions? There are mics. So just please say who you are and a mic will appear before you.

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SARAH AUDELO: Hi, my name is Sarah Odelo and I work at Advocates for Youth here. Did you break down any of the data by age especially the data in D.C. about young people and their concerns? Thank you.

MOLLYANN BRODIE : I'll start. In the report you have here, there's an entire chapter of young adults. The survey of adults who is 18, which I know in a lot of cases is too old for the types of attitudes and experiences you'd really like to know when you're talking about this, but we have 18-to-29-year olds, we have an entire section of the report focused on that. In the D.C. data, Jon do you have some here?

JON COHEN: I have a lot of it here and I'm happy to send you more if you want. We have breakdowns. We're somewhat limited in terms of the age breaks we can give but we can certainly give for any of the questions we ask African Americans under 40 and above 40 and likely at the higher age points as well.

JEN KATES: Others?

JON COHEN: Can I just say if anyone wants any of these data, we're happy to provide them to you. we're polls@washpost.com, p-o-l-l-s@washpost.com.

SPIA PARASHI: Hi, Spia Parashi from Planned Parenthood. I was curious also when it came to statistics for the District, did you by chance break it down by northwest, southwest, northeast, southeast, by section as well?

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JON COHEN: We do. So we have the answers by quadrant, can only talk about three of the four quadrants in D.C. because so few people live in southwest but we can break those down and we can also break them down by African Americans within certain quadrants. Just on the root question, I have any particular question you have about the data. I can show you the breakdowns but on just whether HIV/AIDS is the single most important health problem facing District residents, there's really little difference by ward. White residents of northwest are somewhat more apt than African American residents of northwest to say that HIV/AIDS is the top health concern and that dips a little bit when you get to southeast but it's the breakaway top concern in all quadrants of the city but we have quadrant and ward data as well.

SPIA PARASHI: Okay, thank you.

MOLLYANN BRODIE: I would also just say that one of the things that's great about our partnership is even after *The Post* is done running their stories, we at the Kaiser Family Foundation, tend to be able to do additional analysis and publish sort of additional reports based on the data that can dig down a little bit deeper. And actually we have planned an HIV in the District data note that should be out in a week or two. So we'll make sure everyone who's here has access to that if you're interested.

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JEN KATES: There's a question back there and then up front.

RYAN CARPENTER: Hi, I'm Ryan Carpenter from the National Coalition of STD Directors. I am curious as to why, if there's any research, despite CDC recommendations, how testing has not gone up.

MOLLYANN BRODIE: I'm sorry, can you repeat the question? You want to know why testing hasn't gone up despite the recommendation?

RYAN CARPENTER: The CDC recommendation yes.

MOLLYANN BRODIE: That is the \$60 million question isn't it? Certainly I think the panel can talk about some of that coming up. I mean what we know from the data is what people are reporting on. Certainly the first step is having conversations and having people more desiring and recognizing the need and the positive outcomes of being able to get tested. So I think that the panel that's coming up should be answering this question but I can just tell you what the public says about it right now.

JEN KATES: I can add a little bit from some of the policy work we've done and work of many in the room, the CDC recommendation was for routine HIV screening in health care settings. So the idea there is when people are going to get a routine health visit, there shouldn't be a missed opportunity to get HIV testing. I think as we just saw for the first time,

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we're actually seeing people say their providers are suggesting testing more. Getting providers to start offering routine testing is a barrier and a challenge and actually the Institute of Medicine came out recently with a study that said that. I think the other side is that it's not just about routine testing in health care settings. It's also people needing to know when they should get tested and we saw from our survey a lot of people want more information about when they should get tested. People still have a lot of questions about whether they are at risk, should they get tested? So it's both the individual as well as the system.

We also have on our site, Tina and I were looking at the state breakouts of testing rates by state and there are some significant differences across the country. So one of the things that would be interesting to explore is where places like D.C. have launched big campaigns, you actually see much higher testing rates.

CAROL TRESTON: Hi, I'm Carol Treston with AIDS Alliance for Children, Youth, and Families and I'm going to guess that you did a gender breakdown on answers and I'm wondering if you have in your plans to do an analysis of women's beliefs and concerns and that sort of white paper on that.

MOLLYANN BRODIE: Certainly and also as I said, if you look through the report, there's a number of the findings that

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are already broken out by men and women. Some of the attitudinal stuff is particularly interesting. I will say though that the gaps between men and women aren't nearly as interesting as the other gaps that we've been showing you today. So there's certainly some there but what we find more often than not is how similarly men and women actually think about health care issues but there are some important gaps. Most of those are already highlighted in the report and we will continue to tease those out and get them out to you.

JON COHEN: I will say in terms of the D.C. data, I spent some time looking at, among African Americans, whether there were big differences between men and women and there were not on some of these core AIDS questions about concern and discussions. So it was surprising, to Molly's point, the racial gaps were far larger than the gender ones and most of these questions.

JEN KATES: We have time just for two more questions, one back there and then Mark up here.

JEN: Thanks, Jen with the Sexuality Information Education Council of the U.S., I'm wondering if the D.C. poll asked a similar question about residents, how residents felt about whether the District government, whether the Mayor or local nonprofits were doing enough around the issue of HIV/AIDS?

JON COHEN: We did not unfortunately.

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MOLLYANN BRODIE: There's an awful lot of other questions in that survey about the D.C. government that you may find very interesting about reactions to other kinds of issues in the area but just not HIV.

JON COHEN: The survey shows a lot of criticisms of the D.C. government and that was in our Sunday paper. It costs \$1.50 but it's worth it [LAUGHTER]. In terms of what residents in D.C. want the Mayor to work on most urgently, city government itself is mentioned by about 15 percent of all voters in the city. That's tripled the number of unaided mentions we've seen on that question in the past. So there's a lot of focus on city government now, how much of that has to do with is HIV/AIDS policy is unclear.

MOLLYANN BRODIE: I just want to make one more plug for the report but we talked a lot about HIV testing here but given some of the people who've gone up and spoken, in this survey for the first time, we also asked about testing on other STDs and there's a whole pull-out section on that in here as well that you might find of interest or of use.

JEN KATES: Two more quick questions, we already have them queued up.

FERDETTA WEST: First I just want to say thank you for convening this session. I'm Ferdette West with the Racial and Ethnic Health Disparities Coalition and African American Health

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Alliance. To what extent did you assess solo providers and health plans with regard to testing?

MOLLYANN BRODIE: So we did not ask people exactly. We asked people whether they got tested as part of a routine exam or whether they went in special and we have that data in the report but we didn't ask about whether it was actually at a clinic or in their doctor's office. I don't think we did. We did? We might have.

JEN KATES: It was not in a survey of providers.

MOLLYANN BRODIE: Yes. It was not a survey of providers. So we may be able to see, Liz will have to clarify we've asked that question or not. We've done it in some years and not others but we certainly ask them about whether they thought it was part of a routine exam or whether they had gone specifically in for it. So that is also in the report.

FREDETTE WEST: But is that within health plans too or—

MOLLYANN BRODIE: We don't know specifically about their mechanism is.

JEN KATES: Quick, Mark.

MARK ISHOK: Hi, I'm Mark Ishok from AIDS United. Thanks for really fascinating data and presentations. So I'm not surprised by the misinformation that folks have or the understanding the facts and not wanting to be disturbed by the facts. So I'm not really surprised that they're really high and stagnant in some ways but I'm curious how it compares to

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other polling that you've done on other issues because I think this is a country of people that misunderstand or deliberately misunderstand the facts, evolution, birthers, you name it. So I'm just curious how it compares to other health and social data that you've looked at over the years.

MOLLYANN BRODIE: That's a great question. Of course there's lots of facts that people misunderstand some of it. They understand things based on their ideology whether or not they are facts but some things, they're just complicated. There's a lot of policy in a lot of things that are complicated. Today I was actually looking at some of our views of the Medicaid program and there's, half of people who understand who the Medicaid program serves and half who don't. Is that glass half empty or half full? We were having that discussion earlier. So I think that you're certainly pointing out something that's important to keep in mind for the context but I think that the thing that makes it that much more potentially important to educate in this arena is that we see it so clearly related to attitudes and to particularly stigmatizing attitudes.

So in other areas if you don't know who's served by a program or you don't know whether it's a budget deficit or a debt whatever, it may or may not impact your attitudes but in this case, we see such a direct relationship to misinformation and then how people think and feel about people with HIV. So

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from my perspective, at least in this case, that relationship is so important that it really does argue for continued education effort.

Then the other piece is there's such a huge personal behavioral choice piece about being well informed about this particular transmission and things like that. So I think from both sides that even though the lack of knowledge might be pretty similar to a lot of the other policy areas, the impact about lack of knowledge might be different in this area and disproportionately different enough that we should care a lot about it.

JON COHEN: It's also about how stubborn those numbers are. They have not moved as much as some may like them to. There is a lot of misinformation out there but people aren't immune to the facts. So you mentioned the birther question. We saw 20 percent or so of the American public said that in our *Washington Post* surveys that Barack Obama was born overseas mistakenly. When he released his long form that dropped in half to 10 percent. So it was immediate kind of impact of information out there that we haven't seen when the information and the facts get out there in this arena. They're much more stubborn.

JEN KATES: Okay, thank you so much. Thanks to both Molly and Jon [applause]. Now I'm going to ask Jeff Crowley to come up to the podium. Jeff, as I mentioned before, is the

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Director of the White House Office of National AIDS Policy and Senior Advisor on disability policy for the White House. Many of us have worked with Jeff for years in many different capacities. We're thrilled to be able to hear from you today on the strategy and where it is and what you're thinking just ahead on its almost one year anniversary. So thank you.

JEFF CROWLEY: Thank you Jen. I also want to thank Kaiser Family Foundation. I was listening to what she said about Drew and I'm sure he did want to be here. He's shown a longtime commitment to HIV but he also has a deep bench here because listening to all the staff at Kaiser that really care about this issue. I just want to thank all of them for the important work you're doing today but have done for a long period of time.

So I want to talk, as Jen mentioned, about sort of where we are sort of one year out. One of the things I always say is it feels like we have a lot of momentum and we've also had, in the work we're doing, a lot of support from the community. I think many of us have been doing a lot of reflection as we've commemorated or acknowledged the 30th anniversary but we also have to acknowledge that we've maintained a strong level of support from the American people. We can always argue and I do believe that we need more resources but we maintained a strong commitment and this year, the federal government alone will spend about \$21 billion

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responding to the domestic HIV/AIDS epidemic. That is significant and that hasn't declined.

So I think there are a lot of reasons that give me hope. I also believe that this is a unique moment of opportunity for our country.

There are three main things that I think are coming together and we're lucky that they're coming together all at the same period of time. One is the national HIV/AIDS strategy. I do believe that HIV community pushed for this. The President committed to developing it but we do have a roadmap finally. Again some of you have heard me say this and I'll be a broken record, it's not a federal plan. It's a national plan. So hopefully what's significant is we're really saying what does the nation need to do collectively? What are the small number of steps? I do think that that is important.

The next key thing is the research we've seen over the last year, year-plus. It's a really exciting time to see all this research from the Caprica study about vaginal microbicides, about the iPrEx study, about pre-exposure prophylaxis. It involved an oral pill in gay men but has broader implications for other populations. Then the study that Jen mentioned, the HPTN052 study that showed that really significant role that HIV treatment plays in preventing HIV transmission. So we have a strategy, we know where we're going, we have research that reinforces more than ever the

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direction we need to go in. so much of this turns on treatment both for people living with HIV themselves but also for preventing HIV infection.

The third thing that's significant is I'm not saying it's perfect but we do have an Affordable Care Act that took decades to get and provides a platform for expanding access to insurance coverage. Now insurance coverage alone isn't going to solve all of our problems but it creates new opportunities to work on the other issues that are involved in getting people to know their status, getting them into care, and kept in care, and on therapy, and adherent to their regimen but these are all things that are made easier because we have this focus now and we also have this pathway where we're going to expand access to insurance coverage.

Now it's been an amazing time over the last year and sometimes you can just sort of say, a lot's going on. When I think about what are the things that we've done significantly since we released this strategy, I want to just point to four things. The first is there is a new focus and energy in our efforts certainly within the federal government and to respond to the domestic epidemic. When the President came into office, there was a conversation and a lot of things we said is the PEPFAR program is really great and the American people are doing great things to save the lives of millions of people around the world that are living with HIV. I actually, last

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month, spent some time in South Africa in Swaziland and I knew and I was a Peace Corps volunteer but to be there and to see people tell me that we're keeping them alive, the American people are, it's an amazing thing but the corollary with that is we focused so much for years on the global epidemic, pandemic, we haven't focused on the domestic epidemic. So I think we have seen, in the last year at the federal level, a big area of focus.

In developing the strategy, a number of people were saying we need to institutionalize new leadership at the federal level and there was some talk about different models. What we've done is, I actually believe that it's important and I've learned this since I've been in my job, to have someone in my job, to have someone in the White House who's focused on HIV but there's certain things that don't make sense for me or are really inappropriate to be done from the White House. So when we released this strategy, we also tasked Secretary Sibelius, the Secretary of Health and Human Services, with new responsibilities. She's delegated that to Dr. Koh, the Assistant Secretary for Health. What he's done is he's hired a new position, Deputy Assistant Secretary for Infectious Disease, Dr. Ron Valdesari and Dr. Koh and Dr. Valdiserri have been working day and night really trying to improve coordination within HHS but across the federal government. So there are a lot of things that are going on. I mean I could

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tick through things that we've done at the White House agencies but it's a new level of energy is the first thing.

The next thing I think is significant is that in February of this year, we had previously identified six lead agencies for implementing the strategy and they released operational plans. So when we released the strategy last July, we released the strategy itself, a federal implementation plan, which was intended to really say we're serious these are some concrete things the federal agencies are going to try to do but the President also issued, on that day, a Presidential memorandum that directed that certain things happen. It was really about reinforcing the idea that we weren't just releasing a report and moving on. This was an ongoing effort.

So these six lead agencies, Health and Human Services, Housing and Urban Development, the Department of Justice, Department of Labor, the Social Security Administration, and the Department of Veterans' Affairs, they were asked to identify senior leaders to be responsible for coordinating HIV/AIDS policy in their agencies. They've all identified Senate level, Senate-confirmed positions, generally assistant secretary level people. So at HHS, we have many agencies, Dr. Howard Koh is responsible for coordinating. So I think that's significant.

They also though, the Presidential memorandum also, as I mentioned, delegated to Secretary Sibelius, responsibility

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for improving coordination across the federal government and the President also directed that the agencies come up with detailed operational plans, which they submitted to us last December and then we released in February. What I think you'll see is a lot of thought has gone into looking at the roadmap of the strategy and then each of these agencies saying what are the concrete things we're going to do to implement the goals and achieve the metrics we set up.

So then the third thing that is significant is you all know these are tough times but we're making strategic new investments in HIV. So every budget the President has proposed has proposed increases for HIV prevention. I would note that when he came into office, we basically flat-funded HIV prevention for about a decade. We fought for increases in treatment except for the last budget we have been steadily increasing funding at the NIH. We've been increasing funding HIV programs at Veterans' Affairs but last summer when we released the strategy, we allocated \$30 million for the prevention of Public Health Fund. This year the FY11 budget was really difficult on some agencies.

The Centers for Disease Control and Prevention, they had to cut \$740 million from their budget but yet we increased HIV prevention funding by \$31 million. We have a very serious challenge of waiting list of state ADAP programs. Much of this, not all of it, but much of it is related to dynamics of

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state funding but we fought for increases and again in a tough environment, we increased funding by \$50 million. I think part of the story is the money but part is also where we're putting the money and trying to be really strategic.

The last thing is I think we're starting a path we're making really significant policy changes. One of the things when we put out our budget for this year we committed to is CDC and HUD changing the funding format. So when we award funding through these agencies, we're going to do it through living HIV/AIDS cases. In some cases, we've relied on cumulative AIDS cases, which gives us more outdated data. So we're really trying make sure we use the most current best data to make equitable resource allocations across the states but also there's a number of things. If you look at CDC, for example, we're starting to communicate this idea that we do lots of things but some are more effective than others, so really trying to identify those that are both scientifically proven to be effective but also can be taken to scale.

So one of the things we did is we launched, there's at CDC a program called ECHPP, the Enhanced Comprehensive HIV Prevention Planning Program and that's grown into a broader initiative at CDC called the 12 Cities' Initiative but it's really about going to the 12 cities or metropolitan areas with the highest HIV prevalence in the country responsible for about 44 percent of AIDS cases and really saying how can we really

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work with these health departments to do integrated planning for say pull together their planning for prevention and care, look at the resources available at the state and local levels from the private sector and really come up with smart ways to have a bigger impact. Again, if you look at it in there, there's some things where the CDC is saying these are required interventions, these are recommended. So some of these policy changes we also think are going to have a big impact.

Now one of the things that we recognize in the strategy and actually we think we cited in a previous Kaiser public opinion survey and it's challenging to see how the percentage of Americans ranking HIV as their primary health concern is the challenge. If it feels like people are moving on and a key part of our success is making sure that the American people remain invested in responding to the HIV epidemic.

So when I look at the survey, as I'm sure all of you can, there's some good news, there's some bad news but some of the good news is that the nation believes we're making progress in AIDS. Yes we have a lot to do but we should celebrate this progress. Sometimes, as advocates, I feel like it's almost as though you can't say something good without saying oh here's the challenge. We are making progress and we should be happy about that and happy that people see that. Also it's encouraging, these are tough times but the American people

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still support the funding investments we're making and it's encouraging to see that people think we should be making more.

Now some of the bad news, just these declines in Americans who said they've seen or heard or read something about the domestic epidemic has declined from 70 to 40 percent from 2004 to 2009. One in three Americans still believe they can get HIV from sharing a glass, a pool, or a toilet bowl with a person living with HIV. That's really challenging to know what to do with that. Now I have to say when I look at these, I'm more worried about the decline in the percentage of people saying they've heard something about HIV than ranking HIV as the most urgent problem. We have lots of challenges and people are always having to adjust those but the fact that people aren't hearing about it, that's really troubling.

I also would say that I think there's some wisdom in these surveys. I think sometimes we can be cynical and say well what does the average American know about HIV anyway but there's some truth here. We do have some really serious challenges with access to treatment. Those concerns are real or even looking at the way Black Americans are more concerned about HIV. They should be because their community is more heavily impacted.

My takeaway from some of this is also that policies matter. So when we look at the focus in Black communities, some of this increased concern is because of what these

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individuals experience in their own lives but it's also about policy. So I believe Congresswoman Lee is going to join us. She's been a strong leader in the Congressional Black Caucus, has really kept this issue front and center. That matters. The Minority HIV/AIDS Initiative matters. The work of Phil Wilson who you're going to hear about in the Black AIDS, having organizations like this talking about these epidemic matters, and the greater than AIDS Campaign.

Now I could grow this list and go on but if I could close and just be a little provocative, one of the things that I would note is there's a huge disparity in the impact of HIV on Black Americans but there's an even larger disparity and impact of HIV among gay and bisexual men. I'm not sure, however, that if you did a survey and I know there's methodological challenges because there's two percent of the population, I'm not sure if you did the same survey you'd see this corollary concern because I'm not sure we've had the same level of policy support. Early in the epidemic, we've had all this focus in the gay community. It feels like we've moved on.

So I think that this survey is really fascinating and both surveys. It shows that we have some significant work to do but I also think there's a lot there that's really encouraging to show that what we are doing matters. So with that, I'll stop [applause].

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JEN KATES: Thanks Jeff. Thanks for ending on a provocative note. I think we have time for a couple of questions and Jeff, not to put you on the spot, but you will be here a little while after at the reception so maybe he can take some questions then too.

NATHAN DANSKEY: Thanks, Nathan Danskey with HIV Medicine Association. Jeff, you're saying a national plan, we're looking earlier about people's concerns. Then we saw numbers for people who are tested, so talking about the CDC recommendations of how people are being tested specifically about routine testing being opt-out testing, and then reimbursement being provided for those testes. Do you think that's a state-by-state test that those health departments need to take on or is that a federal lift that needs to happen?

JEFF CROWLEY: Right. Well I think this is one of those complicated areas that there's not one answer. I mean some people talk to me and they've asked the question, is there a conflict between this idea of routinizing HIV screening and targeting our approaches and I actually don't see it. I think when we talk about in clinical settings, we should routinize it. We should just make sure that doctors are not assessing your risks. They're just saying we're going to do this with everybody. It's just a matter of course but when we use public health dollars, we should be targeting because it's not about the number of tests we perform, it's about the number of HIV-

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positive individuals we identify right? So when we look at that, there's different, even within our health care system, there's different payers.

There's a number of policies that have happened but also more that needs to happen to improve this. Since President Obama's been in office, the VA's adopted routine screening in the VA system. Medicaid and CHIP, there's this concept by the state Medicaid Director, a state health director letter, that they sent to the state saying if you want to do population-based screening, so you're just screening everybody, you're not looking for risks, federal matching funds will be available. So we've made progress like that.

One of the challenges that we still have though is Medicare and I think the private sector looks to the recommendations of this U.S. Preventive Services Taskforce. Early on they gave a population-based screening a C grade. It happened many years ago. We've had a lot of evidence accrued about the benefits of population-based screening and a number of people believe if they looked at this again, they might give it a different rate. They gave it even a one notch higher, a B rating or an A rating, it makes it much easier to adopt much more broader based approaches.

We have a Presidential Advisory Council on HIV/AIDS and actually passed a resolution that they sent to the Preventive Services Taskforce asking them to take up this issue again just

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because many people believe that they would rate it differently and that could potentially open the door for a much more expanded testing within clinical care settings or within the insurance system but I also note that CDC, in recent years, they've already supported a lot of testing but they've really taken this approach of expanded testing where they're really focusing on target populations. I think that also is part of the path forward to really again focus on not the number of tests but where we're going to identify the most number of positives.

JEN KATES: We have a question, Jessie, over here and someone, okay.

JESSE MILAN: Jesse Milan from the Altarum Institute, we've heard about the public relations and legal challenges for the Affordable Care Act and we know that the Ryan White Care Act is coming up for reauthorization in about 13 or 14 months, the survey that we just heard about asked a lot of important questions, but where there questions that would've been particularly helpful for you and your role that weren't asked?

JEFF CROWLEY: You know, it's interesting, I don't know how to answer that, because I didn't really look at the study saying, what wasn't asked, but you mentioned that the Ryan White program will need to be reauthorized. We're implementing the Affordable Care Act. One of the things we

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have just begun thinking about are what are the implications of the Affordable Care Act?

You know, the Ryan White HIV/AIDS Program has always existed to fill in gaps left by our health system, so if there's gaps in people that have no insurance, but people that are underinsured it fills in those gaps. Once we expand access to insurance coverage those gaps – there will still be gaps, but they might change dramatically as more people have an insurance card.

So one of the questions we're starting to ask, okay, how are the needs of the Ryan White program gonna change when more people have insurance? So there are a lot of questions I have there, but I'm not sure those are like public opinion questions, but they're more – I just want to make sure when we think about implementing the Affordable Care Act we're going to be transitioning a lot of low income people income Medicaid, a lot of people with HIV above 133% of poverty will gain private insurance, how do we make sure that the coverage they get is robust enough and really try to make sure that's a data driven process, that it's not an anecdote, but we really understand what are the care needs of people living with HIV and how are these programs equipped to serve them. So there are a lot of questions I have, but I guess I hadn't thought about – I'm sure if I sat down I could come up with other public opinion questions I have, but I – I really want

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to focus more on just making sure we get the data we're gonna need when we, you know, sort of get into a discussion about reauthorizing Ryan White.

JEN KATES: The last question for Jeff.

Rod McCoy: Good afternoon, Rod McCoy from the National Association of People with AIDS. Jeff, I wanted to hear more of your reflections on gay men and the epidemic. I think if we look at the epidemic now among gay men, as opposed to back in the early 80s, we're seeing more of an impact in black gay men, which is often a community that is often ignored on a whole lot of fronts. The other thing is also dealing with a conservative congress that really doesn't seem to like to fund anything, openly dealing with anything relating to gay. At best we might get MSM, but not gay, so I'd like to hear more of your thoughts or reflections on that.

Jeff Crowley: Sure, well, you know, the first thing I would say is that I think what we've tried to do with the strategy is make sure everything we do is evidence based, so if we're talking the federal level, at the state level, at the local level, resources should go to the geographic areas, but also the populations that are greatest risk. In the United States, gay and bisexual men are about 2% of the population, but they're responsible for about 57% of new infections. You know, 53% acquired sexually and then there's

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about 4% of gay men that also inject drugs, right? So that's a huge disparity. For the first time in these operational plans, HHS started tracking spending across agencies to look at how are we allocating funds.

When we – doing it by race ethnicity, by risk factor, just to start that, cause we want to make sure the resources follow. Now I will, you know, challenge your assertion about congress, certainly their attentions are refunding. I actually think we've been fortunate that HIV has become less of a partisan issue. I can't think of really a major partisan conflict we've had about HIV since the President's come into office.

You know, President Obama did eliminate the HIV Entry Ban, but that was something that was started by President Bush. You know, the Ryan White HIV/AIDS program was reauthorized in 2009 on a broadly bipartisan basis. You know, we have proposed to really – in our budget for '12 to again, recognizing that we've done a lot of important work that must continue focusing on black Americans. We've felt like we haven't had a corollary focus on gay Americans.

CDC is proposing new programming to really look at how we can target our prevention programs effectively for gay men. I haven't heard a lot of criticism about that. Now – now you're right, there's actually an interesting debate over language, gay or MSM, you know, I held 14 community

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discussions when we were developing this strategy and I heard a lot about this, you know, a lot of people don't want to be identified as men who have sex with men, they want to say I'm a gay man, but then for research and other purposes people see MSM as a more broadly inclusive term, because it covers gay, bisexual, people who don't identify with those labels.

You know, I'm not sure there's tension as much as they have different uses in different contexts. I'm much more comfortable with using MSM in a research context or in a scientific paper, you know, but I don't know that there's really an effort to sort of divorce them as populations, so – but thank you.

JEN KATES: Thanks so much, Jeff, and we were gonna move on to the next panel and thank you for staying here with us. So we're ready to move on to the next panel, and this panel is going to focus on the epidemic in black America and while the panel comes up – I'm gonna ask the panelists to come up.

I'm gonna introduce my colleague Tina Hoff, who's the Senior Vice President at the foundation and the Director of Health Communication and Media Partnerships, and I often say she's my partner in crime on our HIV/AIDS work. She's the creative brain child behind our media campaigns and after so many years of working on HIV, she's an expert on HIV in her own right, so Tina, I'll turn it over to you.

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Tina Hoff: Great, thanks, Jen. While our panel is getting assembled I also just want to recognize my colleagues, some of whom are here in the room with us and other who are back in California. There's a team that works along side the foundation's work on HIV and I want to recognize them as well.

It's appropriate I think that Jeff preceded this discussion, because when President Obama presented the National HIV/AIDS Strategy last summer, he made a point of saying that the government couldn't go it alone in addressing the domestic AIDS crisis and called upon the private sector to lend its support. When we launched Greater than AIDS about a year before in June 2009, together with the Black AIDS Institute, we envisioned a campaign that would bring together a key segment of the private sector, namely the media, to respond to the domestic epidemic and in particular to help reach those most affected, beginning with black Americans.

From the start, Greater than AIDS has been embraced by a cross section of media who set aside competitive interests for a shared purpose and counting among our many partners today in this initiative are both national media companies like Clear Channel Communications, CBS Outdoor Television and Radio, the Fox Television Network, as well as prominent black media like Essence, Ebony, the American Urban

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Radio Network, Radio One, among many others. Not long after we launched Greater than AIDS an interesting thing happened - the campaign began to attract the attention of state and local health departments and community, and AIDS service organizations across the country, who saw an opportunity to use the Greater than AIDS message to reinforce their own responses and soon local versions of the campaign began appearing.

More recently some major corporate brands, notably the NBA and Walgreens have come on board lending their support, both to the national campaign, as well as to these community efforts. And earlier this year we expanded our messaging to reach more gay and bisexual men across races, recognizing of course that this is a population significantly affected and have been supported in these efforts by some of the prominent LGBT media in the country, including OUT, the Advocate, gay.com, Logo TV, as well as an array of community partners.

Today Greater than AIDS is a true coalition that brings together leaders from the private sector, with those on the front lines, reaching Americans across the nation with information and local resources. What's been especially exciting is how the community is embracing the message and making it its own. So you can see for yourself, we put together a short video with some highlights of the past year,

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where you can hear some of – what some of the people are saying about the campaign and ways in which it's being used across the country. So, we'll take a look at the video and then continue the discussion.

Video: What Greater than AIDS means to me is that we as a people are strong and can overcome this disease. We are bigger than this. Greater than AIDS is about all of us doing what we can do, bringing the community together. Being Greater than AIDS means that we have to come together as a community and empower each other. We are Greater than AIDS means to me that we're responsible for educations, being greater is a part of who we are, so let's live up to what we've always been. That's the central idea behind a brand new movement aimed at rallying black Americans around AIDS. I am greater than AIDS. I am greater than AIDS. I'm greater than AIDS, I'm greater than AIDS, because every step I take, I take with precaution. I am greater than ignorance. And safe is better than sorry. I'm greater than AIDS, because I'm not afraid to get tested.

I make it my priority to fully get to know my partner, before starting anything. I'm also getting tested every six months. And I will do any and everything in my power to know that others my age, younger and older know how to get tested, know where to get tested, and know the importance of getting tested. I know the status of my

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status. I'm greater than a statistic, and this makes me greater than AIDS.

A national campaign called Greater than AIDS is also asking Americans to share their deciding moments, personal experiences and change how they think about AIDS. I was in a monogamous relationship, with a guy who I loved and who I trusted. There was one day I didn't use the condom that changed my life forever. When I was pregnant my deciding moment was to stay on treatment, so that my baby could be born HIV negative. I lost someone I really care about to AIDS, and there was a lot of silence around the issue, a lot of shame, but the real shame comes from not talking about HIV and AIDS. My deciding moment was when I first found out that I was HIV positive. When you accept yourself, you make yourself empowered to deal with anything. Regardless of your age, your race, your orientation, this is something that affects us all. My name is Chris. My name is Marvelyn. My name is Chauncey. My name is Marteniz and this is my deciding moment, share yours at greaterthan.org.

What's up? This is Kelly Rowland here asking you to be a part of making the country Greater than AIDS. The Greater than AIDS tour will travel to seven historically black colleges and universities this week. And we have used the Greater than AIDS campaign in our local community.

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Chicago, Chi Town, this is MTV Sway, asking you guys to listen up and be a part of making Chicago Greater than AIDS.

What's up Houston? Together we can be Greater than AIDS. We're at the Essence Expo and we've already tested 150 people within the first three hours, that's amazing. I think it's my responsibility to help our community be greater than AIDS. We're sisters and we wanted to do something together and we want to be Greater than AIDS. The NBA has partnered with Greater than AIDS to mobilize fans, teams, and local communities in response to AIDS in the United States, and reduce the stigma associated with the disease.

You have in front of you some cheer cards and some thunder sticks. Let's see your thunder sticks. On the cheer cards and thunder sticks, our information about how you can get tested for HIV. Let's break this silence. I'm Al Horford. I'm Candice Wiggins. I'm Russell Westbrook. I'm Pau Gasol, and we are Greater than AIDS. It's our time now. It's our time to take responsibility and say we're gonna do something about this. We've done it before, we can do it again. We can end this thing, we just require each and every one of us doing our part. I'm Greater than AIDS. I'm Greater than AIDS. I am Greater than AIDS. Together we can do this. I'm Samuel L. Jackson. I'm Rashad McCants. I am Vanessa Williams. And I am Greater than AIDS.

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Tina Hoff: So, that gives you a little snap shot of what the message is about and some of the ways it's being implemented across the country, and if anyone would like to add their deciding moment to those that are being collected from people across the country, our recording studio on this floor will be open from six to seven, and we encourage you to come back there and record a message. Now I'm going to turn the program over to Darryl Fears, who is – as John mentioned earlier, author of today's piece in the Washington Post about the AIDS epidemic in D.C. is gonna lead a discussion about AIDS in black American and can pick up on some of this conversation about mobilization of the community. Certainly my partner, Phil Wilson, can also speak to some of the other elements of the campaign if there's interest in that conversation as well, so Darryl.

Darryl Fears: Thank you. Good afternoon, everyone or is it good evening. I am honored to be here today, invited by Kaiser, the Kaiser Family Foundation, to moderate this panel. And I feel honored to be sitting next to distinguished panelists. Starting with – to my far right, our congresswoman, Barbara Lee, as a political leader in the fight against the global HIV/AIDS pandemic. Congresswoman, Barbara Lee, co-authored legislation that later became a law, creating a Global Fund to fight AIDS, TB, and malaria in 2000.

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The President's Emergency Plan for AIDS Relief three years later and PEPFAR, the PEPFAR Reauthorization Act of 2008, she has led an effort to establish a national AIDS strategy, and is a member of a house appropriation subcommittee with jurisdiction over domestic AIDS funding. She is the only U.S. Representative on the U.N. development programs, global commission on HIV and the law. Welcome Congresswoman Lee.

Phil Wilson is the Founder and Chief Executive of the Black AIDS Institute, focused exclusively on African Americans and AIDS. Its mission is to stop the pandemic, by mobilizing black organizations and individuals to confront the spread of the disease. Mr. Wilson has served as the AIDS Coordinator for the city of Los Angeles, Director on Policy and Planning at AIDS project in Los Angeles and Co-Chair of the Los Angeles County HIV Health Commission. His articles have appeared in numerous publications, including the L.A. Times, the New York Times, Essence, Ebony, Pause and Arise. Welcome, Phil Wilson.

Dr. Lisa Fitzpatrick has been called a rising star in the field of epidemiology. She is a board certified infectious diseases physician and an HIV expert who has worked domestically and in Africa. She has served as a medical epidemiologist for the Centers for Disease Control and Prevention, and as Director of the Minority HIV/AIDS

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Research initiative established to recruit and mentor young scientists of color to conduct HIV prevention research. Dr. Fitzpatrick has led HIV related field research to better understand HIV transmission among black women, college students, and jail and prison inmates. The list of her work on AIDS in the Caribbean, and other areas goes on and on, and we are pressed for time. Welcome. Dr. Lisa Fitzpatrick.

So, we have heard the statistics on African Americans and AIDS, and know that the situation is dire, and we are looking forward to a lively discussion about that this evening, without speeches. Let me emphasize without speeches. When it comes to HIV and AIDS the challenge facing African Americans is large. African American men and women are many times more likely to suffer from this disease than other members of other races and ethnicities. According to some studies, African Americans are more likely to be misinformed about the disease and how it spreads. It is troubling that this trend is not new.

Today's finding, recent findings that African Americans represent nearly half of estimated AIDS diagnosis reflect findings that date back for years. Our panel today is here to help us understand the dynamics that drive this troubling trend and to discuss solutions that might help reverse it. So, I covered HIV and AIDS for some time in Washington D.C. and my familiarity is there. I've written

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about any number of things that I hope we'll discuss today. I've covered a mayor who was devoted to uber fitness who had a problem with even discussing the disease. I've written about testing in African Americans who don't have conversations or less likely to have conversations with their doctors about testing. I've covered local groups that go out in the community and administer testing on any number of individuals. So, I'd like to start this conversation with Dr. or Congresswoman Lee, who has to leave in about 30 minutes to vote, and I'm sure she'll tell us about that. Let's see.

Barbara Lee: Should I start?

Darryl Fears: Sure, let me –

Barbara Lee: Thank you very much. Darryl, thank you so much for that introduction, and also for your leadership and the panel. Let me just acknowledge you and salute you and thank you for being on the front lines, doing everything you're doing each and every day to scour HIV and AIDS from the face of the earth. It's really an honor to be here with you.

I just arrived from California. And of course I come from Oakland, California, Oakland, Berkley, the East Bay. We had our AIDS walk on Saturday in Oakland, California, and it was very important that we hold this East Bay AIDS walk. This was the fifth year, because we have to now,

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unfortunately, because of these huge cutbacks in the ADAP program and other funding streams, raise more money just to be able to ensure that people receive the medications that they should receive and that they deserve to receive, that they must receive, but I have to just say, in terms of what the federal and state governments are doing really forces us to look at this community response in an even more urgent way.

The black community, we have got to lead, to break the silence first of all. We've made some progress, but we've got to do more. Bringing together the private sector, the media, elected officials, faith leaders, grass roots organizations, policy makers, we've got to have a unified front now, and we have to empower ourselves and our communities to begin to tackle this in a big way, because I see quite frankly a real disinvestment now on behalf of, you know, our governments in terms of funding and supporting all of those new initiatives and the strategies that would help move the African American Community forward to attack this — to attack HIV and AIDS.

I want to commend the Obama Administration though. I want to thank Jeff for your leadership, because I've been here since '98 and I have never seen really a focus on developing it and we talked about this for several years actually during the campaign, a domestic PEPFAR, which is

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what we need, which we have in place, but we need the funding to support this domestic PEPFAR, and so the black communities and communities of color and all of those communities that really see fighting this pandemic as essential in our overall struggle for healthcare reform.

Personally I think what we have to do in a big way is become more political, I think we have to begin to hold at the grass roots level, local state and federal officials accountable, putting their money where their mouths are, and if they're not gonna do that then we need to look at how, you know, we deal with this at the ballot box.

For the life of me I see every day and I hear every day from people who want – who need more resources, who need HIV and AIDS to be a priority in our communities, who need a focus from our elected officials to say that this makes sense in terms of public policy, and we need the community to push for universal healthcare. We made some progress on healthcare reform, but until we have universal, accessible healthcare for all we're not gonna really have the access that many communities, especially communities of color need, in terms of the type of resources and sources that are available. And so we have to rev this up a bit, I think, and we have to politicize this movement, unfortunately, because – and it needs to be developed into a movement.

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And I think with Phil now and the Black AIDS Institute, I'm dying to read this report, because we've worked together many years and for many years, and I know that many of you here feel – all of you have worked so hard at the grass roots level to finally get us to this point, but we can't now backslide.

Darryl Fears: Congresswoman, 67% of African Americans in the Kaiser survey said that African American ministers and organizations are not doing enough to confront this disease. Have you seen any progress there and if so, what, and what do they need to do, and what have they not done?

Barbara Lee: Yeah, I've seen some progress, but not enough. I mean I think all of us know our own churches, I mean I just have to – my church is Allen Temple Baptist Church in Oakland, California. We started an HIV/AIDS housing initiative, an entire healthcare program, and entire HIV/AIDS ministry. Many churches around the country are doing this, but I think that these are far and few between. And I think there needs to be from all of our clergy denominations a message to go out to all of our congregations throughout the country to make HIV and AIDS a priority in terms of the ministries.

I think churches should develop ministries to really begin to do outreach into the community. And also I believe

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and I haven't seen a lot of this, but I see more now happening, pastors stepping up, talking about it, preaching about it, the realities of HIV and AIDS and why we have to tackle this, because African Americans, we go to church and those are places where we congregate and we know that our community listens to our pastors in many respects, and so I think we need to rev that up a bit. And personally I also think that – and I know Reverend Jackson has been on the front line for many years, urging members of the clergy get tested.

It's so important to see leadership in our communities stepping up, getting tested. Monday is National HIV/AIDS Testing Day, I'm gonna get tested again, this will probably be the sixth time – or Friday, we're gonna get tested. I've invited members of congress to join me in getting tested. I think members of the clergy throughout the country should have HIV/AIDS testing days, where members of the clergy get tested. This is pretty bold and it would take a lot to get done, but you know, we have to do this.

Darryl Fears: Phil, some say that what the clergy's doing, what churches is doing, it's too little too late. I've covered churches established by gay, black, men and women, because they felt alienated from their home church, and so they established these churches on their own and not just in Washington D.C., the churches that I've written

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about, but across the country. And, so, what is the say about the problem in the black community where a person with – a gay person without AIDS or with AIDS is not even comfortable in their own church.

Phil Wilson: Well, you know, first of all I think that people should be comfortable in their own churches, but I'm gonna take to task the phrase too little, too late. You know, I've been living with HIV now for 30 years now, and while I would admit that too many churches are doing too little, but as long as they're alive and as long as the epidemic is going on it is never too late. And part of the problem is that as long as we continue this argument about it is too late, that scares people away. No, we need them now, we needed them yesterday, we needed them five years ago. We needed them 10 years ago, but we don't want them to stay away, because we think they're too late, no, so I think that we need to kind of control that kind of language.

Everybody is welcome whenever they get here. There's very few people, you know, this room that were there in the very beginning. All of us had to have that deciding moment to get there and I think that, that's true for clergy as well. You know, I would say the other thing that's really important when we talk about the church conversation is that we need to meet the clergy where they are, you know, that you can move people when you have conversations with them. And

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there's countless number of ministers that were in one place 20 years ago, a different place 10 years ago, and today they're strong advocates. So, we have to continue that dialogue.

The other thing I think on the faith question and this speaks to I think, the complexities of where we are today. You know, we have a very, very, very severe problem in Black America, but at the same time we have the opportunity today to talk about ending the AIDS epidemic, and we have to figure out a way to have both of those conversations at the same time, because if you only talk about the doom and gloom people feel hopeless. You know, while I don't want to underestimate how bad the problem is, but we have to talk to people about the things that can be done, and so in black communities today there are churches, maybe not enough, that are doing things, maybe they're not doing enough, but in addition to that, the churches are not the only institutions in our communities.

There are civil rights organizations, there is fraternities and sororities, there are black block clubs, you know? There are black media organizations that are doing amazing work, you know, 10 years ago not a single national civil rights organization in American had a national plan.

Today most of the national black institutions in America at least have a plan, 14 of the major organizations

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have a national coordinator, that's progress. Are they doing enough? Are we happy with all the things that we're doing? No, but I think that the conversations in black communities today, and this is critically important in our community, I think, is that we talk about the things – and that's what the Greater than AIDS campaign is all about, is that there is something that each and every one of us can do. If we can convince, you know, each of us to do that thing we are far on our way to ending the epidemic.

Darryl Fears: Thanks, Phil. Dr. Fitzpatrick, can you talk to us about one of the groups of African Americans who's most affected by this disease and that's heterosexual women, and why there seems to be an uptick of the disease among black women who are heterosexual?

Dr. Lisa Fitzpatrick: First of all I'm really, really excited to be here and I want to greet the congressman personally, and I missed you in the Caribbean and I'm sorry I wasn't there. Black women and HIV, I think black women and HIV has been a topic for many years, before we started talking about it, and that's why we feel a little bit behind the eight ball now.

I think the biggest problem for black women and HIV is similar to the problems in the rest of Black America, is that we don't talk enough about what's going on. We don't talk enough about relationships, we don't talk enough

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sexuality, we don't talk enough about getting tested, and so on.

When I was at CDC we conducted a study among black women to find out why women were at risk for HIV or why women were getting infected and there were two surprising things. Actually one was not quite so surprising and that was that poverty seemed to be related to transmission.

But the second thing that we were surprised by was that there was a clear association with a lack of communication with their partner, and I think that, that holds today. It doesn't matter if it's a heterosexual couples or if it is a same sex couple. We do not talk enough about HIV/AIDS. So, I think in order to address this, not just among women, but in our society period, we have to talk more about HIV and while I have the mic, I have to respond to the issue with clergy, because I have a talk that I give clergy. And it's difficult to talk to clergy, particularly clergy who are not so interested in addressing the issue of HIV and AIDS, but I have a slide that talks about the seven deadly sins, and I tell the clergy that they have to find their own moral balance, between talking about HIV/AIDS and sexuality and their personal feelings or their spiritual feelings about HIV/AIDS, and that strikes a chord with some of them, because it's not God who's judging or grading sin. It's we who are grading sin, and so when we talk about the

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seven deadly sins, why is someone who's been engaging in risky behavior and is HIV positive worse than someone who's glutinous or someone who's been lying or cheating, so I wanted to share that, because I think it's easy for us to judge people based on their activities and their behaviors, but we should also realize that we're not blameless either, so.

Darryl Fears: There's a lot of research out there and I wanted you to help separate myth from reality. When you talk about people who have been incarcerated and reentering the community, and when you talk about some of the surveillance surveys that have taken place certainly in the district in the past few years, and so I've written about a heterosexual surveillance survey, I don't know if you're familiar with that, that the AIDS office here conducted.

Lisa Fitzpatrick: Mm-hmm.

Darryl Fears: And in that survey something like about 50% of people where their significant other said that, you know, I think I've cheated on my significant other, and then they turned around and said that about 50% said, I think that my significant other cheated on me.

Dr. Lisa Fitzpatrick: Right.

Darryl Fears: And so that gets to personal responsibility, and now the other thing that is the talk that is ramping in the black community is about incarceration and

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men having sex with men in – while under incarceration, and, you know, I don't even know if I believe that that's true, and I wondered if there's any research out there to sort of separate these myths from reality.

Dr. Lisa Fitzpatrick: Well, data is – data can be very confusing, so I was really intrigued by some of the questions in the first session, and if we get a chance I would love to also talk about the testing issue in providers, because that is a very hot button issue for me.

But related to surveillance data it can be very confusing, and I'm not surprised that people are having trouble understanding what is what. With respect to the heterosexual survey, that was a bit of a surprise. There is a specific term for what you're describing, it's called concurrency, and concurrency means that you have multiple partners at the same time, versus having serial partners. So, maybe you have a partner in January, you stop seeing that partner in March, and then you pick up another partner in April and stop seeing that person in June and so on. That's serial monogamy.

Concurrency is between January and March you have three partners and maybe your partner has three partners, and so there has been a lot of research looking at whether or not that is contributing to the epidemic, particularly in black

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people. And there's been a lot of data in North Carolina on this. Dr. Adaora Adimora.

Also there's quite a work in Kenya done by a researcher in Washington, Martina Morris on this. And so, in Washington D.C. We do think that concurrency is one of the reasons we're seeing such high rates of HIV, because of what you're saying. I actually don't think it's a myth. I also don't think it's a myth that there is same sex, couple sex in incarcerated settings.

As you mentioned, at the CDC we also looked at HIV transmission in prison, and we did find that there was same sex going on, but I think the – I think we shouldn't really get lost in the data too much, because ultimately this is about people knowing how HIV is transmitted and how to prevent HIV. So, we need to focus on behaviors and not so much on what we're calling people, or what we're labeling people, or judging people. There's also, I think a myth, and I'm not sure it's a myth, because we don't have enough data. There's a myth that it's the prison populations that are driving the epidemic in black women. We don't know that, because we do not test people when they come out of prison.

In California, I think California is the most forward-thinking state when it comes to testing incarcerated populations, but they are one of the few states, perhaps Rhode Island might be doing some, but I don't think there are

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any other states that are routinely testing people when they come out prison. So, we don't have data to substantiate that prisoners with HIV are driving the epidemic, so it's important to read and ask questions and really understand before deciding or believing in the myths that you're talking about.

PHIL Wilson: But on the topic of prisons, cause I do think this is important, and that is we're gonna talk about testing prisoners. Now I think that black communities, more so than any other communities should be calling for, if we're gonna test prisoners, we need to be testing prisoners as they go in.

Dr. Lisa Fitzpatrick: Right.

PHIL Wilson: And they come out.

Dr. Lisa Fitzpatrick: Right.

PHIL Wilson: You know, because if you don't test them as they go in, you don't know where the infection occurs, and on this issue around how – how mass incarceration of folks is impacting the epidemic, you know, in some ways, you know, the mass destruction of family units contributes to the passing on HIV. To that degree, you know, if you do an analysis and there is data to suggest this, is that when you look at who's going into prison, okay, many of the behaviors that put you at risk for incarceration are the same behaviors that put you at risk, you know, for contracting HIV.

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Many of the folks who are coming out of prison HIV positive are also going into prison HIV positive, so that's one factor that needs to be considered. The other impact around prison is not necessarily just limited to whether or not the prisoner transmits HIV, but what happens to that partner when their primary partner is incarcerated, that partner then is put – their life is also destabilized and therefore they are possibly at risk in other ways as well. So, there are reasons why we need to talk about prisons and we can do it in a non-judgmental way and move away from this kind of blame and shame game that has undermined our ability to confront HIV in our community.

Darryl Fears: But it's an issue that –

Barbara Lee: Darryl, can I just say something on prisons, well after you?

Darryl Fears: Please.

Barbara Lee: I think it's an issue, and I agree with what Dr. Fitzpatrick and Phil has said, and I think it's very important to recognize whether the data, the empirical data is there or not, we know what's taking place, and so we need to do something about it. And that's why the strategies that work before one goes into prison, the HIV/AIDS strategies, in terms of testing, treatment, counseling, prevention, should be also adhered to in prisons and that's why I think we should have condoms in prisons.

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I mean I think we should, you know, I have legislation to do that, I don't know if it'll ever get passed with what we're dealing with, but I think it's very important, that we allow the distribution of condoms in prisons, because we know what's going on there. And we know that we don't want to see more people becoming infected and we want to make sure that when inmates get out, that they know and their partners know, and their families know, you know, what's taking place, and that we have also done everything we could do to protect everyone while in prison.

Darryl Fears: So, it's an issue that 30 years into this epidemic we still don't have solid research to show the impact of men going into prison and black men particularly, because I think, I'm sure two-thirds of African American men, 15 to 34 have some contact with the criminal justice system, so that's an issue. I wanted to ask you a question before you leave, Congresswoman Lee.

Recent reports have said that 3.2% – there's a 3.2 incidence rate of HIV and AIDS in the District of Columbia, yet we could walk outside this building and walk for ten miles and not see any signs that there is an epidemic in this city. It's a very silent thing, it's an invisible thing in this city. And I wonder why is it, is it that there's no funding around awareness. Is there very too little funding

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around prevention and what do you see there, and do you see any political will to provide that funding to make people, especially black people more aware of what's lurking outside their homes and inside their homes.

Barbara Lee: Thank you very much for that question. I serve on the Appropriations Committee and I'm subcommittee on financial services, which really has the unfortunate jurisdiction over funding, you know the District of Columbia. The District of Columbia shouldn't have to come to congress for their money, and we see each and every day, you know, I just - it's wrong, and now we're seeing once again - and I have to say the prohibition against district residents using their own local funds to provide abortions for women, and so that's the environment that we're dealing with, which I totally think is disgusting, it's wrong, it's morally wrong, and it's repugnant.

And so, when we look at the District of Columbia, we have to deal with the political context in Washington - on the Hill, in terms of the appropriations process, and so the political will is really not there to fund much of anything at this point that relates to HIV and AIDS. What I must say though is that there are some real champions, such as Congresswoman Eleanor Holmes Norton, and all of the groups in Washington D.C. that are really fighting for additional

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funding, and in fact we're gonna have the International AIDS Conference here in Washington D.C.

First time in the United States since the 90s, that I hope and that resulted as a result of all of us lifting this travel ban. I hope that will shed some light on what is taking place in Washington D.C. and really force the world to force our own elected officials to realize that we have to sweep this from out of the rug – up from under the rug now in Washington D.C. and really invest our tax dollars into making sure we do, you know, address HIV and AIDS in a real way in the district.

But I think that the city and what has happened though is remarkable with minimal resources, and you know, I know that the White House, I know that all of you here are concerned about what is taking place in D.C., and so we have to again mount this political fight for resource allocation, because you know, on the ground I would suspect organizations that are providing services, care, treatment, testing, are surviving on a shoe string, because of budget cuts and that should – that's unacceptable.

Darryl Fears: This is kind of a jump all question, so anybody can take it and run with it, but Baltimore has a higher incidence of heroine or intravenous drug use than the District of Columbia, and yet he district has a higher level of infection among intravenous drug users. And I wanted to

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ask anyone, what was the impact of a federal ban on spending for the prevention of intravenous drug use or intravenous drug use infection in the district and what's the legacy of that?

PHIL Wilson: What the legacy of that is there are a lot of people that are living with HIV and a lot of people that are dead, I mean that the ban on needle exchange is directly related to a lot of dead folks, plain and simple, and every time – now all the evidence, and all the evidence for over a decade has said that needle exchange programs reduce HIV infections and do not increase drug use. There is no reason why there should be a ban and it's absolutely disgraceful, you know, that it too took so long to lift the band, and it's disgraceful whenever there are barriers that inhibit the ability to do that, you know, so, you know, that's my position.

Dr. Lisa Fitzpatrick: There is some good news on that though, the report – the most report came out in Washington D.C. recently that showed that there has been a reduction in transmission related to injection drug use and we see that playing out in the clinics as well, because most of the people who come in with HIV infection, I can't say I've seen one in the last year or two from injection drug use, so I think although your point is well taken, since

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there has been access to clean needle usage in the district that is a real success story for D.C. right now.

PHIL Wilson: And I think to the Congresswoman's position around people need to be engaged in the policy process, you know, doing this last budget struggle when there are efforts to basically install new limitations and needle exchange programs, that the administration fought that effort and one that battle I think is critically important, and that speaks to the new climate and that speaks to why we are – we have a window of opportunity that we really need to address how to talk about an end game. We are in a place that we should be talking about how to end the AIDS epidemic. We have the tools to do that, the question is whether or not we will use those tools expeditiously and effectively.

Darryl Fears: One of the things that the Washington Post study and the Kaiser study did not address is the diversity within the black community. There's a large influx of African immigrants, particularly Ethiopians in Washington, but any number of African groups where across the board discussions of sex is just highly taboo, you don't discuss that in your native country and you certainly don't discuss it here.

I've spoken with Ethiopian groups who say that, that leaves women, in particular, vulnerable to men who prey on them once they come here, and so when you – of course in

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these diverse communities people interact, and so is there any concern about the interaction between these groups, African American, Native African groups, and African immigrants who come here and the potential spread of the disease there?

Barbara Lee: Well, I can just say I think that what's important is that we have public awareness campaigns, public policies, and grass root organizations that are providing information. We have to recognize there are many, many cultural differences in the black community. Remember what Phil said, like 10, 12 years ago, very few members of the clergy, very few black organizations were taking this on, because it was a no, no, you just didn't talk about HIV and AIDS, and we're making some progress, not enough, but we've made some.

And I believe that we have to continue to work with everyone and provide the information and the resources and help, and hire people in our organizations who get it, who want to try to help educate and provide the awareness that is necessary. But I certainly think it's something we cannot turn our heads on, and we have to be very sensitive and respectful and understand what the cultural appropriateness of what we're doing, but we certainly have to move ahead and provide the public education and awareness campaigns, because this is about life and death.

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Darryl Fears: Congresswoman, I hear whispers that you're being summoned.

Barbara Lee: Oh, well I guess I have to go. Well, okay, let me first thank the Kaiser Family Foundation for your leadership and for putting this together for this report. The foundation's right next to my congressional district and I really am very proud of the work that they have done. I was able to read the report on the airplane, it's a very powerful report.

And I want to thank all of you for being here and reminding us that – as Phil says, 30 years is enough, and so we need to rededicate ourselves today, to really begin to work very aggressively in a very political context to really address HIV and AIDS and stamp it from the face of the earth. Thank you again.

Darryl Fears: Thank you.

Dr. Lisa Fitzpatrick: On that note, can I talk a little bit about a finding in the report that I was a bit appalled by. I think the most surprising thing to me, although I shouldn't be surprised now that I'm thinking about it, was that of the people surveyed, less than 30% of them have been offered an HIV test by their provider, that is disgraceful. In 2011, five years after the CDC released their recommendation, so if I may talk a little bit about that. The recommendations came out in 2006, but I have to

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make sure that you're clear about something, CDC does not mandate anything.

CDC only can put out recommendations and it's up to each state, each jurisdiction to decide how they want to use it. It's even up to each provider to decide if they want to implement those recommendations, but the truth is we have so little uptake of those recommendations, because a lot of people don't even know they exist, so that's still something that we have to address, but this issue related to providers not offering HIV testing, this is a two-way street, so I think the -

Darryl Fears: So, so, what's the problem? I mean what happens when Darryl Fears, black man, steps into his doctors office and talks to his physician, what is sort of the interaction between the two, because you just don't have - I guess surveys show that there doesn't seem to be a very strong interaction between African Americans and their non-African American doctors, and so can you take us into a doctor's office and tell us what the dynamic is, so that there isn't much why those tests aren't being offered?

Dr. Lisa Fitzpatrick: Mm-hmm, well if you come into my office it's a very different story, so what I'm gonna tell you is not what happens in my office, but we talk to lots of providers and there's someone from my staff here, Marilyn Johnson, raise your hand, Hi, Marilyn. So, we beat the

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bushes talking to providers about why they test and why they don't test and trying to get – make sure providers get the information they need and we do this through the HRSA funded AIDS education training center.

We have a local performance site at Howard, so in talking to providers they have a laundry list of reasons, all – from my patients don't have HIV, to what do I do if I find an HIV positive test, to I don't really feel comfortable talking about that to the – and this is real.

The insurance companies drive me crazy filling out the paperwork to justify why I'm going a HIV test on someone who doesn't have symptoms of AIDS, and the list goes on and on. So, some of them don't know about the billing codes, but when we tell them about the billing codes, because there are not billing codes specifically for HIV testing, but guess what, not all of the insurance companies are even recognizing those billing codes, so I have yet to hear a provider hearing they've been reimbursed when they've used the billing codes that we gave them, so there are lots of problems. But I think the billing codes and the insurance aside, the other reasons to me are just excuses, because in this day and age, no one has to get a diagnosis of AIDS, no one has to get a diagnosis of AIDS, because if you're tested late then you'll get late, but if you're tested routinely and if people are adhering to the CDC guidelines, we will catch everyone early

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enough where no one actually has to get AIDS. So, what we're telling providers is that they have a responsibility, we have a responsibility to test people for HIV, the problem is they don't always believe us, but they will believe us when someone gets sued.

I've already had two patients tell me that they're thinking about suing their doctors, because by the time they got to me they had AIDS, but they had been in someone's care for up to 10, 15 years and they weren't tested. It's a sad day, but it's probably coming, so I think there are a lot of issues related to this, but this has always been seen as a gay, white, male disease, so particularly for our populations it's not on the radar, and especially for older people who we know is a growing population with HIV/AIDS, it's not on the radar.

Darryl Fears: Well, and there are some things that can happen, you know, for example, if HIV test was a part of a performance indicators for Medicare a provider, that means all Medicare providers would start to adhere to the CDC recommendations. I'm told that there are mechanisms in which we can do performance indicators for Medicaid providers as well, you know, so those are some things that can happen. We're moving towards – rapidly toward electronic medical records.

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Now, if for example in an earlier meeting today, someone mentioned that if you made it as a question that you cannot bypass, you can't go forward until you answer that question. And if you're not offered an HIV test, you have to give an explanation why you've not offered HIV test, those are other mechanisms. These are easy fixes that would at least increase the amount of HIV testing that's going on, at least for those people who are preventing themselves to providers, okay.

Dr. Lisa Fitzpatrick: But I think the community also has to meet providers half way until we get over this hump, so people also need to ask for an HIV test. And I'm sure there's someone in this room who has never had a test for HIV, so that is also unacceptable. I think everyone at least needs to have one HIV test, regardless of what you think your risk is, get an HIV test, tell your family members, take them to get an HIV test, tell all of your friends, everyone needs to get an HIV test, and so with the community, meaning providers, maybe we can find people who are HIV positive.

Darryl Fears: So, let's pivot to a group that rarely goes to see a doctor, let's say rarely and certainly probably won't be asked if they want an HIV test and we're talking about young people and particularly young, black people. Recently in D.C. there has been an innovative approach in Philadelphia to get around this and that is STD testing in

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the public schools, in middle school and high school, when this was introduced two years ago in D.C. and I think two years before that in Philadelphia, there was a bit of an uproar by parents who were like don't be doing anything to my child that I don't want being done, but you don't hear that uproar being done.

What are your thoughts on this really, sort of aggressive public move to test young people and should this be something that's being done nationwide and how do you get parents to agree to something as seemingly drastic as this.

Phil Wilson: Well, the CDC is recommending HIV testing for anyone from 13 to 60-something, now so I think that -

Dr. Lisa Fitzpatrick: Which is we should do away with, there shouldn't be an age limit.

Phil Wilson: So, so starting at 13, let's be - maybe you're saying there shouldn't be a lower image or not, but right now the guidelines say starting at 13, and so in that context, you know, and I do think that floating it in with other STDs is critically important. I think that the concern that I have is that testing should not be a substitute for education, and I'm equally concerned that we're not doing comprehensive AIDS education or comprehensive sex education as well, so that the testing combined with comprehensive sex

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education and yes, there are going to be resistance, as we've already experienced, but over time what we discover is that, that resistance does go down, but absolutely, offering young people as many tools as possible to save their lives is critically important.

You know and that includes, you know, talking to young people about delayed sexual activity, but also talking to them how to be responsible in their sexual behavior and how to respect their bodies and to make choices for themselves, so they can withstand issues around peer pressure and once they've made the decision, whether we like it or not and I know that there are parents out there that would prefer that our children wait until they're 30 before they have sex, but whenever they make that decision, I think that we want them to have the information that they need to protect themselves, because the price, you know, is HIV infection and potential death, you know, and that price is too great.

Darryl Fears: Okay, do you want to add to that doctor?

Dr. Lisa Fitzpatrick: I do. The – my interjection about the age limit is justified, because in the last year or so we've diagnosed people over the age of 70, and if we had adhered to these guidelines we would not have found those people. So, I think even in the district the age limit is 84, but again I think why have an age limit, especially if

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some of the older people have not had an HIV test and maybe they're in a relationship where Viagra's being used, so we know that something's going on. So, I think –

Phil Wilson: Or they may be in a relationship with someone who's 25.

Dr. Lisa Fitzpatrick: Right, that happens too.

Phil Wilson: So, I –

Dr. Lisa Fitzpatrick: But just one more point I wanted to make about young people. The most recent surveys, the youth behavior risk surveys are showing that the age of sexual debut is pretty young, 12, sometimes even 10, so to think that we – we don't really need to test young people, I think that, that's really misguided, because people are sexually active at very young ages and we need to educate them and insure that they're tested.

Darryl Fears: I'm told that this is my last question, the –

Dr. Lisa Fitzpatrick: Who's speaking to you?

PHIL Wilson: And a good therapist would help that problem.

Darryl Fears: Yeah, yeah, we've noted earlier in this presentation that there's been a significant amount of progress with this disease, but some of the innovations may lead to difficulties. For example, innovations in medical care, and innovations actually in technology, have young

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people, one, thinking that this disease can be managed, that if you contract HIV with the right medical regimen you can live for a very long time, and some people that – some kids I've spoken to said, hey, if I get it, no problem. And the other innovation, technological innovation is the worldwide web, and a lot of young people are connecting on the web, and using that connection to go and have sex at different places.

I've talked to numerous young people, particularly gay males about that, and so how do you address that? One, that people think that this disease can be managed and two, that people can hook up across almost a number of platforms now.

Phil Wilson: Well, you know, HIV is a complicated subject, you know? We want it to be easy, we want it to be simple, you know? We prefer for it to be, you know, the fear game to work, but the truth of the matter is that, you know, in 2011 AIDS can be managed, you know? And I believe that if we tell the truth, you know, about the wholeness of the epidemic that, that we maintain our credibility and young people actually will understand that. And I really don't think that people are actually racing out to get infected, because they could take pills.

I think by in large people – the people who are getting infected are getting infected, because of a lack of knowledge, not because they have information about the

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treatments that are available. I think that, that is the cause, so I think that the conversations that we should be having are really about comprehensive conversations, that yes, HIV is manageable, that is a statement of fact.

Now there are a number of us in this room that are evidence of that and in black communities, you know, we should really be telling people that, because when we look at health disparities, what we find is that it's not the problem that folks are getting infected, because they think there are treatment. The problem is in black communities that people are not on treatment, and so we need to be talking about treatment in an aggressive way, at the same time we need to be talking about how people can protect themselves and they don't have to get infected and the consequences of infected. We can have both of those conversations. I think that we're at a point in our conversations and if that wasn't your last question I was going to ignore your question and lead to this.

Darryl Fears: No, no, no, I was gonna let Dr. Fitzpatrick have the last word and pick up on whatever she wants to.

Phil Wilson: There is one thing that I won't leave the stage without saying then, and that is that this whole issue about the end game, you know, it is – I'm absolutely amazed that we're not talking about the fact that we have the

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tools to end the epidemic, we have those tools, you know, we have the ability to diagnose folks who are HIV positive and we can diagnose them early. We have the ability to identify where the epidemic is hardest hit, down to the zip code, so we know how to find out whose HIV positive, we know how to find out where the epidemic is. We have the ability to prevent people from getting prevented through things like condoms and microbicides and needle exchange. We have the ability – no, we understand, not necessarily we have the ability in all cases, but we understand how to dramatically reduce acquisition through prep and pep.

Darryl Fears: Wait a minute, your points are well taken, but that's starting to sound suspiciously like a speech.

PHIL Wilson: It is, it is, but you didn't ask enough questions, so and then I'm finishing up now, because this room cannot leave here without understanding this point. And we have the ability to prevent transmission through early treatment. Those are the tools that end the AID epidemic and we're talking about 30 years is enough, that's the conversation we need to be having in black communities and we need to be having it everywhere we go.

Darryl Fears: Bravo. Dr. Fitzpatrick?

Dr. Lisa Fitzpatrick: Amen.

Darryl Fears: Quickly.

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Dr. Lisa Fitzpatrick: Okay, I think I have two things that I would like to leave you with. Is there time for questions?

Darryl Fears: I don't know, the voice isn't talking about questions.

Dr. Lisa Fitzpatrick: Over cocktails, that's always the fun part.

Tina Hoff: The voice is saying that we'll move - we'll move to the reception for questions, that's what the voice is telling me.

Dr. Lisa Fitzpatrick: Wow, you - she hears the voices too.

Darryl Fears: Yeah.

Dr. Lisa Fitzpatrick: Okay, so two things -

Darryl Fears: It's like the sixth sense in here.

Dr. Lisa Fitzpatrick: I'm a very inquisitive doctor, so when people come and see me I ask lots of questions and one of them, especially for people who are late in disease is why do you wait so long to get tested, and a lot of them actually tell me that they didn't want anyone to tell them that they had AIDS. And they come in and they're really anxious and they're afraid, and I think it's time for us to start - and this is a little bit related to what Phil is saying, it is time for us to start talking about whether or not we can stop talking about AIDS, only because we don't

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have to see people dying of AIDS anymore, because of testing and because of treatments. So, one of the first things I say to them is, hi, how are you? You're not going to die of AIDS. And then we can have a conversation after that, because they start to relax, and so I wanted to put that out there to you as well, because I need you to help spread this message, that people don't have to die of AIDS, because the treatment is excellent, it's tolerable, very few side effects, it's amazing the difference, and I know I look young, but I saw my first HIV patient in 1992, so I've been at this a while, so it's very, very good news that people can get great treatment.

And the last thing I want to leave you with that we didn't have time to talk about is that there's a phenomenon called acute HIV infection and we have to tell the community about it, because the community is not aware that in the window period you can still be infected with HIV, but your test is negative.

And the only signs and symptoms you may have are the flu, which means you need to go and talk to your healthcare provider to find out if you have HIV. Because if a person has HIV in the window period they're much more likely to transmit the virus to someone else, and so every time I talk to the community, I like to talk about this, because a lot of people stay home, because they think they have the flu and

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then it takes us another three to five years to find them or find out that they have HIV. And in the meantime how many people have been infected. So, I'll leave you with that tidbit, and thank you.

Darryl Fears: Thank you very much.

JEN KATES: Thank you. I do hate to cut it off, but I'm channeling the voice, I'm channeling Drew's voice, which is saying we should actually now break and go to the reception downstairs. But I want to thank everyone on the panel and everybody else who is here, and all of you for coming.

Mind you that if you do want to do a deciding moment, it just takes a moment. We can do it here. You can do it later and upload it on their Facebook page which is Facebook/greaterthan aids, of course. And I'm actually gonna do one, it was preparing for this event that I realized that we should be doing them as well, so I'm gonna model that behavior, and please join us downstairs. Thank you again.

[END RECORDING]

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