

**Administration on Aging  
HIV and Aging Webinar  
*Positive Aging: HIV Turns 30*  
June 14, 2011  
2:00-3:30 pm Eastern**

Coordinator: Welcome. Thank you, everyone, for standing by. At this time all participants are in a listen-only mode. To ask a question during the question and answer session please press star then 1 on your touchtone phone.

Today's conference is being recorded. If you have any objections you may disconnect. And now I'd like to turn the call over your host today, Ms. Danielle Nelson. Ma'am, you may begin.

Danielle Nelson: Thank you, (Fran), and welcome, everyone. Thank you for joining us for today's Positive Aging HIV Turns 30 Webinar. My name is Danielle Nelson, as (Fran) said, and I will be your moderator for today's Webinar.

Before we get started and I introduce our first speaker I have a few quick housekeeping announcements. If you have not done so, please use the link included in your email confirmation to get on to Webex so that you can not only follow along with the slides as we go through them but also ask questions when you have them through the chat function in Webex.

If you do not have access to the link we emailed you, you can also go to Webex.com and click on attend a meeting. That button is at the top of the page and then you'll enter the meeting number which is 668461782. If you have any problems with getting into Webex please call the Webex technical

support at 1-866-569-3239. Again that number for the Webex technical support is 1-866-569-3239.

As (Fran) mentioned, all participants are in the listen-only mode. However you're welcome to ask your questions throughout the course of this Webinar. There are two ways that you can ask questions. The first is through Webex using the chat function. You can enter your questions and I will sort through them and answer them the best that I can throughout as well as at the end of the presentations.

In addition, after our final speaker we will offer you a chance to ask your question through the audio line. When that time comes (Fran) will give you instructions as how to queue up to ask your questions.

It there are any questions that can't be answered during the course of this Webinar we will follow up to be sure that we get those questions answered. If you think of anything after the Webinar you can also email them to us at my email address which is [danielle.nelson@aoa.hhs.gov](mailto:danielle.nelson@aoa.hhs.gov) and that will be at the end of the slides as well, that email as well as the speaker email addresses will be included in the final PowerPoint slide of today's presentation.

As (Fran) mentioned we are recording this Webinar. We will post the recording, this PowerPoint slides and a transcript of this Webinar on the AOA Web site. That's [www.aoa.gov](http://www.aoa.gov). It will be up as soon as possible by the end of this week.

As we get started I'd like to say - black or white, gay or straight, the face that most Americans imagine when they think about HIV and AIDS isn't particularly wrinkled. Yet 15% of all new cases of HIV are occurring amongst people who have lived over half a century and beyond.

With the advent of the 21st Century HIV prevention and treatment have become important issues to older Americans. That being said, who better to get things started for today's Webinar about HIV in Aging than the Assistant Secretary for Aging at the U.S. Department of Health and Human Services? I'd like to now introduce Ms. Kathy Greenlee.

Kathy Greenlee: Thank you, Danielle, for the introduction and welcome, everybody on the call, a significant number of participants as well as the presenters. We are very pleased of your interest and I'd also like to thank the AOA staff who've been working so hard to put on the Webinar.

We know that the Webinar helps us acknowledge here at Health and Human Services the 30th anniversary since the first case of HIV was diagnosed in this country. And for us to move forward and work on the issue of older adults and HIV we really need the help and support of both the private sector and the public sector so we can raise awareness about prevention and testing as well as the treatment needs of aging populations.

Our role at the Administration on Aging in particular is to be part of the implementation plan for the national strategy on HIV/AIDS and to continue to help our partners here at the federal level develop a plan that focuses on older adults and HIV.

In the last 30 years we've learned a lot and we can draw upon that knowledge as we work to educate the aging network which includes state and area agencies on aging, local providers and we need to work with the entire network to focus on the critical importance of educating older adults about HIV prevention as well as informing people about the complexities of treatment for older adults.

We have a number of good partners. Some of them are participating today. SAGE of course, the National Resource Center for LGBT Aging. We work with other populations that focus on other resource centers and organizations that focus on high incidents of population such as the National Caucus and Center for Black Aging and the National Association for Hispanic Elderly.

We really encourage you, both the participants on the call as well as the presenters, to stay engaged with us and communicate with us so that we can bring to the field the best conversation and information as we work with the network and provide services to older people in all settings who are living with HIV.

It's an interesting challenge. I had the opportunity to speak about older adults and HIV at a White House event and said, you know, we've tackled quite a lot to deal with sexual activity, HIV in Aging all in the same kind of initiative. Each of those particular issues are challenging enough separately let alone needing to address them all at the same time. So it will take all of us to bring this matter forward and continue to focus on the support that we can provide.

I wanted to just end and tell you that I remember 30 years ago. I remember when AIDS and HIV were first recognized and diagnosed in this country and the impact it had in that particular time on the LGBT community although I understand it's broader.

When I came to Washington two years ago I had the chance to talk to my staff about elder adults and HIV and I just wanted to share with you, as we kick off the call, my own reaction 30 years later when I started looking at the issue.

And my reaction when we start talking about people with HIV who are older was pretty basic. It was ah, yeah, they lived. And that reaction, it really is testament that I remember 30 years ago and those of us working on this issue for a long time never thought we'd get to this day where we had people living with this disease for so long.

And so I think my message is that people live and people live with HIV and we need to work to support people who've been living with this disease for a long time, people who have acquired it more recently regardless of the source.

But there are older adults living with HIV and there's a lot we can do to continue to education America because this is a day we were hoping would come, that we could all talk about people living to old age with HIV.

And I think it's a positive message to the network as we look at prevention and treatment as well as empowerment of people. And so I really thank the speakers on the phone who are working with us on all three; prevention, treatment as well as empowerment.

So, Danielle, I'll turn it back to you and just wish you all good luck and a very successful Webinar today.

Danielle Nelson: Thank you so much. And now I'd like to thank each of our speakers here with us today for their time and efforts on a very important topic.

I would like to introduce our first speaker today. Mr. Stephen Karpiak has a distinguished career as a research scientist. After 25-year research career in neurobiology and immunology on the faculty of Columbia University Medical School he began his first HIV/AIDS community work in 1995 as the program

director at AIDS Project, Arizona, and founded the Arizona AIDS Project Wellness Center.

He later was the executive director for A Place Called Home which provided congregate nursing for the homeless with HIV/AIDS. He returned to New York City to become a New York foundation sponsored executive director for Pride Senior Network which advocated and did research on the aging LGBT community.

For the last eight years he has been the research director at the AIDS Community Research Initiative of America known as ACRIA where he initiated collaborative seminal research studies on HIV in Aging. His large cohort study, known as ROAH, Research on Older Adults with HIV, has been a catalyst for giving the issue priority status.

He was appointed to the faculty at NYU College of Nursing and NYU Medical CSAR in 2008 and he is a member of the American Academy of HIV Medicine in the American Geriatric Society's effort to provide guidelines for the management of older adults with HIV.

Without further ado I'd like to pass things over to Mr. Stephen Karpiak.

Stephen Karpiak: Thank you, Danielle, and thanks to the Administration on Aging for taking the lead on this issue.

I'm going to first say a few words about my agency, ACRIA. We actually are celebrating 20 years this year in the fight in this epidemic. We have been providing clinical trials to folks who do not normally have access. I'm going to talk about our older adult research and our largest effort is really in education and health literacy and you'll hear more about that as I proceed.

It's been 30 years as was mentioned and in 1990 there had been a 160,000 Americans diagnosed with AIDS and by the end of 1990 110,000 of those had died. In 2010 there are 1.1 million Americans living with HIV and by 2015 the CDC estimates is half of all Americans with HIV/AIDS will be over the age of 50.

The government has taken notice as it has today and that's an important signal to us. In September, 2008, HHS established the National HIV/AIDS in Aging Awareness Day and last October the White House Office on National AIDS Policy convened a special meeting on HIV in Aging.

I just want to go over just as a basic disease process, from the day of infection to when people come down with AIDS, this is a 10-year process. The immune system is fighting back along the way but when we get to AIDS the immune system is collapsing.

With the introduction of HAART, which is treatment for HIV, we find that people who adhere and take their meds will not go onto AIDS and therefore have a much more healthier life.

The CDC policy these days is now to test, test, test and to get folks into treatment. The earlier we test, the earlier we find someone is infected and then put them on treatment, the better will be their health outcomes for the rest of their life.

Also HIV treatment is becoming a prevention methodology in that if people are on their medication, the number of viruses, if you will, in their body is lower and therefore their infectivity is decreased.

Here's some data. In 1994 you can see there were about 20,000 over age 50 living with AIDS. In 2005 that number quadrupled. With the introduction of HAART, before HAART was introduced the average life span was about two, maybe four years unless you had an HIV/AIDS diagnosis. But after the introduction of these very effective medications you can see life span increase from 24, 27, 33 years and increasing.

Here's data from the U.S. showing the number of people, percent of people, living with AIDS diagnosis over age 50 in the U.S. You don't have to be a scientist, you don't have to be a statistician to look at this graph and see ah-ha, something's happening here. It's very clear that the number of older adults is increasing who live with this disease.

New York City is the HIV epicenter; over 10% of the entire U.S. population are here within the city. Today there are 120,000 people living here, 42% are over age 50 and 75% over age 40.

This is a map that I generated of the U.S. just to show you the percent of people living with HIV over age 50. Just a quick glance at the map will show you that those in red and purple account for more than half of the states in the Union and this process is occurring in every single locality across the U.S.A., not just the big cities.

What else is happening? Well, first of all it's happening, as was mentioned, because we have drugs that effectively block the ability of the virus to knock out the immune system. So the overwhelming majority of people who are older today, over age 50, were really infected many years ago or at least before they were age 50.



We should remember that one-sixth today, one-sixth, knew HIV infections occurred in people over age 50 and that why do these infections occur? And there are many reasons but one of them is that there has never been prevention efforts targeted at this population.

There have always been older adults infected over age 50 but no one's ever really, if you will, bothered or take notice of this population and developed efforts to educate them and those who provide them services.

Now ACRIA funded back in 2004 and since, studies on this population and I appreciate their trust in myself and others in making these judgments. What we wanted to know is who are these people. They're not just people with HIV and older. There's something else about this population that we thought we should know and that others should know.

So we developed a research initiative called ROAH and it included 1000 New York City older adults over age 50 and I want to also mention my colleague, Mark Brennan, who is a long-term researcher in the aging world who works with me on this as well as others.

ROAH is comprehensive. I can't go over all the data here but we looked at everything including sexual behavior and substance use; never done before. We looked at the stress, we looked at religiousness, we looked at loneliness, we looked at many factors. A book we published last year, which is data-driven, and it goes over all these topics, there are many papers and press and presentations that have come from this work.

Just a quick example of a population; this is in New York City but it's reflected across the country, 30% of the population are female, the rest male and this virus today as we all know, largely effects the communities of color.

I also want to note that this is not a very old population. Their average age is around 55 to 60. They're getting older which is a good thing but in many respects these are not seniors. Some are but today we're talking about older adults.

If you look at how these folks identify, how they perceive themselves, you can see about 25% is homosexual, 10% bisexual and the rest is heterosexual. This does not define behavior but this is how they perceive themselves and how others perceive them.

Where do they get care; 83% of these participants rely upon Medicaid and only about 20% get it from a private physician. This is true not only in New York but across the U.S.

This the most important slide if you want to take home a message. Seventy percent of this population lives alone and only 15%, 14%, have a partner or spouse. This slide defines the isolation and the social estrangement that has occurred because of stigma to this population and it defines or it underlies many of the needs that they have.

Stigma - I believe stigma today is worse than it was back in the '80s and it was pretty bad then. This is just a sample and we said, who do you tell that you're positive, HIV positive? And you can see they tell healthcare workers, not all. They don't tell their chiropractors. And when we go down the line we'll find that within their congregations they're least likely to disclose which is really sad because frequently for the African America and Hispanic communities, the church, the congregation is a cultural touchstone.

Here's some good examples of substance use. Fifty-seven percent of our sample smoke. That's an extraordinarily high number. I believe in New York City it's about 22%. If we look at other phenomena, if we look at the recovery process because as anyone knows anything about recovery we know there are life-changing events and are critical to their health, the number of people involved in recovery programs is huge. This speaks to the substance use issue.

Depression; okay. If you look at the levels of depression on the right side in ROAH, what we see in the standardized community and we look at people visually impaired - these are people who have macular degeneration - you'll see the depression rates are extremely high and that's disturbing, even five times as high.

Why is it important? Well, depression is the single most valid predictor of non-adherence to medication, not just HIV but all medications. And what's perplexing is that these are folks who are in care and yet their depression is not being well managed and therefore their health outcomes are seriously compromised.

I just want to allude to a study we began in ACRIA where we took the MacArthur Model and that model's based upon, if you will, a song, okay? Bette Midler sings a song, Hello in There. It's based upon making a single phone call a week to people who are depressed. And if you look at this line you can see how their depression scores declined. It doesn't have to be expensive; it just has to show some connection to another human being to facilitate a recovery.

The complications of success; as was mentioned by Kathy Greenlee, we have come a long way. People are living longer. It is remarkable that we would

even sit here today and talk about older adults and HIV. But we've kind of hit another wall. This epidemic never changes enough to let us go.

But older adults are developing many of the aging-associated illnesses at an early stage in life. So for example at age 55 to 60 we're watching people develop multiple cancers, cardiovascular diseases, osteoporosis, liver and kidney (use) and diabetes to mention a few. This is a pattern that you would not see until you were looking at folks who are 75, 80 years old. This is a new challenge.

This is a listing of the comorbidities that they report and this is a summary so they have in ROAH, 3.3 - we have three comorbidities per person whereas the older person because the issues on the right are 55, they only have about 1. This is a remarkable change.

Also if you look at the death rates, most people with HIV/AIDS in this country do not die of HIV/AIDS, they die of other things.

So at the American Academy of HIV Medicine joined with the American Geriatric Society and ACRIA to develop a listing or a number of guides to guide clinicians and clients in how to manage this new challenge. And this challenge is defined as a multi morbidity care management.

This has been largely the domain of the Geriatric Medicine but imagine here you have a client who can present with HIV and any number of these comorbidities against the background of mental health issues and social isolation. It's a challenge.

I want to talk about caregivers. Caregiving is a \$400 billion annual part of the healthcare budget which no one really talks about because they're not seeing it

in real dollars. Our research has for the last many years shown that this population doesn't have good social networks.

We know they have parents, children, siblings, friends, whatever in the social network but when we look at their functionality they need to rely upon them for everything from a daily care issue to emotional support.

We find that only friends remain functional but sadly, of those friends half are HIV positive and half don't even know the other half has HIV. It's a fragile (unintelligible). Why is this important to us? Well, we've already begun working with - we actually just published a paper to show that because they don't have a good social network, which are an important part of aging well successfully, they therefore turn to more formal services in large numbers. And that already they were entering long-term healthcare facilities at a very young age and at a very high cost.

So here's the end. There is life after 50, there is as we are reminded by researchers, some of the work by (Dr. Lindale) as well as AARP who's been very supportive on this in fact, that people have sex, have sexual desires till they can't have it anymore. This is - everybody knows this but doesn't want to acknowledge it.

So that, as I mentioned before, one in every six of new diagnoses in the U.S. is in a person age 50 and over. Why does this happen? I think Doreen and some of our other participants today are going to discuss this in more detail but most of it is a lack of awareness that you are at risk. Everyone is at risk no matter what age and there have been no tailored interventions aimed at this population and those that provide services to them.

This is a map of the U.S. This shows the percent of new infections in each state over age 50 and once again if you look at the red and purple you can see that more than half of the states have fairly high rates of this infection rate.

Also I want to mention that an analysis of their sexual behavior we found out that substance use, mostly alcohol, does effect judgment and that's when they have unsafe sex, that the use of Viagra and other erectile dysfunction drugs does not cause them to be more involved in more risky behavior if they do have more sex.

And then about 16% of this population, these are the folks that carry the virus, do have unsafe sex in the last three months.

The New York City council, to their credit and we thank them, responded to our research and in 2007 began funding an initiative here in New York City which will ACRIA has led with other partners including SAGE who's online today to begin to address this issue.

The core of this effort is really premised on the fact that we need to partner with those who provide services to the older adults community. HIV, AIDS service organizations cannot do this alone. They're not sold up; they don't have any experience to deal with an older population so in order to provide services for this aging population we have begun to hold hands, to create dialogue and to come together.

There's a challenge, sometimes it's a little harder than other times but nonetheless it happens. It certainly has happened in this city.

One of the efforts of ACRIA is to develop materials that are specific to the older HIV population and to older adults in general. This is just a sample of those we hear, there are many more. There are training DVDs, et cetera.

But when we present these and we take them to, especially our educators, conferences and to trainings it's amazing how much people do appreciate this. We've trained over 8000 staff in 18 service providers. We've trained in every one of our city council districts and we've also trained across the country. We've done 75 organizations across the U.S.A. and it's amazing how many call back and want further training.

And lastly this month we launched a very widespread large social messaging campaign where over 250 of our bus, kiosk bus waiting stations have been fitted with these - this is a sampling of the posters - and you'll note the big word sex and that little phrase down there, age is not a condom.

I think that's kind of a good way to look end this and to say thank you. If you need any help in research or particularly as regards to materials and training please contact us. Thank you.

Danielle Nelson: Thank you very much, Steve. We appreciate you being here with us. I would like now to introduce our second presenter, Ms. Jane Fowler who'll be offering a personal perspective. A retired journalist, she currently devotes her time and energies to HIV age prevention and education.

After becoming an activist and public speaker in 1995, Jane co-founded the National Association of HIV Over 50, known as NAHOF. In late 2010 Pause Magazine named her one of the most 100 powerful, influential and inspirational people working in an HIV/AIDS field in America today.

Jane, I'd like to pass it on to you.

Jane Fowler: Thank you very much. A frosty Friday morning in New York in January of 1974 I sat in the Rockefeller Center office of Barbara Walters, then co-anchor of NBC's Today show. I was there as a member of the Kansas City Star's news staff to interview her for a story that would appear later in my newspaper.

I was 38 years old, an enthusiastic young career woman; proud also to be a wife and mother. Fast forward through the years. On a nocturnal Friday night in Kansas City, Missouri, in October 1998 I sat in my urban apartment in front of my television watching and listening to Barbara Walters, then on ABC's 20/20 News Magazine.

From her host chair Barbara introduced a segment, safe sex in seniors, in which I would appear. I was 63 years old, still a proud mother but now divorced and my life course and work had changed. After more than 30 years as a print journalist I found myself in a role reversal. No longer an interviewer, I had become the interviewee, answering questions instead of asking them.

I am currently a spokesperson for a health cause that we all know is not chic but stigmatized. In the addition of 20/20 in which I figured, Barbara confirmed what we HIV activists already knew. That it is imperative to dispel the myth that adults over 50 or 60 or 70 don't have sex and therefore are not at risk for sexually transmitted diseases.

Yet now in 2011, having given hundreds of public speeches and scores of media interviews over the past 16 years, I continue to be amazed by the



response of the general population, even healthcare clinicians and providers of aging services.

How can old people be at risk, they ask, because this is a sexually transmitted disease. To this, yes they can be at risk. The good news is that many persons in the aging population do still enjoy a good romp but the bad news is that too many don't realize they must not have unprotected sex unless the couple is in a mutually monogamous relationship in which neither partner is STD-infected.

I don't pretend to have adopted this role of HIV prevention educator out of the goodness of my heart. No, at present I'd rather be fully retired spending time exclusively with my 7-year-old grandson, (Milo), and my 5-year-old granddaughter, (Matilda). They are a pair precious to me.

So why do I do this work? Because I know the topic intimately because I learned from a health insurance company blood test in 1991 at age 55 the surprising devastating news that I am HIV positive.

My immediate response was to retreat from my 30-year journalism career and tell only my family including my octogenarian parents and a small circle of close friends who were supportive and compassionate. For four years I lived in semi-isolation until my only child, my then 31-year-old son, (Steven), proposed; you're positive, then do something positive.

Thus I was empowered to embark on a new career as a public speaker, to stand up and say look at this old, white, wrinkled, heterosexual face. This is another face of HIV. It's not who you are or how old you are but what you do or don't do that leads to transmission of the virus.

Since 1995 I've been out on the speaker's circuit sharing my story of having lived a traditional conventional lifestyle. I was a 1950's good girl, little booze, no recreational drugs, a virgin on my wedding night at the end of that decade.

Naturally being a good girl I was monogamous for 23 years of marriage, a marriage that ended when my now ex-husband requested a divorce in order to marry his much, much, much younger paramour. What happened next is that I found myself dating again for the first time in a quarter century. I didn't consider myself promiscuous. I didn't frequent the singles bars. I went out with men my age who, like me, had been married and were divorced.

A man I saw frequently, an attractive, intelligent, amusing man of many interests had been a good friend my entire adult life, a former coworker who'd been an usher in my wedding party. He married after I did and divorced before I did and because I knew I couldn't become pregnant it didn't occur to me to ask that protection be used when we engaged in occasional sexual activity.

I knew little about HIV/AIDS, only that a mysterious ailment was affecting the gay community. What did we heterosexuals have to fear? But at age 50 I contracted the virus. It happened over a New Year's Eve when my friend and I went out of town to celebrate. We dined, we danced, we drank a little champagne and we had sex.

How can I be so certain of the date? Because of research I did after I received my diagnosis in January, 1991, I read up on HIV. I studied my day at a glance datebooks, kept yearly since 1958. They're like diaries. And I reviewed medical records in my physician's office. In this manner I was able to establish the exact date of infection.

Today, 24 years after that infection, 20 after diagnosis, 16 after going public I spend countless hours endeavoring to raise awareness in the aging community and just as importantly, among its medical and social service providers about HIV in this age group.

I felt an even greater need for me to point out potential risks when I read a Wall Street Journal report that the number of single persons ages 55 to 64 had increased by 1.5 million in a four-year period. The newspaper article went on to say that the 50-plus crowd represents one of the fastest growing segments of the U.S. dating services industry.

I thought wow; I really do need to reach, in particular, women who are widowed, divorced or coming out of long relationships that have left them vulnerable or depressed, needy or naïve, seeking love and affection.

Today I am 75 years old and grateful to be blessed with good health, to never have progressed to AIDS. Since the introduction of what's known as highly active anti-retroviral therapy, HAART, my HIV has been kept in check. Within two months of beginning those medications 15 years ago the tests that checks the amount of virus in a person's blood indicated I was in the "undetectable" range and I have consistently remained undetectable for which I am grateful.

But most of us who are older and living with HIV or AIDS are for the most part ignored and isolated, fearful to admit to our situations and we face a double stigma; the stigma of having a virus that is contracted sexually or through injected drug use and the stigma of ageism.

After all, common thinking is that Grandma or Grandpa should not have been out there screwing around or shooting up. Here is an example, a personal example, of ageism that I can share.

I once had a young anesthesiologist ask me in a pre-op room where I was awaiting minor surgery about how my body reacts to blood transfusions. Well, I don't know, I answered, confused because I've never had a transfusion. But you have HIV, he countered. I told that young man, you're looking at an old lady who got HIV through sex, so there.

Thus I remain passionate about my mission, to make certain that seniors and their families, their providers and caregivers understand how HIV is transmitted and prevented.

I remind everyone, you never know the sexual history of anybody but yourself. I also like to tell older males who may find themselves suddenly especially frisky thanks to those performance-enhancing drugs, and now if you can get it up, cover it up.

My work as an activist brings me fulfillment as none has before. My years as a journalist, meeting people, seeing my byline weekly in the Kansas City Star, then monthly in Bon Appetit Magazine; those were heady years for me. Now more than at any point in my life I like to think I'm making a kind of contribution to the health of mankind.

Yes, I keep busy with my work for HIV Wisdom for Older Women, a national program I founded nine years ago. It's a program of prevention and care directed to aging women of all racial and socioeconomic groups.

For example elder females may not realize that seeing a physician for a routine checkup does not insure that an HIV test will be automatically included in a blood screening. That's right, women may need to request that test and why? Because providers for the most part continue to omit the topic of sexuality when dealing with seniors, especially women.

We hear this is commonplace because young to mid-age clinicians often are reluctant to talk about sex with patients or clients who are old enough to be their parents or grandparents. This however is a practice that must be reversed and if reversed there might be fewer misdiagnoses of old people who are in fact HIV infected.

These occur because HIV symptoms can be similar to those associated with aging. Think weakened immune system, weight loss, fatigue, respiratory or GI problems, depression, decreased cognitive or physical abilities. The result can be that HIV is not uncovered until after a patient has become ill with an AIDS-defining opportunistic infection. Thus elder people die sooner from AIDS complications than do the young.

My role as an educator, I never ask for sympathy or pity because I have HIV. Of course I regret that two decades ago I wasn't knowledgeable about this disease and became infected but I live with this virus as others live with cancer, ALS, Parkinson's, AMS, congestive heart failure, any potentially terminal disease.

Yes, I have HIV but I do not allow it to control my life. My work gives me direction and I also rely on welcome emotional support from family and friends who offer distractions that keep me from obsessing about my virus.

What I ask is anyone who hears or reads my words is to remember my message. Many in the older set are becoming newly infected while others are living and aging with HIV/AIDS. Please help me in my efforts to educate so that someday we may rejoice together that this virus has at last been eradicated. Thank you.

Danielle Nelson: Jane, thank you so much for sharing your story. We are privileged to have you on this Webinar with us today. I want to share; Jane was a panelist on a video. It's an excellent video that talks about HIV in Middle Age and if you'd like to get a free copy of this episode you can request a DVD of the program, HIV in Middle Age, by sending an email to (Karen Heller) who manages the program. Her email is listed there. And send her your mailing address.

So moving on I'd like to introduce our next presenter, Doreen Bermudez who serves as the national training coordinator of the National Resource Center on LGBT Aging.

This historic research center, the first federally funded center of its kind in the country, provides critical information and tools for aging providers, LGBT organizations, LGBT older adults and their loved ones.

Bermudez was previously the lead trainer for services and advocacy for GLBT Elders, known as SAGE, the world's largest and oldest organization dedicated to improving the lives of LGBT older adults.

Bermudez holds a degree in education and Latin American studies. Prior to her work at SAGE she was a consultant for the Puerto Rican Family Institute and Company on HIV services.

Doreen, welcome.

Doreen Bermudez: Thank you and thank you to my colleagues who are also in this call. I am delighted to be here.

The National Resource Center on LGBT Aging is the only technical assistance resource aimed at improving the quality of services and support offered to Lesbian, Gay, bisexual and transgender older adults.

The LGBT community is no stranger to HIV and AIDS and addressing the needs of LGBT older people in this epidemic. If we take a look back 30 years ago an LGBT older person now was probably attending a funeral once a week for a few years. Those are alarming numbers when you look now after 30 years of this epidemic.

Where do we find older adults and how do we combine the research, the data and how do we go into communities and implement, create, develop programming addressing the unique needs in the older adult community.

How do we gain access to service providers and how do we help them enhance their services to create inclusivity addressing the needs of the older adult person that is HIV positive and addressing prevention initiatives in this community?

Creating, we have created as an example Dr. Stephen Karpiak talked about New York City being the epicenter of HIV and AIDS. We have created a realistic structure promoting the inclusion of HIV conversations that have been challenging for many of us here working in the HIV field and let me tell you why.

Due to limited resources many organizations despite their efforts and despite their interest to be inclusive to create and implement an HIV conversation addressing the needs of older adults, are not able to due to limited resources. Therefore we have been forced to become innovative and to implement initiatives that are non-traditional and inclusive of HIV in older adults.

And we have started very simple, just creating environments that are inclusive by going to where older adults are. The reality is that not all older adults are in senior centers. Many of our older adults in the community, they are working or they are involved to civic engagements. Therefore we have become innovative in going to this setting and addressing everyone and adjusting the content of our program according to the needs where your particular organization is.

Let me give you an example. We have found in our experience that many service providers are using limited language when addressing older adults in regards to their sexual history, making assumptions that an older woman past her 50s or her 60s is less sexually active. Those are challenges that we need to address as service providers in the aging network.

Older adults at times may feel alienated and marginalized and this is inclusive but not only the exception in the LGBT community. Service providers need to start having conversations of being inclusive in addressing the needs of older adults in HIV and to other respects in terms of their aging and ageism within their own settings.

Okay, we take that and we include what of minority stress and how that plays a role in the HIV and aging network. When you have a person that is older and they are dealing with aging-related issues, at the same time if this person is part of a community that is underserved - as an example, if that person is a



gay, lesbian, bisexual, transgender person that is an added stress to their aging process.

And how those issues are being addressed by service providers at times we find that they are not directly referring to those issues and that creates a limitation to the way that we provide services and the quality of services that we want to offer and extend to that older person.

Language can be a barrier and also consistency of programming. So those that work in not-for-profit sectors at times consistency is a big issue in addressing the HIV aging community due to lack of resources and continuity of funding.

Some of the risk factors that in our experience working with HIV in older adults are not addressing sexuality and assuming that an older person is not sexually active. In many cases not having a plan that can be implemented consistently within organizations that could capture data and evaluation for us to know the impact that we have had as service providers addressing this community.

In closing, the aging community in not only New York City but across the country is being faced with many challenges. People are aging and they are dealing with other health-related issues. We need to incorporate HIV into the aging conversation.

It is a disservice to the community in the United States, particularly in the aging community, not to address HIV, not to ask the questions that will be able to open the doors to us service providers to find the information to better serve our individuals within our own organizations.

This is an invitation to start that conversation. This is an invitation to everyone at the table to be inclusive of the HIV conversation to ask and to be able to address our older adult community in better ways and to serve them better.

Thank you.

Danielle Nelson: Thank you, Doreen. We appreciate you speaking today. Last but not least we have Mr. (Courtney Williams) who is a community planner for the D.C. Office on Aging in the District of Columbia. He has been with the office for over 20 years. His extensive experience with the D.C. Office on Aging includes the development, evaluation and implementation of studies, reports and special projects related to the local aging population.

He has spearheaded policy and planning issues dealing with the issue of HIV in older adults since the late 1990s. He previously served as a board member of the National Association of HIV Over 50 as well as organized two local conferences on HIV and seniors.

(Courtney), I'd like to pass it over to you.

(Courtney Williams): Okay, thank you. We had a wonderful discussion today from all our speakers. The Triple-A's, the Triple-A's very important to older adults whatever because it's a way that they access service and provides a lot of information and assistance to older people in need of services.

As we well know, the Triple-A solicits and contracts with private vendors for services, administer and reimburse funding, monitor programs and provide coordination of services and resources for persons over 60.

The Triple-A's Area Agencies on Aging existed long before there was HIV so there's already a system set in place. Over the last year we developed an aging service network - an HIV service network but before that we had an aging service network which in the services now provided by the HIV service network are very similar to what the Triple-A's do now.

Now working with a Triple-A there's few things that I notice and things that I recommended for us to move forward in addressing the needs of our older population as this issue begins to impact them.

One of the issues always is how do we make the connection between our HIV and our service provider network. In most places, not all but some places there are two separate service systems and they don't talk to each other. They don't interconnect.

What I've tried to do over the last 15, 20 years is make the connections. I had some discussions between the two different service networks. In some cases even in our service system you have an organization that will provide new services for seniors but they're also providing HIV services also and they're two separate parts that don't talk to each other.

Now we've had two conferences dealing with HIV in older adults and the idea was to bring the two service networks together. The HIV service network has never talked with the aging service network.

As we see the numbers increase we get a lot of calls now from HIV service organization asking for our assistance in helping older clients. In the District of Columbia we've dealt with persons living with HIV and AIDS as old as 92 years old and we had a significant number of ones in their 70s.

We have been working and partnering with other agencies in HIV. We go to them and we try to advocate on behalf of the older population.

Now we recognize that the largest number right now currently of older adults is now in the 50 to 59 year range but eventually they're going to mature past that and they'll be eligible for our senior service network which starts at the age of 60.

Now we always have to warn them, what impact is that going to have on our service delivery as we stand now because you're eligible for two different service systems now. So what has happened is that we actually now begin to get persons who have gotten older with HIV but now need our help in terms of services.

I just had a situation over the weekend with our social workers is that because of the extreme heat the fire and EMS went into a home of an older person and discovered that this person is not only receiving services from the HIV community but also receiving services from the aging community and we have two service systems that didn't even know that we were both providing similar services.

Some services she was receiving from HIV services because she's matured into that. She started receiving HIV services when she was in her 50s; now she's in her 60s; now she's accessing our service system.

Also some of the other things that we're also looking at is how to provide ongoing training for our social workers in our network on learning more and more about HIV. One thing I want to talk about now is probably about since we had these two conferences, what have we learned?

We've come out with a series of recommendations to present to our health department since our health department has the lead on dealing with HIV and aging issues. So what we did, we came out with a series of recommendations for the city to enact to better provide support and services for persons living with HIV.

One of them, we wanted the health department is to start providing HIV prevention messages for seniors including, also make sure that they included new material brochures, pamphlet depicting older people who are effected by HIV.

Also making sure that this information is available at all of our special events and also at their special events too, health fairs. What we also require now when we do city-wide events for seniors and we do health screenings; it's part of our health screenings that we must have an HIV health screening at our special events.

Also we're looking at how, we have talked with the health department about the possibility of doing condom distribution at our senior wellness centers. Wellness centers are places where seniors, we have five in the city where seniors go for exercise I would consider like a Gold's Gym for seniors because they do a lot of different things there.

So we also want to develop a curriculum for volunteers and also for our network and also trying to teach other seniors and also other people that they come in contact about HIV.

It's so many different, I have like 30 different recommendations but those are some of the key ones. One thing we're trying to do is trying to get the health

department to understand that this epidemic is here, 3% of the population in D.C. is HIV-positive in D.C. so that would be considered an epidemic here.

So we want to try to get them to consider HIV of seniors as an emerging population for HIV infection and as evident by the growing numbers. We can show the numbers, how the numbers are growing as people get older.

The face of HIV at 30 is aging as you can see. Are we prepared for the next 30 years and that's something that we have to look at as an Area Agency on Aging. What impact will older people aging will have on our service delivery and are we prepared for that?

I think I want to open it up for questions now, okay?

Danielle Nelson: Wonderful. Thank you, (Courtney). I appreciate you speaking. I wanted to move to the next slide to show the resources available from each speaker's agency Web site. And again this PowerPoint will be posted on AOA's Web site.

We have had several questions come in through the chat but I'd first like to turn things over to (Fran), our operator, to open the audio lines to queue up our questions from the phone lines.

Coordinator: Thank you so much. If you'd like to ask a question over the phone lines please press star then 1. Please unmute your phone and record your name. That will be needed so you know when your line is open.

So again on the phone lines press star then 1 if you might have a request.  
Thank you very much.

Danielle Nelson: All right. And our first question in chat is for Steve and that question is, does ACRIA plan to make a presentation or poster at the upcoming International AIDS Conference in D.C.?

Stephen Karpiak: We certainly do. In fact we presented the first satellite meeting on HIV in Aging at the past meetings on HIV and Aging in Vienna. So as the issue grows, so does our work so absolutely.

Danielle Nelson: Wonderful. Our next question has come in and that question is, and it's whoever of the speakers would like to take it; what are the critical needs of older adults for HIV prevention and education or HIV care? Is HIV prevention and awareness issue among gay male seniors the same as is it different for non-gay seniors?

Who would like to take it?

Doreen Bermudez: Doreen will take it. Thank you for your question. The HIV prevention and education messages across the board for both gay male seniors or non-gay seniors is the same one. When we do prevention education we talk about how to be protected whether you are gay or not.

So that message is basically the same however critical needs of older adults are different from the younger community and that is because older adults are also dealing with aging issues and other critical illnesses that come with age.

So we have to be very careful when we talk about HIV prevention and how do we incorporate and integrate the aging conversation and education within the HIV component.

Danielle Nelson: Great. Thank you, Doreen. We have another question that's come in through chat and this question is for Jane. Jane, the CDC recommends HIV testing for people of ages 13 to 64 during regular blood screening. What do you think it should be and how should older adults over the age of 64 approach this testing with their physician?

Jane Fowler: Well, I think it should certainly, the age should be...

Danielle Nelson: Jane, could you speak up just a little?

Jane Fowler: Yes, I'm sorry. The age should certainly be higher than 64 I believe. A lot of us do. We were surprised at the recommendation from the CDC. We know it's not a mandate but it's a recommendation.

If a person thinks there's a need for a test and I personally think it wouldn't hurt if everyone had a test, then the person - the patient/client visiting a provider should request the test. It's just not going to be automatically offered as part of a blood screening if you're over 64. If you're under 64 it will be.

Again it's not mandated, it's recommended but if it is recommended and for some reason if a woman or man say at age 60 doesn't want the HIV test included in the blood screening, he or she can opt out.

Danielle Nelson: Great. Thank you, Jane. That is all the questions we have from chat at this time. You can continue to send them through the chat function but now we'll go to (Fran) for our audio questions.

Coordinator: Again thank you. Our first request over the phone lines from (Dale Mitchel). Your line is now open.



(Dale Mitchel): Yes, hi. I was particularly struck by the first presenter who said that there had been no prevention education targeting older adults while at the same time it's a significant age cohort for new infections.

And it occurs to me that AOA itself could be an important transmitter of safe sex education for the elderly population. Title III of the Elder Americans, Older Americans Act funds a whole plethora of services including congregate meal sites all around the country which could be vehicles, very effective vehicles I would imagine for safe sex education for older people.

I'm just wondering how the panelists feel about the federal government and particularly the Administration on Aging taking a more forceful and interventionist role in this area.

(Courtney Williams): This is (Courtney) with the Office on Aging. Since I actually do work for Area Agencies on Aging and we do interact with the Administration on Aging, I'm of the opinion that, you know, they could do more and one of the things they could do is, they could do more funding, special project funding for initiatives that maybe a Triple-A might want to undertake for education.

But also right now since you do have the congregate meal sites and you're supposed to provide activities we encourage our providers and we work with them to make sure that they do HIV education at the senior centers, whatever, and it's important to have someone in a lot of cases in here in Washington we've been blessed to have people who look like them who can go out and talk to them about HIV.

It's the easier thing for them to deal with to better understand if they see someone who looks like them. The only challenge, the big challenge is that we have now we really don't have a lot of good materials that we can hand, to

give to people. We can have people go out there and talk to them but we also need to kind of reinforce that you are affected or infected by HIV particularly in this city.

(Greg Case): (Bill), this is (Greg Case) with the Administration on Aging and let me just take a minute to try and answer your question as well.

While we don't have any funds in the Older Americans Act dedicated specifically to the use of HIV in Aging outreach and programming, the Title III-B dollars can be used for that kind of purpose and we have done a number of things over the years to encourage Area Agencies on Aging like in D.C. but there are a number across the country that have engaged in activities around HIV and older adults both prevention and treatment.

We have not had any discretionary opportunities for HIV in Aging but as you probably know, the discretionary funds that we've gotten in recent years have been very limited and have made it difficult for us to do that. So we appreciate the comment and will appreciate any assistance that any advocates out there can give us in helping us to secure dedicated funding that we could direct directly do activities around HIV and AIDS.

(Courtney Williams): This is also (Courtney) again, is that I think the area agencies on aging should look at actually applying for some of these around (unintelligible) planning grants and also as they get more involved in it, they can advocate that the agencies that provide funding for HIV services fund Area Agencies of senior programs to address this issue.

But there is some funding out there, it's just a matter of what we've done here in the Office on Aging, we have partnered, we've given letters of supports and we also have partnered with non-profit organizations that's providing services,

HIV services, to say that we will give them access to our senior programs and also assist them in providing training for our case managers and social workers because there is funding out there. It's just you have to be a little innovative. As Doreen said, you have to be a little bit innovative and creative.

One thing we did is that we worked with one of our sites to do a senior AIDS education quilt. We had seniors do a big quilt and at the same time they were educating themselves.

Or to hold workshops about dating over 60; seniors will come to a workshop that says dating over 60. They most times won't come to a workshop that says HIV and seniors so you have to be a little creative in the way you approach seniors and also even how you deal with the churches here.

Danielle Nelson: Thank you, (Courtney). (Fran), do we have another audio question?

Coordinator: Yes, we have a few. Now (Mary Hurlburt), your line is open, ma'am.

(Mary Hurlburt): Thank you. Actually I do work with the Area Office on Aging in Ohio but I have been a 15-year researcher for HIV in seniors. I have to agree; we have seniors which I am one now, do the best going out talking to groups.

But we have a very proactive state here for volunteers and community services but as they were saying, very little funding is available anymore. My biggest thing though and Jane already answered this as the recommendation. We all were just absolutely floored when CDC came up just to 64.

I'm going to add a little bit more than that. We that are in the HIV prevention community here are also trying to get that as part of routine health assessment for any age and then opting out, as she said.

Unfortunately I know in Ohio there's state laws as was probably every state has different laws referring to this, you know, what they can and can't do. So anyways I just - since I was already on when Jane talked it was, you know, she's the one that started me researching this actually 15 years ago when I was working on my under-grad so thank you.

Danielle Nelson: (Fran), do you want to take the next question?

Coordinator: Of course. As a reminder, star then 1 if you might have a request and my last at this time from (Stephanie Bates), your line is open.

(Stephanie Bates): Hi. I'm actually with an Area Agency on Aging in a rural county in Western New York and I have two questions. The first one is, do you know where I can find statistics by counties in New York by age of HIV diagnoses, AIDS diagnoses?

The other question I have is, there's a big push in New York State for the chronic disease self-management program out of Stamford. Have there been any discussion with that group to speak specifically to living with HIV and AIDS and implementing that in their curriculum or maybe having a separate curriculum focused primarily on HIV and AIDS?

Stephen Karpiak: This is Steve. Being from New York I think if you're going to go down to the county level you'd have a problem finding that kind of (unintelligible) data although it can be requested.

And I don't know of any contact with the chronic disease management group you mentioned although it's going to be necessary because really managing

multiple chronic diseases is going to be the challenge of the healthcare profession.

(Greg Case): In terms of the chronic disease self-management program, (Stephanie), we'll follow up on that. We're not certain if there's been anything specific to that or not. We see no reason why people living with HIV as another chronic illness can't participate in chronic disease self-management programs but whether or not there's been any specific work in that area, we're going to look into it.

And if you will just email Danielle Nelson whose email address will be given in the very last slide of this presentation so that we know how to get a hold of you, we'll be back in touch about that.

(Stephanie Bates): Great. Thank you. They have a separate program for diabetes so, you know more support programs specifically around that so I didn't know if they wanted to do the same type thing with HIV and AIDS or include it which it should be included with the group as a whole as well.

Danielle Nelson: All right and we have a question that's coming from chat for Steve. It says I do research regarding adherence to HAART. Earlier you said that those who take HAART successfully will not get AIDS. Did I hear this correctly? Is it safe for me to tell participants in a (unintelligible) intervention that they will not get AIDS or is it better to say that it will slow the progression?

Stephen Karpiak: If they're adherent and they haven't had an AIDS diagnosis already they should not progress to AIDS. The treatments are very effective as long as folks as adherent.

Danielle Nelson: And we have another question. This is for any of the presenters who would like to take it. Is AARP helping to prevent HIV among seniors? Is it

advocating for increased funding of HIV prevention programs for seniors?  
Does anybody know?

Stephen Karpiak: This is Steve. I can speak to that. They've been actually very supporting. They've had a series of articles and a major article in their last magazine and has just launched a portal which probably Doreen can speak to more about aging and HIV in the elderly community. They've certainly been an ally.

(Courtney Williams): Yeah, they put out one of the first videos dealing with HIV in older adults over 10 years ago. They call it, It Could Happen To Me. And also they did a manual on HIV and its impact on older women so they have done some things in HIV.

Doreen Bermudez: Yes and yes absolutely (unintelligible). AARP's been very supportive of the gay, lesbian, bisexual and transgender older adult community, just recently launched a portal addressing the needs of this community.

We look forward to their continued support and again integrating the conversation of HIV in Aging.

Jane Fowler: AARP will be publishing some brief profiles and pictures in its next issue which would be I think July/August about the 30th anniversary of HIV/AIDS in this country in older people.

Danielle Nelson: Great information. (Fran), do you have any questions from the audio lines?

Coordinator: Yes, I do. (Hope Barrett), your line is open, ma'am.

(Hope Barrett): Hello. I just wanted to put out there that (Center and Halstead) which is based in Chicago recently produced a video for older adults over 50. It's an HIV

prevention documentary. It's about 30 minutes long and profiles the lives of three LGBT older adults who are living in (unintelligible) with HIV.

The film will be available shortly. We're going to post it on our Web site. You can get a preview of it on YouTube if you enter Aging Positively and that's spelled P-O-Z-I-T-I-V-E - how do you spell positively - yes, P-O-Z-I-T-I-V-E-L-E. So I just wanted to put that out there that there's an additional resource for folks to use in talking about older adults and HIV.

Danielle Nelson: Thank you. We have another question that's come in from chat. As the founding national leader for national HIV and AIDS in Aging Awareness Day, the (ACE) Institute encourages collaborative partnerships to address prevention, education and awareness regarding HIV in Aging. What success have any of the presenters had in working with other target groups and who would you recommend working with at the local level to implement activities on or around the September 18th event?

Doreen Bermudez: Hi, this is Doreen. Some of the suggestions that I can give you in partnering with other organizations around this day is working with your local Triple-A but also the local senior centers and service providers that are uniquely to be all the adult community.

It can be challenging in partnering and doing activities around addressing HIV and that is due to stigma and what I like to call what is the ripple effect on HIV and how older adults may perceive today what HIV is and how you are at risk. We should talk about the need to continue education around this topic.

But definitely work with your local service providers, you know, within the aging network. And again it is just key of the consistency of programming and

continuing and implementing the type of conversations and programs around HIV in older adults.

Thank you.

Stephen Karpiak: This is Steve. I may mention also congregations, many congregations in certain communities - I know Baltimore especially but also here in New York - have begun to recognize this issue and that within their congregations, that seniors who are positive as well as not and who are at risk. And since the congregation's a touchstone for these communities, I think they are willing to and will engage particularly those who have already gotten into the issues of prevention.

(Courtney Williams): In D.C. we plan on having an event in September for HIV in Aging. What we plan to do is help the health department would have developed the materials that we can distribute out to the general public about HIV in older adults so that's what we plan on doing on that particular day and also having an event at each one of our wellness centers around the city focusing on some aspect of HIV in older adults.

Danielle Nelson: Great. (Fran), we're ready for the next audio question.

Coordinator: I have no further questions on the phone lines.

Danielle Nelson: We have no further questions on chat. With that I would like to thank all of our presenters on today's Webinar and also everyone that tuned in, we appreciate your time. If you have any additional question please feel free to email me. That's [danielle.nelson@aoa.hhs.gov](mailto:danielle.nelson@aoa.hhs.gov). Again thank you and enjoy the rest of your day.



Stephen Karpiak: Thank you.

Doreen Bermudez: Thank you.

Jane Fowler: Thank you.

END