

**A Congressional Briefing on ADAP
and Other National HIV/AIDS Policy Issues
Congressional Black Caucus
Health Braintrust
& Congressional Black Caucus Foundation
March 6, 2007**

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DANIEL DAWES, JD: Sorry about the delay. I want to thank everyone for coming today to our congressional briefing on the AIDS Drugs Assistance Program. My name is Daniel Dawes and I am a 2007 Lewis Stokes Health Policy Fellow in the office of Senator Edward Kennedy on the Senate Health Education Labor and Pensions Committee. Before that, I had the privilege of working with Congresswoman Donna Christianson in the Congressional Black Caucus Health Braintrust.

Today's event is a collaborative effort of the Congressional Black Caucus Foundation and the Congressional Black Caucus Health Brain Trust, which is aimed at informing congressional staff on an issue of vital concern to many Americans and to build awareness of current HIV/AIDS policy and concerns within our communities, particularly regarding the AIDS Drug Assistance Program.

This issue is of special concern to African-Americans because of the disturbing trend of the AIDS disease in the African-American community. Indeed, the grave racial and ethnic disparities in new AIDS cases are well documented. Consider, for example, although African-Americans comprise approximately 13.4-percent of the U.S. population, they account for more than half of new HIV/AIDS diagnoses and more than half of all AIDS deaths in the United States. In fact, the death rate among African-American men and women has been higher than any other population group for nearly 20 years. Equally serious is the fact that

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although African-Americans constitute approximately 17-percent of the teenage population in the United States, they represent 70-percent of all HIV/AIDS cases among teens.

Despite the fact that there have been significant advancements in HIV/AIDS medicines and treatments, there still remains a devastating problem concerning access to HIV/AIDS medications and treatments. More than 200,000 people who know their HIV status are not in treatment, and one CDC study estimates that only 55-percent of people living with HIV/AIDS who are eligible for anti-retroviral treatments are receiving this treatment. This issue, which has received little attention, is troublesome because many people continue to die as a result of not having access to these precious medicines. In South Carolina, for instance, three people died several weeks ago because they did not receive the AIDS treatments that they needed. They were placed on that state's ADAP waiting list.

It is undeniable that this issue is particularly worse for African-Americans who disproportionately live in poverty because studies have found an association between higher AIDS incidents and lower income. As you may already be aware, the AIDS Drug Assistance Program provides drug treatments for individuals with HIV/AIDS who cannot afford to pay for drugs and who have limited or no coverage from private insurance or Medicaid. Because African-Americans, in comparison to other racial or ethnic groups, are less likely to be covered by health insurance, this is a significant and beneficial program.

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This is an important issue, especially as we begin the process of reauthorizing the Ryan White Care Act and developing strategies to restructure and simplify the program. For those of you who are involved in reauthorizing the Ryan White Care Act or who are quite familiar with this issue, it is my hope that you'll leave today with more insight into what's occurring in the common lives or in the daily lives of those who are suffering from it, and for those who aren't familiar with it or who are new to this issue, it's my hope that you'll leave with a better understanding about this program and about some of these issues that are taking place.

Right now, I've gathered a pretty distinguished panel, very diverse in their views and in their backgrounds. Some are living with HIV/AIDS and others are not advocating for this. I'd like to begin our discussion, and what I'm going to do now is to introduce you to all our panelists.

The first person that will speak is Miss Jennifer Kates. She's the vice president and director of HIV Policy at Kaiser Family Foundation, a nonprofit private-operating foundation. Miss Kates oversees all of the Foundation's HIV/AIDS policy efforts, directing and conducting policy research and analysis focused on both the global HIV/AIDS epidemic and the epidemic within the United States. Congresswoman Christianson's office considers her the walking guru in HIV/AIDS policy and she will be giving us background information on the AIDS Rights [misspelled?] Assistance Program, how that program is structured and how it

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functions.

Our second panelist is Mr. Brryan Jackson, who is currently living with AIDS, and he's a champion for HIV/AIDS awareness and has given many speeches on HIV and AIDS throughout the country. He recently celebrated his 16th birthday – I think it's about a week and a half ago – and so we are very fortunate to have him. He is a walking miracle. And he's also a sophomore in high school from Missouri. He's driven to become a politician and an actor, he told me, and he'd like to one day establish his own AIDS educational organization and reach out to schools, community organizations and government entities. When he's not busy with school and work, Brryan enjoys playing video games and socializing. Mr. Jackson will be telling us his story and his concerns with the current ADAP program.

He will be joined by his mother, Miss Jennifer Jackson, who is a full-time mother of six children ranging in ages from 3-18. When she's not busy with her motherly duties, she chairs both the Parent Committee and the Policy Council of a Four County Headstart Program, which serves over 500 students and their families. She is a deeply spiritual person and credits God with blessing Brryan and her family. She will discuss her experiences as a primary health care advocate for Brryan and discuss the concerns that both she and Brryan have about the future of his well being once he reaches adulthood and seeks eligibility for ADAP.

Our next distinguished panelist is Bishop Joyce Turner-

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Keller, who is currently living with HIV/AIDS herself. She's an ordained minister now for 30 years and is a proud grandmother of 13 grandchildren. In her hometown of Baton Rouge, Louisiana, she has been at the forefront in promoting HIV/AIDS awareness.

Bishop Turner-Keller has extensive training in the area of HIV/AIDS counseling, including youth awareness and integrating HIV/AIDS counseling with hepatitis C counseling. She has been recognized nationally for her HIV/AIDS awareness work and has received several proclamations in her state of Louisiana. Bishop Turner-Keller will be telling us her story and giving us insight into her experiences as a participant in the ADAP program.

Our fifth panelist is Dr. Rani Whitfield. Dr. Rani Whitfield is a medical director from Baton Rouge, Louisiana, who is known to many as the hip-hop doc. He has committed his life to raising awareness of health-related issues such as HIV/AIDS, obesity, cardiovascular disease, and substance abuse affecting African-American youth. Dr. Whitfield's mission, especially concerning HIV/AIDS awareness, has gained national attention. He has been featured on BET's "106 and Park" and has been a medical consultant for BET Black Entertainment Television, where he conducted a national online discussion about HIV/AIDS on World AIDS Day. He has also been a contributor to the recently released book *Not in My Family: AIDS in the African American Community*, which I think most of you should have gotten a flyer about, and he talks about the need for greater understanding, education and dissemination of information in the black community

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about HIV/AIDS. Though nationally acclaimed, Dr. Whitfield still remains committed to his extensive youth community health initiatives within his home state of Louisiana. A physician by trade, community activist, motivational speaker and philanthropist by passion, Dr. Whitfield is a vital figure in HIV/AIDS awareness. Dr. Whitfield will discuss his experience as a practicing physician treating HIV/AIDS patients and how HIV/AIDS affects the body.

And lastly, but not the least, certainly not, is Mr. Bill Arnold. He is a longtime national and international HIV/AIDS activist and consumer organizer, and has been active in developing HIV/AIDS organizations and HIV/AIDS policy at the local, state and national levels since the mid-1980s. He's the founding director of the Title II Community AIDS National Network, which is T2CAN [misspelled?] for short, and is currently its CEO. He's also a founder of the National ADAP Working Group, a Washington D.C.-based advocacy coalition, which advocates at the federal level for ADAP AIDS Drugs Assistance Program Resources and Policies. His involvement with grassroots AIDS work has included roles from board chair and board member to buddy, to AIDS educator, community outreach director, and pre- and post-test HIV counselor. Mr. Arnold will be discussing the various problems that have been confronting ADAP patients on a national level.

I see that we have Congresswoman Maxine Waters and it's my pleasure to introduce you to her. Congresswoman Maxine Waters

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is considered by many to be one of the most powerful women in American politics today. She has been tireless, fearless, and an outspoken advocate for women, children, minorities and the poor. Elected in November 2006 to her ninth term in the House of Representatives, with an overwhelming majority of the votes in the 35th District of California, Congresswoman Waters represents a large part of the South-Central Los Angeles, the communities of Westchester and Playa del Rey, as well as the diversities of Gardena, Hawthorne, Englewood and Lawndale. One of her most important priorities centers on the AIDS epidemic within the African-American community. As a result, she has led congressional efforts to reduce and eliminate this disease. In 1998, she spearheaded the development of the Minority AIDS Initiative to address the alarming spread of HIV/AIDS among African-Americans, Hispanics and other minorities. Under her continuing leadership, funding for the Minority AIDS Initiative has increased from the initial appropriation of \$156 million in fiscal year 1999 to approximately \$400 million per year today. Most recently, she has authored several pieces of legislation aimed at controlling the spread of the virus. Please join me in welcoming the distinguished congresswoman, Congresswoman Maxine Waters.

REP. MAXINE WATERS (D-CA): Thank you very much. When I accepted the invitation to join with you today it was my understanding that you would be talking about ADAP and our need to increase the appropriation for ADAP. And I was a little bit

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concerned that I had not paid more attention to the fact that we have waiting lists. It does no good to talk with you about these new bills that I have introduced if I cannot talk about how we are going to take care of the people who find out that they are infected with HIV and AIDS. So let me just not go through all of the damage statistics, which you all know better than I do. Let me ask a question first.

I understand that is Mr. Gil Robertson IV here? Where is he? Oh, I just read the book, and I was absolutely overwhelmed with the information. Not that I'm not familiar with a lot of HIV and AIDS cases, but the absolute clarity and honesty in which some people discuss what was going on was absolutely enlightening to me, so thank you. I happen to have the book. I carry a lot of them on the plane. Most of the time I don't get to them, but I thought, well, let me see what they're saying about AIDS. Probably everything they're saying, I already know. But this was a completely different take, and I would recommend that everybody read this book. It's very important.

Now, let me just say that I've introduced HRA 822, the routine HIV/AIDS Screening Coverage Act. I introduced HRA 822, the routine HIV/AIDS Screening Coverage Act because the Bill would require health insurance plans to cover routine HIV/AIDS tests under the same terms and conditions as other routine screenings. Standard health insurance plans generally cover HIV/AIDS screening when there are clinical indications of infection or when there are known risk factors present. It has

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been estimated that between 24- and 27-percent of people with HIV/AIDS in the United States do not know they are infected. Admitted, these people do not fall into high-risk categories such as [inaudible] or intravenous drug users. On September 21st 2006, the Centers for Disease Control and Prevention released new guidelines that recommend routing HIV/AIDS screening in health care settings for all patients aged 13-64. I won't talk about that much more.

Let me just tell you that I also will be introducing in a few days the Stop AIDS in Prison Act. This bill will require the Bureau of Prisons to test all prisoners for HIV/AIDS upon entering prison and then test them again upon release.

Now, without going into the bills any more, let me just say this: Because I was invited here today, it forces me to focus on the need for support for anti-retroviral drugs and that we cannot keep talking about testing without talking about where people are going to get the help that they need and the medicines that they need.

As you know, I don't know why as Democrats coming in we've adopted this Paygo Plan. When the Republicans were in, they spent like drunken sailors, and they were not concerned about budget deficits. As you know, when Bill Clinton left, he left us with a surplus. They spent and spent and spent, and now because we're trying to be I don't what - great legislators with more concern than anybody else - now we've got a plan that talks about not being able to spend money without identifying where

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that money's going to come from because of the constraints of the budget. But let me just say to you without taking any more of your time, I certainly am in support of testing, and I want everybody to get tested. As a matter of fact, in all of the speeches that I've been making recently, no matter where I go, I've been encouraging people to get tested and trying to educate people about not thinking that they don't have to be tested if they don't fall into the so-called old high-risk groups. But what I was not able to tell them, because I was not focused on the fact that we don't have the coverage for everybody for the medicines that they need, I was not able to tell them, but once you're tested, if you don't have health insurance and if you don't have luck enough to be in that place, that state and that program where you can be covered, you may have to stand in line, and you may have to wait for two years. I'm embarrassed. I'm absolutely embarrassed.

And because of the invitation today, I'm now focused and I will use just as much energy to fight to make sure that we expand and fund the ADAP program as we do talking about the need for everybody to get tested. Thank you very much.

DANIEL DAWES, JD: All right. Thank you very much. We're going to begin our panel discussion now with Miss Kates, so I'll turn over the mic to her.

JENNIFER KATES, MA, MPA: Good afternoon, everyone. I'm very happy to be here. As Daniel mentioned, I'm from the Kaiser Family Foundation, and we are a nonprofit, private-operating

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foundation that focuses on health issues including HIV. We're nonpartisan. We aim to provide a source of information and facts for conversations like this. I will try to make it interesting. More importantly than that, I just need you all to know that Kaiser Family Foundation is in no way associated with Kaiser Permanente or other Kaiser industries, so that health insurance bill won't affect anything that we do, although we think it's a good idea.

First, I'd like to thank the Congressional Black Caucus Foundation, the CBC Health Braintrust, and those involved for convening this important briefing that I know has been a long time in the works. I specifically want to thank Representatives Clyburn[mispelled?], Waters and Christianson for their continued leadership on this issue and for being involved in this briefing, and Representative Waters for actually coming and being able to share some time with us. I also want to thank Brit Weinstock and Daniel Dawes, who put this together, and Daniel especially, for making this happen. He was committed to doing this from even before beginning his fellowship, and really wanted to make this briefing happen, so thank you, Daniel, for doing this.

And then, finally, before I quickly run through some slides, I want to thank the National Alliance of State and Territorial AIDS Directors. They've been a partner of the Kaiser Family Foundation for about a decade looking at this very program. And a lot of the data I'll present today are data that we collected together and continue to do so. So I want to thank them, and I

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know some of them are here as well.

So I'll do a quick overview of the AIDS Drug Assistance Program, and then we'll hear from people who are really living every day trying to navigate this program and understand how it works and help clients navigate it as well.

So a few key things about the AIDS Drug Assistance Program - I know we have different levels of knowledge about the program here - first, they are authorized under Part B, and I'm saying that specifically because that was the former Title II of what was formally called the Ryan White Care Act and now is called - I won't say the long name - the Ryan White Program. So they are authorized under Part B of the Ryan White Program, and ADAPs are our country's prescription drug safety net for low-income people with HIV who have no insurance or are under insured. This is the safety net program.

ADAPs provide medications and also insurance coverage through purchasing that coverage or continuing coverage for people as long as it includes medications. So those are the two main ways, primarily medications directly, in which ADAPs help people with HIV.

They are federally administered by HRSA - that's the Department of Health and Human Services - and operated by the states - 57 jurisdictions. I know there are some questions about the number of eligible jurisdictions. Now and last year, all states and territories for the most part are eligible for federal ADAP funding.

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The best way to think about ADAPs, I think, is to think of them as the payer of last resort, the gap filler, the program that really wraps around the other programs, particularly Medicaid, also Medicare, especially with Part D, the program that fills in the gaps when those programs either cannot completely provide for people with HIV or people with HIV are not eligible for them or have a lapse in eligibility. That's where ADAP is critical, very critical.

The other important thing to know about ADAPs and part of the Ryan White system: It's not an entitlement program. It's a discretionary grant. And that means a very important thing in terms of how we understand it. It is funded each year through appropriations. It is not funded on an entitlement basis like Medicaid or Medicare. And primarily, it's funded by the federal government although many states, most states, actually do provide funding to their ADAP, and ADAPs can get funding from many other sources.

But all of these complex factors combine and produce a program that looks very different in every state in this country, and there's lots of variation.

I'm not going to go through all of these dates, but these are some really key dates in the history of this program, and the main thing I just wanted to highlight here is that the origin of this program started a long time ago. In 1987, when the first anti-retroviral drug was approved by the FDA, states were in a real challenging position to get that medication out to people

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with HIV, and that's when the precursor to what we call ADAP began. So there's a long history in this desire to get medications to people with HIV as quickly as possible, but real challenges with states and others being able to afford them. That was the origin of ADAP. It eventually became part of Ryan White.

And these are some other key dates along the way where changes were made in ADAP that have impacted how that program is structured and what it does and can do. Some have made ADAP more flexible, some have put more requirements on ADAP.

And some big important shifts and context changes to understand about this program from when it was first beginning and conceived of to now. First, on the medical side, you all know this, but the treatment environment has shifted so much. Think about one anti-retroviral in 1987. Not only was there just one, but now we would never recommend one anti-retroviral only for someone with HIV. That's counter-indicated. There was only one approved, and now we have over 25. They're much more complex combination therapy and a very different treatment environment. So that is a big, big shift.

Also, the population. In general, the number of people living with HIV in the United States has increased significantly and continues to each year, and the demographics of who's affected has changed. So we have a shift in population.

And then, thirdly, costs. Over time, the drug costs have increased for many reasons. They've increased to the program

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because there's a growing number of people living with HIV. They've increased per person because therapy is more complex. When new drugs become approved, we have noticed over time that the cost is additive. So a new drug might come out, it might be a combination therapy. It's always additive. So in general, drug costs are increasing. So we have a growing population and an increasing cost.

A few things also to understand about why there might be variation across the country and how ADAPs are structured. The federal government determines certain things about ADAPs and the states determine the rest, and both of those have to react and play off of the financing environment that may exist in a particular state and the epidemic in a particular state. So the federal government determines which jurisdictions are eligible for funding and it can also, through Ryan White and through policies and advisories, provide information about how the programs can interpret the law and what they can and can't do.

The states determine who is eligible for the program, what income level. States determine what drug-purchasing strategies they may want to use, for the most part, whether they are going to use their ADAP funding for insurance purchasing as well as medications, and that also depends on the state environment and regulations. And so the most recent reauthorization – this is probably one of the biggest changes in the program since its beginning – there was state discretion as to what should be on a formulary, and that is now changed with

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the new reauthorization of Ryan White. There is a minimum formulary requirement.

But the end result of these different roles played by the federal government and the state government and the different responsibilities given to each in terms of determination of the program means that the program looks very, very different across the country.

So what does an ADAP do to try to match the need on the ground with the resources that it has from the federal government, from the states, from other sources? These are the levers that an AIDS Drug Assistance Program Director, and there are some sitting here, so I don't mean to speak for them, but these are the levers that they have available to them to figure out how to manage based on a set, finite amount of resources and growing need. They can change income eligibility, until recently had pretty much discretion over what went on a formulary, could set and still can prescription drug limits, saying a certain amount of drugs per person per month or per year, could institute co-payments and cost-sharing for clients, and other options, such as using insurance purchasing or continuation. And we actually have seen in our reports every year that this is a very, very cost-effective way if a state can do it, to make dollars go further, drug purchasing strategies, cost recovery and coordination with other programs.

The top part, I would say, are really the immediate program levers, and you can see there's a limited number of

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levers that one can move and they have implications. More people become eligible or less people become eligible. If you throw a new drug into that mix, you can see it can throw off that balance, and these are the challenges that programs are facing.

I want to highlight the project that we do with NASTAD every year for two reasons. One is the data that are going to come next, which I promise to run through very quickly, are based on that project. And two, we are going to be releasing our next report on April 10th in Washington at a D.C. briefing with NASDAT and actually it's going to be formally part of their conference with the AIDS Drug Assistance Program Managers and Directors from across the country. So we're really excited to be able to do this.

The release is part of that conference, but most importantly, we'll have new data. We'll have new data, the latest data available on all the aspects of ADAP, so much of the data that I'm going to show you now is from our prior report, but we wanted to make you aware of this date, and there will be a public briefing and information will be going out.

So running through the data really quickly, this was what we released last year. So it was based on primarily a month's snapshot, which was June 2005, but you can see well over 130,000 clients enrolled on an annual basis, and within each month less clients are served but it's close to 100,000 clients being served, and that's through medications directly. In addition, ADAPs, as we mentioned earlier, are providing insurance coverage

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and continuation.

Profile of ADAP clients, and I think this is really critical. A few key things: First, the majority are people of color, most are low income, most are uninsured, most are men, and half have indications of advanced HIV disease. So this program is serving the target that it's intended to serve - people who don't have access because they don't have insurance or have limited insurance, people who are at low income and actually very low income, and people who are increasingly affected by this disease, and with indications of advanced HIV infection. So it's really reaching the target.

Drug expenditures: This just shows a monthly drug expenditure snapshot as well as the per capita expenditures, and the main thing to take away from here is that most of the expenditures are on ARVs, the most expensive component of AIDS treatment today.

The budget: Very quickly, just to reinforce the point I made earlier, most of the funding that ADAPs receive is from the federal government, although there are many other sources, and we continue to track this over time.

A few things on the variability. The next few slides just show you the variability of these programs, just to help understand that where you're set up - if you're in Missouri, if you're in Washington-the program is going to look very different based on all the things I said. This was from a year ago - the income eligibility across the country - and you can see some

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states have more generous income eligibility than others, and that's based on a whole host of factors.

Formulary coverage for ARVs: We believe this is going to change moving forward now with the new requirement under Ryan White, but this was as of last year, and you can see for the most part states were covering all or almost all of the ARVs that have been approved, but that wasn't across the board.

This is for the medications that are highly recommended for the prevention and treatment of opportunistic infections. Much more variability here.

And this is actually from NASDAT's most recent ADAP watch. This combined states that have waiting lists, which is four as of the most recent one, with states that also have other cost-containment other than waiting lists in place. And one thing that I think is good and positive, and we'll be talking more about this in April at the Release, is that the number of states with waiting lists has decreased, and there are several factors for that. One, very notably, is the implementation of Medicare Part D, so that will be a big part of what we talk about next month when we release the report. Is that a onetime thing? What does that mean? But the number of states that have waiting lists has decreased, although there are still four with waiting lists.

This is from last year to show you that in addition to waiting lists, because we always all focus on waiting lists. It's a very obvious marker of a limitation of the program. The most

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important thing to understand about a waiting list: People on that list are eligible for their program, they meet all of the eligibility requirements. There is just no capacity to serve them. So it's a very visible marker of the lack of capacity. But there are other ones. There are other things that states do or have to do to manage this balance, and we just want to make you aware of those.

So moving forward, we'll probably hear some of this from your questions and from the other panelists, we know that ADAPs will continue to play this vital role for low-income people with HIV. That is a given. And one important thing about them, too, is that ADAPs serve as a bridge to other programs, to other support of a growing population of people in need. And we'll continue to monitor waiting lists and other markers of resource constraints over time.

And the impact of reauthorization: It's unknown as of yet, but there are a few key things that we'll be paying attention to, and I know a lot of you, I know, will, with this formulary change in requirement. There's been a change in the ADAP supplemental, so that's a higher percentage of funding that's available to states with demonstrated need. And there's changes to Ryan White that aren't about ADAPs specifically, but ADAP is part of this larger system, so what happens in other parts of Ryan White can affect ADAP.

Medicare Part D, as I mentioned, and as always, anything that happens with Medicaid is going to affect ADAP. The two are

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sort of interconnected, and now Medicare Part D even more. And then anything that might happen on the clinical and treatment environment will stand to affect ADAP.

So I just encourage you to come to our briefing in April. It will also be webcast so for those of you who aren't in D.C., you can view it as well. And thank you very much. I'll be here to answer questions at the end.

DANIEL DAWES, JD: Thank you, Miss Kates. Right now I'd like to recognize Congressman Payne, the Honorable Congressman from New Jersey. Not only is he the strongest legislator on HIV domestically, but he is also the strongest legislator on HIV/AIDS policy globally, and it's beyond an honor, sir, to have you today. Would you like to give some brief remarks?

REP. DONALD PAYNE (D-NJ): Thank you very much, and to the panel and to the Congressional Black Caucus Foundation and our Health Braintrust, headed by our good Dr. Christian Christianson. It's really done an outstanding job. And to your moderator, I'm just here to sit in for a few minutes and to try to hear what is going on out in the community. The only way that programs like this, the AIDS Drug Assistance Program and other programs that benefit people, is by virtue of people in the community being advocates for financial support. As you know, this place here in Washington works on pressure, pressure from groups. You hear about lobbying, and it's talked about in a negative connotation and big lobbying firms and people have gone to jail and all that, but lobbying, by and large, is usually a positive thing if the

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people like yourselves and those who represent legitimate groups and represent people out there in the community come to lobby your representatives, you'd be surprised how important it is that the voice of the people back home, back in the hinterlands, that their desires and needs come to the Congress so that their needs can be followed.

So I'm just here to say that we have to continually increase the pot. We've seen some of the latest debate about the new formulas and rural and southern areas as opposed to the old urban at the inception of Ryan White. We really can't afford arguments of that nature. It comes to the point, do you fund AIDS or do you fund senior prescription drug benefits? You know, we need to just say there has to be a larger pot. There is available funds there. You always see the defense budget continually get all of the funds that they need - always - and even more. And so the money is there. We just have to be strong advocates to have it go into the needs of the people, and so I will continue to be supportive. You have excellent panelists. We have a number of members of Congress who are working hard.

Actually, we have finally decided that global health is extremely important. You know and talk about the West Nile Virus in the United States because it's the West Nile. It's over in Africa. So it was something that was happening over there, and didn't impact on us too much over here. But now, for the last six, seven years they give the number of birds that die in Central Park in New York from West Nile Virus, which simply means

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that Joe Lewis, I love that you can run, but you can't hide. And so what happens in another part of the world comes to other parts very, very quickly. And the quicker we can get our legislators here to realize that the better. Our Advocacy Committee now will deal with global health. The first time that global health has been put in a specific jurisdiction in a subcommittee, and we will certainly have some hearings dealing specifically with global health and, of course, at the forefront of that is HIV and AIDS, malaria, tuberculosis.

On December 1st on World AIDS Day, I was in Kenya in Nairobi speaking at their World AIDS Day program, and the struggle that people in Africa and other Third World countries have is just unbelievable. We have a lot to do here, but we simply have to widen the pot, and you can count on my continued support as we move forward. Thanks very much.

DANIEL DAWES, JD: All right. Ladies and gentlemen, now we're going to hear from Brryan and his mother, Miss Jackson.

BRRYAN JACKSON: In 1996, I lay dying in a hospital bed. In the matter of two months, I went from a playful, energetic and happy 5-year-old to a bloated, feverish, vomiting kid who could not walk. My mother struggled to carry me to numerous appointments, and also begged and prayed for doctors to find a reason why I was appearing near death.

They checked me for a large number of diseases, even ones that exist in other countries, but since I was not at risk for HIV I was not tested for it until May 24th, three months after I

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became severely ill, that my mom and my doctor asked for me to be tested. The result was devastating. I was diagnosed with full-blown AIDS, and a number of other AIDS-related infections too. And my family was told that I was not going to live long. The doctor said six months at the most. And according to the medical journals at the time, anyone in my condition died within three months.

Yet being diagnosed with AIDS has been the only tragedy. The way I got to be HIV-positive was even more horrible. My own father was the one who injected me with HIV. He worked in a blood lab and took it from work. Not that I was only dying, but I was also a victim of a crime. Yet, by the grace of God, the power of prayer, and medications, I stand here before you today as a miracle, wanting to tell my story to bring home to many and knowledge to all.

I celebrated my 16th birthday 11 days ago, a miracle indeed, but there's a downside to each birthday I celebrate. That's put me one step closer to not having merit [misspelled?], when my birthday present one day may be no health care coverage, no much[misspelled?]. Happy birthday to me. I think not. Even a bow and wrapping paper would not make that present pretty.

JENNIFER JACKSON: You see, at the present time, Brryan is covered under Title IV, or Part D, for women, children and youth. Girls grow up and turn into women and still are covered under that area, but Brryan and many other boys will grow up into men and what then? Put on waiting lists or reduced formularies?

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Unfortunately, the proper term for waiting lists are death lists. No more money to ADAP could mean either Brryan dies or someone else, if not many others, have to die so Brryan could be moved up on the list to be covered.

Or, you say, let's have a reduced formulary and not cover all the medications that are available. The big problem here is that the meds that a physician believes are best for his patient may not be available through that formulary. Therefore, people who are only HIV-positive are ending up with AIDS due to being inadequately medicated. And, of course, the cost to assist someone with AIDS is usually 10 times more than assisting someone who is only HIV-positive. It's due to longer and more frequent hospitalizations, more opportunistic infections, and more medications needed. We have been there with him.

There is even more of a down side to this digression, though. Side effects from medications, which can be deadly themselves under the present formularies, many times aren't even covered. For instance, it's usually impossible to get the proper meds to treat the chronic diarrhea, the muscle atrophy or the wasting syndrome that goes along with it, intestinal problems, the high cholesterol, the neuropathy, the mental disorders or the pain that goes hand in hand with being treated for HIV.

And, yes, mental health is definitely an issue that needs to be addressed. Did you know that a common occurrence with HIV is something called white matter on the brain? This so-called white matter can present itself in various mental disorders such

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as ADD, depression, unstable mood disorders and numerous others. One can even suffer from post-traumatic stress syndrome just from being diagnosed and the stress and stigma that comes along with it. Not keeping someone who is HIV-positive mentally healthy only feeds the spread of the disease. A mentally unstable person is more likely to be non-compliant with the medication routine and make poor choices involving health, nutrition, substance abuse and sexual activity. So not only does this lead to both the HIV-positive person becoming an AIDS diagnosis, but quite possibly others getting infected. The end result, no matter how you look at it, is more expensive and more deadly.

One other thing you may not know. In order to qualify for Ryan White services in Missouri requires poverty. How horrible. As if the diagnosis is not devastating enough, in order for Brryan to receive any services from the present care act, his family - five siblings and myself - have to remain in poverty. So it appears you not only punish the infected, but those affected must also suffer, endure more hardships, and have their lives controlled by the disease. A diagnosis of an HIV family member means the rights of the entire family are greatly compromised.

BRRYAN JACKSON: The fight of those infected and affected by HIV is different today than when Ryan White was alive. His fight was trying to stay alive until new medications were found. My fight is to have access to those meds does not exist. When Ryan White's [inaudible] was originally written, a diagnosis of HIV-

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positive soon became a machine death. But today, the medications can prolong life and reduce progression to AIDS and prevent death. Yet people are still dying. Why? Because many refuse to see AIDS as a health issue, and it is the government refuses to fully fund Ryan White to assist all those infected and affected by HIV in all areas, and refusing to see the truth and not completely funding the necessary care and medications for all those infected.

Those in government are willing to allow people to die, even if they say they support fully Ryan White as its current level. What they really mean is they are choosing to kill millions of people with HIV and AIDS in not providing them with the care and medication that's available. Therefore, they are choosing who lives and who dies. More people are diagnosed every year. More people are living longer with this disease. Yet no more money is set aside to help them. It is like we've been thrown a bowl of mashed potatoes and told to feed the world. Our prayer for you today is that you will find courage to win against the war of AIDS by choosing to save lives and fully fund Ryan White Care Act at its necessary level.

HIV [misspelled?] hope is vital so stand strong, pass it on. Thank you. God bless.

DANIEL DAWES, JD: Thank you very much, Brryan, and thank you, Miss Jackson, for your statement. Now we're going to proceed to Bishop Joyce Turner-Keller from Louisiana.

BISHOP JOYCE TURNER-KELLER: Good afternoon. I'm Bishop

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Joyce Turner-Keller, a 58-year-old African-American woman living with AIDS.

My story: One of the things I think it's important to do and to speak about is ADAP, what it has done for me. You look at me now and you can't tell that I'm living with AIDS, but in 2001, I weighed less than 115 pounds, after having weighed 193 pounds. This is ADAP has done for me. It has given me a new lease on life. ADAP, because of the funding that ADAP has so far supplied to the State of Louisiana, I am able to be a viable contributing member of society. I am able to stand before you and to speak about what it's like to live with this disease.

What you see on the outside is someone physically fit, but what you do not see on the inside is someone who is physically wounded, oftentimes physically abused, mentally abused, because of the stigma that's attached to HIV and AIDS. ADAP is a necessary - exceptionally necessary - instrument that we have in this fight against HIV and AIDS. Ryan White should be fully funded.

In Mississippi in 1995, I found myself in the fight of my life for my life. Today, 2007, I'm still in the fight of my life for my life. If Ryan White is not fully funded, if ADAP ceases to be, and there is a season change, who will notice that I am no longer among you? Who will notice that my grandchildren may not have a grandmother, or that my sons, my daughter, will no longer have a mother, that I will no longer have a voice? ADAP is necessary. It is so necessary.

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I have a quilt and I noticed that when the invitations went out, it said, "What should ADAP look like?" This is what ADAP should look like. No name on the quilt. This is what it should look like but the sad thing is, is that this is what ADAP does look like. Visuals are so necessary. The names on that quilt are the names of those of us that are positive. The names on that quilt are those of us that are receiving Ryan White and ADAP. Some are. There are some on that quilt that are not.

I walk around Washington and I see - I was here in September - and the leaves were beginning to change on the trees, and as that was happening there were workers on the grounds of Washington, of our nation's capital. They were refurbishing the grounds so we could not notice the season change. The dead leaves falling from the trees or the flowers dying, they didn't want that to be noticeable. But yet, I stand before you as a woman living with Stage 4 AIDS. If you're going to water the ground of Washington and fund the war, fund my war, please. Water my life with some funding. Water Ryan White with adequate funding. I know that you go back to the table over and over again and decide how much we should have. Well, why can't you make one trip to the table and make this a national necessary part of our - I'm an American - make it a part of what my health care is, and I don't have to wonder next year if I will be taken care of? I don't have to wonder next year when I've become resistant to the medicine I'm on now, if those meds are going to be in the formulary for me next year. If you're going to do your

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duty here in Congress and on the Hill, save my life. Fully fund the Ryan White Care Act. Thank you.

DANIEL DAWES, JD: Thank you, Bishop Joyce Turner-Keller for your statement. And now, we're going to move along quickly to Dr. Rani Whitfield.

RANI WHITFIELD, MD: Thank you, guys. In essence of time, we'll keep it a little bit short. I must say along with my other duties, I'm the proud primary care physician of Miss Keller and I have to deal with her all the time. So it's a tough job being me. Again, my name is Rani G. Whitefield, MD. I'm a family practice sports medicine physician that practices in Baton Rouge, Louisiana.

My students and colleagues affectionately call me the hip-hop doc, as I have used medicine and music to educate young people on health issues. Among my daily duties, which include being the father of Rana, a physician in private practice, a medical director of two substance abuse clinics, a community spokesperson, I also provide primary care services to HIV-positive men and women daily at the local prison in Baton Rouge. I am responsible for 30 to 40 men and women patients, at any given time, who have been diagnosed with HIV/AIDS and are probably co-infected with hepatitis C. Most are African-American men living well below the poverty level who will be homeless upon release from prison. Their only source of treatment for HIV comes from a referral from the prison to the specialists at the Ryan White-funded, ADAP-supported early intervention clinic in

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Baton Rouge. There is often a two- to three-month delay for appointments, however, so most of these guys get transferred or discharged from prison without ever receiving adequate treatment. This delay in treatment and non-compliance with drug regimens are two of the contributing reasons why we have a high incidence of developing drug resistance.

Several studies have shown that the ethnic and racial inequalities in the U.S. health care system have translated into health care disparities in the treatment of HIV/AIDS. Access to HIV/AIDS health care for African-Americans is lower than that for other ethnic groups on a number of measures, including access to PCP or PJC prophylaxis, a form of pneumonia that you get when you're HIV infected, and highly active anti-retroviral therapy.

These issues are real and I see them each week as my jobs in the substance abuse clinics and at the prison show the direct links between substance abuse, homelessness and the transmission of HIV and AIDS. It is truly amazing to me that in the greatest country in the world and with all the advances in medicines, Americans are suffering and dying at alarming rates from preventable diseases such as heart disease, stroke, the complications of obesity and smoking and, of course, HIV/AIDS. We may, for the first time in our history, see a decrease in life expectancy in our young people due to unhealthy lifestyles, poor decision-making and lack of access to medications.

As a result of my community involvement with young people as the hip-hoc doc, I was selected among many African-American

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voices to share with the world my perspective on this pandemic. *Not in My Family: AIDS and the African American Community*, a book written by Gil Robertson, is a collection of personal testimonies, essays and polemics, used as a tool to stimulate more discussion about this dreaded disease.

Treatment of HIV infection in communities of color is difficult because of long-standing stereotypes, poverty, denial of disease status and risk behavior, mistrust of the medical establishment, challenges in patient provider communication, and misperceptions about the disease.

The HIV/AIDS epidemic hits very close to home as the southern states have the highest AIDS rates in the country. Baton Rouge, my birthplace, has the highest HIV/AIDS diagnosis rate in the State of Louisiana the last five years. Baton Rouge also suffers from the sixth highest AIDS case rate in the nation compared to New Orleans, which has the seventh highest AIDS case rate in the nation. Hurricane Katrina placed a tremendous burden on the HIV/AIDS population throughout New Orleans and Baton Rouge regions. Many HIV/AIDS residents, primarily African-Americans displaced by the storm, have attempted to return home only to find the necessities of housing, employment and health care fragmented and unstable.

The AIDS Drug Assistance Program, which is a part of the Ryan White Act is a much-needed program. Continued funding will ensure that those who are uninsured and underinsured will receive medication that will not only slow the progression of the

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disease, but help to stop the transmission of HIV. Access to care and/or medication should never be an issue. Funding is needed in the areas of physician training, research for a vaccine or cure, community awareness and education, as well as community-based treatment centers that address all the needs of the patients, including access to care, medication, child care service and transportation.

Is eradication of HIV possible? I cannot answer that question today. However, I do know that if we do not fully support programs such as Ryan White and ADAP, the answer is emphatically no. Thank you for your time.

DANIEL DAWES, JD: Thank you, Dr. Whitfield. And now we're going to proceed with our last panelist, Mr. Bill Arnold.

WILLIAM ARNOLD: And we're going to see if we can't set some sort of a speed record so that we have some time for questions and answers.

The first thing I was going to comment on was to try and do a very short synopsis of the real problem with ADAP at the national level, in other words, looking at all 57 programs. And from the patient's point of view, the problem is probably it's not the same everywhere. We need to find out in our re-evaluation of the ongoing Ryan White program here over the next two or three years, how can we, and what do we need to do to get the program so that from a patient's point of view if you live in Guam or Nome, Alaska, or the American Virgin Islands or rural Arkansas, somehow or other what you have access to is at least roughly comparable.

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There are bunches of other problems too, but it seems to me that that's the particular one.

The resources, which everyone has spoken to one way or another, are a problem in the sense that ADAP is flat funded in the FY07 budget. When those funds are released in a few weeks, some ADAP programs will actually take reductions. And it's flat funded for the first time ever, which is shocking in and of itself.

If the medical objective for the HIV-positive population is to get people tested and get them into care – other people have already said, okay, let's test them, and even as Maxine Waters said, let's make sure that we can get them into care – the way things are functioning now, too many people are being picked up too late in the game. They're too sick when they're diagnosed. The meds do not necessarily have optimum effect when it's that late in the disease process, and you end up piling up an awful lot of hospitalization and extra care bills. So if we're trying to do the best thing we can from a medical point of view, which is also the most fiscally responsible, and probably the most cost-effective approach, we have to do a better job of getting people into care early and getting them on drugs early in the game.

We have data and statistics on HIV and AIDS and the ADAP program up the kazoo, and I say that in a nice way, and that's thankfully over the last 10 years due to NASDAT and the Kaiser Family Foundation. They have handouts out on the desk outside,

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but they're an ongoing source. In fact, without their work, the rest of us couldn't make much sense out of the ideas that we try to express in our advocacy.

Jen just went through quickly a batch of the basic data. You've heard from Brryan and Jennifer, who are living with both the infected and affected parts of it. When I first started working with Brryan three years ago, he was this tall. Yesterday when he got off the plane and showed up at the hotel, I'm looking over, and now he's this tall. I mean, that really says it all. You would like to see that for everybody. Brryan's been very fortunate so far, and we have a couple hundred thousand other people, I'm sure, who would like to be in the same boat.

You've heard from Bishop Joyce, walking the walk and learning to do the talk. You've heard from Dr. Whitfield who is trying to take care of folks. And that's a pretty good cross-section for a quick hour and a half, or a little over an hour, in a busy Washington.

I'll just add my thanks to everybody who helped make this possible. Daniel, you did a great job. You did not go completely crazy. The product is very good.

And then the last question, which came from on high was, "What should ADAP look like from hereon in?" So I wrote down two sentences. Number one, there have to be adequate resources for HIV patients and for their health care providers, MDs, staffs and clinics. If you don't have those cards in play you're not playing with a full deck. If you're not playing with a full

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deck, you're not addressing 100-percent of the problem.

We will probably in the not-too-distant future get the Early Treatment for HIV Act dropped. In the House, I'm sure they'll have the same bipartisan supporters they've always had. I urge all of you who are on staff who are not familiar with it to take a look at it. Perhaps your boss would like to become a co-sponsor of it. It will provide ADAP relief if it passes and, who knows? This might be the year when it should pass.

If we get down the road another two years or so, we may end up all needing to go back and take a look at that infamous IOM Report from a few years ago that told us all how we really should be taking care of the HIV-positive people in the United States. If we need to go back and take a look at that route, I hope that there will be literally a stampede of people saying, yes, it's time for instituting something like that, even if it has the nasty word "entitlement" attached to it, because, number one, it would be universally available; number two, it would be portable; and number three, it would be fiscally responsible and cost-effective. Thank you, everybody, and I hope we have time for some questions.

DANIEL DAWES, JD: Okay. Thank you Mr. Arnold, and yes, I'm going to open it up to questions now. Does anyone have a question they'd like to ask? Yes, sir.

GENE KAPPELL [misspelled?]: My name is Gene Kappell with the AIDS Institute. I want to thank the whole panel for their remarks, and I want to just say that I think we need to push it

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out today that the waiting lists that we're all concerned about really are just the tip of the iceberg, and Bill and I have talked about this a lot as well as others. There are many other people with eligibility limits that could benefit from ADAP and have access to medication problems. So that waiting list number is really just the tip of the iceberg, and that's why it's so important that ADAP be funded at higher levels.

DANIEL DAWES, JD: Okay. Thank you. Does anyone have a question that they'd like to ask? Yes, sir.

HAL MYERS: My name is Hal Myers. I'm with the Health Care Foundation. I'm wondering if anyone has thought about one of the issues I'm hearing that hasn't been talked about. In the last 10 years, as far as I understand it from [inaudible] drug spending has been increasing at twice the rate that finance has been moving. So that all of the money that's being paid for the extra funding for ADAP is going straight to drug companies. And if that doesn't stop, everyone's going to have a problem with structural deficits [inaudible] part of our financial solutions will be based on how to get a handle on drug costs.

DANIEL DAWES, JD: Does anybody want to take that?

RANI WHITFIELD, MD: One way that that could be done is to be in a position, and this has happened recently. We were approached a lot by pharmaceutical reps with different opportunities to go out to dinner, dine and dash, and so they [inaudible] a lot of those things because it had an influence on physicians to prescribe certain medications, at least that was

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the premise. So I think one way that that could be done is the government has to put some control on medication costs, because even as a physician, when I prescribe medications to patients, sometimes I'm not even conscious. They'll bring in cards that says, well, we're Tier 1, Tier 2, Tier 3 type of medication. This is how much this costs, this is how much that costs. But you're not always really sure if your patient calls you back at three in the morning and says, "Doctor, the antibiotic that you [inaudible] for me is \$87. I can't afford that."

So I think that there need to be some policies passed down from the government, whether it's state or local or national, that will control the medication costs, especially when dealing with medication that deals specifically for patients with HIV. I think that would be one avenue to address that cost.

BISHOP JOYCE TURNER-KELLER: I think one of the things that needs to be addressed in a situation like that, just like there are certain restrictions for what lawyers can do, some of those restrictions should apply to some of the drug companies, because when they go in and tell a physician that we'll give you this, that or the other to prescribe this med, and oftentimes the danger in that is that a physician may prescribe something for you without even knowing if you should take that medicine, and it's after the side effects that you've been devastated with that they begin to address what that medicine is really for.

I think that we just need to place more restrictions on how the drug companies are marketing the medicine. I think that that

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is intelligent.

RANI WHITFIELD, MD: The companies have addressed that. That was one of the things. They've taken away a lot of the perks that physicians are given so that their prescribing habits won't be influenced, and that's just [inaudible] just with medications, but I agree, that is one area that needs to be addressed.

DANIEL DAWES, JD: I was just told if we can't get you on the podium, they can't hear you on the webcast, so I'm going to ask, next time just come up here and speak. I'm sorry about that. I should have explained better.

I have a question I'd like to ask the panelists, and this one is if you all could describe, if Dr. Whitfield or Jen Kates, one of you all would like to describe the differences in health care or the needs of a person diagnosed with HIV versus a person who's diagnosed with full-blown AIDS.

RANI WHITFIELD, MD: Most of my patients have multiple comorbidities or other illnesses, so when I treat a patient with HIV in the prison system they also have heart disease, they may have kidney disease, undiagnosed diabetes, so prescribing those medications and also the issue of co-infection, they could have Hepatitis C, which affects the liver, or Hepatitis B, or both. So usually in the prison system I'm starting behind the eight-ball, because they have multiple issues and illnesses that haven't been addressed. And so to start them on medications that also potentially could be dangerous, because you know some of the highly active anti-retroviral therapies cause heart disease,

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kidney disease and/or liver disease. So you're already initially behind the eight-ball, so it's much, much harder to manage these patients. It's a true art of medicine. And one of the reasons that I'm here today is to hopefully implement some policy, not just with ADAP but with Congress and with the government to provide training for physicians to treat, because in the State of Louisiana, there's only one African-American physician that actually treats HIV-positive pregnant females, and so, due to my attempts to raise awareness and educate, now I've become more involved, and I'm actually seeking training, but that takes me out of my actual practice, to learn how to better manage and treat HIV. So we're starting way behind the eight-ball with most of these patients, especially when dealing with African-Americans. If you name an illness—heart disease, hypertension, HIV/AIDS, prostate cancer, breast cancer—usually African Americans are in that top 10. So we're behind the eight-ball when we get started. So it's much more difficult to treat a patient that has HIV/AIDS, possibly hepatitis C, and then they have the audacity to have hypertension on top of that. So it's actually a very tough task. I don't know if I answered the question.

JENNIFER KATES, MA, MPA: Just to answer Daniel's question a little bit more, I actually think of it as HIV disease, and people have HIV disease or are infected with HIV and progress at different rates for different reasons. And at some point we call it an AIDS diagnosis. That point is determined by a whole host

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of factors and it actually has changed over time. So I think the most important thing is that if someone is infected with HIV they need to be connected to a health care provider, such as you, so that provider can figure out the best time that they need to start on treatment, and they don't have to have an AIDS diagnosis to start on treatment. In fact, if they start on treatment before reaching AIDS diagnosis, they might not progress to that diagnosis. So there's a lot of variation here, but I think it's important for everyone to think of HIV disease. And there's a continuum of illness or how sick someone may be along that continuum.

JENNIFER JACKSON: I'd actually like to add to his question our actual personal experience with Brryan, and when Brryan was actually diagnosed, he was diagnosed with full-blown AIDS and it required two years of pretty much constant hospitalization. It required 23 oral medications, each were given three to four times a day, and you were also having to give each dose more than one time because of excessive vomiting or digestive tract failure and what not. He also had three IV antibiotics that were given three times a day, two shots to help produce blood cells, so he wouldn't die, and he had continuous supplemental nutrition through both intravenously and through intestinal. And we also, when we were home on short periods of time, he required eight hours of nursing so that I could at least get a little bit of sleep, otherwise I was up from 4:30 in the morning till 1 o'clock and then starting again. And today, Brryan stood before you on

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only six medications a day and three of those are once a day, and three of those are only twice a day. So if we take the initiative to stop this before we progress to AIDS, more people can be treated.

DANIEL DAWES, JD: Thank you. Does anyone else? Yes, sir.

MICHAEL HARMON: I'm Michael Harmon from Oklahoma, and year after year after year we continue to advocate for more funding for ADAP all across this country while the growing number of American citizens without health insurance is growing from 40-50-60 million throughout the country per year. When are we going to see universal health insurance for all Americans to shift the burden of this health care to the insurance companies that are producing billions of dollars of profit?

DANIEL DAWES, JD: Does anybody want to take that?

FEMALE SPEAKER: I have two. One is for Miss Jackson and for Brryan. I'm in South Carolina. Our organization puts out the [inaudible] newsletter for HIV/AIDS. It's the only one of its kind in the states. Our next issue is going to focus on young people, and so I wanted to ask if I could retain a copy of your speeches so that I could make sure that we publish them in the newsletter so that we can transmit at least 30,000 copies of that newsletter in our state?

BRRYAN JACKSON: Yeah. Okay.

FEMALE SPEAKER: I also have a question for Dr. Whitfield. Black physicians have an association that's national, and one of the questions that I've asked over and over in different forms

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that I have yet to get an answer to has to do with what you've already addressed, which looks at the attitudes, the beliefs, and the potential apathy among black physicians around HIV/AIDS and what the black medical association is doing to address that so that we have a large cohort of physicians who are prepared and education. Because I heard the question related to physicians and it concerns me when we try to talk about pharmaceuticals and physicians. Personally, I think it's the physician's responsibility to be able to decipher the kinds of information that's being brought forth each day when making recommendations to a client. I know in South Carolina that we are facing that issue. There are few, if any, black physicians that want to do HIV/AIDS work. Do you have any [inaudible] coming up with the association, or any movements that are taking place to increase the number of black physicians that are willing, ready and able to do HIV/AIDS work?

RANI WHITFIELD, MD: The front now is not unified, and that's one of the reasons why I participated in the book project. And I got a little flack for being the hip-hop doc, you know. You can be the heavy metal doc, the rock and roll doc, the country music doc, whatever it takes to educate is what I was trying to do. And it's actually opened some doors for me, because I think some people want to ostracize the whole concept, but actually it's opened some doors for me. But *Not in My Family*, the book, and I'm not here to sell the book. I'm just here to tell you why I participated. I thought it was one of the best ideas because

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it's a collection of different people from Al Sharpton, Calvin Brooks[misspelled?], George Elders[misspelled?] and Donna Christianson, and all these people are in the book sharing either personal testimonies, experiences that they had, to just bring the dialogue. Gil actually came to Baton Rouge. We did two days of touring. We went to prisons, the high schools, drug rehabs, and when we encountered groups of African-American young people, they were scared to talk about their sexuality, if they had been tested for HIV, and I couldn't understand it. I still don't understand it. So I feel like you do. It's a challenge to me, it's my duty to educate these young people and to go out and to bring the messages to them, and I think it's definitely going to take a collective front.

Truthfully, Gil and I talk about this. Sometimes in Baton Rouge - I'm speaking about my territory - I feel like I'm by myself. And Bishop Keller can attest to that. I mean, she'll call me. We need to do a discussion or hepatitis C and HIV testing, and we're recruiting physicians to come out and it'll be her and I and the community. And so maybe it's my own stubborn grassroots approach that's not getting these guys involved, but even in the individual practices, I'm not quite sure why that's not happening. And the title of the book, *Not in My Family*, speaks to the denial that I think is happening in the African-American communities. So we need to start getting the messages out, and that's why I asked a group of students, if I was to come to the New Orleans Arena, and free food, and you're going to hear

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Dr. Whitfield talk about HIV, and I'm going to bring another special guest, how many guys would come out? And in a room of about 50 kids, only 10 of them raised their hand. And I said, well, if Jay-Z the rapper said that he was going to be there, free food, how many of you guys would come out? And they said, all of us would come out. And I said, how long would it take to get this done? We could fill that arena in less than an hour. So I said, hey, if that's what I have to do to get you guys' attention, then that's what I'll do, but it still speaks to us not being responsible for our health.

So it's my job. That's what I do. I'm a physician, so I have to make my patients more responsible for their health. And once I put it in your lap, then it's there for you to make that decision.

BISHOP JOYCE TURNER-KELLER: I needed to add to that because there is another African-American doctor whose name is Dr. Joseph Gatt [misspelled?], who is one of the leading HIV/AIDS researchers in the country. He's in Houston, Texas. And another issue is that we do have African-American doctors who are treating. It's just that they're not well trained in the field of HIV, and they need more training.

JENNIFER JACKSON: I just want to add one thing to what the doctor said, and that that denial of all those people is leading to 42-percent of the new cases diagnosed today are among the youth of this nation - 42-percent of the new cases.

DANIEL DAWES, JD: Well, I just want to thank our

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distinguished panelists today. I have to wrap things up right now. But before we leave, there's a couple of people I wanted to acknowledge today. I wanted to let you guys know that this event is being webcasted so if you signed up on our sign-up sheets, I will forward you that link. You can distribute it as well, and it will also have - I think Bambi mentioned getting the speeches - we'll have transcripts of that on the site as well.

So I just want to thank Congresswoman Donna Christianson for being supportive of this event. She's been my boss. She's been very, very supportive and encouraging. I want to also thank Brit Weinstock. I know she and I were just losing our hair trying to get everything organized here, so kudos to her, definitely. I want to thank the Kaiser Family Foundation, the Kaiser Network for webcasting this event, and I want to thank Jen Kates, in particular, for educating me on this issue as well. I want also to thank Dieter [misspelled?] Ken and Bill Arnold for helping me to coordinate this event. And then I also want to thank Heineken USA. I have Miss Hillary Johnson who is the public affairs manager for the Southeast region, and has been a good friend to me. Their organization supports the Lewis Stokes Fellowship, and they're actually one of the founding supporters of this fellowship, so I wanted to thank you guys very much.

I also want to thank Daniel Andrews Lavell [misspelled?], who helped me out with getting everything organized as well. I want to thank Lynn Jennings who helped as well, Dr. Marjorie Innocent for helping me as well, Julia Litman and my wife

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Naddy[misspelled?] Kadoz[misspelled?], who helped out with this event as well today.

I just want to thank you all for coming and I hope that we'll continue to discuss this and remain active on this issue. So with that, I'm going to close everything. I just thank you so much for attending.

[END RECORDING]

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