

**OLDER AMERICANS: THE CHANGING  
FACE OF HIV/AIDS**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
**ONE HUNDRED THIRTEENTH CONGRESS**

FIRST SESSION

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## **OLDER AMERICANS: THE CHANGING FACE OF HIV/AIDS**

**WEDNESDAY, SEPTEMBER 18, 2013**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The Committee met, pursuant to notice, at 2:06 p.m., in Room SD-562, Dirksen Senate Office Building, Hon. Bill Nelson, Chairman of the Committee, presiding.

Present: Senators Nelson, Baldwin, Donnelly, Warren, and Collins.

The CHAIRMAN. The meeting will come to order. We are expecting Senator Collins momentarily.

Let me say before the hearing that the Ranking Member, Senator Collins, and I have checked with the members of this committee and we have found favorable replies to proceed tomorrow to file the resolution for the committee budget for the remainder of the 113th Congress. If there are any further questions, I encourage members to contact our staff. But what we will do is, either between the first and second vote tomorrow, or if there is only one vote, immediately after that vote, we will convene in the anteroom off of the Senate floor and take care of that administrative matter.

I want to thank all of you for coming today. We have made great gains in the national and international fight against HIV/AIDS.

Senator Collins, I literally just started—

Senator COLLINS. Sorry, my fault.

The CHAIRMAN. [continuing]. And what I am going to do is, since I will be introducing the panel members, I am going to flip it to you first. I have made an administrative announcement that tomorrow, we will convene off the floor after the first vote to take care of the matter of the resolution for the committee budget.

So, let me turn to you for your comments.

### **OPENING STATEMENT OF SENATOR SUSAN M. COLLINS**

Senator COLLINS. Thank you, Mr. Chairman. I apologize, first of all, for being late. I never like to be late for anything, but much less your hearings.

I want to also thank you for holding this hearing to examine the many challenges associated with an HIV/AIDS population that is aging. Since today is National HIV/AIDS and Aging Awareness Day, it is particularly appropriate that we take this opportunity to focus attention on the issues facing older Americans with regard to HIV prevention, testing, care, and treatment.

The face of AIDS in America is aging. Thanks to major scientific advances in anti-retroviral drugs, HIV is no longer an early death sentence and people with HIV/AIDS can now live near normal lifespans. By 2015, the average age of an HIV patient will be 50. While that is a testament to just how successful our research and treatment efforts have been, the fact is that the increasing numbers of older adults being diagnosed with HIV has also contributed to the graying of the population. According to the CDC, people older than 50 accounted for 17 percent of new diagnoses in 2011, up from 13 percent in 2001. The success of HIV treatments combined with the increasing number of newly diagnosed older individuals means that people age 50 and older will account for the majority of people living with HIV in our country by the year 2015.

At the beginning of the AIDS epidemic in the 1980s, people who were diagnosed with HIV could expect to only live a year or two after their diagnosis. Consequently, issues associated with aging were simply not a major focus for people with HIV. But new medications and treatments have changed all that. These individuals now have to face the challenges of aging with HIV.

While living with HIV is not easy at any age, older individuals face different issues than their younger counterparts. HIV is still viewed by many people as a young person's disease and older adults with HIV may encounter ageism and additional stigma. This may make it even more difficult for them to disclose their status to family and friends, limiting their access to emotional and practical support and increasing their sense of social isolation.

The CDC only recommends routine HIV testing up to age 64, which prevents some older adults from learning their status. This can delay a diagnosis, which, in turn, delays treatment and reduces its effectiveness. It also increases the opportunity for further HIV transmission.

While HIV patients are living longer, many appear to be aging prematurely and are coming down with chronic conditions related to aging, such as dementia and cardiovascular disease, a decade sooner than their uninfected peers. Anti-retroviral drug therapy can affect and perhaps even worsen these medical conditions. Moreover, the decreased immune function that naturally results from aging makes older persons more vulnerable to a rapid progression from HIV infection to AIDS.

Before closing, I would like to welcome today Kenny Miller, the Executive Director of the Down East AIDS Network in Ellsworth, Maine. Kenny is here to talk about the special challenges faced by older individuals with HIV/AIDS who live in rural areas, and I am very much looking forward to his testimony and the testimony of our entire panel.

Thank you, Mr. Chairman.

#### **OPENING STATEMENT OF SENATOR BILL NELSON, CHAIRMAN**

The CHAIRMAN. Thank you, Senator Collins.

So, today, we are going to look at AIDS and the aging. And when you consider the fact that today, 30 percent of all AIDS cases are age 50 or older, and in two years, 50 percent—half—with HIV will be over the age of 50. You come into a State like mine, Florida, that as a percent of the population has a higher percent of elderly,

it is even higher. Today, not 30 percent, 39 percent of those with the disease are over the age of 50. And so this so-called graying of the population of AIDS comes with the need to refocus our work on these new challenges.

Now, we want to reaffirm again that aging with HIV, some people think that just because they are older, they are not going to get HIV. Well, regardless of how you look at it, we still have to find a cure for it, no matter what age you are. So, our work for a cure should take into account the fact that any such drug or vaccine will miss half an epidemic if it is not tested and proven effective for the elderly population.

Now, out in the State of Oregon, there is this extraordinary experiment right now successfully on a vaccine that is eliminating HIV in monkeys. It is called SIV. It is even more virulent in monkeys. And they now have a vaccine that in this first test out in Oregon University has stopped it by creating the vaccine that does something to the t-cell that goes and attaches itself to the virus. So there is some real promise. But that, needless to say, has to go then into a test with humans, and as we get into a test with humans, is there going to be a difference in what we are experimenting with on how it will affect the young and how it will affect the old? In fact, many conditions that often occur in the elderly, such as diabetes or Alzheimer's, that has implications, then, when you combine AIDS with that.

So, we are going to hear from our witnesses about how our research dollars contribute to our understanding of how to treat AIDS and we are going to do so today in the context of those other diseases that often occur in the elderly.

Now, we want to hear also from the witnesses about providing HIV services and support to seniors. Are our programs that train providers and offer housing and assistance with medication and the medication cost, are they prepared for an aging population?

So, as we continue this battle against AIDS, now, we want to refocus today's hearing on the aging population.

I want to thank our committee. I want to thank Senator Collins for her contribution here. And I want to introduce our panel.

Is there anybody on our committee that is compelled to make a statement at this point?

Senator WARREN. Could I make a statement?

The CHAIRMAN. Of course.

#### **OPENING STATEMENT OF SENATOR ELIZABETH WARREN**

Senator WARREN. Mr. Chairman, I just want to take this—because I am going to have another hearing at the same time and may not be able to stay for all of this—

The CHAIRMAN. Yes, ma'am.

Senator WARREN. [continuing]. So I do want to say, when you are talking about the magnitude of the problem, in Massachusetts, 52 percent of those who are HIV-positive are 50 or older, and 15 percent are 60 or older. This is an issue that now is profoundly affecting an aging population and I want to commend you and the Ranking Member for having a hearing on this.

But I want to add on this, there really are moments of hope in this battle. We have made tremendous progress in treating HIV

and are making exciting headway toward a cure. Just a few months ago, researchers in Boston presented exciting clinical results that two patients had undetectable HIV after bone marrow transplants. And Fenway Health has been engaged in important population studies, clinical research studies with the LGBT community, since the very beginning of the HIV epidemic and they have really helped bring forward our research and our understanding of this issue.

I just want to make the point that progress is made possible by smart investments in basic research and population research by the government, by private industry, and by nonprofit groups. And as our population living with HIV and at risk for HIV ages, we need to make sure that we are gathering and coordinating data on the long-term effects of HIV drugs, on HIV drug interactions with medications used by an older population, and on how best to treat older HIV patients who are developing common comorbidity problems.

So I just want to thank you for having this hearing, for getting us this focus, and I hope we will talk more about the importance of continuing research in this area.

Thank you, Mr. Chairman.

The CHAIRMAN. So you are already over 50 percent today?

Senator WARREN. Yes, we are. Yes, we are. This is an urgent—

The CHAIRMAN. Over 50 percent of your HIV population is age 50 or over.

Senator WARREN. [continuing]. That is right. This is an urgent problem in Massachusetts. It is a coming problem for all the rest of the country. And that is why it is so important that we continue research in this area, Mr. Chairman.

The CHAIRMAN. Senator Donnelly.

#### **OPENING STATEMENT OF SENATOR JOE DONNELLY**

Senator DONNELLY. Thank you, Mr. Chairman.

I would just like one minute to mention that my home State is also the home State of Ryan White, who was such an American hero, but also such an historic figure in this fight. And when you head into the city of Indianapolis, you go down the street, Meridian Street, and there is a huge cathedral there. It was one of those days when I think American history changed, when, after Ryan passed away, there was not only no seats to be filled, but the parking lots were filled, as well, to honor this young man and his fight. And so many people who are still challenged with this, there is the Ryan White Program that provides assistance to so many who do not have the financial means to help themselves.

So I just wanted, on a day like today where we are trying again to make sure we can beat this, that we had a real American hero early on in the fight.

The CHAIRMAN. Senator Baldwin.

#### **OPENING STATEMENT OF SENATOR TAMMY BALDWIN**

Senator BALDWIN. Now, I cannot pass on the opportunity to actually make the opening statement live rather than submit it—

[Laughter.]

The CHAIRMAN. Of course.



Senator BALDWIN. [continuing]. Because I know some of you will not be reading the record. I am guessing.

But, anyway, I want to thank you, Mr. Chairman and Ranking Member Collins, for holding this really important hearing.

This topic holds real special meaning for me. I think it is fair to say that the AIDS epidemic really shaped my early career in public service and helped me focus squarely on what became my goals of achieving quality, affordable health care for all and achieving equality and equal rights for all.

It was in 1986 that I was first elected to public office, the Dane County Board of Supervisors, and in my home county, it was in that year that the first cases of HIV/AIDS were being reported in my county and in the State of Wisconsin. Many of the men who had been diagnosed in larger cities on the coast—Boston, New York, Los Angeles, San Francisco—and at that time, it was accurate to say we were only hearing about cases involving men—they were coming home and they were coming home at that point to die. And there was a tremendous amount of fear and paranoia and sorrow in our community, and I would say that it was not just fear of the epidemic, it was an epidemic of fear and both needed to be grappled with.

At that time, society, government, and our health care system was not responding adequately or appropriately to the crisis. So little was known about the disease that we found ourselves waging the war on two fronts, against a deadly virus and against discrimination and fear.

Three decades later, I can honestly say that it has gotten better. But the significant improvements raise important new challenges, and so one of Wisconsin's AIDS providers, the AIDS Network, recently shared with our office, quote, "The HIV-positive population that we serve is indeed growing and aging. Over 50 percent of the patients and clients we serve are over 45 years old and our oldest is over 80 years old. We are seeing the benefits of better treatment. That means services and care must be available as the demographic change and our clients age. We need to make sure that we have great medical and dental care and that we are able to help with public benefits like Medicare and that we provide mental health counseling and other integrated services."

So, though the landscape has changed, myriad challenges remain and we cannot lose sight of eradicating the epidemic once and for all, as you said, Mr. Chairman. Hearings like this are a very important part of that effort, so thank you again for holding and convening us today.

The CHAIRMAN. First, we are going to hear from Ronald Valdiserri. Dr. Valdiserri is the Deputy Assistant Secretary for Health, Infectious Diseases, and the Director of the Office of HIV/AIDS and Infectious Disease Policy at HHS.

Next, we will hear from Daniel Tietz, who serves as the Executive Director for the AIDS Community Research Initiative of America. Mr. Tietz is heavily involved in his organization's mission of training and educating older adults on HIV, including several training sessions in Florida.

And then we will hear from Carolyn Massey, a lifelong HIV activist.

Next, we will hear from Kenneth Miller, the Executive Director of the Down East AIDS Network based in the State of Maine.

And then we will hear from Rowena Johnston. Dr. Johnston serves as Vice President and Director of Research at amfAR, The Foundation for AIDS Research.

Welcome to the committee. If each of you could give us a presentation of around five minutes apiece, your written testimony will be entered as part of the committee's record.

Dr. Valdiserri, we will start with you and go right down the line. Please.

**STATEMENT OF RONALD O. VALDISERRI, M.D., M.P.H., DEPUTY ASSISTANT SECRETARY FOR HEALTH, INFECTIOUS DISEASES, OFFICE OF HIV/AIDS AND INFECTIOUS DISEASE POLICY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Dr. VALDISERRI. Thank you. Good afternoon, Chairman Nelson and members of the Special Committee. I am pleased to be able to offer testimony on the challenges of human immunodeficiency virus infection among persons age 50 or older and how the national HIV/AIDS strategy and other Federal initiatives are helping to address their prevention, treatment, and care needs.

Now, we have heard both from Senators Collins and Nelson about the aging of the AIDS epidemic in the United States, so I will not repeat those statistics. I will share with you another statistic from CDC that it is estimated that of the 50,000 or so new HIV infections that occur every year in the United States, 11 percent of new infections are occurring in older Americans.

Prevention for this age group is complicated by a number of factors. First, as is true for younger age groups, there are large racial and ethnic disparities in HIV diagnoses among persons who are age 50 or older. Between 2005 and 2008, the rates of HIV diagnoses for older African Americans and Hispanics and Latinos were respectively 13 and five times higher than the rate for whites.

Second, although a large fraction of Americans remain sexually active into their mid-60s and beyond, including people living with HIV, many lack the awareness of the risks of infection, take few precautions against HIV acquisition, and do not discuss their sexual health with care providers.

Third, prevention for this age group may also be complicated by established health risk behaviors, like alcohol and substance use.

Now, treating persons aging with HIV presents its own special challenges. Older persons are more likely to be diagnosed late in the course of their HIV infection and have an inferior, a less robust, immune response to anti-retroviral therapy compared to younger people. This can be remediated in part by fully implementing the routine HIV screening for all persons between the ages of 15 and 65 years of age in accord with the recent U.S. Preventive Services Task Force recommendations.

Yet, even among those diagnosed and receiving HIV treatment, persons age 50 or older may prematurely experience chronic comorbidities common to advancing age, including cardiovascular disease, infectious and non-infectious cancers, liver disease, renal disease, and neuro-cognitive decline.

And, finally, because HIV disproportionately affects sexual, racial, and ethnic minorities who often have fewer economic and social resources, optimizing health outcomes for those aging with HIV requires care services that address housing instability, food insecurity, and social isolation.

Our progress toward achieving an AIDS-free generation in the United States has been assisted by three recent developments. First, the Affordable Care Act is expanding access to quality care for millions of uninsured Americans, some of whom were previously refused health care due to preexisting conditions like HIV infection. The law also includes new provisions to support patient-centered medical homes, which are expected to increase care coordination, improve health outcomes, and lower treatment costs.

Certainly, the National HIV/AIDS Strategy that was released in 2010, which strives to reduce new HIV infections, improve access to care, and reduce health-related disparities for all Americans, including older Americans, promises to have a great payoff in terms of improving health. Other parts of the Federal Government and agencies are also addressing the needs of older adults as they age to implement the goals of the National HIV/AIDS Strategy. Much of the data that we have heard so far presented comes from CDC, who collect and analyze HIV surveillance data. They support routine HIV testing and prevention services and educate practitioners on the HIV prevention needs of persons who are 50 years and older.

I do also want to comment that the National Institutes of Health has been very active in looking at the issue of HIV and aging. They have commissioned a special work group which has led to a number of new initiatives focused on studies addressing many of the medical complications that you have heard referred to, and I will not repeat them here.

Third, I want to let you know that there is a new Executive Order that was released by the White House just in July of this year which is attempting to come up with further responses to improve the health outcomes of all Americans living with HIV, including people who are over the age of 50.

We have a very shocking statistic in the United States in that it is estimated that only 25 percent of the 1.1 million Americans living with HIV have achieved virologic suppression. That means that over 800,000 people in the United States, including those over the age of 50, do not receive the full benefits of current medical care that we have available in the United States.

So, in conclusion, while we have made progress, more remains to be done. We look forward to working with partners across all segments of society to improve the health of older Americans living with HIV.

This concludes my testimony. I appreciate the opportunity to appear before you and will be happy to answer any questions you might have.

The CHAIRMAN. Thank you.

Mr. Tietz.

**STATEMENT OF DANIEL TIETZ, R.N., J.D., EXECUTIVE DIRECTOR, AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA (ACRIA)**

Mr. TIETZ. Thank you, Chairman Nelson and Senator Collins and members of the committee, for this opportunity. I greatly appreciate it.

As the Chairman noted, ACRIA has delivered training and technical assistance in Florida, most notably in Broward and Dade Counties, where there is a significant number of older adults with HIV and a host of providers struggling to serve them.

I will not repeat some of the statistics that the Chairman and the Ranking Member have already given, as well as were repeated by Dr. Valdiserri, but I will note that folks with HIV who are in their 50s and early 60s who make up the bulk of the above-50 crowd have the same number of age-associated comorbidities as an uninfected person ten to 20 years older. These may include cardiovascular diseases, cancers, osteoporosis, hypertension, and depression. Older adults with HIV have a host of health and services needs that really neither HIV nor aging services providers are fully prepared to meet, and their significantly greater disease burden is often complicated by social isolation and stigma.

Older adults with HIV have rates of depression, for example, that are five times higher than their HIV-negative peers. Depression is arguably the most reliable predictor of medication non-adherence and is associated with poorer treatment outcomes. Much of this depression is fueled by HIV and LGBT-related stigma and social isolation. Studies, including those done at ACRIA, have shown that almost 70 percent live alone and less than 15 percent have a partner or spouse. With often distant families and fragile social networks, they lack instrumental and emotional support. Moreover, many of these older adults have disabling conditions that limit employment and often live at or below the poverty line.

In the context of the National HIV/AIDS Strategy and the new HIV Care Continuum Initiative that Dr. Valdiserri mentioned, I believe we will not reach the end of AIDS unless we effectively address the barriers to routine HIV testing and consistent engagement in HIV treatments among middle-aged and older adults.

As with younger people, HIV disproportionately affects older gay and bisexual men, especially men of color, and African American and Latina women. These disparities are often fueled by homophobia, HIV stigma, racism, and ageism. We need targeted, evidence-based efforts, including cultural competency training, to address these alarming disparities.

Therefore, I urge you and your colleagues in the Senate and the House to promptly reauthorize the Older Americans Act and to include people with LGBT and HIV persons as groups with greatest social need. This would lead State and regional aging services agencies to explicitly incorporate the unique needs of these populations into their five-year planning efforts. The National Resource Center on LGBT Aging, which is funded by the Administration on Aging in a reauthorized OAA, would continue to fight HIV and LGBT stigma and discrimination among providers.

Likewise, I urge adequate support for the Health Resources and Services Administration for targeted demonstration projects and other funding for training HIV and aging services providers.

I further urge adequate resources for the HIV initiatives of the CDC. Research shows that most older adults, including those with HIV, remain sexually active. One in every six new diagnoses, as we heard, occurs in adults 50 and older, and as Dr. Valdiserri noted, that is to be distinguished from folks who are newly infected. So among that sort of 16, 17 percent who are diagnosed, fully half of those older adults are found to have AIDS. They are sick enough to be concurrently diagnosed with AIDS. And, in short, they have had HIV for some time but were never tested and treated. Older adults rarely seek HIV testing and many, many providers are unaware that current CDC guidelines recommend routine testing up to age 65. Therefore, we need CDC-funded HIV primary and secondary prevention campaigns for older adults.

For older adults living with HIV today, as Dr. Valdiserri noted, ensuring the success of the Affordable Care Act is really critical. This includes the expansion of Medicaid in all States and robust HIV medication coverage as part of the essential health benefits package as defined by CMS for both the new insurance marketplaces as well as the expanded Medicaid programs. Unfortunately, 40 percent of Americans with HIV live in States that are not presently planning to expand Medicaid. These include several States with the highest new infection rates, lowest rates of overall insurance coverage, and worst health disparities.

Today, half of all Americans with HIV rely on Medicaid to cover their health services. The Kaiser Family Foundation notes that people with HIV are about three times more likely to be covered by Medicaid than the U.S. population overall. Almost 75 percent of Medicaid beneficiaries with HIV qualify because they are both low income and permanently disabled, and nearly a third are dually eligible for Medicaid and Medicare. As they develop multiple chronic conditions at a relatively young age, most will require long-term care.

In a related vein, older adults with HIV need the Ryan White Care Act, as Senator Donnelly had noted earlier, to be fully funded to meet current needs, or at the very least, at the level requested by the President for fiscal year 2014. In inflation-adjusted dollars, Ryan White has essentially been flat for the last decade, and that is even as the number of people with HIV grows and the need grows among those who are living.

So Ryan White is vital for many reasons, not least because the median age for older adults with HIV is 58, which means that they are not eligible for Medicare in many instances or other services from the Older Americans Act. Most older adults with HIV rely on Ryan White funded programs, including the AIDS Drug Assistance Program. Ryan White funded completion services, such as transportation support and case management, are also vital to ensure sustained engagement in care and treatment success. With about half the States choosing not to expand Medicaid, the Ryan White Program will remain vitally important for essential services.

In sum, if we are to effect real improvements in the HIV treatment cascade, particularly the very large gap between those ini-

tially linked to care and those retained in care, we will need to pay close attention to the intersection of the Affordable Care Act and the Ryan White Program.

In addition, we must not only maintain but increase funding for NIH-targeted research on HIV and aging. The NIH Office of AIDS Research Special Working Group on HIV and Aging, which was convened in April of 2011, was a unique gathering of scientific experts from biomedical, clinical, and social science disciplines tasked with identifying critical research areas to better inform the treatment and care of this growing population.

One of the four subgroups, which included ACRIA's Dr. Mark Brennan-Ing, focused on societal infrastructure, mental health, and substance use issues, and the caregiving challenges that have been identified as critical to better treatment outcomes for these older adults.

Specific recommendations include—

The CHAIRMAN. I need you to wrap up, Mr. Tietz.

Mr. TIETZ. [continuing]. All right. Let me scoot right to the end, then.

The last thing I might mention is that we really need the FDA to look at multi-drug resistance for this population in finding new treatments for folks with HIV who are aging.

Thank you for the opportunity.

The CHAIRMAN. Thank you.

Ms. Massey.

**STATEMENT OF CAROLYN L. MASSEY, CHIEF EXECUTIVE OFFICER, MASSMER ASSOCIATES, LLC, AND HIV/AIDS EDUCATION ACTIVIST**

Ms. MASSEY. Chairman Nelson, Senator Collins, and the distinguished members of the committee, thank you for the opportunity to address the very important subject of HIV and aging.

I am here to issue a clarion call, to give you the inside story on HIV and aging and the real cost of continuing to minimize the impact that HIV, left unchecked in aging adults, will have on our country and aging citizens. My prayer is that by sharing some of my personal experiences and those of people who have died from HIV and AIDS or are currently living with the disease, you might consider them as you determine how best to meet the needs of more than 1.2 million persons who are known to be living with this disease in our country today. I say "known to be" because estimates are that approximately a quarter of the people who are HIV-positive in the United States right now do not know their HIV status.

We are fast approaching the point where truly 50 percent of those that are living with this disease are at least 50 years of age. This pivotal study, Research on Older Adults and HIV, was conducted by the AIDS Community Research Initiative of America years ago and it told us years ago that HIV and AIDS has a major impact on the quality of life for older adults living with the disease. I ask that you consider the economic impact, the loss of life, loss of productivity, loss of tax revenues, trauma to families and loved ones, that will only grow if HIV in aging adults is left unchecked.

I was initially diagnosed with HIV in the fall of 1994, the same year that my only brother died as a result of complications associ-

ated with AIDS. His name was Theodore Anthony Jackson, a budding young businessman having just opened his third and what was to be a franchise of barber shops called Tony's. He would be 55 years old today. Our country lost the benefit of his gifts and of the contributions that he would have made for more than 19 years.

Only months after his death, I was diagnosed. I was 38 years old then. During that time, the only drug widely available and prescribed was AZT, and in Anthony's case, we believe that it did him more harm than good. As our family struggled emotionally with Anthony's rapid decline in his physical health and mental state, we were traumatized yet further by my diagnosis. I am convinced that only because I moved my family to Philadelphia in 1996 and vigorously pursued medical treatment there and ever since that I am alive today.

The sad fact is that many of the people who are aging with HIV today do not know that less stigmatized environments and more knowledgeable physicians are available to them. In fact, many of the people who are living with HIV today still do not know that there are lifesaving treatments and care available to them. This is especially true of people known as baby boomers, those of us who are over 50 years of age. The older a person is, the less likely they are to be health literate about HIV, their HIV risk levels, how to establish healthy relationships, how to self-advocate, and how to access the life-saving services that they need.

One of the things for which I am immensely grateful is that, with your support, health information technology will be used more. I believe that as the technology matures, you will see that HIV is truly not particular about infecting a particular group of people, but that there are more people already infected than we think and that each of us is at higher risk for infection than we ever imagined. In fact, if any of us have had unprotected sex, we are at risk for HIV infection.

As you are aware, the field of geriatrics and gerontology is a relatively new one, still emerging within the larger medical community. I urge you and your Senate and House colleagues to provide increased resources to study, better understand, establish, and widely implement the best care and treatment practices to address the needs of people who are aging with HIV. Support people who want to study medicine and work on these complex, difficult, and intersecting problems of aging and HIV. The aging adults being diagnosed with and living with HIV, if left unattended, is one of the next big health challenges that we will face as a nation.

We have learned a lot over this 30-year journey with HIV in the United States. Among the things that we have learned is that most successful prevention interventions and approaches to care are those that begin with and continue to meaningfully involve the affected communities.

The Ryan White Care Act has provided a tremendous gift through lessons learned in the creation of a continuum of care that actually works. That continuum should be informing our work going forward in order to undergird the health care reform that is now underway.

Another lesson we have learned is that the approach to ending HIV must involve many sectors and various disciplines that must

be—this must be an interwoven and integrated effort that involves academic, scientific, political, at-risk populations, and other community stakeholders. We must find ways to effectively improve and measure the change and the quality of life for persons who are living longer with HIV and to begin to connect them, to the extent that they are able, to more productive lives. Too often, in our zeal to solve one problem, we create other challenges.

With improving care and services and wider access for all people living with HIV, we can expect that some will be able to return to work and will want to do so. Therefore, we need to develop ways to help support them as they do that and ensure that supports and approaches are realistic and age and culturally appropriate. This improves [sic] working with employers and industries to develop new ways to work and developing more thoughtful outcome-driven benefit structures that do not perpetuate poverty but support progress and hope.

Finally, I strongly support and urge that you not let our mothers, fathers, and elders die simply because we refuse to sensibly and effectively act. We have the means and wherewithal to better serve older adults with and at risk for HIV and to end this terrible epidemic, but only if we learn the lessons of the past and commit the resources to get there.

Please, dear Senators, do not forget us.

The CHAIRMAN. Thank you.

Mr. Miller.

**STATEMENT OF KENNETH MILLER, EXECUTIVE DIRECTOR,  
DOWN EAST AIDS NETWORK**

Mr. MILLER. Good afternoon, Chairman Nelson, Senator Collins, and distinguished members of the Senate Special Committee on Aging. Let me start by saying that I am honored to be here today.

I look at my fellow panelists and I see representatives from the DHHS Office of HIV, ACRIA, a lifelong activist, and amfAR, and then there is me, Kenny Miller, Executive Director of Down East AIDS Network, a small rural HIV service organization in Down East Maine with about four employees providing case management services to about 55 to 66 people living with HIV, around 57 percent of which are age 50 and up. I am also proud to say that I was recently elected Vice Chair of Maine's HIV Advisory Committee, which provides—advises the Governor's cabinet, the legislature, and—the State legislature, that is—and public and private organizations with regards to HIV issues.

Maine is one of the greatest States in the nation, with about 17.5 percent of the population age 65 and up. With about 43.1 persons per square mile, it is also one of the most rural. And while information concerning population density may seem out of place, it is important to note that people living with HIV and the providers that serve them face a complex set of challenges resulting from the rural nature of the State.

Rural patients, in general, face increased barriers to care. These are exacerbated by health complications, stigma, and the expertise of local providers. A number of studies indicate that local health systems in rural areas lack the knowledge and experience required to treat specialty conditions like HIV and this affects patients' per-



ceptions of providers' capacity to help them manage HIV and is associated with increased likelihood that a patient will not be taking anti-retroviral medications.

Beyond knowledge, some studies also indicate that increased levels of provider stigma and discrimination exist in rural areas. Take a client of ours, we will call him Adam Lawrence. His name has been changed for confidentiality reasons. Fifty-five years old, Adam contracted HIV through the use of injection drugs a number of years ago. When you talk to him, you get a sense that there is some moderate psychological disturbance there that could also be a sign of early neurocognitive dysfunction.

Over the course of a year, Adam cycled from one doctor to another seeking treatment for an open wound that just refused to heal. And just as quickly as he entered into care, he was ejected, labeled a difficult patient due to some of those things related to his psychological issues, prone to outbursts, a kind of narrative that he had created about the wound.

There was no overt provider stigma in this case. There would not be, but it is difficult to imagine that his status and his history with injection drugs did not play a role in their decision to discharge him. Such stigma as seen in Adam's case has a negative relationship to people's ability to receive the care that they need.

It is further complicated by concerns over confidentiality. As some of you may be able to attest to, in small towns, everybody knows everybody else's business. So keeping your status secret when you are seeking medical services in those situations is rather difficult.

This suggests another issue felt particularly strongly in rural areas and that is community stigma. Rural persons living with HIV indicated more severe community stigma towards people living with HIV than their urban counterparts did in some studies. This is not particularly surprising. Many rural communities remain hostile towards gay and bisexual males. People who use injection drugs continue to be stigmatized throughout the U.S. And in spite of ongoing attempts to turn the narrative regarding HIV towards one of a medical issue as opposed to a character flaw, in rural America, it is still linked to these marginalized communities in many ways, these marginalized and often looked down upon communities.

Such stigma raises another question as to whether or not depression and isolation experienced by people living with HIV throughout the U.S. due to such stigma is also felt more sharply in these rural contexts, and as pointed out earlier, depression is a serious adherence risk.

We see this in the case of Hayden Mitchellson, again, his name changed for confidentiality reasons, in his late 40s. Hayden was born and raised in rural Maine. A gay man, Hayden suffered family and community rejection and eventually fled his home town to build a new space in one of Maine's bustling tourist communities. Very outgoing, very vocal about HIV issues, he is nonetheless very protective of his status, an isolation of a whole different sort. Burdened by his past and his secret, Hayden sank into depression, self-medicated with alcohol, and ended up bouncing from job to job until he wound up on the streets, floating from couch to hotel to

park bench. Without stable housing, another important factor in adherence, Hayden was unable to seek medical care for his HIV.

The last point, and most simple point, in some respects, is one of geography, of distance and transportation. Lacking adequate health providers, people living with HIV are often forced to travel long distances to urban areas, and the inconvenience incurred is enough to prevent many people from seeking care.

These are just a few of the challenges faced by rural populations. Others include housing, access to mental health providers, and on and on. But the issue is not just challenges faced by people with HIV in rural areas. It is people aging with HIV in rural areas. There has been a lot written and said about aging and HIV and HIV in rural contexts, but there appears to be a dearth of information concerning the intersection of the two as they relate to HIV.

I think it is a reasonable hypothesis that the challenges posed by aging and living in a rural area amplify one another. People aging with HIV in a rural environment face significantly greater stigma, isolation, and barriers to care compared with their younger counterparts—younger or urban counterparts. Receipt of care is negatively affected by their functional and neuro-cognitive decline, the adequacy of local providers, provider stigma, and geographic distance. Community stigma is exacerbated by ageism and functional and neuro-cognitive decline articulate with the experience of stigma to lead to greater levels of depression. The end result threatens a patient's adherence to their HIV treatment regimen and, consequently, their health.

Thank you, and I am happy to take any questions.

The CHAIRMAN. Thank you.

Dr. Johnston.

**STATEMENT OF ROWENA JOHNSTON, PH.D., VICE PRESIDENT  
AND DIRECTOR OF RESEARCH, amfAR, THE FOUNDATION  
FOR AIDS RESEARCH**

Ms. JOHNSTON. Chairman Nelson, Ranking Member Collins, members of the Special Committee, thank you very much for inviting amfAR to participate in today's hearing on Older Americans: The Changing Face of HIV/AIDS. I am pleased to share our views on what we see as the difficulties as well as the opportunities of this growing challenge in the United States.

In the next few years, there are projected to be half-a-million people living with HIV over the age of 50. Some of these people will be people who have been living with HIV for many years or even decades, and others will be people who are newly infected, but they will all face the difficulties of aging and of doing so with a serious and a potentially fatal disease.

For many years, as was noted before, we never expected to have to deal with HIV infection in older Americans. But anti-retroviral therapy has dramatically lengthened the lives of those living with the infection. However, that means that increasing numbers of people are living with HIV who are older than ever, and our challenge is that we do not know enough about the biological causes and consequences of aging with HIV infection or about the social burdens borne by those living with HIV.

HIV and aging is at the intersection of several of the most pressing health challenges that face Americans who are aging, and these include cardiovascular disease, cancer, osteoporosis, liver and kidney disease, hepatitis C, and neurological diseases like dementia. People living with HIV face an increased rate of all of those diseases and at a younger age than those who do not have HIV.

And underlying all of these diseases is the aging of the immune system itself. Older adults, even in the absence of HIV, experience a reduction in the ability of stem cells to develop into immune cells. They experience a shrinking of the thymus, which is a key organ that generates new immune cells, a decrease in the ability to respond to new infections, and an increase in the production of hormones that lead to an immune inflammation, which in turn perpetuates the cycle of the loss of ability to respond to new infections.

Evidence from the HIV research field suggests that this collection of immune phenomena occurs in both aging and in normal HIV infection. That means older Americans living with HIV are subject to immune inflammation on two fronts. Any research that can shed light on the process of inflammation in HIV disease will, by definition, benefit millions of Americans who will face diseases associated with aging now and in the future.

In addition, researchers currently believe that many of the manifestations of this inflammation of the immune system pose a significant barrier to our ability to cure HIV and, therefore, a greater understanding of the fundamental cellular processes underlying aging, such as inflammation, will help us to address many, perhaps even most, of the diseases that take the lives of older Americans living with or without HIV and may at the same time help us to achieve one of the greatest medical challenges that we face this century, namely, curing an infection that has taken the lives of tens of millions of people around the world.

And I did note with interest the introductory comments about the cases of HIV cure that have already taken in place, in particular, the Boston patients, the research on our way to finding a cure for HIV. I would also like to bring your attention to a Mississippi child who was cured earlier this year. And I am very proud to tell you that these are both cases—pieces of research that were supported and funded by amfAR. We understand, as you do, too, that curing HIV infection is going to be critical to bringing an end to HIV in the United States.

Robust support for a strong research agenda will be crucial to understanding and addressing these challenges. Research has resulted in drugs that are saving the lives of millions of HIV-infected people around the world, but the fact is that many new treatments for diseases such as cancer, heart disease, hepatitis, and osteoporosis have also arisen from research aimed at preventing, diagnosing, and treating HIV.

Protease inhibitors are being tested in the treatment of cancers. Some cancers require treatment by transplantation and the immune suppression that can lead to opportunistic infection, such as cytomegalo virus and pneumocystis pneumonia are treated using treatments that came out of AIDS research. Protease inhibitors are also being tested in the treatment of Alzheimer's disease and along

with neutrocyte analogs, which were also developed to treat HIV, are being used to treat hepatitis C.

Biomedical research saves lives and it generates economic benefits and it yields scientific insights that catalyze future medical breakthroughs. And although the U.S. has long been recognized as the world leader in biomedical research, stagnant funding, which actually translates into funding reductions when you take into account inflation, imperils the U.S. leadership and jeopardizes future life-saving research advances.

Funding for health research at the National Institutes of Health lost 22 percent in purchasing power in the decade from 2003 to 2012. The sequester which went into effect this year on March 1 resulted in the inability to fund 700 research projects. And this will inevitably delay—in some cases prevent altogether—the exploration of potentially transformative new approaches to understanding and treating the leading causes of death and disability.

When we invest in HIV research, we are committing to understanding and solving the health challenges faced by millions of aging Americans. The benefits accruing from an investment in AIDS research spread well beyond people who are infected with HIV in ways that we might not initially predict, but which have a track record of having improved the health of millions of Americans.

amfAR strongly supports an increase in funding for the NIH and research on HIV and aging, understanding that the knowledge that we gain from that research has the potential to touch the lives of all of us.

Thank you again for giving amfAR the opportunity to testify on this important topic. I would be happy to answer any questions you may have.

The CHAIRMAN. Thank you.

I am going to turn first to Senator Collins for her questions.

Senator COLLINS. Thank you very much, Mr. Chairman. Very gracious of you, as always.

Mr. Miller, I am obviously very familiar with the two counties where you are providing case management services. One of them, Washington County, is one of the most rural counties in a State that is a rural State. Could you talk to us a little bit more about the barriers that individuals with HIV/AIDS who are living in very rural parts of Maine have in obtaining access to the care and services they need.

Mr. MILLER. Certainly. So, our service area covers Hancock and Washington County, and as Senator Collins mentioned, Washington County is one of the most rural counties in Maine and also one of the most economically disadvantaged. So it faces a lot of challenges both in terms of the economy as well as geography in terms of its rurality.

Like most rural people living with HIV and other specialty health conditions, people in rural areas face significant barriers when accessing care. In Maine, the majority of HIV care is provided by infectious disease doctors, of which there are currently about eight HIV medical providers operating in the State. And with a population of about 1,654 people living with HIV, this amounts

to about 236 high-needs patients per provider, if all were seeking treatment.

Senator COLLINS. Are any of those in Washington County?

Mr. MILLER. None of them are in Washington County. We do have one in Ellsworth, in Hancock County, but he has about—he works about two days a week, and, bless his heart, the patients love him. The clients love him. But he is semi-retired. And Ellsworth is about a two-hour drive one way, so four hours roundtrip from Calais, the most distal part of Washington County. We have one client, in particular, who lives on a reservation up there in Washington County and has very little income and is facing a four-hour roundtrip for about a 30-minute visit with her doctor.

Lacking transportation of their own, lacking financial security and a reliable support system to provide them with transportation, it often leads to frequently missed or skipped visits. We try and work with them around these things, so we get some funding through Ryan White Part C administered by the Regional Medical Center of Lubec in order to provide some transportation assistance in the form of gas cards. It does not cover everything. It does not cover an entire visit, but it helps to defray the costs a bit.

We also maintain two offices. So we have one office in Ellsworth and one in Machias, as well as an outreach office in Calais to try and reach out to some of those people in more distant areas, at least to provide case management services through those means. And our case managers are willing and frequently do conduct home visits, so they will go directly out to people living in the more distant areas of the county there.

Senator COLLINS. Thank you.

Dr. Valdiserri, it was startling to me to learn that the State of Maine has already reached the threshold where 50 percent of those living with HIV or AIDS, full-blown AIDS, are already age 50 or older. And yet when I look at the messaging that is done on AIDS, whether it is public announcements, PSA announcements, it is targeted at young people. And when I look at the CDC recommendation for testing, it is up to age 64. Do we need to revisit those policies and our educational awareness campaigns in light of the fact that the population is aging? I was thinking of what Ms. Massey was saying about that very issue.

Dr. VALDISERRI. Certainly. Let me answer that question. First, in terms of the testing, I would say, actually, that the ruling by the U.S. Preventive Services Task Force this spring, which is up to the age of 65, routine testing between the ages of 15 and 65, was widely viewed in the AIDS community as a tremendous step forward, because prior to that time, CDC since 2006 had the recommendations that you had in place.

The reality, though, is, as several of the panelists have noted, nationally, about 20 percent of all infected individuals are unaware of their diagnosis, and one of the reasons for that—there are many reasons. One is stigma. But the other is that many of these people are in health care and they are not willing to talk to their providers about risk or the provider is not comfortable talking to the patient about risk. And so moving to routine testing—I would start out by saying, I agree, it is not all the way up to 65, but it is a tremendous step forward.

Also, as you likely know, in the Affordable Care Act, if the U.S. Preventive Services Task Force has given a Grade A recommendation to a clinical preventive service, and they did do that when they recommended routine testing, it will be covered without copay.

So, let me start by saying that is widely viewed as movement forward. I think where we are still challenged is the fact that too many health care providers do not know how to talk to their clients and patients about sex, and they also make an assumption that older Americans are not sexually active. So, I do agree with you that we have to continue to work with medical and nursing and other professional organizations to get the word out.

Just briefly on the issue of public education campaigns, I would say that, certainly, there is the need for more campaigns that are specifically targeted to older Americans and that is why having a day like today where we can come together and recognize the special needs of older people with HIV is extremely important. There are some examples of some very fine targeted campaigns across the United States, but I would agree with you, we need to do more.

Senator COLLINS. Thank you.

The CHAIRMAN. Senator Donnelly.

Senator DONNELLY. Thank you, Mr. Chairman.

To Mr. Valdiserri, you have a long and storied name, your family and relatives in Indiana, and we greatly appreciate everything they have done.

I want to follow up with a question for you, which is this, and to you and then to Dr. Johnston, and that is the status of the research that is being done. We heard what our Chairman was referring to and I was wondering about the path forward, how you see that, when you see—you know, we are making such progress, but when do you see the day when we can look and say—and I am not asking for an exact date, but—although I am.

[Laughter.]

Senator DONNELLY. But how do you see the status of research right now?

Dr. VALDISERRI. So, let me say that I am old enough to remember when a former Secretary of Health at HHS made a prediction, so I am not going to go there.

Senator DONNELLY. Right.

Dr. VALDISERRI. I think when you talk about research, and you understand this, Senator, that is a huge, huge domain. I mean, we talk about virus—Senator Nelson mentioned viral research. We have continued research into drug treatments. We have research into basic science, about, as Dr. Johnston said, what is actually happening. How does the virus impact the aging process?

You know, it is really hard to predict, but I will say that in the last few years, there have been some really amazing breakthroughs, and in my field, in the world of public health, the randomized control trial that demonstrated unequivocally that early treatment of HIV infection—we always knew that was good for the individual person, but this study demonstrated that early treatment of HIV infection actually helped to prevent transmission to partners. And that is why so much now in the field of public health, we are hearing great interest around the issue of treatment

as prevention. So I cannot predict, but we are definitely making substantial progress and we will keep making progress—

Senator DONNELLY. Just a follow-up on that. You are coming at it from a number of different directions. Who helps to coordinate so that they do not stay in their stovepipes, that they are talking to one another?

Dr. VALDISERRI. Good idea. So, that is the job—in the Federal Government, that is the job of the Office of AIDS Research at NIH, which is an entity that spans all of the Institutes and offices at NIH, and as a result of direction from you and your colleagues, every year develop a strategy with priorities that they are going to organize.

Now, as Mr. Tietz and others referred to, the Office of AIDS Research also will—they have a Federal Advisory Committee that will also identify important areas that need special attention. So a lot of the newer studies that I just very, very briefly referred to do come out of the OAR discussion on HIV and aging. So, in the Federal Government, it is the Office of AIDS Research.

Senator DONNELLY. Ms. Massey, in terms of the effect of HIV/AIDS on seniors, do you find that there are more depression-related challenges, there are more psychological-related challenges than other age groups, or is there any difference in that? And, Mr. Tietz, if you would—

Ms. MASSEY. I will just respond by saying, for many people, growing older is not always a good thing.

Senator DONNELLY. Right.

Ms. MASSEY. So there are depression issues anyway, particularly when you start talking about folks that are more disproportionately affected by HIV and AIDS based on the data we have now. You are talking about people that are poorer, with less education, less health literate, that do not have as strong of support networks around them. So, yes, you are going to have that. And when you add the HIV and AIDS and the stigma and the unsurety and lack of access and supports to that, yes, there is more. There is a lot of it. And it really does impact people wanting to know their status.

Senator DONNELLY. Okay.

Ms. MASSEY. And then once they do, doing something about it.

Mr. TIETZ. Yes. The study that I cited, the ACRIA data is consistent with others where several times, five times or so the rate for similarly aged older adults without HIV. So depression is pretty significant.

Senator DONNELLY. Okay.

Mr. TIETZ. And I think, you know, for some of the reasons we mentioned—so thinking about some of the most affected populations, as Ms. Massey just noted, and I think as Mr. Miller noted, as well, so I think social isolation, stigma, discrimination, and feeling like you could not disclose, so there is nobody to talk to, if you will, except for, say, maybe your provider, who is going to give you these days ten minutes, maybe once every three months. So I think there are those challenges about small community.

But I would say small community is small community everywhere, right? So the community which you are living in New York City may seem like a small community, too, and you may not want to go to your church and tell those folks that you have HIV. You

may not want to tell your geographically or emotionally distant relatives that you have HIV. So I think that can play out a lot of places, and I think it has a real impact in terms of adherence.

So depressed people do not take their meds, and they do not take any of their meds. They have not saved it up just for the anti-depressant that they do not like, but they do not take the other ones, either.

Senator DONNELLY. Thank you very much. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Baldwin.

Senator BALDWIN. Thank you, Mr. Chairman.

We know in general that access to health care coverage has a strong relation to accessing medication, accessing services. And so I wanted to hone in on something, Dr. Valdiserri, that you said at the end of your testimony, that only 27 percent of Americans older than age 65 are able to suppress their viral load. This is significantly less than the rates for infected Americans between 44 and 64, and it is especially troubling because Americans older than 65 have much greater access to health care through Medicare. So I am wondering if you can give us a sense of why this is happening and whether HHS is doing anything to examine this issue more closely.

Dr. VALDISERRI. Certainly. Let me start out by saying, generally, just to state that across the board, across all age groups, we have not yet as a nation achieved an optimal response to addressing the epidemic, and that is the essence of the concern about the so-called care cascade. So, across the board, it is 25 percent.

Your point is well taken, though, that when you break that down, and those data come from a CDC study and they look at differences, they looked at gender, they looked at race, ethnicity, they looked at age, and they did find some very distinct differences.

The bottom line is, we do not know for certain, but I think there is a strong indication of a couple of things in play. Number one, the statistic that several of my colleagues mentioned of late diagnosis, the fact that nearly half of all older Americans, the first time they are diagnosed with HIV go on to develop AIDS within a year, essentially means they have been, as Mr. Tietz said, essentially means they have been infected for years and not diagnosed. All the while, the virus is damaging their immune system. So, probably late diagnosis.

It is probably also an issue related to, as we heard from Dr. Johnston, the older immune system is not quite as nimble as the younger immune system.

And I would say just a comment about—your last comment about many of these, especially 65 and older are Medicare eligible, I think this gets back to the need to educate health care providers that older people can be infected with HIV. Older people are sexually active. And older people, older Americans need to be counseled about HIV infection and be tested if they have not been tested.

Senator BALDWIN. Mr. Tietz, I was also interested in something you said at the very last moment of your testimony, also, that I think I would love to hear you expand on a little bit, and that is the resistance that can be developed to HIV medications in the population over 50. And you suggest that the FDA and the drug industry should do more to help address this problem. I wonder if



you could delve a little bit more deeply into that topic. Are high drug costs a factor here? What action do we need to be taking at the Federal level, in particular, to address the resistance to medications that are effective in other age groups?

Mr. TIETZ. So, right now, we—thank you, Senator. I think, right now, we have, essentially, six classes of HIV drugs on the market, some very good new treatments for folks who are newly diagnosed, particularly if they are younger and have an HIV which appears on testing not to be resistant to much of anything. So there are lots of options there.

But for folks who are much older, particularly those who have aged into this, so they have had HIV for 15, 20, 25, 30 years, may have participated in early studies before we knew better. We were giving people one drug at a time or two drugs at a time and they promptly developed, then, resistance to those classes of drugs or similar drugs and that means they have run out of options. So there is sort of an unknown number. Our guess is somewhere around ten percent—I do not know if Dr. Valdiserri would agree, but somewhere around there, probably cannot put together a fully suppressive regimen. So, they cannot come up with a mix of different medications such that they are ever undetectable in terms of viral load, and as a result, are always in fear of, if you will, everything going to hell quickly and their dying.

So, for those folks, what we really need is for industry and the FDA to work together to have sort of multi-drug combination trials, so having more than one investigational agent at the same time with a background regimen in an effort to get them to viral suppression. Thanks.

The CHAIRMAN. Let me describe a situation not only in Florida, but in 19 other States, where the Governors and the State legislatures have refused to expand Medicaid. Therefore, if one has AIDS, they are not poor enough to be eligible for Medicaid at a very low threshold in those States, but they are not old enough for Medicare and they are uninsured. What do you think? Please, Doctor.

Dr. VALDISERRI. Well, what I think is it is wonderful that we have a very important safety net program known as the Ryan White Program that is the payer of last resort and was put into place specifically to provide HIV care, services, to uninsured and underinsured Americans. So I think it is very important to recognize, and certainly the Department, my Department and administration is on record as saying that the Ryan White Program is a very important program, even as we enter into a reformed health care environment.

So, I would begin by saying that, Senator Nelson, that we do have that safety net program.

The CHAIRMAN. Well, that is a positive, but several of you have testified about how AIDS and/or other maladies reinforce each other. And so the Ryan White is going to directly affect or try to help with AIDS, not all these other things.

Dr. VALDISERRI. Well, if I might—

The CHAIRMAN. In other words, my questions make a point.

Dr. VALDISERRI. [continuing]. Sure, and I do not want to minimize that point. It is an excellent point. But I would say that the Ryan White Program has also been a leader in showing the medical

establishment how to integrate a variety of different services for people living with HIV, how to integrate services for viral hepatitis, for mental health, for treating opioid addiction, as well as all of the very critical social needs that everyone you have heard express here. But I suspect my fellow panelists want to comment on this, as well.

Mr. TIETZ. Yes, if I may. I agree, Senator. I think there is a big gap there. It is a big worry in the community in terms of providing treatment for all those who need it and getting them the services they need. Ryan White is, right now, about \$2.3 billion, I think, and if you look at the sort of numbers of people with HIV and their needs, given what you pointed out, the sort of comorbid conditions as the epidemic ages, versus the Ryan White Program, it goes like this. I mean, we are not keeping up here with what we need.

So I think that there is a real challenge there and that is partially solved because of the Affordable Care Act, without a doubt, greater access, and, in fact, the ability that I think the Secretary's wise moving in terms of giving States the ability to use their Ryan White resources to, if you will, cover the deductibles and copays and, in fact, even the premiums for the new exchanges, for the new marketplace, is a very wise move.

But there is no doubting that the point you are making is the right one, which is that there is going to be a gap in there. There has always been a gap in there and that is not likely to get solved, particularly in those States that are not going to expand Medicaid.

The CHAIRMAN. For the record, hypertension, diabetes, dementia, Alzheimer's, cancer, and hypercholesterolemia—that is a long one.

Okay, now, Ms. Massey, tell me, in your AIDS activism, if I recall, you reached out to the faith-based community. Tell me about that.

Ms. MASSEY. Well, on a personal basis, I reached out to my bishop and explained to him that—at the time, I was trying to return to work. I was working at University of Maryland, and to be honest, I was doing more of the church's work than I was the University's, so I let the bishop know that I really had a heart to work with HIV in women.

But the faith communities are ready to be engaged. There is more work going on now in faith communities than there ever was. I am lucky enough to co-chair the Places of Worship Advisory Board for the District of Columbia and we have more members at the table now than we have ever had. Wesley Theological Seminary is there. The National Children's Center is there. The large churches, the big churches. The Black Leadership Council on Age is there. And these are folks that are—some of them have been doing this work a long time. Others are brand new to it. And so it is a ripe time for getting people at the table. That is one of the gifts that God has given me, is to be able to get people to the table. I truly believe if the right folks are at the table, anything is solvable. And so the faith community, we do a lot of good work that is done and covered in programs like Ryan White, to be honest.

The public health, they do a lot of good work. They are talking—they are speaking German, we are speaking Chinese. They keep a certain kind of records. We measure other things. There has to be a way to culturally sensitize each one of us to each other and find

ways to communicate and to show benefit of what we do, what they do, and ways to enhance both of them.

So, we are very lucky to have some conversations that involve ecumenically communities of faith and we are very good partners with the public health agencies here in the District and in Baltimore, Maryland, as well. I was lucky enough to chair the Ryan White Greater Baltimore Health Services Planning Council. So we involve faith community there, too. It is just continuing to have the right people at the table, the conversation.

The CHAIRMAN. Dr. Valdiserri, you talked about the President's Executive Order, that there are going to be recommendations forthcoming. When?

Dr. VALDISERRI. The Executive Order called for the recommendations within a certain time period, and I believe that the Office of National AIDS Policy is committed to having those available in December. So, we are actually actively working—and the “we” here is not just Department of Health and Human Services, but other Federal partners. And we are also soliciting input from outside of government about how we can address some of these very critical gaps in the care continuum. So, those are expected to be issued by the White House sometime in December.

The CHAIRMAN. Will you send a copy to this committee?

Dr. VALDISERRI. It would be my pleasure to do so.

The CHAIRMAN. Okay. Dr. Johnston, I talked about the research on primates. From the initial look at this research, this works in primates. That does not mean it is going to work in humans. Tell us, in your professional opinion, what do you think about this research?

Ms. JOHNSTON. Thank you, Senator Nelson.

The CHAIRMAN. This is for vaccine.

Ms. JOHNSTON. That is right. The research that you have brought up is, indeed, very interesting. This was led by a researcher by the name of Louis Picker, who works in Oregon, and he has been developing a vaccine that is actually based on another virus, interestingly enough. He has developed this vaccine out of cytomegalo virus, which is a virus that can—it is quite dangerous in AIDS patients, actually, or at least it can be, which is something to keep in mind when we look at this research.

But one of the features of cytomegalo virus is it is very persistent, and this is, I think, the secret behind the success of the vaccine that he has developed. Some of the challenges the previous vaccine researchers have faced is that you can generate an immune response—an immune response is what we want when we are developing an AIDS vaccine—but it does not persist for very long. And what he has done is he has used this virus that does persist for a very long time and he has seen that it works in monkeys, as you have mentioned. It works in about 50 percent of those monkeys.

This research is very interesting also from a couple of other angles. Mostly when people think about a vaccine, they think about a way to prevent HIV. And initially, he designed this vaccine because he was hoping that this was going to be a vaccine that would prevent HIV. What is interesting about this vaccine is he actually gave it to monkeys who were already infected with SIV, the very

closely related virus, and this vaccine was able to clear the virus out of about half of those monkeys. And so what that, of course, introduces to us is the notion that we might be able to use a vaccine to cure HIV if this concept were to work in humans.

And, of course, it does need to be tested in humans. I think we are probably a little ways away from that just yet. I know the researchers I have spoken to about this very finding are very interested in knowing why did it not work in the other half of the monkeys. It is going to be critical for us to understand that.

It is going to be critical for us to come up with a form of cytomegalo virus that would be safe to give to humans because it really can cause disease in patients who have AIDS.

And then let us be very hopeful and optimistic, as we are at amfAR, that we are going to be able to find a cure for HIV. We do believe that is going to be crucial to ending HIV and AIDS. It is going to be a critical component to that.

And in addition to that research, of course, we are keeping a close eye on all of the other research that is going on. We are supporting a lot of research around a cure and we do believe, to reiterate a point that I had been making, that if there is the right investment made in HIV research, we really do believe that we are going to be able to bring an end to AIDS via, for example, a cure, in our lifetime.

The CHAIRMAN. Well, it would be the request of this committee, because of the subject matter of this hearing, that when we get to the point of testing a vaccine for AIDS cure, that we particularly designate part of the clinical trial for aging patients, as well, in case there is a difference with regard to the vaccine, and we would appreciate if you would share that with your colleagues.

Let me ask you all about when a person can get Social Security Disability benefits, they encounter a 24-month waiting period before Medicare coverage begins. Can anyone comment on whether this waiting point is a significant issue for HIV?

Dr. VALDISERRI. I regret that I do not know enough to be able to respond to that question, but I am willing to go back and get information and submit it to the committee.

The CHAIRMAN. Okay. There is no cap on out-of-pocket expenses for Medicare beneficiaries. What support do you think is available to those Medicare beneficiaries who can no longer afford the expensive and lengthy treatment other than the Ryan White that you mentioned?

Dr. VALDISERRI. That, too, is a complicated issue in that Ryan White, as you likely know, is the payer of last resort. And so by legislation, the clients who are in the Ryan White program, and actually, I just heard from the leader of that program this morning that about 70 percent of all of the current clients enrolled in Ryan White have some level of health insurance. But the way that it works is that primary insurance has to pay down first and then the Ryan White kicks in.

I am not—in terms of Medicare, I would have to get more details for you, but I know that—and again, I heard this this morning. It just so happens the Presidential Advisory Council on HIV and AIDS is meeting at the Department today and they are talking about the Ryan White Care Act and the future of the Ryan White

Care Act, and one of the presentations at this public meeting was from a member of the committee who is from Massachusetts who was sharing essentially the experience in Massachusetts, which essentially underwent health care reform much earlier than other parts of the country.

The major point there is that even in a reformed health care environment where Medicaid is expanded, they actually use their Ryan White dollars to help, in some instances, to help buy private insurance for clients. And I think, Daniel, you were referring to that. Maybe you can provide a little more detail about how that works in the real world.

Mr. TIETZ. I am not sure that I can. I got that from Laura Cheever.

Dr. VALDISERRI. Oh, okay.

Mr. TIETZ. But—so—

Dr. VALDISERRI. Well, that is a good source.

Mr. TIETZ. [continuing]. It is a good source. But, I think that is right. So, I mean, one of the options here—I think you are referring, Mr. Chairman, to the Medicare eligible over 65—mostly 65 and older. If they are poor enough, of course, particularly with Medicaid expansion, well, then they can become dual eligible and that will cover a lot of costs, although still worth noting, as Dr. Cheever at HRSA would point out, that still leaves about 30 percent who are getting some services—it could be transportation, it could be nutrition, it could be some case management service—that neither Medicaid nor Medicare will pay for, and then they turn to Ryan White to fill in that gap.

The CHAIRMAN. Senator Warren.

Senator WARREN. Thank you, Mr. Chairman.

I, again, apologize. I am trying to cover two hearings at once. But I want to go back to the screening question. I know that we started down the line on it, but there is something else I would like to press about screenings, and that is when I look at the information we have, that the risk of HIV is rising for the older population, that a larger proportion of older Americans, that our risk profile is changing, that those who are 50 and older have the lowest use of condoms, rate of use of condoms. Those who are 50 and older have the lowest rates of screening for HIV. And that for those who are 50 and older, it is harder to screen because of comorbidities, symptom identification. So it is more difficult sometimes to catch it simply by symptoms or other factors.

So, what I would like to do is I would like to start the question by asking you, Mr. Tietz, could you just identify and really push on the point for us about the importance of screening and how screening older Americans for HIV would make a difference.

Mr. TIETZ. Yes. Thank you, Senator. I think, as Dr. Valdiserri also noted earlier, the current recommendation, of course, from the U.S. Preventive Services Task Force is up to 65 and CDC up to 64 for routine screening. Lots of use in what routine means here. But the point would be that we should encourage providers and patients alike to think about HIV screening as getting your blood pressure done, as getting your cholesterol checked. It just becomes routinized. It becomes normal, that this is the thing we do. So

there is a big need for education here, both public and private provider.

We think that the—the CDC, I think, thinks that the bulk of the above-50 new diagnoses and new infections and greatest risk is really in the 50 to 65. So, yes, I personally would like to see the recommendation go higher, and I think there are some good economic data. CDC has to consider the cost of everything they recommend. So, considering the cost, there are some good data that suggest that HIV testing is cost effective up to the low 70s. So, yes, I would like to see it go higher, but, frankly, we are not doing very well with the 50 to 65, so maybe we could just start with that.

Senator WARREN. But, Mr. Tietz, if I can, just because I want to be sure we get it on the record, just identify for us, if we do the screening—you cannot do cost without talking about the benefit—

Mr. TIETZ. Yes.

Senator WARREN. [continuing]. If we do the screening, what are the benefits of the detection?

Mr. TIETZ. Oh, sure.

Senator WARREN. That is the part I would like to hear.

Mr. TIETZ. Oh, well, you will find folks who are younger, closer to the point at which they got infected. We all know that treatment outcomes are much, much better the sooner you find folks. The closer you get to treating them after their infection, the more likely they are going to have a good outcome.

We, as Dr. Valdiserri noted earlier, and I think Dr. Johnston, as well, older folks have, you know, just in general, an immune system that, for lack of a better way of putting it, is wearing out. So—and it just does not respond as well. So you will see that even though older adults tend to be better about taking their meds, particularly above 65, the response is not quite as good for that reason.

So, the sooner the better. I think the truth is with HIV, the sooner the better with all.

Senator WARREN. Okay. So we get better outcomes. Anything you want to add to that, perhaps about transmission?

Mr. TIETZ. Well, yes, of course.

Dr. VALDISERRI. I was going to say that if he did not.

[Laughter.]

Senator WARREN. All right. I think that was known as leading the witness, Mr. Chairman.

[Laughter.]

Mr. TIETZ. Right. Yes.

Senator WARREN. Please.

Mr. TIETZ. You are very good at leading the witness.

[Laughter.]

Mr. TIETZ. So, yes. So, the study that Dr. Valdiserri noted earlier, HDTN052, I think, 96 percent reduction in terms of risk of transmission for someone who has an undetectable viral load. So, the better we do at this cascade, at this nice picture that Dr. Valdiserri gave us, the better we do on this end, the low end here, the greater likelihood we get to the end of AIDS by preventing that many more new cases.

Senator WARREN. Okay. Good. So—

Dr. VALDISERRI. And may I add one thing, Senator, that we know from a variety of research studies—this is not just specific to older Americans—but the vast majority of people, when they find out they are infected with HIV, are very motivated to not transmit that infection to partners. That is aside from the treatment issue, which is tremendous in itself. But that information is empowering and most people want to take and will take steps to interrupt transmission.

Senator WARREN. [continuing]. Okay. So, better treatment outcomes and lower rates of transmission, substantially lower rates of transmission.

So, Dr. Valdiserri, what are you doing to increase screening among older Americans?

Dr. VALDISERRI. Well, as I had mentioned when you were out of the room, we actually think the U.S. Preventive Services Task Force recommendation, ruling, was a tremendous advance forward, because in conversations—frankly, in conversations with large payers and large insurance systems, there was some concern sometimes among medical directors about, well, the CDC says we should be doing routine screening, but the U.S. Preventive Services Task Force does not recommend it. So I would start by saying—now, that just happened this spring, in April. So that was a tremendous step forward.

I can also tell you, wearing another hat, still government but not HHS, I spent four years at the Department of Veterans Affairs and one of the major efforts that we undertook—I was part of the team that led that—is that we got the legislation changed across the entire VA system which required scripted pre-test counseling and signature consent before any veteran could be tested for HIV. And what that translated into, because health care providers are busy, the HIV testing rate was, like, ten percent across the entire VA system.

Now, certainly, we still want informed consent. We do not want people tested without their knowledge. But we were able to change the Federal law, change the regulation, change policies in health care settings to verbal consent documented in the chart, some basic information, and that rate has shot up and is continuing to go up.

So what we need to do is get—also, as Daniel said, we need to have providers and clients alike start thinking about the HIV test like they think about cholesterol screening and not as some kind of special test that just these high-risk people from who knows where have to take, that everyone needs to take the test.

Senator WARREN. Good. So, let me just push on that just a little bit. I understand the point about trying to get people to change how they think about it. What I want to know is does HHS have any programs in the works as you did at VA to try to move toward that—

Dr. VALDISERRI. Oh, absolutely—

Senator WARREN. [continuing]. So we get better screening?

Dr. VALDISERRI. Absolutely. I mean—

Senator WARREN. I will give you a chance to showcase it.

Dr. VALDISERRI. [continuing]. Sure. Absolutely. CDC has a number of major public information and awareness campaigns that are targeted to various populations about the importance of early diag-

nosis, also trying to destigmatize testing, because as we heard from Ms. Massey, that is still an issue. Many people are still fearful about learning their status. So we have those kinds of efforts underway.

And I think, also, a lot of work with professional organizations. We also want to try to influence the care providers to develop more of a culture of prevention in primary care settings.

And then, finally, I would say the other really important avenue and opportunity to increase HIV testing is through the Community Health Centers. We are talking about, as you know, a national system serving individuals, many of whom are at high risk for or living with HIV and undiagnosed. So efforts to get HIV testing into Community Health Centers where we currently do not have testing are a very active part of what HHS is doing to try to promote awareness.

Now, I do want to say that is just the first part of the cascade. So, once the testing takes place, we need to make sure we have systems in place to link people actively in care and to meet their needs so that, you know, if they are depressed, if they have unstable housing, if they cannot eat, all of these things are going to impact their ability to stay in care. So we have to work all the way down the cascade. But you are right. It begins with diagnosis.

Senator WARREN. Thank you, Mr. Chairman. Thank you for your generosity on the time.

The CHAIRMAN. Thank you.

Senator COLLINS.

Senator COLLINS. Thank you, Mr. Chairman.

I have just one final question. Dr. Johnston, I am going to direct it to you, but then ask our other witnesses if they have any comment, as well. While HIV patients are living longer, as I mentioned in my opening remarks, many people with the virus appear to be aging prematurely and coming down with diseases and conditions that are associated with people who are older than they are. Has amfAR done any research on the relationship between HIV and aging that might shed light on the cause of this? Is it the result of the disease itself or the drugs or some combination, or do we just not know?

Ms. JOHNSTON. Thank you, Senator Collins, for that question. amfAR is very interested in this issue. I think I have probably demonstrated that a lot of the research that amfAR supports pertains to finding a cure for HIV, and although it is not necessarily expected, I think there really is a very tight interlinking between the issues of aging with HIV and curing HIV for this particular reason that they are both very concerned with immune activation, and immune activation is at the center of the challenges of aging with HIV.

I think we do have a very good sense that of all the diseases that are associated with aging with HIV that occur at a younger age in people with HIV, the ones that you have listed, cardiovascular disease, cancer, dementia, these are at least in part attributable to the increase in immune activation, which is the increase in the activity of the immune system exactly because the HIV is in the body. The HIV persists in the body and, therefore, the immune system keeps



trying to fight off that infection and it never gets to rest from being able to do that.

So, with this persistent immune inflammation, it actually runs itself down. The immune system literally gets tired out and is unable to function properly anymore. And this directly contributes to this higher prevalence of these aging diseases at younger ages in people with HIV.

And to the extent that we also think that this is a barrier to curing HIV, a lot of our research is centrally focused on understanding what it is that drives the immune system, how it is that we can break that cycle of the immune system being in constant overdrive that leaves people susceptible to these diseases of aging.

And to be honest with you, there are also pieces of evidence that suggest that the drugs, in some cases, do contribute to this, too, in particular, protease inhibitors. Unfortunately, protease inhibitors are probably the most powerful drugs that we have to treat HIV. They are also those that can cause—possibly cause the greatest level of bone damage, for example, that could lead to osteoporosis, liver and kidney damage, and some of these other diseases that we associate with aging.

But to circle back to your original point, I think immune inflammation is increasingly understood to really be central to all of these issues of why can we not cure HIV and what is happening in terms of people who are aging with HIV.

Senator COLLINS. Thank you very much.

Dr. Valdiserri—

Dr. VALDISERRI. Yes, if I might add, in addition to the virus itself and the treatments, host factors, including co-infection, viruses like hepatitis C virus, which are known to cause persistent liver damage that can develop into cirrhosis and hepatocellular carcinoma.

This has not come up at all, but wearing a public health hat, the issue of smoking among older Americans with HIV, there have been some startling studies that have shown now—the study was in Scandinavia, but in a country that has essentially open access to treatment, very good retention and care, Denmark, some researchers demonstrated that more years of life were lost from cigarette smoking than from HIV.

So, I think, to answer your question, there are a lot of factors at play here. I will tell you that the NIH does have a number of studies. I cannot give you the exact number, but there are a number of studies that are looking specifically at what you questioned. What is the interaction of the virus and how does the inflammation that Dr. Johnston referred to, the persistent activation, for instance, how does that contribute to cardiovascular disease? How does it contribute to neurologic disease? So, there are studies underway looking at that particular issue, typically within the context of an organ system or a disease set.

Senator COLLINS. Thank you.

Mr. Tietz, you get the last word, I believe.

Mr. TIETZ. Thank you, Senator Collins, and I would just add with regard to the NIH, as was earlier mentioned, the Office of AIDS Research, as a result of a White House Conference, a half-day meeting on HIV and Aging in late 2010, the NIH Office of AIDS

Research put together that Working Group on HIV and Aging in early 2011 and we have referred to the recommendations from that.

I think, given Senator Donnelly's earlier question about stovepiping, almost one of the greatest benefits of that effort that is ongoing is that it is across the NIH. It is across all the Institutes, you know, Aging, NIMH, NIDA. So, folks are looking in a very sort of multidisciplinary way across the Institutes because aging, in fact, so much of it is across organ systems, it is across—there are a whole lot of needs there. And so I think that is particularly valuable in terms of the thinking about this going forward.

Senator COLLINS. Thank you.

Thank you, Mr. Chairman, for an excellent hearing.

The CHAIRMAN. Thank you, Senator Collins.

And on that note, at the end of October, NIH will be having a two-day conference on all of its research Institutes, the ones that you just talked about the stovepiping, to look at aging, the end of October, two-day conference.

On that note, it has been an excellent hearing. Thank you.

The meeting is adjourned.

[Whereupon, at 3:52 p.m., the committee was adjourned.]

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## **APPENDIX**

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**Prepared Witness Statements**

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Written Statement of

**Dr. Ronald O. Valdiserri, Deputy Assistant Secretary for Health, Infectious Diseases  
Office of HIV/AIDS & Infectious Disease Policy, U.S. Department of Health & Human Service  
to the United States Senate Special Committee on Aging  
September 18, 2013**

Chairman Nelson and Members of the Special Committee,

Good afternoon. I am Ronald Valdiserri, MD, MPH, and I serve as the Deputy Assistant Secretary for Health, Infectious Diseases, at the U.S. Department of Health and Human Services. I am pleased to offer testimony on the challenges of human immunodeficiency virus (HIV) infection among persons age 50 or older and how the National HIV/AIDS Strategy and other Federal initiatives are helping to address their prevention, treatment, and care needs.

According to the Centers for Disease Control and Prevention (CDC), an estimated 11 percent of the nearly 50,000 new HIV infections per year in the United States occur in persons age 50 years or older. The Nation is witnessing a major demographic shift toward older age groups among the estimated 1.1 million Americans living with HIV. In 2009, CDC surveillance data estimated that 33 percent of persons living with HIV infection were age 50 or older; by 2020, this age group may represent *half* of those living with HIV infection.<sup>1</sup>

Prevention for this age group is complicated by a number of factors. First, as is true for younger age groups, there are large racial and ethnic disparities in HIV diagnoses among persons age 50

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<sup>1</sup> Brooks, John T., et al. "HIV infection and older Americans: The public health perspective." *American Journal of Public Health* 102.8 (2012): 1516-1526.

or older. Between 2005-2008, the rates of HIV diagnosis for African-Americans and Hispanics/Latinos were 13 and 5 times higher, respectively, than the rate for whites.<sup>2</sup> Second, although a large fraction of Americans remain sexually-active into their mid-sixties and beyond – including those living with HIV infection – many lack awareness of the risks of infection, take little precaution against HIV acquisition, and do not discuss their sexual health with care providers. Third, prevention for this age group may also be complicated by established health risk behaviors such as smoking, alcohol abuse, and substance use.<sup>3</sup>

Treating persons aging with HIV presents its own challenges. Older persons are more likely to be diagnosed late in the course of their HIV infection and have inferior immune responses to antiretroviral therapy than younger people. This may be remediated in part by fully implementing routine HIV screening for all persons 15 – 65 years of age in accord with new U.S. Prevention Services Task Force recommendations.<sup>4</sup> Yet even among those diagnosed and receiving HIV treatment, persons age 50 or older and living with HIV infection may prematurely experience chronic co-morbidities common to advancing age, including cardiovascular disease, infectious and non-infectious cancers, liver disease (particularly among those with hepatitis co-infection), renal disease, and neuro-cognitive decline.<sup>5</sup>

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<sup>2</sup> Laurie Linley, Joseph Prejean, Qian An, Mi Chen, and H. Irene Hall. Racial/Ethnic Disparities in HIV Diagnoses Among Persons Aged 50 Years and Older in 37 US States, 2005–2008. *American Journal of Public Health*: August 2012, Vol. 102, No. 8, pp. 1527-1534. doi: 10.2105/AJPH.2011.300431  
[http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2011.300431?url\\_ver=Z39.88-2003&rft\\_id=ori:rid:crossref.org&rft\\_dat=cr\\_pub%3Dpubmed&&](http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2011.300431?url_ver=Z39.88-2003&rft_id=ori:rid:crossref.org&rft_dat=cr_pub%3Dpubmed&&)

<sup>3</sup> Nakagawa, Fumiyo, Margaret May, and Andrew Phillips. "Life expectancy living with HIV: recent estimates and future implications." *Current Opinion in Infectious Diseases*. 2013, 26(1): 17-25.

<sup>4</sup> Screening for HIV: U.S. Preventive Services Task Force Recommendation Statement. *Annals of Internal Medicine*. 2013, Jul;159(1):1-36.

<sup>5</sup> High, Kevin P., et al. "HIV and aging: state of knowledge and areas of critical need for research. A report to the NIH Office of AIDS Research by the HIV and Aging Working Group." *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2012, 60: S1-S18.

Finally, because HIV disproportionately affects sexual, racial, and ethnic minorities who often have fewer economic and social resources, optimizing health outcomes for those aging with HIV requires care services that address homelessness, food insecurity, and social isolation.

Our progress toward achieving an AIDS-free generation in the United States has been assisted by three recent developments. First, the Affordable Care Act is expanding access to quality care for millions of uninsured Americans, some of whom were previously refused health insurance due to pre-existing conditions, including HIV infection. The law also includes new provisions to support patient-centered medical homes, which are expected to increase care coordination, improve health outcomes, and lower treatment costs.

Second, in 2010, the White House released the National HIV/AIDS Strategy (NHAS), which strives to reduce new HIV infections, improve access to care and health outcomes, and reduce HIV-related health disparities. The White House subsequently convened an HIV and Aging meeting that included leading researchers, representatives from HHS agencies, and a video address from a well-known actor whose recurrent character on a popular TV series (*Brothers & Sisters*) was that of an older man living with HIV. Other Federal Departments and agencies are also addressing the needs of older adults in their NHAS implementation activities. CDC collects and analyzes HIV surveillance data, supports HIV testing and prevention services, and educates practitioners on the HIV-prevention needs of persons age 50 years or older. The National Institutes of Health (NIH) has commissioned an HIV and Aging work group to identify research priorities for the treatment and care needs of those aging with HIV infection, which has led to new initiatives focused on the aforementioned medical complications of aging with HIV. The



Administration for Community Living has released fact sheets, educational videos, and community resource webinars to help increase awareness of the prevention, treatment, and care needs of older adults. The Department of Justice has pursued several cases of HIV-related discrimination as called for by the NHAS, including a successful lawsuit against an Arkansas nursing home that refused to provide care for a retired professor living with HIV.

Third, on July 15, 2013, the White House issued Executive Order 13649, *Accelerating Improvements in HIV Prevention and Care in the United States Through the HIV Care Continuum Initiative*, establishing a work group to offer the President recommendations for actions Federal agencies can take to improve HIV care continuum outcomes. As you may know, only 25 percent of the estimated 1.1 million Americans living with HIV infection achieve virologic suppression,<sup>6</sup> which requires being diagnosed, linked to and retained in HIV medical care, and prescribed combination antiretroviral therapy. That is, approximately 830,000 people in the United States – including those age 50 years or older – do not receive the full benefits of HIV medical care, which can promote health, reduce risk of onward transmission, and extend life expectancy to levels approaching those of persons not living with HIV infection.

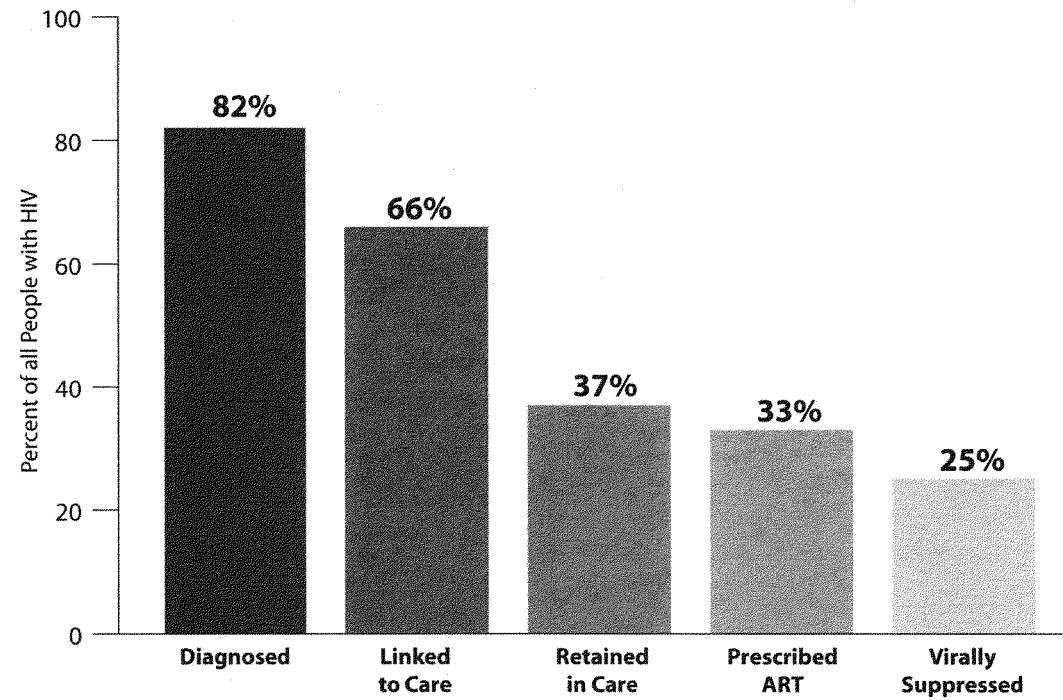
Taken together, these key developments will enable the Federal Government to better anticipate demographic shifts in the epidemic and address the HIV prevention, treatment, and care needs of all Americans, including persons age 50 or older.

This concludes my testimony, Mr. Chairman. I appreciate the opportunity to appear before you and I will be happy to answer any questions the committee may have.

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<sup>6</sup> Hall, H. Irene, et al. "Differences in Human Immunodeficiency Virus Care and Treatment Among Subpopulations in the United States HIV Care and Treatment in the United States." *JAMA Internal Medicine* (2013): 1-7.

**OVERALL: Of the 1.1 million Americans living with HIV, only 25 percent are virally suppressed.**



Source: CDC, 2012. <http://www.cdc.gov/nchhstp/newsroom/2012/Continuum-of-Care-Graphics.html>.

**Prepared Statement of Daniel Tietz, Executive Director, AIDS Community Research Initiative of America (ACRIA)**

Chairman Nelson, Senator Collins and distinguished Members of the Committee, on behalf of my colleagues at ACRIA, I thank you for holding this hearing. ACRIA has long conducted and participated in research on older adults with HIV in the U.S. and abroad. We have also delivered training, technical assistance and capacity building services to HIV and senior services providers across the U.S., including in Miami/Dade and Broward counties in Florida. I am pleased for the opportunity to join you.

From the epidemic's start, most people diagnosed with AIDS faced death within a few years, if not a few months. With the effective antiretroviral treatments available since the mid-1990s, HIV infection has become a manageable chronic illness, best demonstrated by the "graying" of the epidemic. The CDC predicts that half of all Americans diagnosed with HIV will be age 50 or older by 2015. That proportion will rise to more than 70% by 2020.

In 2000, a 20 year old infected with HIV could, on average, expect to live to age 36. Today, that same 20 year old can expect to live to age 71. This extraordinary success is a result of the remarkable commitment of scientists, clinicians, and activists, and the investments made by the American people. But that success has also brought new and ever-increasing prevention and care challenges for those aging with HIV.

People with HIV who are in their 50s and early 60s have the same number of age-associated comorbidities as an uninfected person 10-20 years older. These may include cardiovascular disease, cancers, osteoporosis, hypertension, and depression. Older adults with HIV have a host of health and services needs that neither HIV nor aging services providers are fully prepared to meet. And their significantly greater disease burden is often complicated by social isolation and stigma.

Older adults with HIV have rates of depression that are five times higher than their HIV-negative peers. Depression is arguably the most reliable predictor of medication non-adherence and is associated with poorer treatment outcomes. Much of this depression is fueled by HIV- and LGBT-related stigma and social isolation. Studies, including ACRIA's research, show that almost 70% live alone and less than 15% have a partner or spouse. With often distant families and fragile social networks, they lack instrumental and emotional support. Moreover, many of these older adults have disabling conditions that limit employment and often live at, or below, the poverty line.

In the context of the National HIV/AIDS Strategy, and the new HIV Continuum of Care Initiative announced by the White House in July, I believe we won't reach the end of AIDS unless we effectively address the barriers to routine HIV testing and consistent engagement in HIV treatment among middle-aged and older adults. As with younger people, HIV disproportionately affects older gay and bisexual men, especially men of color, and African-American and Latino women. These disparities are fueled by homophobia, HIV stigma, racism and ageism. We need targeted, evidence-based efforts, including cultural competency training, to address these alarming disparities.

Therefore, I urge you and your colleagues in the Senate and the House to promptly reauthorize the Older Americans Act (OAA) and to include people with HIV and LGBT persons as groups with "greatest social need." This would lead state and regional aging services agencies to explicitly incorporate the unique needs of these populations into their five-year planning efforts. The National Resource Center on LGBT Aging, which is funded by the Administration on Aging in a reauthorized OAA, would continue to fight HIV and LGBT stigma and discrimination among providers. Likewise, I urge adequate support for the Health Resources and Services Administration for targeted demonstration projects and other funding for training HIV and aging services providers.

I further urge adequate resources for the HIV initiatives of the CDC. Research shows that most older adults, including those with HIV, remain sexually active. One in every six new HIV diagnoses occurs in adults 50 and older. And fully half of older adults first diagnosed with HIV above age 50 are sick enough to be concurrently diagnosed with AIDS. In other words, they have had HIV for some time but were never tested and treated. Older adults rarely seek HIV testing, and many providers are unaware that current CDC guidelines recommend routine HIV testing up to age 65. Therefore, we need CDC-funded HIV primary and secondary prevention campaigns for older adults.

For older adults living with HIV today, ensuring the success of the Affordable Care Act is critical. This includes the expansion of Medicaid in all states and robust HIV medication coverage as part of the Essential Health Benefits packages as de-

financed by the Centers for Medicare and Medicaid Services—for both the new health insurance marketplaces and expanded Medicaid programs. Unfortunately, about 40% of Americans with HIV live in states that are not presently planning to expand Medicaid. These include several states with the highest new HIV infection rates, lowest rates of overall insurance coverage, and worst health disparities. Today, half of all Americans with HIV rely on Medicaid to cover their health services. The Kaiser Family Foundation notes that people with HIV are about three times more likely to be covered by Medicaid than the U.S. population overall. Almost 75% of Medicaid beneficiaries with HIV qualify because they are both low-income and permanently disabled. And nearly a third are dually-eligible for Medicaid and Medicare. As they develop multiple chronic conditions at a relatively young age, most will require long-term care.

In a related vein, older adults with HIV need the Ryan White CARE Act to be fully funded to meet current needs or, at the very least, to the level requested by the President in his FY14 budget. In inflation-adjusted dollars Ryan White has been essentially flat-funded for the last decade, even as the number of people with HIV continues to grow. Ryan White is vital for many reasons, not least because the median age for older adults with HIV is 58, meaning many are not eligible for Medicare or other services funded through the Older Americans Act. Most older adults with HIV rely on Ryan White-funded programs, including the AIDS Drug Assistance Program. Ryan White-funded completion services, such as transportation support and case management, are also vital to ensure sustained engagement in care and treatment success. With about half the states choosing not to expand Medicaid, the Ryan White program will remain vitally important for essential services.

In sum, if we are to effect real improvements in the HIV treatment cascade, particularly the very large gap between those initially linked to care and those retained in care, we will need to pay close attention to the intersection of the Affordable Care Act and the Ryan White program.

In addition, we must not only maintain, but increase funding for NIH-targeted research on HIV and aging. The NIH Office of AIDS Research Special Working Group on HIV and Aging, convened in April 2011, was a unique gathering of scientific experts from bio-medical, clinical, and social science disciplines tasked with identifying critical research areas to better inform the treatment and care of this growing population. One of the four subgroups, which included ACRIA's Dr. Mark Brennan-Ing, focused on societal infrastructure, mental health and substance use issues, and the care giving challenges that have been identified as critical to better treatment outcomes for these older adults. Specific recommendations included prioritizing research into co-morbidity management, behavioral health needs, and caregiving social support resources. The program announcements issued by NIH in April 2012 were sponsored by seven NIH institutes in recognition of the complex nature of aging with HIV and the multidisciplinary expertise necessary for relevant research. As will be further discussed by my amfAR colleague, Dr. Rowena Johnston, HIV research has and will continue to inform our understanding of other diseases, including age-related diseases.

Similarly, older adults with HIV need the FDA to support and encourage pharmaceutical companies to conduct combination drug trials for people with resistance to most HIV medications. A significant proportion of individuals with such resistance are above age 50. We also need the FDA and industry to examine the impact of long-term antiretroviral use in an older adult population.

Lastly, it is our hope that HHS will soon develop formal guidelines for providers treating older adults with HIV. Last year, ACRIA, the American Academy of HIV Medicine, and the American Geriatrics Society issued a report entitled *The HIV and Aging Consensus Project: Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV* ([http://www.aahivm.org/Upload\\_Module/upload/HIV%20and%20Aging/Aging%20report%20working%20document%20FINAL%2012.1.pdf](http://www.aahivm.org/Upload_Module/upload/HIV%20and%20Aging/Aging%20report%20working%20document%20FINAL%2012.1.pdf)). *These treatment strategies were developed by an expert national panel, which included ACRIA's Dr. Stephen Karpiak, and could serve as a starting point for formal guidance from HHS.*

Again, I greatly appreciate this opportunity to speak on the subject of HIV and aging. I'm happy to answer any questions.

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**Prepared Statement of Carolyn L. Massey, CEO, Massmer Associates, LLC,  
and HIV/AIDS Education Activist**

Chairman Nelson, Senator Collins and the distinguished Members of the Committee, thank you for the opportunity to address the very important subject of HIV and aging.

I am here to issue a clarion call, to give you the “inside story” on HIV and aging, and the real cost of continuing to minimize the impact that HIV, left unchecked in aging adults, will have on our country and aging citizens. My prayer is that by sharing some of my personal experiences and those of people who have died from HIV and AIDS, or are currently living with the disease, you might consider them as you determine how best to meet the needs of more than 1.2M persons who are known to be living with HIV in our country today. I say “known to be” because estimates are that approximately 25% of the people who are HIV-positive in the United States right now do not know their HIV status. We are fast approaching the point where truly 50% of the people who are living with this disease are at least 50 years of age. The pivotal study, *Research on Older Adults with HIV*, conducted by the AIDS Community Research Initiative of America, told us years ago that HIV/AIDS has a major impact on the quality of life for older adults living with the disease. I challenge you to consider the economic impact, the loss of life, loss of productivity, loss of tax revenues, trauma to families and loved ones that will only grow if HIV in aging adults is left unchecked.

I was initially diagnosed with HIV in the fall of 1994, the same year that my only brother died as a result of complications associated with AIDS. His name was Theodore Anthony Jackson, a budding young businessman, having just opened his third in what was to be a franchise of barbershops, called Tony’s. He would be 55 years old today; our country lost the benefit of his gifts and the contributions that he would have made over the past 19 years. Only months after his death, I was diagnosed—I was 38 years old. During that time, the only drug widely available and prescribed was AZT—and in Anthony’s case, we believe that it did him more harm than good. As our family struggled emotionally with Anthony’s rapid decline in his physical health and mental state, we were traumatized yet further by my diagnosis.

I am convinced that only because I moved my family to Philadelphia in 1996 and vigorously pursued medical treatment there (and ever since) that I am alive today. The sad fact is that many of the people who are aging with HIV today did not know that less stigmatized environments and more knowledgeable physicians were available then. In fact, many of the people who are living with HIV today still do not know that there are life-saving treatments and care available to them. This is especially true of people known as ‘Baby Boomers’, those of us who are over 50 years of age. The older a person is, the less likely they are to be health literate about HIV, their HIV risk levels, how to establish healthy relationships, how to self-advocate and how to access the life-saving services that they need.

One of the things for which I am immensely grateful is that, with your support, health information technology will be used more. I believe that as that technology matures, you will see that HIV is truly not particular about infecting a particular group of people, but that there are more people already infected than we think and that each of us is at higher risk for infection than we ever imagined. In fact, if any of us has had unprotected sex we are at risk for HIV infection.

As you are aware, the field of geriatrics and gerontology is a relatively new one; still emerging within the larger medical community. I urge you and your Senate and House colleagues to provide increased resources to study, better understand, establish and widely implement the best care and treatment practices to address the needs of people who are aging with HIV. Support people who want to study medicine and work on these complex, difficult and intersecting problems of aging and HIV. The aging adults being diagnosed with and living with HIV, if left unattended, is one of the next big health challenges that we will face as a nation.

We have learned a lot over this 30-year journey with HIV in the United States. Among the things we have learned is that the most successful prevention interventions and approaches to care are those that begin with and continue to meaningfully involve the affected communities. The Ryan White CARE Act has provided a tremendous gift through lessons learned and the creation of a continuum of care that works. That continuum should be informing our work going forward in order to undergird the healthcare reform that is now underway.

Another lesson we have learned is that the approach to ending HIV must involve many sectors and various disciplines; this must be an interwoven and integrated effort that involves academic, scientific, political, at-risk populations, and other community stakeholders. We must find ways to effectively improve and measure the change in the quality of life for persons who are living longer with HIV and begin to connect them, to the extent that they are able, to more productive lives. Too often in our zeal to solve one problem, we create other challenges. With improving care and services, and wider access for ALL people with HIV, we can expect that some will be able and want to return to work. Therefore, we need to develop ways to help support them as they do so and ensure that those supports and approaches are realistic and age and culturally appropriate. This involves working with employers and

industries to develop new ways to work and developing more thoughtful, outcomes-driven benefit structures that don't perpetuate poverty, but support progress and hope.

Finally, I strongly urge you to not let our mothers, fathers, and elders die simply because we refuse to sensibly and effectively act. We have the means and wherewithal to better serve older adults with and at risk for HIV and to end this terrible epidemic; but only if we learn the lessons of the past and commit the resources to get there. Please, dear Senators, do not forget us.

Thank you for this opportunity to share some of my story. I welcome your thoughts and questions.

**Prepared Statement of Kenney Miller, Executive Director, Down East AIDS Network**

Good afternoon Chairman Nelson, Senator Collins and members of the Senate Special Committee on Aging. Let me begin by saying that I am honored to have been invited to testify before the Committee about this incredibly important issue.

**Introduction:**

My name is Kenney Miller, and I am the Executive Director of the Down East AIDS Network (DEAN), a small, community-based HIV Services Organization providing services throughout the rural Downeast District of Maine. I also serve as Vice-President to Maine's statutorily mandated HIV Advisory Committee, advising the Governor's cabinet, the Legislature and public and private organizations around issues related to HIV.

The state of Maine is often regarded as one of the grayest states in the nation, with 17.5% of the population aged 65 and up (35). With only 1,654 people living in Maine diagnosed with HIV as of December 2012, Maine is considered a 'low incidence' area (14). Reflecting the aged nature of Maine's population, roughly 50% of persons living with HIV in the state are age 50 or older (14).

At 43.1 persons per square mile, half that of the U.S. as a whole (35), Maine can most definitively be regarded as a rural state. While data concerning population density might seem somewhat out of place in a hearing regarding the changing face of HIV, it is important to note that while 'low incidence,' both people living with HIV and the providers that serve them face a complex set of challenges related to the rural nature of the state. While much has been said and written about HIV and aging, and HIV and rurality, there has been little exploration of intersection of these issues: HIV and aging in a rural context.

**A brief biomedical overview:**

The world of HIV services is entering previously unexplored territory. With the astounding success of increasingly effective treatment regimens and extensive HIV screening efforts, people are living considerably longer with HIV. Two things are clear. Long-term health outcomes and the extension of life hinge on early diagnosis and entry into care (26) and strict adherence to a carefully planned treatment regimen following diagnosis (15).

On average, in the U.S., life expectancy from diagnosis for people living with HIV increased by 12 years from 1996 to 2005, rising from 10.5 to 22.5 years (16). This dramatic increase in life expectancy is a significant victory in the fight against HIV. A victory against a wasting disease that traumatized an entire generation of gay and bisexual men, people who used injection drugs, and others who watched their friends and loved ones pass away in droves. But such success also represents new ground for people living with HIV and those who serve them, raising a host of new questions about HIV and the aging body.

Biomedical studies concerning HIV and aging are currently trending, the subject of voluminous papers, articles and conferences, all trying to grasp this new reality. From these studies a theme emerges: people living with HIV age at an accelerated rate, well beyond their chronological age, leading to a host of comorbidities that have significant bearing on quality of life.

According to Guaraldi, Orlando, Zona, et al., age-related, noninfectious comorbidities are more common in people living with HIV than the general population. So much so that, with regards to the expression of multiple pathologies, people living with HIV were comparable with persons ten years older (14). This is echoed by Onen and Overton, who argue that premature frailty, dysregulation resulting in an increased susceptibility to environmental stressors, is a manifestation of HIV-related accelerated aging (27). Such rapid aging is thought to be at least in



part the result of persistent inflammation and the gradual deterioration of the immune system (6, 7). Immunosuppression, common both with age and among people living with HIV is associated with both HIV and non-HIV related morbidity and mortality, with the lack of a strong immune system leading to the emergence of diseases normally suppressed (38).

It is clear that comorbidities common among the elderly are manifesting at an earlier age among people living with HIV. There are fewer people with no age-related diseases and more people with multiple comorbidities and earlier onset of comorbidities (32). Researchers have noted increases in illnesses including incidence of cancers (20, 11), liver disease (20, 28), cardiovascular disease (31, 15, 38, 27), reduced bone mean density (20) and renal disease (38, 27) and others.

#### **HIV and Aging – Treatment Adherence:**

Beyond the prevalence of comorbidities, the aging process comes with its own set of independent challenges. These are enhanced by an HIV diagnosis, they begin earlier. But they are also of special concern for people living with HIV.

Much like the disease conditions discussed above, people living with HIV demonstrate earlier and with more severe neurocognitive decline including the emergence of cognitive disorders such as dementia (3, 38, 2). This has real consequences for adherence to a treatment regimen, one of the most important factors to maintaining health among people living with HIV. While in general, persons aged 50 and up demonstrate better adherence, those with neurocognitive impairments were found to be at increased risk for suboptimal adherence (19, 12). Poor

adherence opens such individuals up to further immunological and neurocognitive dysfunction, compounding the issue even more (12, 3).

Neurocognitive dysfunction coupled with increased incidence of frailty, reduced bone mass density, cardiovascular disease and other ailments amounts to an early overall functional decline, as is often observed among the elderly years later. Essentially, pain, confusion and low energy make it more difficult to carry out the business of daily living. This means people aging with HIV may experience added difficulty getting to Doctor's appointments, taking their medication, maintaining their hygiene and other functions that are critical to maintaining their health, controlling the virus and preventing infection.

Both functional decline and neurocognitive decline are often cited as influential in higher rates of depression and suicidality among people aging with HIV (13, 37). Such depression is enhanced by the dual isolation experienced by the elderly and infirm and persons living with the stigma of an HIV diagnosis (10, 37). In-depth interviews conducted by C. A. Emler among people living with HIV aged 50 and up found that 68% of participants had experienced by ageism and HIV stigma. Themes that emerged through the course of Emler's interviews ranged from rejection, to stereotyping, to fear of contagion to internalized ageism (8). This supports findings that a growing group of aging adults is isolated from informal support networks due to the dual stigma of HIV and ageism (34). Where the quality of social relationships and established social support networks are held to be of great importance to the mental health and outlook of people aging with HIV, this trend may amplify rates of depression and suicidality (4, 24, 17, 36). Depression, meanwhile, has a well-known negative impact on Antiretroviral adherence (40, 36).

*Many of DEAN's clients have isolated themselves over the years. Jack Driscoll grew up and spent most of his life in rural Maine. He suffered under the stigma of a conservative rural community, first as a gay man and later due to his HIV status. In spite of this, Jack had been one of the most vocal advocates around HIV issues since he was first diagnosed in the early years of the epidemic. Bombarded with stigma, however, over time Jack withdrew into himself, removing himself from public life. Even the gay community, with which he had felt kinship with at one point, pushed him away. At 55 his self-enforced isolation amplified his issues with alcohol, compounding his social anxiety and depression and keeping him largely homebound. His generally negative outlook on life has alienated his friends, resulting in a relatively weak support system that may be to little in later life.*

To summarize, people living and aging with HIV are more susceptible to neurocognitive dysfunction, functional decline and depression. These in turn challenge treatment adherence, one of the most significant predictors of long term health for people living with HIV.

#### **HIV in the Rural U.S. – Treatment Adherence:**

Missing from the dialogue concerning HIV and aging thus far, is a consideration of geographic variation in health outcomes, adherence and those intervening variables that affect both of these.

HIV aside, rural patients generally experience barriers to accessing care. These are exacerbated by health complications and stigma for people living with disabilities such as HIV. Local health care systems in nonmetropolitan areas are frequently inadequate in addressing the complex needs of these HIV/AIDS populations, lacking the specialist and primary care physicians trained to work with such disabilities (22). Health care providers in rural settings have broadly been found

to lack the experience, knowledge and understanding needed to adequately work with people living with HIV. In some studies, providers were less likely to have HIV-positive patients and thus less likely to be experienced in the care and treatment of HIV (5). This affected patients' perceptions of their providers' capacity to help them manage their HIV (23).

Beyond sheer knowledge of HIV and HIV treatment and care, many studies indicate that increased levels of provider stigma and discrimination in rural areas constitutes a barrier to receiving needed care (30). Such provider stigma is held to have a negative relationship with receipt of care (21). This is further complicated by concerns over confidentiality, especially given the size of towns in rural areas and the likelihood of encountering people you know (30, 23).

*Adam Lawrence was about 55 years old, a somewhat short, slender man from Downeast, Maine. He had contracted the virus through the use of injection drugs some years earlier. Throughout Adam's time with DEAN he was moderately psychologically disturbed, possibly the result of neurocognitive dysfunction. This made him jumpy, prone to outbursts and near conspiratorial imaginings. Over the course of a year Adam cycled through several doctors as he sought care for an open sore that refused to heal. He would enter care and be ejected just as quickly, labeled as a difficult patient due to his outbursts and the narrative that he'd developed around his wound. While overt provider stigma never rose to the fore, it is difficult to imagine that his HIV status and history with drug use did not impact their judgment of him as a patient.*

Beyond the adequacy of rural health care providers, geographic distance and transportation are significant barriers for many people living with HIV/AIDS in rural areas (30, 18). This is only

fueled by concerns over the adequacy and confidentiality of local health care providers. Many people living with HIV are forced to travel long distances, and into urban areas, to receive quality care or to see the appropriate specialist (23). The inconvenience incurred by way of longer travel times leads many to put off seeing their doctor (33).

Such barriers to care pose significant risks to adherence and resultant health outcomes. Knowledge and adequacy of a patient's HIV health provider in particular is linked to the likelihood that they are on Antiretroviral Therapy (5).

It bears mention that rural settings may be home to more pronounced levels of stigma and discrimination when compared to urban settings. In a study conducted by Heckman, Somlai, Peters et al. rural persons living with HIV assigned significantly higher problem severity ratings to community residents stigma towards people living with HIV than their metropolitan counterparts (18). This is no surprise, given the closed nature of many rural communities. To this day HIV remains intrinsically linked to gay and bisexual males, people who use injection drugs and other frequently disenfranchised populations that are not always well received by rural communities. That HIV stigma should be felt with special sharpness in rural areas begs the question as to whether depression and isolation resulting from stigma, are felt more sharply in these areas as well, posing significant adherence risks.

*Hayden Mitchellson is one of the most ebullient men you'll ever meet. In his late forties, Haden was born and raised in rural Maine. A gay man, Hayden suffered both family and community rejection. Fleeing his home town Hayden built a new space for himself in one of Maine's vibrant tourist communities. Very outgoing, very vocal about HIV issues, Hayden is none-the-less very protective of his status, disclosing it to few for fear of*

*alienation – isolation of a different sort. Burdened by his past, by his secrets, Hayden sank into depression and self-medicated with alcohol. He bounced from job to job, and eventually wound up on the streets, floating from couch to hotel to park bench. Without stable housing, without transportation, Hayden was unable to seek medical care for his HIV, resulting in prolonged periods between Doctors' visits to check his viral load and CD4 counts and discuss treatment adherence.*

**The intersection of HIV, Aging and Rurality:**

While much has been written and said about HIV and aging, and HIV in rural contexts, there appears to be a dearth of literature concerning the intersection of these two variables as they relate to HIV care. One could reasonably hypothesize that the challenges posed by aging and living in a rural area may amplify one another, much as multiple minority statuses tend to increase risk for negative health outcomes. As such, an aging person living with HIV in a rural environment faces significantly greater barriers to care, stigma, and isolation than an HIV positive person that was either younger and/or lived in an urban setting.

Receipt of care would be negatively affected by both functional and neurocognitive decline, the adequacy of local providers, provider stigma and geographic distance from quality care. HIV stigma, potentially amplified within a closed rural community, would be exacerbated by the individual's experience of ageism. And functional and neurocognitive decline would articulate with the experience of stigma and geographic distance to enhance isolation. Stigma and isolation would in turn lead to greater levels of depression. All of the above combines to threaten the patient's adherence to their HIV treatment regimen and consequently their health.

**Conclusion:**

The discussion of the relationship between HIV and Aging has emerged at a critical time. As a large cohort of people living with HIV approaches old age it is important that service providers consider how they will accommodate their aging clients. Equally important is a full consideration of the complexities of geography and other variables that may affect adherence and health outcomes. In short, while many rural areas may technically be classified as 'low-incidence,' they face special challenges that require special attention. By necessity rural programs have had to adapt and innovate in order to provide high quality HIV services at a time when funding is largely dictated by disease prevalence.

This innovative spirit will serve rural agencies well as they prepare for this brave new world. It bears mentioning, however, that these prevalence based funding formulas do not account for the unique needs and complex problems of people aging with HIV in rural areas and the providers who serve them. Adequate resources are necessary in order to ensure that this particularly vulnerable population is not left to weather the tides of time in isolation, surrounded by stigma and discrimination. Rather they should be supported and empowered, given the tools and resources in the short run that will enable them to live long, full, healthy lives.

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**Prepared Statement of Rowena Johnston, Ph.D., Vice President, Director of  
Research, amfAR, The Foundation for AIDS Research**

Chairman Nelson, ranking member Collins and members of the special committee, thank you for inviting amfAR to participate in today's hearing on Older Americans: The Changing Face of HIV/AIDS in America. I am pleased to share our views on the difficulties—and the opportunities—of this growing challenge in the United States.

By 2015, there are projected to be half a million people living with HIV over the age of 50. Some of these will be people who have been living with HIV infection for many years or even decades, and others will be people who are newly infected. They will all face the difficulties of aging, and of doing so with a serious and potentially fatal disease.

For many years, we never expected to have to deal with HIV infection in older Americans. The good news is that research has given us antiretroviral therapy, which has dramatically lengthened the lives of those living with the infection. A young person who is infected today, and who enters into and stays in medical care, can expect a lifespan that may not differ dramatically from that of a person who does not have HIV. While this is good news, it means that increasing numbers of people living with HIV are older than ever, and our challenge is that we do not know enough about the biological causes and consequences of aging with HIV infection, or about the social burdens borne by those living with HIV. Hundreds of thousands of people will be entering into a phase of their life in which they and their caregivers are not sure whether their health issues are due to HIV infection or aging, or how these challenges should be met. Meanwhile, many older Americans are unaware of their own risk for acquiring HIV, or how to deal with the stigma of being an older person with a disease that is, even today, more commonly associated with young people.

Aging with HIV is at the intersection of several of the most pressing health challenges that face Americans who are aging. These include cardiovascular disease, cancer, osteoporosis, liver and kidney disease, hepatitis C and neurological diseases like dementia. People living with HIV face an increased rate of all of these diseases, and at a younger age, than those who do not have HIV.

Teasing apart the contribution of HIV versus its treatment towards the increased risk for these diseases is difficult, but most researchers believe the virus plays a pivotal role. While studies have found higher rates of cardiovascular disease in HIV-infected populations than in age-matched HIV-uninfected populations, the mechanisms underlying this difference are not fully understood. However, we know that patients who can control their virus even in the absence of antiretroviral treatment have higher rates of carotid disease. Several cancers that are believed to be caused by chronic infections, such as anal cancer, Hodgkin's disease and liver cancer, occur at a higher than expected rate. The dysfunction in the immune system caused by persistent HIV infection is believed to be the major contributor to these higher rates of cancers. Liver and kidney disease are particularly problematic, as the virus can cause damage to these organs, either directly by viral replication or indirectly by destroying immune cells. These tissues are also susceptible to damage caused by all medications, including those used to treat HIV infection. The same is true for bone weakness and damage manifested as osteoporosis and probably caused by a combination of the virus and the drugs used to treat it.

Underlying all of these diseases is the aging of the immune system itself. Older adults, even in the absence of HIV, experience a reduction in the ability of stem cells to develop into immune cells; a shrinking of the thymus, a key organ that generates new immune cells; a skewing of existing immune cell populations away from the ability to respond to new infections; and an increase in the production of hormones that lead to immune inflammation and perpetuate the cycle of the loss of ability to respond to new infections.

Evidence from the HIV research field suggests that inflammation, an increase in cellular and hormone activity in the immune system, occurs in both aging and in HIV infection. Older Americans living with HIV are therefore subject to immune inflammation on two counts. Both for aging as well as in HIV, it is believed to be a major cause of damage to blood vessels and for the increased risk of heart disease. Any research that can shed light on the process of inflammation in HIV disease will by definition benefit millions of Americans who will face heart disease now and in the future.

Researchers currently believe that many of the manifestations of this inflammation of the immune system pose a significant barrier to our ability to cure HIV. Therefore, a greater understanding of the fundamental cellular processes underlying aging, such as inflammation, will help us to address many, perhaps even most, of

the diseases that take the lives of older Americans living with—or without—HIV and may at the same time help us to achieve one of the greatest medical challenges of this century, namely curing an infection that has taken the lives of tens of millions of people around the world.

Robust support for a strong research agenda will be crucial to understanding and addressing these challenges. Research will help us understand how to reach older Americans and provide them with the information and support they need to prevent HIV infection. It will also allow us to improve our HIV testing outreach so that all people who are infected know their status and enter into appropriate medical care. Once we bring people into care, research will help us to provide new and improved tools to help treat not only the HIV but also all of the other diseases we most often associate with aging but that occur more frequently in HIV infection.

Research has resulted in drugs that are saving the lives of millions of HIV-infected people around the world. The fact is that many new treatments for diseases such as cancer, heart disease, hepatitis, and osteoporosis have also arisen from research aimed at preventing, diagnosing, and treating AIDS. Protease inhibitors, initially developed to treat HIV, are now being tested in the treatment of cancers, for example breast cancer. Treatments developed for Kaposi's sarcoma are now being tested in bladder, vulvar, breast and colon cancer. Some cancers require treatment by transplantation, and the immune suppression can lead to opportunistic infections such as *gg* and pneumocystis pneumonia. Treatments for those infections came out of AIDS research. Protease inhibitors are also being tested in the treatment of Alzheimer's disease. Along with nucleoside analogs, which were also developed for treating HIV, protease inhibitors are also used to treat and even cure hepatitis C.

Biomedical research saves lives, generates economic benefits, and yields scientific insights that catalyze future medical breakthroughs. Although the U.S. has long been recognized as the world leader in biomedical research, stagnant funding (which translates into actual funding reductions when adjusted for inflation) imperils U.S. leadership and jeopardizes future life-saving research advances. Funding for health research at the National Institutes of Health (NIH) lost 22 percent in purchasing power in the decade from 2003 to 2012. The federal budget sequester, which went into effect March 1, 2013, resulted in an inability to fund 700 worthy research projects. Limited funding will inevitably delay (and in some cases prevent altogether) exploration of potentially transformative new approaches to understanding and treating the leading causes of death and disability.

When we invest in HIV research, we are committing to understanding and solving health challenges faced by millions of aging Americans. This committee is well aware that the population of this country is growing older and that tens of millions of people will face the serious health issues being discussed here today. The benefits accruing from an investment in AIDS research spread well beyond those with HIV in ways we may not initially predict, but which have a track record of improving the health outcomes for millions of Americans. amfAR strongly supports an increase in funding for the NIH and for research on HIV and aging, understanding that the knowledge we gain from such research has the potential to touch on the lives of all of us.

Thank you again for giving amfAR the opportunity to testify on this important topic. I would be happy to answer any questions you may have.



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**Additional Statements for the Record**

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**The American Academy of HIV Medicine**  
**Statement to the Select Committee on Aging**  
**United States Senate**  
**September 18, 2013**

The American Academy of HIV Medicine commends the committee for using the National HIV/AIDS and Aging Awareness Day to focus on this very important issue. The Academy has been working in collaboration with agencies like ACRIA (AIDS Community Research Initiative of America) since 2008 to address the treatment needs of this new and growing patient population.

Just last week the Academy received notification from the Archstone Foundation that they have provided a substantial grant for us to begin the second phase of our *HIV & Aging Consensus Project* with the implementation of an interactive web based project to seek out and document the real life experiences of HIV providers treating elder Americans with HIV disease.

In November of 2011 we published a first of its kind document entitled: *"Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV."* An excerpt is quoted in the remainder of this statement. The full document can be found on the AAHIVM website.

By mid-decade the CDC predicts that nearly half of the expected 1.2 million in the US living with HIV (Human immunodeficiency virus infection) will be age 50 and older. This aging of the epidemic is largely the result of effective ARV (Antiretroviral) treatments which have prolonged the life span of those with HIV disease. During the past decade, several organizations have convened groups to assess the state of knowledge and science at the nexus of HIV and aging, including a White House Office of National AIDS Policy Special Meeting on HIV and Aging in October 2010.

The NIH has recognized the emerging issue by establishing intra- and extramural workgroups in early 2011. As the lines of communication have grown between HIV care providers and geriatricians, common themes have emerged involving the health management of older persons with HIV infection. Members of the Academy of HIV Medicine (AAHIVM) and the American Geriatrics Society (AGS) with the AIDS Community Research Initiative of America (ACRIA) have collaborated over the past five years to address the clinical management of older persons with HIV/AIDS.

**The Complications of Success**

Among those with HIV infection receiving HAART, the proportion achieving viral suppression is growing, aging, and experiencing a widening spectrum of "non AIDS" diseases (S. Deeks & A. Phillips 2009). Concurrently, AIDS defining conditions are less common (Monforte et al. 2005) and correlate with CD4 count and mortality (Mocroft et al. 2009). Further, while life expectancy among those on HAART has increased dramatically, it is not "normal" (Losina et al. 2009). There is increasing evidence that HIV infected individuals on HAART experience an array of "non AIDS" conditions associated with HIV infection, HIV treatment, and/or behaviors, conditions, and demographics that typify those with HIV (Justice 2010; Deeks & Phillips 2009) The evidence describes an older adult population living with HIV, most of whom are between the ages of 50 and 65

years, who are experiencing high rates of comorbid illnesses (Havlik et al. 2011; Deeks & Phillips 2009). The interaction of aging and HIV may be frequently manifested by elevated risk for comorbidities which include liver disease (could be hepatitis-related), cardiovascular disease, kidney impairment, non-AIDS cancers, osteoporosis, neurocognitive decline, and "frailty" which is characterized by weight loss, weakness, and increased risk of disability and death. This multi-morbidity contributes to overlapping injury to multiple organ systems (Justice 2010; Deeks & Phillips 2009). The result is the transformation of HIV infection into a complex chronic disease associated with multi-morbidity requiring the attention and expertise of multiple health care domains and their providers (Sevick et al. 2007). We do not know at this time what the underlying mechanism of this change is. The comorbid conditions occurring in those with HIV and on HAART are often defined as "non-AIDS". However they are associated with HIV infection (HIV associated non-AIDS or HANA), HIV treatment, and/or behaviors, conditions, and demographics more common among those with HIV infection (Justice 2010; Deeks & Phillips 2009). The "non-AIDS" conditions experienced by those with HIV infection may be strongly influenced by HIV, HIV treatment, and behaviors and conditions more common among those with HIV. Thus, these conditions may behave somewhat differently among those with HIV infection compared to uninfected individuals.

These HANA conditions are common in the general aging population who are without HIV disease. But since they occur in association with HIV, one can conclude that HIV infection, its treatments and the long term results may be significant factors. Multiple mechanisms have been suggested, including microbial translocation, chronic inflammation, oxidative stress, and immune senescence (Purohit et al. 2009; Butt et al. 2004; Butt et al. 2009; Crothers et al. 2011). More studies are exploring the risk factors among those with HIV infection for these "non-AIDS" conditions. In addition to expected associations with known risk factors there is an increased risk for many non-AIDS conditions among HIV infected individuals when compared to uninfected subjects. As a group these studies demonstrate that traditional risk factors together with the risks variables of HIV, HIV treatment, and in some cases, HCV co-infection (Butt et al. 2011; Butt et al. 2009; Butt et al. 2010) combine to establish the patient's overall risk for morbidity and reduced life-span.

#### **Assessing Frailty and Functional Capacity**

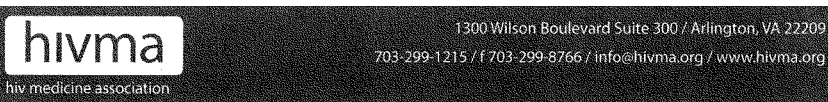
Geriatric syndromes such as "frailty" and "disability" may require adaptation for those aging with HIV infection to account for the role of HANA in accelerated aging. The geriatric literature describes "frailty" as a pentad of loss of height, exhaustion, slowness, low physical activity and weakness (Desquilbet et al. 2007). According to a geriatric consensus conference, "frailty" is evident over time through an excess vulnerability to stressors, with reduced ability to maintain or regain homeostasis after a destabilizing event" (Walston et al. 2006). Key to this concept is the sense of vulnerability to injury resulting from depleted physiologic reserve caused by multiple overlapping and interacting mechanisms. However, the geriatric research community continues to debate the best means of measuring vulnerability (Walston et al. 2006). A modified version of the frailty phenotype, the frailty related phenotype, has been applied among those with HIV infection with mixed success. While the measure demonstrated a stepwise association with increasing years on therapy when stratified by age at initiation, only 3.4% of HIV infected men 55 years or older demonstrated the phenotype (Desquilbet et

al. 2007). Functional capacity may be a more useful measure because functional capacity can be (Oursler et al. 2006). Indeed, initial work in the post HAART era suggests that functional limitation is at a much higher end of the spectrum than that seen among older, more typically considered a geriatric sample (Oursler et al. 2006; Oursler et al. 2009). But middle aged and older adults with HIV are not typical of the general aging population (Karpiak 2006; Brennan et al. 2009). They evidence high rates of depression and suicidal ideation that contribute to reduced health outcomes (Havlik et al. 2011) (Oursler et al. 2006). As they age, many use alcohol, tobacco, and/or illicit drugs, further compromising their health (Groves et al. 2010; Golub et al. 2010). This is an older, but not senior, population that has difficulties with day-to-day tasks, including housekeeping, transportation, meal preparation, employment, finances, and entitlements (Oursler et al. 2011, Oursler et al. 2006; Oursler et al. 2009). Almost 70% live alone, estranged from their families and friends as a function of AIDS associated stigma (Brennan et al. 2011; Emler 2006; Shippy & Karpiak 2005; Karpiak 2006; Brennan et al. 2009). As a result they have fragile social networks that are not a resource for the informal caregiving they will need in order to age successfully (Shippy & Karpiak 2005). Ostracized and rejected, many isolate themselves with a self-protective withdrawal where they hide their HIV status. Others choose to be isolated because they have lost their friends and extended families to HIV/AIDS. Without functional social supports from which care and assistance can be obtained this population will seek more formal supports in a period of reduced economic resources. Without such support they will be relegated at early ages to costly home health care services and long-term care facilities. Choosing treatment strategies for an older adult with HIV must consider their often poor support networks (Emler 2006; Vance et al. 2011; Vance et al. 2010; Shippy & Karpiak 2005; Karpiak 2006).

In conclusion, the aging of the general US population, including the aging HIV demographic, coupled with the shortage of geriatricians and HIV specialists, seriously complicates the access to quality care for these patients in the future.

The American Academy of HIV Medicine  
1705 DeSales Street, NW, Ste 700  
Washington, DC. 20036  
(202) 659-0699  
[www.AAHIVM.org](http://www.AAHIVM.org)





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**Testimony of the HIV Medicine Association (HIVMA)  
United States Senate Special Committee on Aging Hearing:  
Older Americans: The Changing Face of HIV/AIDS in America**

September 18, 2013

The Honorable Bill Nelson, Chair  
Special Committee on Aging  
G31 Dirksen Senate Office  
Building  
United States Senate  
Washington, DC 20510

The Honorable Susan Collins, Ranking  
Member  
Special Committee on Aging  
628 Hart Senate Office Building  
United States Senate  
Washington, DC 20510

Dear Senators Nelson and Collins:

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) is pleased to provide testimony for the Special Committee on Aging's Hearing on "Older Americans: The Changing Face of HIV/AIDS in America," and we commend the committee for taking up this important issue. Our comments below are submitted on behalf of our more than 5,000 clinician and scientist members that are dedicated to the field of HIV medicine and provide HIV care and treatment across the United States.

Many of us who began our medical careers in the early days of the HIV epidemic witnessed firsthand a remarkable revolution in HIV care and treatment. Patients whose only option at one time would have been palliative care now can live near normal life spans thanks to the advent of antiretroviral treatment. Treatment that effectively suppresses the virus keeps the individual infected healthy, while also significantly reducing his or her risk of transmitting HIV to others. With this tremendous progress, the field of HIV medicine continues evolving to address the medical and psycho-social challenges, including vulnerability to co-morbidities, which face the growing cohort of patients that are living with HIV infection into their senior years.

Data from the 2010 HIV Surveillance Report, published by the Centers for Disease Control and Prevention (CDC),<sup>1</sup> indicate that as of 2009 an estimated 256,259 Americans over age 50 were living with diagnosed HIV infection. Moreover, this population continued to grow, with an increase of 14.3% between 2007 and 2009 (from 28.6% to 32.7% of total diagnosed HIV infections). Older persons were also

found to be more likely than younger persons to be diagnosed with HIV infection late in the course of their disease.<sup>2</sup>

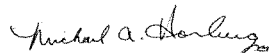
Compared with the non-HIV-infected population, persons living with HIV face increased vulnerability to premature onset of illnesses typically associated with aging, such as cardiovascular, kidney, and liver disease; bone loss and increased fracture risk; frailty; cognitive impairment; and cancer. As the proportion of older individuals living with HIV grows, it is critical that we support robust funding of medical research to better understand and more effectively treat the broad array of factors that may be contributing to these manifestations of aging in a younger cohort. These factors include inflammation, chronic immune activation, long-term drug toxicities, and co-infections and comorbidities that are disproportionately prevalent among people with HIV, such as viral hepatitis, stress, and depression.

In addition, in today's era of an evolving health care landscape, it is crucial that we take great care to ensure continuity of access to quality HIV care for this medically vulnerable population. This requires continued strong bi-partisan support for adequately funding the Ryan White Comprehensive AIDS Resources Emergency Act, and ensuring integration of its successful model of comprehensive care and support services into health care delivery systems. While many Ryan White Program clients have some form of insurance coverage, without the Ryan White Program, they would risk falling out of care. Barriers include poor reimbursement rates; benefits designed for healthier populations that fail to cover critical services, such as care coordination; and inadequate coverage for other important services, such as extended medical visits, mental health and substance use treatment. Full implementation of the Patient Protection and Affordable Care Act plus continuation of the Ryan White Program will dramatically improve health access and outcomes for many more people living and aging with HIV disease.

Again, we thank the committee for its attention to this important issue. Only through a sustained federal commitment to maintaining our investment in efforts to drive down rates of new HIV infection; diagnose the nearly 20% of persons living with HIV infection who are unaware of their HIV status; engage and retain individuals diagnosed with HIV infection in quality care; and press forward with vital HIV medical research can we realize the dream of ending the HIV epidemic in the United States and around the globe.

Please consider HIVMA a resource as this Committee works on this important issue, and call on us if we can be of any further assistance. We can be reached through HIVMA Policy Officer, Kimberly Miller at [kmiller@hivma.org](mailto:kmiller@hivma.org) or (703) 740-4957.

Sincerely yours,



Michael Horberg, MD, MAS, FIDSA  
HIVMA Chair

cc: Members of the U.S. Senate Special Committee on Aging

<sup>1</sup> Centers for Disease Control and Prevention: Diagnoses of HIV infection among adults aged 50 years and older in the United States and dependent areas, 2007–2010. HIV Surveillance Supplemental Report 2013;18 (No. 3). <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/#supplemental> Published February 2013. Accessed 9/12/2013.

<sup>2</sup> *ibid.*, page 7.

## Written Testimony

Senate Special Committee on Aging Hearing September 18, 2013

Older Americans: The Changing Face of HIV/AIDS in America

by Jason Cianciotto, Director, Public Policy, GMHC

On behalf of the over 9,000 New Yorkers living with HIV/AIDS served by Gay Men's Health Crisis (GMHC), I would like to thank the committee for focusing on HIV and aging. GMHC has been advocating for the health of those affected by HIV and AIDS for over 30 years. This includes many who came to us at the onset of the epidemic who are now over age 50.

The story of Carol Logan, a GMHC client who became a Peer Health Educator, is just one example of how the changing needs of clients led us to research, policy advocacy, and service delivery at the intersection of HIV and aging.

In 1990 I was 40 years old, in love, and celebrating the birth of my daughter. I was not considered at high risk for HIV. I was not using drugs and was married. After my daughter was born, she started having health problems and was in and out of the hospital. At 11 months she was diagnosed with HIV, and I knew that I was positive as well.

At first I thought I had been given a death sentence but, after the initial shock, I realized that I was still healthy. At the same time, people with HIV/AIDS were dying all around me. I wanted to start taking medication as soon as possible. I wanted to stay alive. After two decades of living with HIV I have learned how important it is to take care of myself. Most people, doctors included, really believe that after a certain age people are not having sex, and that is just not true.<sup>1</sup>

The development of antiretroviral therapies that helped Carol in the 1990s, among many others, has turned what was once a deadly infection into a chronic, treatable disease. Today over 30% of GMHC's clients are over age 50. The largest proportion (43%) are ages 30 to 49, foreshadowing the estimate that over 50% of people living with HIV/AIDS in the US will be over age 50 by 2015.<sup>2</sup>

This growing population will require the U.S. health care system to respond to the unique health effects of growing older with HIV. For example, HIV-positive older adults experience premature aging of their immune system, as well as increased incidence of non-AIDS comorbidities, including hypertension, diabetes, bone loss, cancer, kidney failure, and depression.<sup>3</sup> A peer-reviewed study published in 2013 based on analysis of survey data collected from 180 GMHC clients over age 50 confirmed that they experience high rates of these age-associated illnesses 10 to 20 years before expected. The study also found that participants had fragile social networks that were unable to provide health information and support, requiring greater access to community-based social and health services.<sup>4</sup>

<sup>1</sup> Adapted from: Cahill, S., Darnell, B., Guidry, J.A., Krivo-Kaufman, A., Schaefer, N., Urbano, L., Willyard, C., & Valadez, R. (2010). *Growing older with the epidemic: HIV and aging*. Gay Men's Health Crisis (GMHC). Available at: [http://gmhc.org/files/editor/file/a\\_pa\\_aging10\\_emb3.pdf](http://gmhc.org/files/editor/file/a_pa_aging10_emb3.pdf)

<sup>2</sup> Rita B. Effros et al. "Workshop on HIV Infection and aging: What is known and future research directions." *Aging and Infectious Diseases* 47:542-553.

<sup>3</sup> Cahill, S. et al. (2010).

<sup>4</sup> Brennan-Ing, M., Seidel, L., London, A. S., Cahill, S. & Karpiak, S. E. (2013). Service utilization among older adults with HIV: The joint association of sexual identity and gender. *Journal of Homosexuality*. (Forthcoming).



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Analysis of HIV surveillance data by the CDC, also published in 2013, indicates alarming trends in HIV transmission among older adults with important policy implications. For example, the estimated percentage of adults over age 50 living with HIV increased from 29% in 2007 to 33% in 2009. HIV among this population is also disproportionately affecting African Americans and Latinos/as, who were over 12 and 5 times, respectively, more likely to be diagnosed with HIV than older white adults. The rate of concurrent AIDS diagnosis also increased with age, indicating that older adults were more likely to be tested long after infection.<sup>5</sup>

These data support the need for a comprehensive analysis and assessment of how federal research, health infrastructure, and policy can better support and prepare for the needs of our aging population with HIV. The following are GMHC's policy recommendations related to HIV and aging.<sup>6</sup>

**Policy Recommendations: Healthcare and Senior Services**

1. The Older Americans Act (OAA), which is currently due for reauthorization, should be strengthened so that HIV-positive and LGBT older adults are included in its definition of populations of greatest social and economic need. The law should also be revised to include education and programmatic aspects that address HIV-related stigma experienced by older adults. The OAA should support and implement HIV prevention interventions in OAA-funded senior and community centers nationwide.
2. Leaders of senior centers and other institutions serving older adults should ensure that all clients receive equal and respectful treatment, regardless of sexual orientation, gender identity, and HIV status.
3. Staff at nursing homes, long-term care facilities, and senior centers should be trained in the particular needs and experiences of older adults living with HIV to ensure culturally competent care.
4. As the HIV-positive population ages, Medicare will need to be more responsive to the needs of older adults living with and at risk for HIV. The inclusion of HIV testing as covered Medicaid and Medicare expenses by the Affordable Care Act (ACA) is an essential step in both treatment and prevention. Healthcare providers should be encouraged to increase awareness and utilization of HIV testing under the ACA.
5. The 24-month waiting period for someone on Social Security Disability Insurance (SSDI) to access Medicare should be decreased to eliminate barriers to health care for some people living with HIV.
6. Coverage gaps in Medicare Part D need to be addressed, including coverage for medications necessary to treat comorbidities. This coverage was not included under the ACA's requirement that Part D Prescription Drug Plan (PDP) sponsors cover antiretroviral medications.
7. The federal government should grant states the option to expand Medicaid eligibility to people with asymptomatic HIV infection. We respectfully request that this committee support the Early Treatment for HIV Act (ETHA), which would amend Title XIX of the Social Security Act to provide states with the option of covering low-income, HIV-positive people as "categorically needy." States taking advantage of this option would be provided with an enhanced federal Medicaid match.
8. The federal government should ensure that same-sex partners, including those living in states that do not recognize same-sex marriage, have access to the many health benefits afforded to

<sup>5</sup> Centers for Disease Control and Prevention. (2013). Diagnoses of HIV infection among adults aged 50 years and older in the United States and dependent areas, 2007–2010. *HIV Surveillance Supplemental Report* 2013;18(No. 3). Retrieved September 24, 2013, from [http://www.cdc.gov/hiv/pdf/statistics\\_2010\\_HIV\\_Surveillance\\_Report\\_vol\\_18\\_no\\_3.pdf](http://www.cdc.gov/hiv/pdf/statistics_2010_HIV_Surveillance_Report_vol_18_no_3.pdf)

<sup>6</sup> Adapted from: Cahill, S. et.al. (2010).



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married, different-sex couples. For example, Medicaid regulations should be changed to ensure that same-sex partners are able to remain in their homes without jeopardizing their partners' right to Medicaid coverage. The government should continue to support the equal treatment of same-sex couples under Social Security's spousal and survivor benefits policies.

9. Veteran living with HIV should be educated about their rights to access Veteran Administration (VA) benefits. In order to eliminate the confusion reported by veterans about eligibility as it relates to time of service or their sexual orientation or gender identity, the VA should expand outreach efforts in order to enroll more veterans and eligible family members.

**Policy Recommendations: Epidemiology and HIV Testing**

1. The CDC should increase the upper age limit of its HIV testing recommendations from age 64 to age 70 and continue to encourage the collection and reporting of HIV surveillance data among older Americans, providing analysis by age and risk category.
2. The CDC should collect data on gender identity to provide national-level data on HIV transmission among transgender persons.
3. The CDC should fund the development, tailoring, and targeting of an effective behavioral intervention (EBI) designed for the unique needs and behaviors of older adults at risk for HIV.
4. Healthcare providers should proactively assess older patients for sexual health risks and sexual activity and routinely screen for HIV.

**Policy Recommendations: Clinical Research and Standards of Care**

1. More clinical research relevant to and including people over 50 living with HIV is needed to better understand how antiretroviral medications interact with aging bodies. Clinical researchers should be encouraged to develop trials that obviate the need for exclusions based on comorbidities in people over 50, whether by designing research that takes account of comorbidities, or by loosening comorbidity-based exclusions for older HIV-positive individuals.
2. Clinical research should explore how treatments for comorbidities interact with antiretroviral medications and what effects these interactions may have on older adults. The FDA should require more active post-marketing follow-up and research for all drugs to better understand interactions.
3. Standards of care for older adults living with HIV should be changed to encourage health care providers to screen people for comorbidities, particularly those found to be more prevalent among older adults living with HIV.
4. Doctors treating patients living with comorbidities found more frequently among people living with HIV, such as anal or cervical cancer, should regularly offer their patients an HIV test.
5. Healthcare providers to older adults, including nurses, medical technicians, and volunteers in medical, social, and housing facilities should be trained on factors that affect older HIV-positive patients, including sexuality, social isolation, and stigma.
6. HIV medical providers should screen their patients for depression and other mental health and substance use problems and refer them to appropriate treatment.

Access to care and quality of life has increased significantly since Carol Logan's HIV diagnosis over 20 years ago. However, the federal government can and should do more to not only ensure that our research and public health systems address the needs of older adults living with HIV, but also focus on reducing new HIV infections in populations over age 50, particularly among people of color. GMHC is grateful to this committee for providing a much-needed forum for discussion and dissemination of research and policy recommendations on HIV and aging.



446 West 33 Street, New York, NY 10001-2601 (212) 367-1000 gmhc.org

Visit the GMHC Center for HIV Prevention: 224 West 29 Street, New York, NY 10001-5204

Written Statement of  
Shane Snowdon  
Director of Health and Aging  
Human Rights Campaign Foundation

To the

Special Committee on Aging  
United States Senate  
Older Americans: The Changing Face of HIV/AIDS in America  
September 18, 2013

Mr. Chairman and Members of the Committee:

My name is Shane Snowdon, and I am the Director of Health and Aging at the Human Rights Campaign Foundation. HRC is America's largest civil rights organization working to achieve lesbian, gay, bisexual and transgender (LGBT) equality. By inspiring and engaging all Americans, HRC strives to end discrimination against LGBT citizens and realize a nation that achieves fundamental fairness and equality for all. On behalf of our one and half million members and supporters nationwide, I am honored to submit this statement into the record of today's groundbreaking hearing addressing the changing face of HIV/AIDS in America and the increasing impact of the disease on older Americans.

Patients diagnosed with the disease at the start of the U.S. HIV/AIDS epidemic, over thirty years ago, were left with few treatment options beyond emotional support and palliative care. A generation was ravaged by the epidemic: over 600,000 died, and another 1.2 million are living with HIV/AIDS. Since the first cases of AIDS were reported in 1981, however, advances in research, prevention, and treatment have helped reduce new infections and allowed people with HIV to live longer, healthier lives.

With these medical advances, people living with HIV/AIDS are beginning to face what was once thought impossible: aging with the disease. By 2015, half of those with HIV/AIDS in the United States will be 50 or older. They are facing new, uncharted challenges in managing their health and sustaining their quality of life. The long-term impact of the virus and its treatment on patients, long unknown, is now unfolding every day across the country, in the homes of older adults. For example, older adults with HIV/AIDS are at increased risk for cardiovascular disease, cancer, liver and kidney disease, and depression.

Older adults represent a significant portion of the newly infected population. Many older Americans remain sexually active and may have many of the same risk factors for HIV as younger Americans, including a lack of knowledge about HIV and how to prevent it, inconsistent condom use, and a belief that HIV is not an issue for their peer group. Older adults also often

have a delayed diagnosis, which can cause more advanced damage to the immune system and make future care more difficult.

To ensure that LGBT elders who are HIV-positive receive optimal care, HRC actively educates hospitals, clinics, hospices and long-term care facilities nationwide about the needs of LGBT patients. In addition, HRC's national LGBT Healthcare Equality Index evaluates healthcare facilities from an LGBT standpoint, allowing them to demonstrate their commitment to equity and inclusion and allowing LGBT patients to identify welcoming care options. We are also encouraged by efforts across the country to achieve greater health coverage among HIV-positive individuals via the Affordable Care Act and Medicaid expansion. We know that access to consistent, quality treatment is key to increasing life expectancy and preventing the spread of HIV and these and other HRC initiatives support knowledgeable, sensitive and respectful healthcare for HIV-positive elders.

We call on Congress to share in our commitment to ending HIV/AIDS and providing the resources urgently needed by those who are infected, including older adults. We urge sustained and increased funding for research on HIV/AIDS in this vulnerable—and expanding—population. We also urge support for broadened mental health services for older adults living with HIV/AIDS, who often experience depression and social isolation that can lead to breaks in treatment and self-care. In addition, HIV prevention education must expand to better address the needs of older adults: elder-focused outreach will be a critical tool in decreasing infection rates among this population. It is also vital that senior services providers and medical and mental health professionals receive specialized training in caring for older patients with HIV/AIDS.

We celebrate the fact that so many Americans diagnosed with HIV have become older adults. We must also remember that aging with HIV/AIDS is an endeavor with which we have very limited experience. It is critical that we support those facing the twin challenges of HIV and aging with the dedicated healthcare, research, education, services and programs that they need and deserve.

