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Turning the Tide in the HIV/AIDS Epidemic in Washington, DC
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GREGORY PAPPAS: — STD, and tuberculosis administration in the City Department of Health here in the District of Columbia. It's my real honor and pleasure to introduce our session, turning the tide but in the HIV/AIDS epidemic in Washington, DC. I want to thank my mayor. We have an unparalleled leadership in the District of Columbia, both from the mayor and from our director of health, Dr. Mohammed Akhter, who'll be last speaker on a presentation.

This is kind of a story. This panel of esteemed experts and colleagues and community members is a story about steady progress, a successful collaboration. I'll say it in kind of a basic way. DC was kind of a backwater scientific town five, six, seven years ago, and now we've emerged as a very vibrant academic community making a really important contribution. That contribution came through a collaboration between the NIH, the DC Dept of health, DC research community, and the DC community members. Here at AIDS 2012 at this meeting, DC is represented with 61 abstracts. We're very proud of that development.

I want to provide just a little bit of context about DC. I want to maybe dispel an urban legend that DC is the worst in the world or the worst of whatever. About 50-percent of the people who are HIV-positive in the United States live in 12 cities. DC is one of those 12 cities. The district, for those of you don't know our local geography, is a little cutout of about 600,000 people in a large metropolitan area. We're comparable to the other 12 cities. We're not the best; we're not the worst.

We have a serious epidemic in the District of Columbia, and two or three people are infected every day. With that said, we're seeing steady declines in death rates, and we're beginning to see declines in new infections which we're very happy about.

One of the important drivers of that reduced infection is our very successful needle exchange program. In 2007, we began a very rapid increase in needles exchange and began to see a very rapid drop in new infections among those who use intravenous drugs.

We've got a packed session. I'd like to remind all my speakers here on the stage please stick to your time, and I want to end with a special thanks to Carl Dieffenbach, Henry Masur and Alan Greenberg who provided tremendous leadership for this session, but also for the entire – this progress has a lot to do with the leadership of these three men.

With that, I'm going to introduce the next speaker. Tiffany West is the Chief of Strategic Information Bureau at the Department of Health here in HASTA, and she's going to speak about the response of the Department of Health and epidemiological overview. Thank you [applause].

TIFFANY WEST: Thank you very much. This afternoon, I wanted to just briefly speak about the epidemiology of HIV in the district. The role of public health system is not only to monitor and evaluate the epidemiology in jurisdictions, but also to facilitate disease interruption, assist in a scale up of prevention care and treatment strategies as well as assess the cost and cost effectiveness of interventions within restrictions.

In the District of Columbia, we have over 14,000 people who are reported to the health department as living with HIV. Over the last five years, over 5,200 new HIV cases were reported in the district. This is a prevalence rate of around 2.7-percent. As you can see from our geospatial analysis, seven of eight wards in the district have a prevalence rate of over 1-percent.

Also in the district, we're struggling with issues of health disparities. While just half of district residents are HIV positive, more than three-quarters of living cases are among African-Americans. UNAIDS defines a high-prevalence, severe epidemic as an epidemic where greater than 1-percent of the population is living with HIV.

As you can see from this stratified analysis by race and by gender, over 6-percent of black males in the district are living with HIV. Over 3-percent of black women are living

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with HIV, and over 3-percent of black Males are living with HIV.

When you look at new diagnoses of HIV cases from 2006 to 2010, you can also see that we are seeing shifts in trends of mode of transmission. While MSM is still the leading mode of transmission in 2010 with approximately 40-percent of cases, heterosexual sex is the next most common mode of transmission with 34-percent of new HIV diagnoses within 2010 attributed to that mode of transmission.

Part of the responsibility of health departments is again, not only to monitor the epidemic, but also use data in ways that assess and evaluate health outcomes. This is a continuum cascade we developed within our surveillance unit which looks at the cases from 2005 to 2009. Of the 4,800 cases that were diagnosed in HIV, 80-percent of those cases were linked to care within three months of diagnosis.

However, you can see from our analysis of either continuous care defined by two lab reports within 12 weeks of one another, or sporadic care which is one lab report in that particular time frame, there's an issue that we have that we must address around retention and care. Again, only 50-percent of the diagnoses in this particular timeframe had ever been virally suppressed over the last five years. Only half of those who were ever virally suppressed maintained viral suppression through 2010.

When you assess treatment outcomes, it's also important to recognize the syndemics that impact HIV. This is a syndemic analysis where we looked and all the diagnoses in 2010. We then matched our HER surveillance HIV surveillance bases to our other disease registries. Of the 845 people who were diagnosed in 2010, you can see that almost 10-percent had a diagnosis of hepatitis C, and over 5-percent had a diagnosis of an STD.

Again, part of our job as a surveillance unit is also to use data to evaluate policies and programs. In 2010, the Office of National AIDS Policy released a national HIV/AIDS strategy. In the district, we've taken the national HIV/AIDS strategy and developed metrics that help us assess our progress toward reaching those goals. It's important to look at this information because all these data are publicly available for all health departments within our jurisdiction.

Objectives one through three of what the national HIV/AIDS strategy include metrics for reducing new HIV infections. Objective two looks at increasing access and care and improving health outcomes for people living with HIV. The next goal looks at reducing health disparities.

Thank you for giving this opportunity to introduce our next speaker, who will be Dr. Carl Dieffenbach. The title of his presentation is *Partnership for AIDS Progress: Role of the National Institutes of Health*. Dr. Dieffenbach is the director of the Division of AIDS at NIAID and is responsible for

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planning and managing a global research portfolio on HIV and AIDS. Thank you [applause].

CARL W. DIEFFENBACH: Good afternoon, everyone. It's a pleasure to be here to talk to you today about the partnership for AIDS progress, the role of the NIH. As Tiffany has laid out for you, and Dr. Pappas did as well, we're dealing with a crisis here in Washington, DC. These are the articles that appeared in the Washington Post and the New York Times back in 2007.

We decided at the NIH, it was time to try something new. There have been many attempts to try to work with the DC government in the past, some with success in some institutes, but we decided it was time for a fresh start in AIDS. We sat down in 2007 with our partners in the Department of Health and GW. We set out a set of what we would try to achieve through a Washington, DC, initiative. What we wanted to really be able to do was perform research in a way they could develop effective measures that could help control the HIV epidemic in the city.

We wanted a way of monitoring the progress. We thought about setting up a citywide data system to measure the effectiveness of the interventional programs. Ultimately, in many ways, we were looking at the city as a way of developing systems that could provide a scientific basis for a strategy

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that could be implemented in other U.S. cities with expanding epidemics.

From those goals, we set forth in 2009 with a series of projects. In between that time, there were a series of community consultations that were held throughout the city, and also a series of provider consultations to help to identify what the providers and the community felt great speeds. Out of that came a series of research initiatives, first to see how effectively we could identify the highest-risk population and encourage them to enroll in studies where we could study ways of reducing risk behavior.

Additionally, we set forth the process of establishing the citywide data system. At that point in time, the famous Granich Paper had been published in the Lancet, and we attempted or started a pilot of voluntary test and treat, which has evolved into treatment as prevention. Additionally, through the provider survey, there were a number of the areas of subspecialty care that it was felt we could really augment in the city. You'll hear today about the hepatitis work from Dr. Shyam Kottilil.

I'll take each of those points one by one and go through some of the activity. First, identify high risk populations. Immediately, we set forth and performed two pilot studies, HPTN 061 and HPTN 064 that involve the number of jurisdictions around the United States including Washington, DC. Those studies have now been completed, but the point of this is that this creates an evolutionary path for research.

Now within the city, we're taking the next step. We have to interventional studies that opened in August and are in development. HPTN 069, which is a safety and tolerability study of next generation PrEP. Additionally, HPTN 073 is in development. That's going to look at the uptake acceptability and safety of PrEP for young black MSM in two cities using client-centered care coordination models. Again, this is part of the evolution, keeping the progress moving.

The citywide data system, I'm happy to say, is well underway. We're in the process of linking the electronic medical records and establishing electronic medical records of the 12 largest providers in the city. DC's unique in that regard in that there are a number of large-scale providers that make this relatively straightforward. We can cover 80-percent of the HIV-positive patients in the city by linking these 12 providers. As you see on the slide, the current enrollment is slightly more than 4,200 and we're currently really moving forward in 8 of the 12 sites. You'll hear more about this on this panel today.

We're in the process, about halfway through the pilot of the test and treat concept. HPTN 065 has been up and running in 38 sites throughout the city. It provides expanded testing through social mobilization. Looking at specific activities and testing sites with randomization to financial incentives versus standard of care. HIV treatment is also occurring in 39 sites. We're initiating treatment accorded to guidelines. In addition, we have prevention for positives program. Again, this is about halfway completed at this point in time.

Additionally, we've sought ways of augmenting subspecialty care. We've interviewed partnerships with a number of groups within Washington, DC. You see we have clinic locations in four areas, Walker Jones, DC General, Family Medical, and VA. There are currently five protocols underway. As I said earlier, Shyam is going to cover the progress that we've made on hepatitis C in just a few minutes.

While we had those four pillars, we didn't stop there. We have now added a fifth pillar which is looking at mental health research and mental health research services. This pillar has really expanded quite rapidly with eight planned and ongoing protocols at this time.

One of the measures of success of any academic endeavor is the quality and quantity of research going on in the city. A really universal metric is the number of research project grants that are funded within city. Through the auspices of the CFAR that Alan will talk about in just a minute, we can track the number of grants that have occurred in DC.

Think about the period of time from 2008 to 2012 when the NIH budget was flat. DC has grown its grant base from a total of eight RO1-type grants in 2008 to 22 and 2012. In the end, we have really worked to develop innovative research programs that can develop systems through the DC cohort and the database to measure the effectiveness, and really, to my mind, we're making very good progress in establishing a scientific basis for successful strategy that could be implemented in other U.S. cities.

Now, it's my pleasure to introduce our next speaker, Dr. Alan Greenberg, who is going to speak to us today on the coordination and development of HIV research, the DC Developmental the Center for AIDS Research. Alan is professor and chair of the Department and Epidemiology and Biostatistics at the GW School of Public Health and Health Services and is director of the NIH-supported District of Columbia Developmental Center for AIDS research. Alan [applause].

ALAN GREENBERG: Thank you, Dr. Dieffenbach. I'll be talking about the DC Developmental Center for AIDS research, or the DCCFAR. First, a little background about the centers for AIDS research program, which has been supported by the National Institutes of Health since the 1980s. We have representatives of many of the institutes here in this room who support the program including NIAID, NIMH, and NIDA and other institutes. We're grateful to their support.

As you can see, the DCCFAR is part of a network of 21 CFARs in the US that address the NIH CFAR mission of supporting a multidisciplinary environment that promotes basic clinical epidemiologic behavioral and translational research in the prevention, detection, and treatment of HIV infection and AIDS.

If you look across this, most of these CFARs are based at major U.S. universities, and you can see their names on the slide. There are several that are multi-institutional, and ours is really unique in that it really represents the whole city. We've tried to be inclusive of all community groups, of all community providers, care providers, and all academic institutions that do NIH-funded HIV research in this city.

We were very fortunate that despite the severity of the epidemic in DC that you heard about from our colleagues at the health department, DC had never had a Center for AIDS research. We were very fortunate in that we were able to establish one, and we competed successfully in June 2010 when NIH awarded a five-year grant to establish the CFAR.

The CFAR is a multi-institutional collaboration. We now have six institutions; George Washington, Georgetown, Howard and American universities as well as Children's National Medical Center and the Veteran Affairs Medical Center. The overarching goal is to reduce HIV transmission and disease in Washington, DC.

Our mission is to provide scientific leadership and institutional infrastructure to promote AIDS research and to develop the next generation of HIV investigators in the district by providing leadership, promoting the development of new investigators, especially junior and minority investigators, and increasing connectivity and collaboration among all investigators in DC. It's taken us a couple of years, but we have our arms around them, and although not everyone that has joined, there are now 154 professors and faculty investigators that compose our membership.

This very briefly is our structure. I serve as the director along with Gary Simon, who's the head of infectious diseases at GW. The key part of this graph is the executive committee which is composed of the leading AIDS researchers, NIH-funded researchers, from the aforementioned institution, who together, virtually run the CFAR.

We receive very close input an oversight by a scientific advisory committee composed of CFAR leaders from around the country, from an oversight committee, which is composed of our deans and vice presidents, who we on the executive committee report to from the six institutions, and a very active community advisory board that you'll actually hear from several members today, which is composed of a lot of the presidents and CEOs and leaders of various community advisory boards and community-based organizations in DC.

We're structured as many of the CFARs are structured according to cores would provide services the, notably the administrative core which helps coordinate the funding and the administration. The developmental core which oversees the pilot grant awards program that spurs the careers of junior investigators, and basic science clinical and behavioral and bio-stats cores that provide mentorship and services to investigators who are putting together applications and grants to do science.

My last two sides, what does the CFAR do? We encourage the conduct of HIV science through the provision of services from those cores and pilot award funding. We have a very active professional development program for new investigators. We have grant writing and research seminars. We do a lot of community building network. We have a very access web site you can access, very extensive web site, and weekly e-mail updates that go with new grant opportunities and new scientific opportunities in the district to 150 plus members.

Very importantly, we assemble teams to respond to NIH grant applications, and we support individual investigators to support investigating grant submissions. We also really encourage all these institutions to hire HIV investigators. This is an important public in the district, and trying to get the academic institutions' leadership to focus on HIV is a very important part of the CFAR.

This is my last slide with some of our results in the first two years. We've now been operational for two of five years, and we hope to apply for a full Center for AIDS Research in the district. We received five years of funding for about $3.7 million, which is over five years and divided up over six institutions. It's a lot of money involved, but when you start divvying it up, it's actually the a modest amount.

We have a five-year award period. As I mentioned, 154 investigator members. We've received 16 new NIH HIV awards, R series awards, since the CFAR was established two years ago. We've encouraged these institutions and worked with them to recruit 16 newly hired investigators who have an active interest or primary interest in HIV/AIDS research.

We've established four scientific working groups that are now very active in HIV in malignancies, in mental health, in criminal justice-affected communities, and in men who have sex with men, and we're starting to use our developmental core resources to promote research and the district in these four areas.

We've given out 15 pilot research awards for $580,000, and we've been very fortunate to compete successfully for administrative supplements that thus far have brought an additional $2.5 million in AIDS research funding to the District of Columbia. We're very proud of our accomplishments. We're very grateful to the community of academic investigators and community leaders and the health department that's supported us, and most importantly, to the various NIH institutes that contribute to supporting the CFAR program.

With that, I'll close and turn it over to our next speaker. The following speakers will continue to lay out the pillars that Dr. Dieffenbach described. Dr. Manya Magnus is an associate professor in the Department of Epidemiology and Biostatistics at George Washington School of Public Health. She is the project principle investigator for the DC NHBS and HPTN studies that she'll tell you about. Dr. Magnus [applause].

MANYA MAGNUS: Good afternoon. I'm going to talk a little bit about some of the research as has been referenced by my colleagues. These are important community-based studies that have laid the foundation for understanding the epidemic here in Washington, DC.

Prior to 2006, there was very little community-based prevention HIV research. Without knowing what is happening in a community, it's very hard to develop effective strategies to overcome the epidemic. There's an incredible importance that can be learned from data that are gained from non-clinical settings, specifically with regard to behavior and seroprevalence information about people were not in clinics, but rather people who are in the community so we can understand how to best address their prevention needs.

We also find that the community focus is really critical to fostering community engagement. Working with communities, we're working with everyone here in DC as opposed to just working in an ivory tower. Some of the early research that happened through all these multiple partnerships in citywide collaborations really came from strong collaborations with the DC department of Health and Hasta.

The first one that we were involved in was the national HIV Behavioral Surveillance Study, also known as NHBS, which is a CDC-funded study. NHBS is a multisite study and many sites participate, 20 this year, and what NHBS does is it characterizes in cross-sectional samples, so snapshots in time every year focusing on a different high-risk populations. This study focuses on men who have sex with men, injection drug users, and heterosexuals who are elevated risk for HIV.

NHBS is unique because again, it's community based. It does not look only at people who access care, but rather, it looks at whole communities and looks at sexual and drug risk behaviors, HIV testing behaviors, exposure to and use of prevention services and their impact, as well as missed opportunities for prevention, prevention service gaps, and missed opportunities.

When we look at seroprevalence, we can look at trends in prevalence, although we are not following the same people over time. We can also most importantly look at HIV-related behaviors, so behaviors that happen before people are HIV infected. In partnership with the Department of Health, we conduct an AHBS multiple times for heterosexual cycle twice, men who have sex with men cycle twice, and we're about to launch the second injection drug using cycle this year.

Subsequent to our NHBS implementation, as a community, we've implemented the HIV prevention trials network studies that Dr. Dieffenbach mentioned and most importantly, we have some really important information that come out of the studies. The HPTN 061 study, we had very important data released this week. We enrolled 227 black MSM, and we followed them for one year. We presented multiple studies at this conference.

HPTN 064 is the ISIS study. And there's a seroincidence study were 210 women were followed over time to identify factors associated with new HIV infections. Those results were presented this year at CROI. We are also, as you mentioned, we are excited to launch a new study called NEXT-PrEP, which is HPTN 069. HPTN 069 will look at new avenues for pre-exposure prophylaxis using Maraviroc as a new type of agent in combination with other agents. We'll enroll 50 participants in that study. Finally, HPTN 073, which will represent the next step from the 061 study, and we'll look at young, black MSM and trans women locally.

Some of the outcomes; what's the impact of all this information? Really, a partnership with multiple groups and with the Department of Health and NIH, we've had rapid dissemination of information and really translating what we're finding in the research setting, we and many other collaborators in the city looking at how this information can be translated to action effectively and rapidly. I think we've really come a long way with that from where we were, and that's very exciting.

In the absence of data, interventions are really not possible to develop. They wouldn't the community appropriate; they wouldn't be culturally relevant. It's very exciting to be able to use information to translate what we're finding and to make prevention and treatment interventions that are innovative and responsive. We've also develop multiple community researcher collaborations. The beauty of that is it's not just some people working, it's a whole city working towards the same effort.

Future directions; I'm very proud to be part of NHBS and HPTN. I feel very strongly that they are in incredible wealth of information, and may provide a foundation for future research here and in other places as well. NHBS gives us ongoing insight into the current epidemic and looking at behaviors antecedent to HIV infection. HPTN provides a cutting-edge prevention research to the community, which is extremely important.

We have a tremendous community advisory board here at GW. as well as other community advisory boards throughout the city, which provide a link to understanding the community better and collaborating with them. Finally, we have new studies that will leverage information that we're collecting into action.

One of our community members said the other day when we're talking about the HIV Prevention Trials Network study 061, we were talking about what it meant to him. He had a great Maya Angelou quote which said "Do the best you can until you know better. Then when you know better, do better." I thought he really brought to light what we're trying to do and that that was very helpful.

It's my pleasure to introduce Dr. Amanda Kastel who will talk about the research response with the DC cohort. Dr. Kastel is an assistant professor at the Department of Epidemiology and Biostatistics at the George Washington University School of Public Health and Health Services. Thank you very much [applause].

AMANDA KASTEL: Good afternoon. It's my pleasure to talk to you all about the DC cohort, which is a citywide cohort of HIV-infected persons in care in the District of Columbia.

What is the DC cohort project? The goal here is to build a database of all consenting HIV and AIDS clinic outpatients in DC that contain information about a multitude of risk factors, treatments, diagnoses, lab results and procedures that these patients are receiving at the participating clinics.

It will be a longitudinal data collection from the time of consent going forward, and at the end of this data collection process and periodically, we provide reports to the sites which enable them to conduct research on HIV in their particular populations as well as to assess the quality of care that the patients are receiving. The idea here is that this will be a longitudinal study and that the intent is that we will receive long-term funding from NIH.

The project goals are to improve the quality of care and treatment among HIV-infected patients in DC, to provide evidence for gaps in care and the need for resources, and to also identify new areas for research on HIV and AIDS and treatment in the city. In 2009, we've conducted a comprehensive feasibility assessment of 12 participating sites. This slide show you the cohort clinic sites by size, type, and EMR. Just to illustrate, the number of patients cared for at these 12 sites varies from as few as 150 two as many as over 2,000 and perhaps 3,000 in some clinics.

We also have a diversity of clinic types. We have community based clinics, academic hospitals; we have a Federal Hospital. The VA is also participating in the cohort. Some of these sites have a lot of research experience, and some of them, this will be their first foray into conducting research.

Lastly, but importantly, we also assessed the status of the electronic medical record, or EMR at each of these sites. The reason we did that is that one of the backbones of the cohort is to be able to abstract the information from the EMR versus doing a lot of manual data abstraction. We assessed which EMRs are being used at these sites and the year of implementation, and again, you'll see that some sites have had EMRs in place since the mid-90s and others do not yet have their EMR in place or they just launched their EMR.

This slide is to show you the organizational structure. As was mentioned, the DC cohort is one of those four initial pillars for the Partnership for AIDS Progress. At the top of the slide, we have the DC Partnership for AIDS Progress, executive committee, the DC cohort PIs. To your left is the DSCC, which is the Data and Statistics Coordinating Center. These are the individuals from George Washington University and from Cerner Corporation that manage the study on a day-to-day basis.

We have a DC cohort executive committee that's comprised of a site principle investigator from each of the 12 sites. Again, the members from GW and Cerner Corporation that work on the study, representatives from the national institutes of health, the DC Department of Health, and we also have two patient representatives that serve on the DC cohort executive committee.

We also formed a patient CAB, which also is comprised of 12 patients from each of the 12 sites. They meet quarterly and have provided extensive input into the approach to the city, our recruitment materials, and as I mentioned before, they have representation on the DC cohort executive committee.

A little bit more detail about how the DC cohort works. At each of the 12 sites, after obtaining informed consent, patient data are abstracted from the sites' EMR and entered into a web based system called Discovery. This is a platform that Cerner Corporation has created and that we're using for the DC Cohort.

There is some manual abstraction of limited historical data, and then all data are combined and stored securely in a warehouse at the data and statistics coordinating center. They are made available for analysis again by the sites themselves and for the overall DC cohort executive committee. We are maintaining a non-consent log for those patients who are considering or have refused to participate in the study. We want to make sure that we are getting a representative sample of those patients who are in care in DC and who are deciding to participate in the cohort.

Importantly, we will also be matching our DC cohort database periodically with the DC Department of Health Data. That will allow us to not only increase the completeness of our data, but that will allow the health department to also fill in gaps where they may be missing data. It will also help us to be able to de-duplicate our patients. We understand that there may be patients who receive care at multiple of the DC cohort sites, and this is one mechanism to enable us to do that de-duplication effort. Reports are semiannually to sites which compare a site's particular data to the rest of the cohort data so that they can have a sense of how well they're doing overall at their site and with regard to the citywide snapshot.

Progress to date; we began enrollment in January of 2011. We actually have eight sites that are enrolling patients. As was mentioned before, we approached over 4,000 patients and have over 3,000 consented. Our refusal rate as of this point is 6-percent. We are now working very closely to extend the study to the four remaining sites, and those should be up and running by the end of this year. The current focus is also on finishing the electronic transfer of information from sites to that central database. Then we will be working very closely with the health department to start that matching process.

With that, I'm going to stop and I'm going to introduce the next speaker, who is Dr. Shyam Kottilil. He's going to be talking about research response with regard to hepatitis care. Dr. Kottilil received his MD and PhD, and he went on to complete an internal medicine residency at Brown University and

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an infectious disease fellowship at NIAID under the mentorship of Dr. Tony Falchy [applause].

SHYAM KOTTILIL: Thank you. We all know that hepatitis C and HIV coexist in the United States. If you look at the numbers of hepatitis C infection in the United States, in about 5 million people infected with hepatitis C, comparing that number to HIV-infected patients, it's a little less than 1 million patients.

Due to the shared burden transmissions of both infections, about one-third of all HIV-infected patients are also infected with hepatitis C. If you acquire HIV by intravenous route, you're most likely to be infected with both viruses at the same time. The prevalence rate of both infections are close to 100-percent.

The story is quite similar in Washington, DC, as our nation's capital. When we first started the District of Columbia initiative, the approximate broad numbers that we had expected to see was about 3-percent prevalence rate of HIV infection. In terms of numbers of estimated was around 18,000 patients, and about 1.8-percent with antibody positivity for hepatitis C, which is a staggering 12,000 patients with hepatitis C.

Many of these people, because of the shared route of transmission, when harbor both viral infections. They'll be co-infected with both HIV and hepatitis C which makes it very

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difficult to manage. Under the leadership of DC PFAP, we established for different sites, and eight different clinics are active right now. We established these clinics primarily to provide state-of-the-art care for hepatitis in patients who have hepatitis as well as HIV infection in the district.

The sites include in ward one, ward six, ward seven, and ward eight, and now we have about eight clinics under the leadership of Dr. Dawn Fishbein and Anu Osinusi. We're seeing a large number of patients here. As expected, the distribution of the patients we see here are predominately co-infected with HIV and hepatitis C, which is about 60 to 70-percent of the patients.

We also see other hepatitis infections which may not have HIV, or different combinations of hepatitis and hepatitis B. These patients are very difficult to manage because they have problems not only because of HIV infection, but also because of other hepatitis infections. Over the last few years, we have been able to treat and develop clinical protocols that bring access to state-of-the-art medical care for these patient population.

This particular chart will tell you the some of the ongoing studies and some of the planned studies for the next year or two that we're conducting as part but of the hepatitis program of the District Columbia initiative. These studies are from phase one to phase two to phase three studies debris either a standard of care or the novel drugs that may have promising activity against hepatitis B as well as C in this patient population.

Let me walk you through some of the studies. Studies and the red are the target specifically hepatitis C. We have these studies on going. Some of these studies are using directly acting antiviral agents that do not contain Interferon are being planned to be conducted later this year. We have studies that address the natural history of hepatitis B and C in the district. We also have studies that target liver fibrosis and this patient population, regardless of the cause of liver fibrosis, whether it is viral hepatitis or antiviral induced hepatitis.

We also have studies planned in HIV-infected patients. Some of them provide standard of care, and some of them will address fibrosis issues, and some of them will address specifically Interferon and Ribavarin-free treatment, which will be highly effective in controlling hepatitis C epidemic in this country. We also have studies, future studies planned that are better combinations of medications available. We do this in close partnership with industry that the NIH is able to conduct some of these studies that bring these novel drugs for the patients in need in the District of Columbia.

We also have hepatitis B studies, which is one of the ignored epidemics in the United States. Some of these very

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novel antibiotic targeted medications that will affect hepatitis B treatment in a dramatic way. There are four objectives for our studies. One, we want to offer a simple regimen that can be easily taken. The regimen has to be safe and tolerated. Three, it has to be highly effective. Four, it should be able to shorten the duration that is required to eradicate hepatitis C. In that way, the hepatitis program is going to be the leaders in this field in developing and changing the paradigm of hepatitis C treatment.

Overall, our objective is to complement very effective HIV management program elaborated by the our colleagues in this podium with a very effective hepatitis C program that is underplay which will expand the in the District of Columbia a label eradicate hepatitis C and probably hepatitis B in the future. Thank you [applause].

I would like to introduce the next speaker. Dr. James Peterson is an associate professor at GW School of Public Health. His research activities include HIV and AIDS [inaudible]. Dr. Peterson is a community research coordinator, the DC CFAR and the DC cohort. Dr. Peterson [applause].

JAMES PETERSON: Thank you, Dr. Kottilil. In this presentation, my objective is to address the question how the community interfaces with research planning. I'll discuss community groups as one of the examples for this interface.

Community advisory groups collaborating with HIV/AIDS research but conducted here are understood within a context of creating an integrated and collaborative research infrastructure. Community groups provide a framework for collaboration among community, the researcher, and the research staff to facilitate a two-way communication. Community advisory groups can facilitate access to knowledge of the community resources and resources relevant to the actual research.

The benefits of the interface between community-based research partners and professional researchers are evident when each can empower one another and become empowered in the process of working together. Thus the community group research interface can contribute in developing relevant scientific agendas as has been previously mentioned. Ethical conduct of clinical trials, community-based education tools, community training, and information dissemination in a manner that ensures respect for the community and the research priorities as well as continued community involvement.

The interface serves as a productive experience when the experiential and the professional knowledge compliment and influence one another. In this example of the community advisory group and the research interface, two types of community groups are highlighted. First, the community advisory boards have been established to collaborate with each of the research initiatives discussed by Dr. Greenberg, Dr. Magnus, and Dr. Kastel. Each of the halves have emerged with specific structures created to interface with different types of research project or research entities.

Second is the community-based organization. There are a number of contributions to research planning made by CBOs. One example is realized when obtaining a representative enrollment of the target population to provide subgroup analysis where necessary is important. The community-based organizations, or CBOs, interfaced with research serves as an important resource to gain access to potential research participants.

Shipper [misspelled?] and her colleagues understand community groups interfacing with research planning as a concept with a rich, multilayered meaning. More specifically, community groups interface on multiple levels that range from doing research as partners to becoming partners in the research. Thank you, and he gives me great pleasure to introduce the next speaker, which is A. Toni Young. Toni Young is the president and CEO of the community education group in Washington, DC. She will talk about CBOs, community and CBO research interface [applause].

A. TONI YOUNG: Good afternoon, and thank you all for joining us. I start my slide presentation and my presentation overall where Dr. Dieffenbach started. Before we do that, I actually think I see my friend, Byron Mason [misspelled?] on the front row, who just celebrated his 40th birthday, so I'm hoping you can all say happy birthday, Byron.

I do that only because Byron doesn't know how much he taught me about community engagement when I lived in San Francisco. I learned a great deal from you, so it's always an honor for me to see you.

I think they said I was going to talk about community participation in research or something like that, but I'm not going to. Now they're all really, really nervous. Trust me. What I'm actually going to talk about is I think you saw that slide, and it said that there was this modern epidemic. There was this crisis in the District of Columbia. I think we've gone through, what, one, two, three, four, five, six, seven, eight speakers so far, and I would make nine. I think a part of the story that they didn't tell you – they told you the what we did, but they didn't tell you how we did it.

How we did in is that we turned the tide of the epidemic in the District of Columbia frankly together. We did it with our Federal Partners. We did it with the DC Department of Health. We did it with community. We did it with people living with HIV. We did it with our academic partners. The theme of this conference this year is turning the tide together, and frankly, that's how we did do it in the District of Columbia.

I want to take my five and a half minutes to go them a list of how we did it, whether it was Dr. Pappas or his predecessors, Dr. Martin or Dr. Shannon Haider. They had to really kind of build a framework, and that framework that they put into place allowed us to develop new partnerships. The national institutes of health had been up the road, and it still is up the road from the District of Columbia, for a long, and long time.

I think a couple of things happened. I think one of the things that happened is actually, the guy who's sitting here and the guy that was in the back of the room earlier, I think Dr. Dieffenbach as well as Dr. Falchy and actually Dr. Masur kind of got it that what they could bring to bear on the epidemic in the District of Columbia was crucial, critical, and it was a perfect storm, and it was perfect timing.

I'm jumping over Tiffany because Tiffany, Alan, Manya, and Amanda, they don't tell the story the way I think the story should be told, which is that the District of Columbia did not have the necessary infrastructures to gather the surveillance data that we so desperately needed. You can't know what you're looking for if you can't count it. We didn't know how to count it. We didn't know where to look for it to count it. What they were able to do is to bring their expertise to bear in the District of Columbia and say, here's a system. Here's how you create that system. Here's how you run a system. Here's how you implement that system.

Then it was like a toddler. They kind of taught us how to walk, and then they said okay, you can do this on your own. Then Amanda was able to go back to her regular office over at GW and stop staying in the health department all day every day with people like me calling, going what's that number mean?

I say that, and I think with Alan and with Manya, and again with Carl, they kind of downplay this whole research thing in DC. There was none. It wasn't that there was a limited amount. It wasn't there. With the development of the DC FAR, what we again have is the opportunity to build the infrastructure to do some of the most robust research in the United States. Why? Because we have A, one of the most research-naïve populations. We also have some of the greatest academics in the world who now want to come work in DC.

That's not what it was before. One of the things I've always said, and I use this analogy a lot, is that the HIV/AIDS epidemic in the District of Columbia was more like turning around the Titanic in the Potomac. That's how awful it was. You didn't want to be there; you didn't want to be a person living with HIV there. You didn't want to be working in HIV there. You don't even want to work health department there. You just didn't want anybody to know you even lived there half the time.

That's not the case today. I want to say that that's very honestly due to our health department. That's due to our federal partners. That's due to our academic partners. That's due to our community. That's due to our involvement in saying that we had to make HIV more of a priority in the District of Columbia.

I think in the framework of the national AIDS strategy, and we kind of started doing this before the strategy, is that we said we can't do this alone. None of us can. Our federal partners can't do it. Our academic partners, our public and private partnerships can't do it alone. Community can't do it alone. The only way we successfully achieve our goal of reducing the rates of infection in the District of Columbia is if we do it together.

I have to say sometimes we we'll fight like cats and dogs. Trust me, that still occurs, but the thing I can say about everyone on this panel is that what I know about that that number one, their number one commitment is the reduction and elimination of HIV infection in the District of Columbia.

I leave Tiffany last because she's still in the health department counting the widgets and teaching us in the community how to use the data that we have. How to use those datasets not only for our grants and financial, but for us to help better understand where the epidemic shifts are, where the infection shifts are in community and how to use that.

Alan and Manya again are more like – I don't want to say parents because I'm older than them and then they would hit me after this – but they have taught me so much about research. They've taught me so much about how to galvanize people and to make a better understanding. Manya has taught me how to make a better serving. Alan has taught me how to think better. James is my friend and as well, he teaches me how to use datasets and look at the ethnographic components of communities, of how they may be different.

I think Dr. Akhter, and I hope he mentions this when he comes up here now that I just put him on the spot, he mentions where he's come from with the District of Columbia because he was here a long time ago, and he's back now. I think that we are far, far, far from where we were then, and I think we all keep trying, and we keep trying to make the District of Columbia a much better place.

With that, I want to thank you and say welcome to Washington, DC, my hometown and a place that's fighting the good fight. Thank you [applause]. With that, I'd like to introduce Marcia Ellis from the United States, and she will share her insights on participation and community advisory boards [applause].

MARCIA V. ELLIS: Good afternoon, everyone. My name is Marcia, Marcia Ellis, and I have the pleasure of chairing one community advisory board and participating in several community advisory boards here in DC. I've been doing it for the last several years, and what I want to do is take our story a step further and make it a little more real for everyone in terms of who the community is and what happens in our engagement, what our engagement really is so you can see and get a feel for the community as real people.

We know the research depends on participants. I want to show a story, tell a story about a recent engagement process that I was in. I've taken three things from our mission statement on community advisory boards. Many of you know that community advisory boards came about in the early days of HIV/AIDS when the activists demanded a place at the table around research about what was happening to them.

Now at each research site, there's a community advisory board. Here are three points I wanted to highlight. Research depends on an informed, empowered community that understands the clinical research process, that voices concerns and grievances regarding specific clinical studies and these are grievances that should be addressed, and gives assistance concerning issues related to the accrual and retention of trial participants which is very importance to a successful trial.

We recently had a CAB meeting. Let me just let the context for your for a minute. We have our CAB meetings alternating between the sites, and this in this case was Georgetown, at a location in the community outside of

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Georgetown. This meeting took place at the Women's Collective, and it was actually the last day of Women's History Month. We thought it was very appropriate to have that CAB meeting at the Women's Collective.

We invited the community. In our case, we define community as people who are trial participants, people who are the voices for those trial participants who may be agency heads and who represent the voices, and affected people. We had an audience of about 20-something people. It was a beautiful day. We were all celebratory, but we wanted to focus on the science and on one particular study that was looking to enroll some of our participants.

Project directors from the study were there, and what happened was but a very lively sometimes tense exchange between the community members and the project directors about the study. The trial participants and potential participants had some very real bones to pick with the project about the study. These were bones they wanted to pick before they even thought about enrolling or staying in the study.

My role as the facilitator of that conversation was to open up the space, say okay, this is what we're going to deal with, and we're going to deal with it very openly and honestly. These are some of the issues that were raised in that CAB meeting by the participants. They said that they had to come for screening interviews using their own money that was not reimbursed. Now, remember these, in this case mostly women, who had very complicated lives, very little income, and yet they were asking. We know how trials happen and that sometimes, they're asked to come and do screenings and maybe another screening. In this case, they were not being reimbursed.

They voiced the concern that sometimes their calls were not returned in a timely manner. Some participants came for screening more than one time only to be told in the end that they did not qualify for the study. They did not make them very happy, particularly a woman one who had parked her car and got a ticket that also could not be reimbursed. She was really, really very angry. She brought all that out in that meeting.

The project director was also facing a challenge because they were facing challenges enrolling people in the study. It was a study, a long-term study that had done very well in rolling and keeping women in studies, but the re-enrollment process was not going as well. That meeting lasted for a good hour and a half. It was and very heated, but at the end of the day, the research staff went back to their own office, and they discussed the all the things that came up by these women because they saw that they weren't going to have it.

They came and they decided that it is appropriate to reimburse transportation costs for a screening interview. They changed the consent form, and it was approved by the IRB. They changed their calling process and decided that all calls are now returned within 24 hours, and an appointment will be made at that time.

The screening procedure on initial contact called changed so that individuals almost immediately know whether or not they are eligible. You know how it must be for people we have very difficult lives to keep coming back and forth to a place that's way away from their neighborhood, and only to be told later that they don't qualify.

These were the takeaways for me certainly as a community facilitator and as an activist and advocate myself around clinical trials. These are my lessons and my takeaway. I hope they will be yours. We need to build upon, nurture, and utilize long-standing relationships between the study sites and community organizations. As it's been said, we have numerous, very rich, very knowledgeable organizations, and we've established relationships with them that should be nurtured so that when it's time for us to have a meeting and talk, we're not starting from scratch.

Create the space for an open and honest and sometimes intense facilitated dialogue. Both study participants and site staff learn in the process. When concerns are voiced and actions taken, report back to the community any changes or explanations. In this case, the project directors came back to my next CAB meeting and were very happy to report to the trial participants what changes were made, and the trial participants were very happy about that.

Tensions can subside, and the way can be paved for creative legal and ethical problem solving on both sides. One problem that was solved was if you get a ticket, for example, can't we the community come up with some kind of way to have a fund that would pay for such the things or some other creative ways we can deal with things as they come up? These things can make or break your participation. Not addressing what may seem like small things can have a huge impact on the success of a study.

This is a quote I'll end where is that was from the study site staff who were courageous. They listened; they wanted to make changes; they wanted to be participants and see themselves as participants in this study. She said, "It proved to be an eye-opening experience for us. The women that were present and voiced their concerns succeeded in allowing us to view the study from their eyes, from their perspective, and we are most grateful.

Please thank them. We don't thank them enough. Please thank them again, and let them know we are always open to hear their concerns in an effort to better assist in the community."

That's the story I wanted to tell you, and it was one that was most gratifying for me as someone who was facilitating the dialogue. Thank you very much [applause].

It's my pleasure now to introduce Dr. Mohammed Akhter, who's going to talk about *Partnerships in Turning the Tide in DC.* Dr. Mohammed Akhter is the director of the DC Department of Health, and under Dr. Akhter's leadership, the DC Department of Health is focused on improving the quality and of care in the districts. Thank you [applause].

MOHAMMED N. AKHTER: Let me say good afternoon first and then bow to all my colleagues here. What a wonderful presentation by all of them, and how delightful it's been for me to sit and listen to this robust partnership that exists in our metropolitan area. I'm very proud of the leadership that they have provided to our city, their participation in our programs, and their continuous collaboration as we move forward.

I want to make three basic points. The first point is that researchers look at the issue the microscope, and the community-based activists look at the issue with the telescope. They can't wait when this epidemic will end. Somebody needs to be in a position where they are constantly looking through the microscope and through the telescope so you could provide the proper perspective. We were very fortunate in this case that we have a great leader in Dr. Pappas who does that work for us.

He not only has the domestic experience, but also international experience in dealing with HIV/AIDS epidemic. He's constantly shifting back and forth and providing the right balance of perspective so we keep moving forward to make things happen.

If there's one lesson in this, the that is that we, if we want to continue to move forward and continue to make progress, we need to have partnerships. Toni said it the best. If you want to go fast, go at it alone. If you want to go far, go in partnership. No matter where you are, no matter what you work it, it has to be going the distance until we overcome this epidemic. That is the reason to really have this partnership going.

For us, what you see here, a robust collaboration between planning institution, university, political leadership, staff is the guarantee for the program's success. For program to be successful, you need four things at a time. First, you need robust research that give you the answer, not only about with the right treatment is, but also where, when, what, and how to do it. I'm very grateful for the National Institutes of Health and our institutions to be able to provide that info to the local community where the rubber meets the road.

Second, you need a political leadership that provides the resources and the cover under which we can act. Action is not always easy because without resources and without political cover, it's hard. We're very fortunate to have Mayor Gray, and prior mayors who provided consistently over a long period of time cover for the folks to act.

Third, you need absolutely qualified best stuff to carry the work forward. Otherwise, you end up wasting a lot of your resources. We're very fortunate to have some of the best staff in the Department of Health. If there are some folks from the Department of Health, would you please stand so we can appreciate the work that you have done here? [Applause].

After the research, the political leadership, and the staff, the fourth element or the fourth pillar is the activists in the community. The activists in the community, and thank God for the activists, they play a very crucial role. Not only they agitate, they advocate.

They get out there so that there are resources available for research and for programmatic implementation. They also keep the bureaucracy on the straight and narrow line, so they continue to do what need to be done. At times, surely, we have difficulty working together. We have disagreements, but on the whole, we wouldn't be where we are today if it wasn't for the activist community and the community partnerships that we have in our city.

Going forward; we're very proud of where we are, but going forward, there are four or five areas that I want to leave you with the where we're going to be making progress with our folks. Certainly, number one, I can't say more about the research. It's going to be absolutely essential so that we can target our limited resources to the right place at the right time to really make the difference and produce the results that we need to produce.

Second, HIV is not a virus. It's not a disease. We're dealing with people who have the disease. We're dealing with people who have the virus. We need to treat the whole person. 40-percent of the folks in DC today are above the age of 40 who have the HIV virus. They have the same problems as everybody else; high blood pressure, arthritis, and other diseases.

They needed to be really treated in a coordinated fashion. The whole person has to be treated. Going forward, that's going to require a different kind of research, continuous partnerships so that we can produce the kind of programs that will be useful for the folks who are living so they continue to live with dignity and have quality of life.

The third piece that I want to say, it's so very important, is the issue of trained manpower. Nobody pays any attention to the folks who are doing the HIV/AIDS work. There was a different kind of work 20 years ago when we all started in the community. It was all about holding hands. Today's work that is a lot more technical. It's working with the people, taking care of their needs, making sure they stay on the medication required a different kind of training; training

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for people to work in research, training for people to run the program, training for people to provide the services.

Partnerships would be like this sitting around this table. It's so very important to really have the right people available to do the job that need to be done and have ongoing training programs so we continue to do the work.

Finally, the last piece is equally important. That is to have public private partnerships. Government alone cannot do it. Community alone cannot do it. If the businesses come together in this effort – for example, in the District of Columbia, we are providing education and testing to all 32,000 employees thanks to Dr. Pappas and his staff.

If every business came together and said at the bare minimum, we're going to do the same for our employees, we will be way ahead in this fight. At best, the community could contribute their resources like Bill Gates is doing and like Clinton Foundation is doing into this fight, we can do better research. We could do bigger research. We could do better programs. We could do better training programs. We could do better education.

Folks, I leave you with this message that the future lies – the future currency is partnerships, and it is the partnerships that come together for one purpose and one purpose alone: to produce a result, to get ahead of this epidemic, and to make sure the people who are living with HIV live with dignity and respect. Thank you very much [applause].

AMANDA KASTEL: Thank you, Dr. Akhter, for those inspirational words, and thank you to all of our panelists for the wonderful presentations. We have about 15 minutes for questions and answers. If you could come to one of the mics, introduce yourself and your affiliation. If you have a question, if you could direct it towards one of the panelists, that would be great. We also ask you to be succint so that we have time for everyone to get their questions in. We'll start with you.

NICOLE SIMMONS: Yes, hi. Nicole Simmons, Johns Hopkins University. I'm a long-term DC resident. I congratulate you for turning the HIV situation around. I think it's wonderful. I have one question that I don't think was addressed, but and it's based on some of the articles in the Washington Post this week. They identified a number of cases of misdiagnoses by community medical providers. I was wondering, and one of the things that hasn't been addressed is whether you've done any continuing medical education of the general medical community? Not those 12 big HIV specialty clinics, but how to properly diagnose and test people in a community with high HIV prevalence. Thank you.

GREGORY PAPPAS: Thank you so much for that question. I'll address the second question first. We are engaging — that

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you're absolutely right. There's a lot of doctors in town, and they're not all at the same level. We're engaging doctors in a very innovative program. Like the drug companies send doctors out to educate doctors to buy their drugs, the public health department's sending doctors out to educate them about appropriate treatment for HIV. It's a very innovative project that we're starting into very soon.

Regarding testing, I'm not sure about the Post article that you talking about. All testing is confirmed in the District of Columbia, so in normal process, there are false positives and false negatives. Do you have another piece?

TIFFANY WEST: I think you were talking about Dr. Fitzpatrick's article around routine testing and how there was an individual who came to the hospital several times before they were tested for HIV. They were misdiagnosed. I think that since 2006, but we've been trying to implement after-hour the routine HIV screening in all of our hospitals and our medical settings. However, we do have a long way to go. We do hope that with the new task force that is going to make a ruling on HIV that HI bill be able to be reimbursable. That will facilitate more clinical settings implementing routine testing for everyone who walks in the door.

MOHAMMED N. AKHTER: One of the things we are requiring is all health professionals to complete six hours of continuing education in HIV to renew their license. This law will go into

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effect at the end of this year, so every two years, this is a continuing education requirement. Every physician will have to go through the process of getting themselves educated; how to test, how to counsel, how to treat.

MICHAEL ARNOLD: Thank you all for your talks. Michael Arnold with the office of HIV/AIDS Network Coordination and Legacy Project in Seattle. This might be for Carl; I'm not exactly sure. You brought it up, but nobody has actually addressed it. I was wondering if somebody could provide just a really brief description of some of the eight mental health protocols and what that would actually been for on-the-ground service delivery of HIV services and mental health services in DC.

CARL W. DIEFFENBACH: There are a number of activities related to research that Kim Blankenship at American University that is performing and protocols that we're putting into place. One specific one they'll highlight is reworking the depression scale to make it so it is specific and addresses what depression truly looks like in African-Americans. The current scale that's used is not accurate, so there's a collaboration going on with psychiatrists between Howard University and psychiatrists in the National Institutes of Mental Health to rework that scale.

CANDY MOSS: Hi, my name's Candy Moss [misspelled?]. I live and work in DC; I've been here for 26 years, so I've seen

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many of the changes that have been spoken to. I work currently in a community-based mental health agency. I've also worked in residential drug treatment. I've also worked in homeless services all here in the district.

My kids go through DCPS. I'm glad to hear Dr. Akhter speak about the whole person, and having worked in these different areas, I wonder if you and could say more about the working group on mental health and how this wonderful collaborative effort is including these different service areas and providers.

CARL W. DIEFFENBACH: Suad is here, the person who's heading the – stand up and answer the question [laughter].

SUAD KAPETANOVIC: Alright. Hello. Hi, I'm Suad Kapetanovic. I'm a psychiatrist from NIH that was mentioned earlier in Carl's response. Basically, what we've done in the last couple of years, we have followed the model that Alan has described earlier except that we have focused specifically on mental health and basically tried to include – again, to get the community members, community agencies as well as people from academia in DC to basically collaborate together on developing research protocols that will really be addressing important research questions, but in the same time, really speaking to the needs of the community so we can get some meaningful data that will actually but and form our treatment efforts but as we interpret mental health into comprehensive HIV care.

Just very briefly, one protocol focuses on of cultural adaptation of screening in detecting depression in and across the community at the family and medical counseling services. That's a collaboration between myself and Psychiatrist Evaristus Nwulia from Howard University as well as several psychologists from GW. Then we have a protocol that's going to be looking into severely mentally ill individuals in Washington, DC, who are actually the only ones that are still left out when it comes to the efforts to aggressively test and treat everyone in DC, even though they have very high rates of HIV/AIDS. They're at higher risk than the average population.

There are many practical reasons why that's the case. We're trying to understand structural factors and provider-related factors as to why these people are not being tested and what it will take to actually meaningfully test them and link them up with care. Instead of going through all eight projects, I just mentioned those two as an example.

In terms of the scientific working group that you asked us about, we recently found this group. Basically since April of this year, we've met three times. What we're doing, we are trying to provide a forum, a platform for DC-based investigators in the mental health field. We tried to make it as interdisciplinary as possible and inter-institutional.

Hopefully, this discussion that we have on a monthly basis in this forum will result in development of new, collaborative research protocols, and ultimately, independently funded DC-based researchers in the HIV field.

AMANDA KASTEL: Thank you, Suad. We'll take the question over on the other side.

ROB: My name is Rob. Thank you for a very informative presentation specifically about the city of called home for 16 years now. My question is, I've been involved in clinical trials back in the late '90s, but I was never on CAB. This is really I guess for Marcia. Can you talk a little bit about the role of the CAB in disseminating but the results of this study in a meaningful message to the community as opposed to the heavy scientific stuff that's often in the scientific literature?

MARCIA V. ELLIS: The issue of disseminating information about studies and trials is one that each of our CABs is really dealing with very seriously in terms of working on how to get that information. I think that sometimes the researchers are constrained by how and when to get results out. There are good reasons sometimes where there may be some restraints.

What we are asking for and working on together is — even information on the progress of a study, I think that really would help the community to stay more engaged in the study and also feel that their participation is important. You start on a study; it may be some time, some years, even, before the study ends. Some of us would like to see and are working together with our sites to find ways to get information more on ongoing basis. Not information where someone points you to Lancet or some publication, the ways that we can really bring down.

What I can say is that in the CAB meetings, and the beauty of alternating between the site and the community location is that the community that has access to the PI. They have access to the study nurses, study coordinators, and we actually sit down and go through in some detail the studies that are being conducted.

The participants get to ask very specific questions of the PI and the investigators, so that provides a forum that they look forward to, that opportunity to have that discussion on ongoing basis. I think that really does help, and it's one that I think the community gets a lot of value from. We will be looking at ways to get results of studies once they're completed out in a way to the whole community fora so that the whole community can hear what happened as a result of certain studies.

AMANDA KASTEL: Thank you. Manya, did you want to mention something?

MANYA MAGNUS: Yeah. I just want to add that we've had a really steep learning curve with learning how to disseminate results. I think we're getting much better at it. This year alone, we've had two HIV prevention trials network studies, and we we've worked not only to give the information feeding back to a large community advisory board, so one of them many CABs that Marcia is on is one of ours, our GW prevention CAB.

We have about 150 people on our mailing list, many community members as well as scientists. We have a regular attendance of about 30 people quarterly. When these results came out, the HPTN was fabulous and really helped us not only just told us, but help us to facilitate conversations with the whole community.

We've had not only just sharing results sort of uni-directionally, but getting information from our constituents about how we can leverage that information to future studies which were doing together as well as how they would like to see that information come out to be effective and translate into change.

I think you're right. I don't think we always knew how to do this. It's been a learning curve, but thanks to some fabulous experts, I think we're learning. If you want to join our CAB, call me, and we'll send you letters all the time. Thank you.

AMANDA KASTEL: Thank you.

JAMES PETERSON: Can I add, as a part of the cohort CAB, add on to what Manya and Marcia said? We're currently in the process of developing a newsletter. It's right now going through the necessary process to be able to disseminate to the broad community.

AMANDA KASTEL: Thank you. Come back to this side of the room.

CRAIG WASHINGTON: Thank you. My name is Craig Washington, and I serve as the prevention programs manager at AID Atlanta, and I also right for the Atlanta Voice. I just want to say thank you for the work that you're doing, and it's such an inspiring story. I see it really as a best practices model in terms of community-based research, particularly in terms of developing the data infrastructure and the community advisory boards. I'm really excited about that.

I want to know to what extent, maybe this is already happening, that you're sharing the story? Do you have the capacity to provide literally some form of TA to other cities, other localities that may have some similar challenges? I'm sure that Washington, DC, wasn't the only city that was really struggling around effective engagement with the board and data infrastructure.

CARL W. DIEFFENBACH: Through the 12 Cities Project — the CDC has a program called the 12 Cities Project. Alan, through the CFAR, is anchoring a process to help take the activities in Washington and help put those out of the other 12 cities. Parenthetically, one of the other cities that has reached out specifically to my office is the city of Atlanta through Emory University and their CFAR to see how they can take, through the auspices of the university, this kind of a model and implement it in a city. Stay tuned.

CRAIG WASHINGTON: Thank you.

TIFFANY WEST: On the health department level, there's two entities that offer peer-to-peer TA. There's National Association of State and Territorial AIDS Directors, NASTAD, and we've been participating in peer-to-peer TA with them, and also with the surveillance program, the Council of State and Territorial Epidemiologists. They also have a peer-to-peer program that we also participate in as well.

A. TONI YOUNG: Can I add something, Amanda?

AMANDA KASTEL: Sure.

A. TONI YOUNG: Amanda went to Dr. Greenberg, and I have been screaming – okay, discussing with Dr. Greenberg on the regular that I think that we should publish a paper on how this all transpired because I do that it unfolded very organically, but it was very successful when it did unfold. I think that there are some very valuable lessons that other jurisdictions could learn from that paper that I beg him on the regular to publish, but he'll now yell at me when I'm done.

ALAN GREENBERG: Some of that is in the Health Affairs article we published in 2009, but Toni's quite right. We do need a follow-up.

AMANDA KASTEL: We'll go to this side of the room now.

EDDIE MACHTINGER: Hi. Eddie Machtinger, Director of the Women's HIV Program at UCSF. I'm similarly very impressed with what you've accomplished and your message of partnership. There's an increasing recognition of violence as a predictor of incidence of HIV, and then of poor outcomes wants someone has HIV infected. A lot of this data is in women, but it's also relevant and shown in men. Very little information at this conference has described interventions to heal from violence and to prevent further violence integrated into the HIV care for people who are already HIV-positive.

I wonder in the DC model and in what you're all thinking and doing if you have considered violence as part of the multidisciplinary care of an HIV-positive person?

MANYA MAGNUS: I can speak about people who are uninfected and getting some of those information and that that will actually help us. We've actually — a lot of these prevention-based studies that we're working on provide us new insights into violence, post dramatic stress disorder, and other types of issues faced in the community. I can't speak to the HIV-positive side.

Someone else can speak to that, but in terms of gathering information to learn the extent of the child abuse, intimate prior violence, we actually are – NHBS data as well as the HPTN data are really rich with that. It's a tremendous problem. We're actually developing some manuscript to look at child sexual abuse in both of those studies, including nationally. It is a tremendous problem.

I think for us, I'm a prevention person, so my view is data are power. That we can find out things to learn about what to do about them, but I think someone else would have to take the positive part because I can't speak to that.

A. TONI YOUNG: I can say that – I don't know why I just blanked on Priscilla's last name right now.

AMANDA KASTEL: Priscilla Dass-Brailsford.

A. TONI YOUNG: Thank you. We have submitted one letter of consideration to the National Institutes of Health to look both at our HIV counseling and testing staff, what their histories are with violence, either a violent-related crime or self reported the post traumatic stress disorder or some other sort of challenge. We're also looking at whether not we could develop some sort of sample or some sort of survey of the individuals that we screen for HIV as well looking at it as you state as some sort of predictor, but the question becomes, a predictor of what?

MARCIA V. ELLIS: I just want to say as an agency, I also share the board of the other women's collective. Of course, domestic violence is one of the issues we deal with on a daily basis, that women deal with on a daily basis and girls. One of the things that we would like – and we have a lot of practice in working with those women because we know that that also prevents them from disclosing; it prevents them from getting treatment; it encourages risky behaviors and all kinds of things. It's a major issue, and we also plug into those agencies that provide that kind of support.

We also have social services or mental health counseling and things for those women and effective programs. One of the things that we want to do is also contribute to the body of knowledge through our practice.

I think this is where we'd like to see community-based research on what has worked in terms of addressing domestic violence based on our practice. We'll be working along with researchers and others interested in that topic so we can be a participant in that kind of research. I think we still need information that comes out of the years and years of practice some of these areas, domestic violence being one of them.

AMANDA KASTEL: Thank you. We only have time for one more question.

MICHELLE BIEDELHOLDER: Hello, everyone. My name is Michelle Biedelholder [misspelled?]. I'm a student at the

University of Maryland, College Park. My question is directed to the panel to see what has been done to turn the tide but to address the issues that affect African-American women in Washington, DC, given the new report that was recently released?

Another is what has been done to address issues related to housing and unemployment, so lack of stable housing or homelessness, to address that issue. I know that that's an issue in Washington, DC. It was reported in Washington Post. What has been done since then to address those issues?

AMANDA KASTEL: Thank you.

TIFFANY WEST: There were three different studies that indicated that there were elevated rates of HIV in poor black women in Washington, DC. I think that from our perspective at the health department, we are very much focused on implementation of the Affordable Care Act. We're very focused on ensuring that we deliver messages that are culturally competent around HIV testing and screening.

We have dedicated $12 million worth of resources directed at women in DC. However, we know that that is not enough, so we're issuing two RFAs to focus on ensuring that we have the appropriate cultural competence around HIV and women specifically targeted at faith-based organizations.

I think the piece around housing is extremely difficult. I think that we cannot solve the issue of housing and employment alone. Those are very structural issues that have to be addressed from not only a governmental standpoint, but also as Dr. Pappas indicated, a public private partnership standpoint around employment and ensuring that we have a holistic approach to decreasing the social determinants to health.

I think we're focused on ensuring the people who are HIV-positive, no matter what their status in life, whether they're homeless or they are homed, have healthy outcomes whether that's treatment, linkage, and retention. I think that's the best that we can do right now.

AMANDA KASTEL: Thank you. With that, we're going to end. I want to thank again our panelists and just remind you all that there is a session at 4:30 p.m. in session room five. It's a regional session on USA and Canada where Secretary Sebelius will be there as well as the Minister of Health of Canada, Leona Aglukkaq. We encourage you to attend that regional session as well. Thank you [applause].

[END RECORDING]
