



The AMIDA CARE View



Albany/Rensselaer



Rochester



Buffalo

Together

**WE CAN
END AIDS
in NYS by 2020**



Westchester



Sullivan County



Syracuse



Long Island



New York City

WINTER 2016/2017

Special **END THE EPIDEMIC** Issue

in cooperation with the End AIDS 2020 Community Coalition

Amida Care would like to convey our deep appreciation to the many community organizations that join us in supporting this trailblazing Blueprint to end the AIDS epidemic in our state.



The Blueprint is our road map to get to the finish line and end AIDS in our communities.

— Doug Wirth, President and CEO, Amida Care

Contents



AIDS in New York: My Story

Even without a cure for HIV, the possibility of a future without AIDS is on our horizon. Getting involved in the fight against AIDS as an activist was a lifesaver for me. Becoming an AIDS activist came naturally, since I had to struggle for everything I obtained.



Current EtE Investments

As we seek funding to implement next steps toward ending the AIDS epidemic in NYS, it is encouraging to review our tangible progress to date and the positive impact that the EtE has already achieved statewide.



Legislative Wins 2015-16

Since Gov. Andrew Cuomo launched our state's EtE initiative in 2014, a few of the legislative recommendations made in the plan's EtE Blueprint have already been passed by NYS lawmakers.

AIDS in New York: My Story	4	Positive Impact So Far	21
Treatment and Advocacy.....	6	Legislative Wins 2015-16.....	22
The EtE Blueprint: 3 Pillars	8	Calls to Action	24
The Undetectables	10	Consequences of Not Funding the Blueprint.....	26
PrEP & PEP for Prevention	12	Advocating for More Community Representation and Involvement	28
Housing Is Treatment.....	14	The Vision: A NYS Without AIDS.....	30
Housing for All.....	15	<i>Resources & Acknowledgments</i>	32
HIV & Housing Upstate.....	16		
Employment Is Treatment	18		
Current EtE Investments.....	20		



AIDS in New York: My Story

Valerie Reyes-Jimenez, Associate for NYC Community Mobilization, Housing Works

I moved back home to NYC in 1989, after my husband and I tested positive for HIV in Puerto Rico. We moved into my mother's overcrowded apartment with our two young children. With my family's full support, we hoped to get proper housing and medical care.

I witnessed so much stigma, many deaths, AIDS phobia, racism, sexism, homophobia and transphobia. People with HIV/AIDS – or those perceived to have HIV/AIDS – were kicked out of their homes, fired from jobs, denied health care, and ostracized without shame.

Stigma, discrimination, and fear were and often still are widespread. Support services were sorely lacking for women, families, people of color, drug users, sex workers, transgender people, prisoners and the homeless. Homelessness was, and still is, a major social driver for becoming HIV positive and not being able to receive appropriate medical treatment.

Getting involved in the fight against AIDS as an activist was a lifesaver for me. Becoming an AIDS activist came naturally, since I had to struggle for everything I obtained.

Helping others gave me hope and direction in a time of fear, ignorance, and death. I vowed to be an instrument of change and live to see my children grow up. I became part of the AIDS movement along with national, state, and local community members, civil servants, and lawmakers. Together, we worked to make lasting changes by eliminating barriers to care, housing, support services, benefits, and entitlements for PLWA (people living with AIDS).

These changes, in addition to the development of anti-HIV medications, saved my life and many others. For my husband, these improvements arrived too late. He died in 1992.

1981

Rare cancer (Kaposi's sarcoma) is diagnosed in 41 gay men in New York and California. This and other opportunistic diseases would soon be defined using the term AIDS.

★ ★ ★ **“Even without a cure for HIV, the possibility of a future without AIDS is on our horizon. We have the willingness, know-how, supportive services, health care structures, and organization to bring testing, treatment, and prevention to the next level.”** — Valerie Reyes-Jimenez, *Housing Works*

Even without a cure for HIV, the possibility of a future without AIDS is on our horizon. We have the willingness, know-how, supportive services, health care structures, and organization to bring testing, treatment, and prevention to the next level.

We can create a future in which there will be an AIDS-free generation, where no one loses a loved one to AIDS, where all PLWHIV/AIDS continue to thrive, and all HIV-negative people stay negative. Become part of the End AIDS 2020 initiative, because there’s no better day than today to end AIDS.

A Youth Perspective

Jarrett Lucas

Executive Director, Stonewall Community Foundation

“In considering youth of color impacted by HIV, especially queer and trans youth, the word ‘resilience’ comes to mind. Though subject to lethal forces of disadvantage, they continuously show us what it means to overcome. But their resilience needs to be supported with resources. To end AIDS we must meet youth where they are in their journeys of prevention or treatment, without stigma, and we must increase funding for testing, education, housing as harm reduction, and access to PrEP/PEP.”





Treatment and Advocacy

Mark Harrington - Executive Director, Treatment Action Group (TAG)

Ever since the AIDS epidemic began in the 1980s, the New York community – especially those who live with HIV – has helped lead the drive for more research, better treatment, prevention, human rights, and social services for people with HIV.

The first national meeting of people with AIDS in 1983 helped spawn the AIDS activist movement, emphasizing representation in the media, shared decision-making with treatment providers, and participation in AIDS forums. This approach inspired the activists who founded ACT UP (AIDS Coalition to Unleash Power) in NYC in 1987, with a mission that included seeking expanded, effective, and ethical clinical trials of potential treatments for people with HIV. ACT UP urged the Food and Drug Administration to speed up testing and approval of new drugs to treat HIV and related opportunistic infections and cancers. Their activism helped yield faster approval of drugs to prevent AIDS-related pneumonia, blindness, and wasting syndrome. It also helped spur pre-release access to promising experimental therapies, such as AZT-like drugs ddI, ddC, and d4T.

AIDS activists then sought participation in clinical trials by the National Institutes of Health through the AIDS Clinical Trials Group (ACTG) and other networks. In the early 1990s, AIDS activists gained admission to ACTG and newly forming community advisory boards (CABs) at study sites. Next, the activists pressed for higher-quality data on protease inhibitors, the newest class of HIV drugs in the pipeline.

6 **1985**

U.S. Department of Health & Human Services identifies the retrovirus HTLV-III as the cause of AIDS and announces the development of a diagnostic test.

★ ★ ★ ***“Working together, community leaders, lawmakers, researchers, and government agencies have succeeded in advancing the development of effective treatments to the point where the virus becomes “undetectable” in people living with HIV. This collaborative teamwork has saved the lives of millions worldwide.” — Mark Harrington, TAG***

By 1996, research showed that combinations of drugs – including a protease inhibitor and two AZT-like drugs – could reduce HIV in the blood to undetectable levels. People with AIDS who had been near death rose from their beds, and many were able to resume leading healthy lives. Nationwide, the AIDS death rate dropped by 67% in two years.

Recent studies show that immediate or early ARV (antiretroviral) therapy preserves health and reduces transmission of HIV by at least 96%. Furthermore, a two-drug combination (Truvada, or TDF/FTC) can reduce HIV transmission by up to 86% when used as pre-exposure prophylaxis (PrEP). New York State’s End the Epidemic Blueprint calls for providing early ARV therapy and PrEP to all New Yorkers who need them, while reducing drug costs through Medicaid rebates. It also recommends statewide expansion of housing and social services for New Yorkers with HIV.

In four years, NYS will reach its deadline to end the AIDS epidemic by the end of 2020. Without heroic efforts made collectively for 35 years by generations of AIDS activists and their communities, this trailblazing initiative would not have come about. They have sought action, resources, and the political will to end AIDS. This work continues.



In 2014, Gov. Andrew Cuomo appointed more than 60 activists, health care providers, researchers, consumers and others to participate in NYS's groundbreaking **End the Epidemic Task Force**. Together, they developed 30 recommendations for a Blueprint to End AIDS in NYS by 2020. Its Three Pillars focus on testing, treatment, and prevention.



The EtE Blueprint: **3** Pillars

GET TESTED

Identify New Yorkers with HIV who remain undiagnosed and link them to health care.

TREAT EARLY

Link and retain in health care New Yorkers diagnosed with HIV and help them gain access to antiretroviral (ARV) therapy. They will remain healthy, HIV viral loads will be suppressed, and further transmission will be prevented.

STAY SAFE

Expand access to pre- and post-exposure prophylaxis (PrEP and PEP) for high-risk New Yorkers, to keep them HIV negative.

★ ★
★ ***New York is poised to become the first state in the U.S. to end its HIV epidemic by undertaking this pioneering EtE initiative. If fully funded and implemented, it will reduce new HIV infections and end AIDS deaths.***

The Goals

- ↓ Reduce new HIV infections in New York State from 3,000 to **750** or fewer per year.
- ↓ Reduce by **50%** the rate at which New Yorkers diagnosed with HIV progress to AIDS.

The Need

Success of the EtE initiative hinges in part on targeting New Yorkers at greatest risk of HIV infection. The U.S. Centers for Disease Control and Prevention (CDC) reports:

- ↑ African American MSM (Men who have Sex with Men) ages 18 to 25 are twice as likely to contract HIV as young MSM in other ethnic groups;
- ↑ Latinos are also disproportionately affected, accounting for nearly 25% of all new infections, according to the latest figures; and
- ↑ Transgender women are at highest risk of contracting HIV, with a 27% infection rate – nearly 50 times that of other U.S. adults. Among African American transgender women, 57% test positive for HIV, compared to 16% of their Latina and 17% of their white counterparts.

Housing instability, homelessness, and unemployment are also serious risk factors for HIV infection, especially for young New Yorkers. Research closely correlates housing status and employment with HIV health outcomes. Focused EtE efforts among young MSM of color, transgender women, and homeless youth are crucial to realizing our vision: a New York without AIDS.





Viral Suppression: Becoming Undetectable

by **Charles King** - President and CEO, Housing Works

Helping all New Yorkers who are living with HIV achieve viral suppression is a vital and necessary part of the strategy to end AIDS as an epidemic in NYS. Lowering or suppressing one's viral load is the path to becoming "undetectable."

Undetectables are less likely to transmit HIV to others. Viral suppression not only saves lives, but also helps reduce the steep costs associated with each new case of HIV: an estimated \$500,000* in lifetime health care expenses.

Currently, about 66% of New Yorkers who knowingly live with HIV have achieved undetectable viral loads, the NYS Department of Health (DOH) reports. Meanwhile, in the most recent year for which records are available, the number of new HIV infections in our state fell to fewer than 2,500 – a record low.

To help all New Yorkers with HIV become virally suppressed, we must link them to continuous care with antiretroviral (ARV) therapy medications and supportive services.

The Undetectables Program

In 2014, Housing Works, a NYC nonprofit dedicated to fighting HIV and homelessness, launched a groundbreaking program called The Undetectables to help its HIV-positive community achieve and maintain viral suppression.

The Undetectables program offers a toolkit of social supports to help participants adhere to their HIV medical treatment in order to achieve an undetectable viral load. The program combines financial incentives with integrated primary care, case management, and social

* Lifetime treatment costs plus support services total about \$500,000 per person.

★ ★ **“HIV treatment is not just pills and doctors’ visits. People with HIV can achieve and maintain an undetectable viral load when they get support to overcome barriers to health care such as homelessness, food insecurity, mental illness, and chronic substance use.”** — *Dr. Jerome Ernst, CMO, Amida Care*

marketing to educate participants on the importance of viral load suppression. It also offers medication reminders, support groups, and linkage to non-medical needs that may impact health.

By addressing barriers to health care such as homelessness, food insecurity, mental illness, trauma, incarceration, and chronic substance use, The Undetectables program helps participants work toward achieving and maintaining an undetectable viral load.

To date, The Undetectables program pioneered by Housing Works has surpassed its goal of an 80% viral suppression rate. The NYC Department of Health and Mental Hygiene is currently expanding the Undetectables model to reach more New Yorkers. They recently awarded grants to several organizations to replicate this program in their communities.

A Doctor’s Perspective

*Demetre Daskalakis M.D. - Assistant Commissioner,
Bureau of HIV/AIDS Prevention and Control,
NYC Department of Health and Mental Hygiene*

“Viral suppression, supported by high-quality HIV primary care and services to address other life needs, prevents disease progression and makes it nearly impossible to transmit HIV.”





Prevention: PrEP & PEP

By **Eric G. Leach, NP** - Director of Medical Management, Amida Care

PrEP and PEP are two highly effective tools that repurpose HIV medications to prevent new HIV infections. Used in combination with condoms, regular HIV testing, and open discussions with sexual partners, PrEP and PEP can greatly reduce a person's chance of becoming infected with the HIV virus.

PrEP, or pre-exposure prophylaxis, is a highly effective anti-HIV medication that – if taken daily – has been shown to be over 90% effective in lowering the risk of getting HIV.

PEP, or post-exposure prophylaxis, works somewhat like a “morning-after pill” to prevent HIV infection. If administered correctly and taken daily for 28 days, PEP is effective in preventing new HIV transmission. The first dose should be taken as soon as possible, within three days of a single high-risk event.

In fiscal year 2016, NYC's Department of Health and Mental Hygiene credited a nearly 10% annual decline in new HIV diagnoses to its investment in promoting PrEP and condom use as preventative measures.



“HIV medications not only suppress the virus and help people living with HIV achieve an undetectable viral load, they can also be harnessed as tools to prevent new HIV transmissions. Never before have we had such promising methods of actively treating HIV that also serve as means of prevention.”

— **Terry Leach**, Pharm.D., VP of Pharmacy, Amida Care

Special Needs Plans (SNPs) should be expanded to provide high-risk individuals with new prevention tools, such as PrEP and PEP.

By reducing the spread of HIV, PrEP helps more New Yorkers lead longer, healthier lives while also greatly reducing health care expenditures. The price of taking PrEP for over five years is about \$55,000 per patient, while the lifetime costs of HIV treatment are estimated at \$500,000*.

* Lifetime treatment costs plus support services total about \$500,000 per person.

The Importance of Testing

Carlos N. Molina - Community Advocate, Amida Care

“Estimates show that as many as 22,000 New Yorkers with HIV are unaware that they are infected. Greater access to HIV testing is needed to identify those who remain undiagnosed and link them to health care, antiretroviral (ARV) treatment, and supportive services. Young MSM (Men who have Sex with Men) of color and transgender women are at higher risk for HIV infection. Targeted testing would connect PrEP to those who most stand to benefit from it, improving health outcomes and helping them remain HIV negative.”





Housing Is Treatment

by *Jacquelyn Kilmer* - CEO, Harlem United, and
Paul Vitale - President and CEO, Brightpoint Health

Housing is health care. For New Yorkers with HIV, having a stable place to live is the first step to becoming virally suppressed. Nationwide, fully 9% of people in treatment for HIV are homeless. In our state, homelessness has nearly doubled in the past decade. According to current estimates, NYC alone has at least 60,000 homeless people.

Homelessness and housing instability are significant barriers to accessing health care. A recent study closely correlates this problem with detectable viral loads. A long-term Community Health Advisory & Information Network (CHAIN) study of people with HIV/AIDS in NYC and nearby counties indicates that their greatest unmet needs are for food and housing support. Much research has shown that housing status is one of the strongest indicators in HIV outcomes, as well as a risk factor for further HIV transmission.

Supportive housing programs offer on-site supportive services. They are proven to be the most cost-effective way to address homelessness among New Yorkers most in need, including those with chronic health conditions, mental illness, and substance use, as well as families with disabilities.

Currently, NYC has too few supportive housing units available, and four out of every five people who are eligible have had to stay in a shelter or on the street, instead. Housing intervention prevents new HIV infections and improves the health of people and communities most affected by the epidemic. It saves lives while also saving public dollars over the long term. Spending on housing brings savings through improved health care utilization and prevention of new HIV infections.



"Access to stable housing plays a critical part in our state's groundbreaking End the Epidemic Blueprint. Having a place to call home improves medication adherence and nutrition. It provides a firm foundation for access to care and better health outcomes."

— *Lyndel Urbano, Director, Public Policy and Government Relations, Amida Care*

Housing for All

by *Reed Vreeland - Policy Director, Housing Works*

In August 2016, New York City became the world's first jurisdiction to guarantee stable, affordable housing for every low-income person living with HIV (PLWH). NYC and our state have long recognized the findings of a large body of research: that housing is a key factor in helping PLWH to access health care, benefit from life-saving antiretroviral therapy, and reduce the risk of ongoing HIV transmission.

Since the late 1980s, NYC has provided support for housing, nutrition, and transportation to low-income people with advanced HIV illness. This support – a crucial part of the city's HIV response – has helped bring about a 40% reduction in new HIV infections in the past decade. Nationwide, there has been no such decline.

In June 2016, Gov. Andrew Cuomo announced that NYS would expand eligibility for publicly funded HIV housing and services to include *all* New Yorkers diagnosed with HIV. Previously, these benefits were available only to people whose HIV infection had progressed to AIDS. In NYC, Mayor Bill de Blasio and the Human Resources Administration expanded eligibility for the city's HIV/AIDS Services Administration (HASA) to include all income-eligible NYC residents with HIV.

HASA estimates that as many as 6,000 New Yorkers with asymptomatic HIV infection could benefit from these expanded benefits, including as many as 1,000 PLWH who stay in NYC homeless shelters nightly. But much work remains. Without further action, the expanded medical eligibility is unlikely to increase housing and other supports for low-income PLWH elsewhere in our state.

Many communities lack the resources to extend these essential supports. NYC has made history by expanding access to HIV housing supports to city residents.

Let's finish the job and meet the housing, nutrition, and transportation needs of low-income New Yorkers with HIV statewide.





HIV and Housing Upstate

by *Mary Jones* - BSN, RN, Director, Nursing and Care Management Operations, Trillium Health (Rochester, NY)

Outranked only by NYC, the Rochester area is home to the second highest rate of people with HIV in the Empire State. According to the Rochester Area Task Force on AIDS, an estimated 3,000 people in this upstate region are currently in treatment for HIV.

In and around Rochester, HIV viral load suppression is closely connected with supportive services – especially services for housing instability. Among the 755 people with HIV we care for at Trillium Health, the 100+ patients (14%) who encounter significant barriers to care tend to be those experiencing housing instability.

Housing issues seriously impede the ability of these patients to sustain positive clinical outcomes and exacerbate the other barriers to care that they face. Housing instability interferes with our efforts as we strive to realize an overall viral load of under 200 for each of our patients at Trillium Health.

Trillium Health has developed a model that integrates clinical and social supports to promote health, with a special focus on transitional housing. This strategy produces results accomplished in part by our developing multi-agency and community partnerships.



“To end the epidemic statewide – from Long Island to Buffalo, down to Sullivan County and back up to Rochester and over to Albany/Rensselaer – New York needs a housing strategy to address basic needs in order to lower community viral loads and new HIV infections.”

— Doug Wirth, CEO and President, Amida Care

Using viral load as our guiding performance measurement, we echo the recommendations of the New York State Blueprint to end the AIDS epidemic – in particular, the need to support the non-medical needs of people with HIV. Stable housing is the most crucial of these needs. Even without a cure, the possibility of a future without AIDS is on our horizon.

A Member’s Perspective

J. Smith - Member and Community Health Outreach Worker, Amida Care (Brightpoint Health)

“Without a place to live, it’s very hard to be adherent with medication and get proper rest and good nutrition. Also, it’s important to have a permanent address to get mail from your doctor. Being housed helped me become undetectable. My T cell count was once at 400. Now that I’m undetectable, it is over 1,000.”





Employment Is Treatment

by *Sharen Duke* - CEO, ASCNYC, and *Barbara Cikatelli* - CEO, CAI

Jobs, Jobs, Jobs!

Research shows that getting and keeping a job helps people with HIV stay in medical treatment. This, in turn, enables them to achieve and maintain viral suppression. The EtE Blueprint repeatedly cites employment as an essential factor in helping New Yorkers with HIV maintain their health. Improving job opportunities for young men of color who have sex with men (MSM) and transgender individuals – who are at high risk of being infected with HIV – is especially effective. It helps prevent new HIV infections and advances our collective goal of ending the AIDS epidemic in our state.

From Job Training to Job Creation

New job training programs coach those living with HIV on how to use their life experiences in employment connected to peer health care outreach and education. For instance, Amida Care's Workforce Initiative Network (WIN), in partnership with Housing Works and ASCNYC, empowers people with HIV to develop marketable skills and take ownership of their health and control of their lives. Cikatelli Associates works with Amida Care primary-care sites to employ 10 graduates of their AIDS Institute Certified Peer Training Program. To support graduates of training programs, a Consumer Workforce Initiative was recently launched to generate living-wage jobs for peer outreach workers and health educators at community organizations, where they can use their experience and knowledge to connect people to care.

Peer Health Educators

Trained peer outreach workers and health educators work with hundreds of New Yorkers every year. They help those who do not yet know their HIV status to get tested, help those with HIV to get treatment, and help teach those at greater risk of becoming infected about prevention



“Jobs enable people with HIV to get and stay virally suppressed. Research shows employment is an essential factor in helping people with HIV maintain their health.” — *Lee Garr, Director of Integrated Care, Amida Care*



tools like PrEP. Peer health educators reflect the communities they serve. They draw on personal experiences to help fellow New Yorkers with HIV navigate the health care system and inspire them to make healthy choices.

Already, these new workers have succeeded in reaching out to more than 1,000 New Yorkers with HIV. Many of those contacted by these peer health educators had been at risk of dropping out of care or failing to refill their life-saving medications.

A Transgender Perspective

*Gykyira Shoy, Program Director
New York Transgender Advocacy Group*

“Although transgender women in NYS have recently made some dramatic gains in the workplace, lots of work remains to be done. We have come together and started advocating for equality. Now we can create our own organizations and support ourselves through earned income. These improvements let us be ourselves, without being judged or discriminated against. Yet these things still happen in a lot of workplaces. So it’s up to us to keep using our voices to fight for what is right and what belongs to us. Lack of a living wage puts us at risk for violence and HIV.”





Current EtE Investments

by Kelsey Louie - CEO, Gay Men's Health Crisis (GMHC)

Currently, our state commits \$2.5 billion annually to fighting HIV/AIDS. New York's EtE Blueprint calls for more than \$2.5 billion in targeted additional spending to meet its goal of reducing new HIV infections to 750 or fewer by 2020.

Since implementation of the Blueprint began in 2015, more than \$20 million in new funding has been added, dedicated to multiple initiatives aimed at ending the epidemic. These funds have been used to help identify more than 6,000 HIV-positive New Yorkers who had not been receiving care, while also tripling the number of PrEP prescriptions for New Yorkers enrolled in Medicaid.

Within New York City, the Mayor and City Council have allocated roughly \$30 million in dedicated funding toward ending the AIDS epidemic, an effort spearheaded by the city's Department of Health and Mental Hygiene. This funding is being used to ensure that NYC commits necessary resources to reducing new HIV infections.

Finally, to fund expansion of the vital HIV/AIDS Services Administration (HASA) program, NYC's Mayor and City Council funded \$26 million in start-up costs for fiscal year 2017, with plans to allocate \$44 million a year for this program when it's fully ramped up. In total, expansion of the city's HASA program is projected to cost \$99 million, with additional funds to come from NYS.



“As we seek funding to implement next steps toward ending the AIDS epidemic in NYS, it is encouraging to review our tangible progress to date and the positive impact that the EtE has already achieved statewide.” — Lyndel Urbano, Amida Care

Positive Impact So Far

by Lyndel Urbano - Director, Public Policy and Government Relations, Amida Care

↓ Fewer New Cases of HIV

In 2009, there were 4,900 new infections. In its latest reporting year, the NYS Department of Health (DOH) reports that the number of new HIV cases fell to a record low of fewer than 2,500.

↓ Near Elimination of Mother-to-Child Transmission

For the first time since the AIDS epidemic began, there were no cases of HIV transmission from mother to child in our state as of 2015. Back in 1990, 700 babies tested positive for HIV.

↑ More People in Treatment

According to the NYS AIDS Institute, EtE funding has helped to identify at least 6,000 New Yorkers with HIV who previously were lost to care or unaware of their status, and linked them to treatment and support services.

↑ Higher Rate of Viral Suppression

More than two-thirds of New Yorkers who know they have HIV now have undetectable levels of HIV virus in their blood. NYS DOH indicates that the number of New Yorkers living with HIV at detectable levels has decreased by approximately 10%.

↑ Greater Access to PrEP

Access to PrEP (pre-exposure prophylaxis) medication – which helps prevent HIV transmission – has increased. PrEP prescriptions have more than tripled among people enrolled in Medicaid, according to the NYS DOH.

These milestone achievements validate that our state is on the right track. Further investment by NYS in this groundbreaking initiative will bolster the gains made so far.





Legislative Wins 2015-16

by **Kimberleigh Smith** - Senior Director for Community Health Planning and Policy,
Callen-Lorde Community Health Center

Since Gov. Andrew Cuomo launched our state's EtE initiative in 2014, a few of the legislative recommendations made in the plan's EtE Blueprint have already been passed by NYS lawmakers:

Streamlining of HIV Testing

NYS physicians no longer need written consent to administer HIV blood tests. Only a patient's verbal agreement is required. Also, the age limit of 64 was lifted. Physicians must offer HIV testing to all New Yorkers aged 13 and older.

Easier Access to PEP

PEP (post-exposure prophylaxis) will soon be more accessible at pharmacies, making it more widely available to those who need it. Previously, PEP was dispensed mostly through designated clinics and some emergency rooms.

Funding for Supportive Housing

Gov. Cuomo directed the release of \$2 billion over the next five years to provide supportive housing to help homeless New Yorkers with HIV. Housing is a critical component of the EtE.

★ ★ ★
★ **“With great support from NYS lawmakers, we have made progress in breaking down barriers to HIV testing, prevention and viral suppression. Much more remains to be done to fully realize the vision of ending AIDS in our state.”** — Kimberleigh Smith, Callen-Lorde

Next Steps

These legislative wins give us much to celebrate, but more legislation is needed to reach the goals set out in the EtE initiative:

- **Young people who lack parental support should be allowed to lawfully accept HIV prevention and treatment without parental consent;**
- **Syringe possession should be fully decriminalized, and reforms made to the Expanded Syringe Access Program – including permission for pharmacies to advertise that syringes are available to the public;**
- **HIV-positive New Yorkers with private health insurance should get the option of letting their health care providers share patient data and other key information to coordinate their care and improve their health outcomes; and**
- **Housing, transportation, and nutrition benefits should be extended to HIV-asymptomatic New Yorkers outside of NYC.**

With great support from NYS lawmakers, we have made progress in breaking down barriers to HIV testing, prevention, and viral suppression. Much more remains to be done to fully realize the vision of ending AIDS in our state.





CALLS TO ACTION

EtE Funding Needed for an AIDS-Free NYS

by **Doug Wirth** - President and CEO, Amida Care, and
Eli Camhi - VP, General Manager, SelectHealth, VNSNY CHOICE

For the 2017-2018 New York State budget, the EtE Community Coalition will advocate for an additional \$72.2 million. This funding is needed to support our collective goal of ending AIDS by 2020 through the following programs and services:

- **\$20 million** - Rental assistance for HIV-positive New Yorkers living outside NYC – where homelessness or housing instability also pose formidable barriers to retention in care and effective antiretroviral (ARV) treatment.
- **\$3 million** - Funding for NYS DOH to closely investigate every AIDS death and each case of mother-to-child transmission, to determine whether transmission or mortality can be avoided.
- **\$6 million** - Expanding HIV and STD testing at STD (sexually transmitted disease) clinics statewide.
- **\$2 million** - Expanding statewide access to clean syringes and drug treatment.
- **\$5 million** - Strengthening analytic capacity at NYS DOH and AIDS Institute, to measure progress on achieving the EtE plan by 2020.
- **\$3 million** - Increasing access to vocational services and employment for people with HIV.
- **\$3.5 million** - Increased funding for NYS LGBT Health and Human Services Network, which has not seen a budget increase for years, and which gives technical assistance to LGBT service providers.
- **\$6 million** - Developing more Health Hubs in harm reduction programs, where trained hospital staff members make concerted efforts to engage overdose patients and connect them with treatment options or follow up with them to assess readiness for treatment.

2015

NYS reports zero mother-to-child HIV infections for a full year.



“For the 2017-2018 New York State budget, the EtE Community Coalition will advocate for an additional \$72.2 million. This funding is needed to support our collective goal of ending AIDS by 2020.”

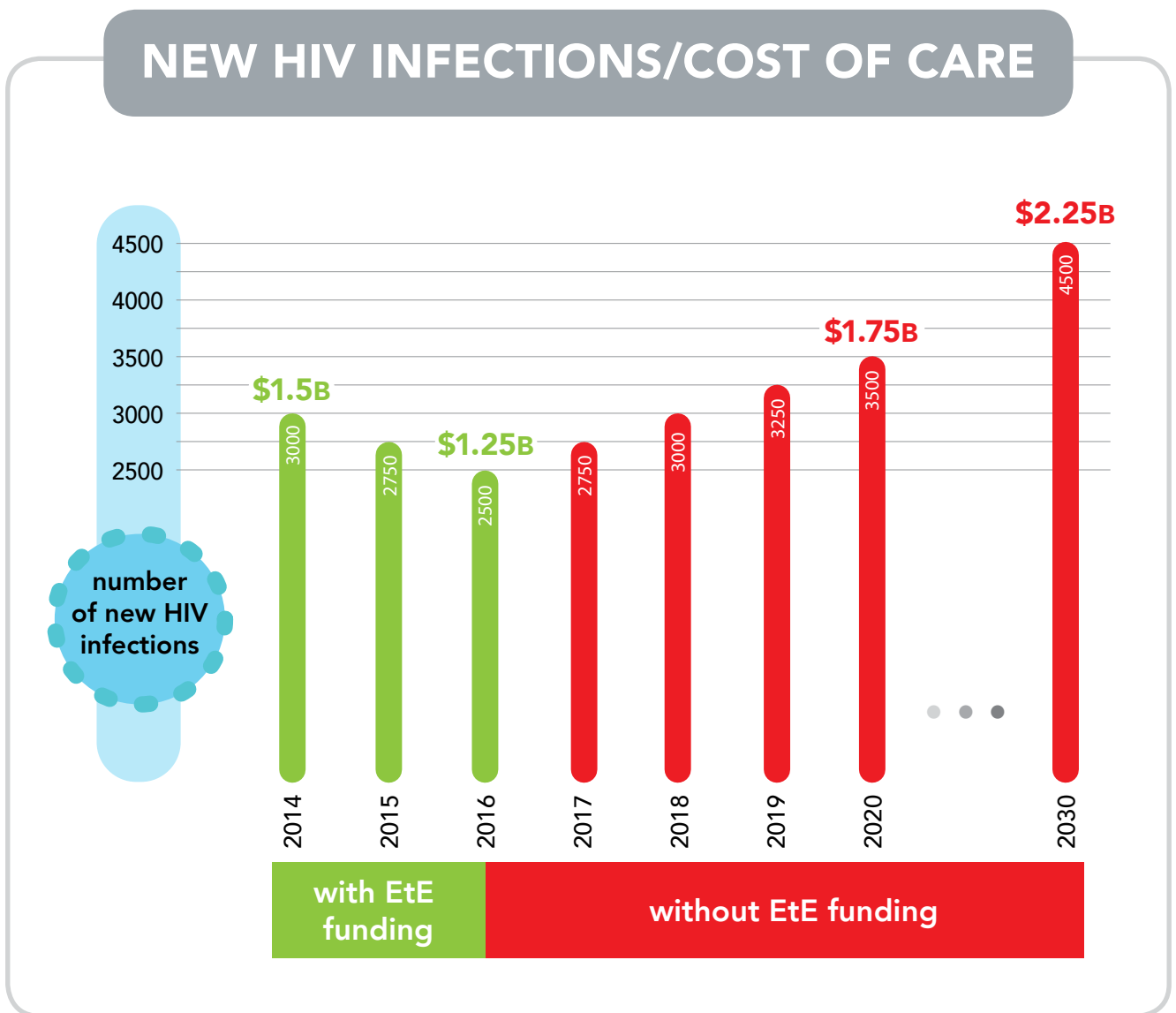
— *Eli Camhi, SelectHealth, VNSNY CHOICE*

-
- **\$2 million** - Scaling up harm reduction in traditional drug treatment programs.
 - **\$10 million** - Creating a program to monitor, evaluate, and improve quality of access to PEP and PrEP, to ensure more effective treatment for high-risk New Yorkers; and also funding a statewide PrEP and PEP education and awareness campaign.
 - **\$3 million** - Establishing Centers of Excellence for People of Trans Experience outside NYC, removing barriers for those seeking high-quality, culturally competent health care.
 - **\$2.4 million** - Increasing housing for homeless HIV-positive and HIV-negative youth, including LGBT youth at risk of HIV infection.
 - **\$3.3 million** - Expanding hepatitis C testing and linkage to care and treatment support and prevention programs statewide
 - **\$3 million** - Expanding transportation and nutritional support to enhance viral suppression.



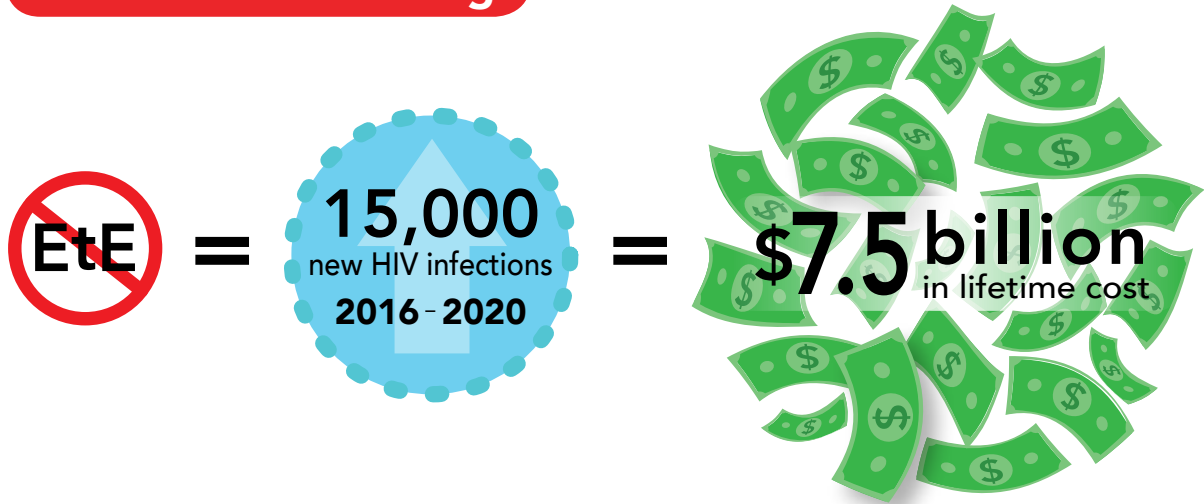
“HIV special needs health plans depend upon a robust and fully funded system of care. Supporting HIV providers – including community health centers, designated AIDS centers, community-based organizations, and housing providers – will advance the vision of a world without AIDS, taking root in New York and growing out from here.” — *Doug Wirth, Amida Care*

Consequences of **NOT** Funding the Blueprint

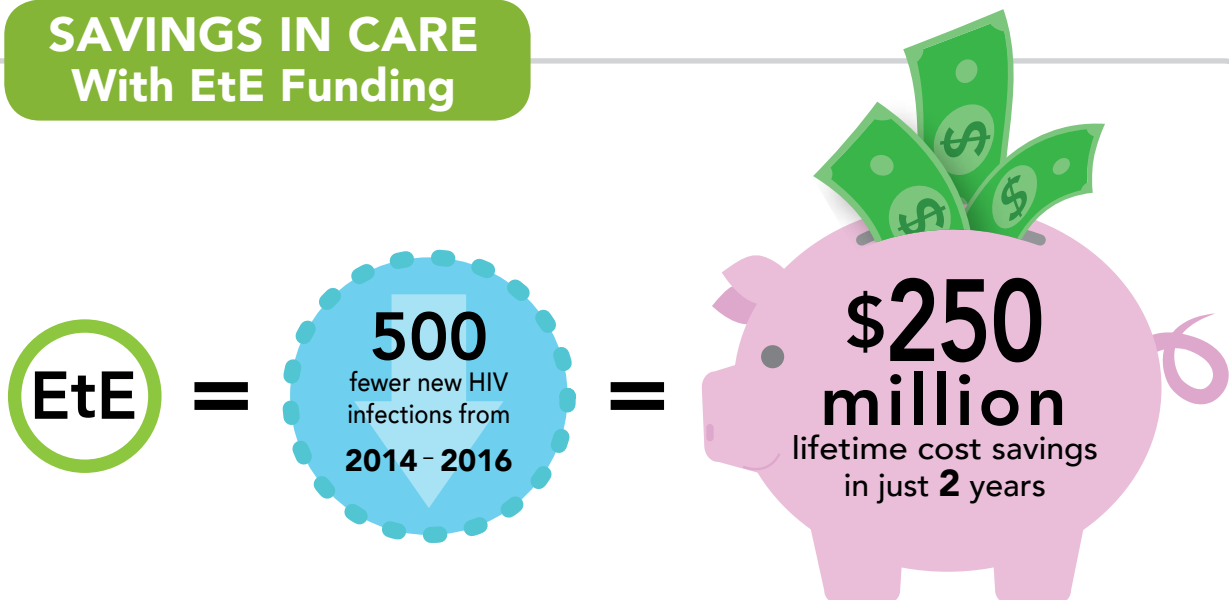


Note: Cost of care equals lifetime treatment expenses plus supportive services that total about \$500,000 per person.

**COST OF CARE
Without EtE Funding**



**SAVINGS IN CARE
With EtE Funding**





Advocating for More Community Representation and Involvement



“We congratulate New York State on its efforts thus far to address the need for diverse leadership in the ETE initiative, such as including the heads of NBLCA and other organizations addressing communities of color as members of the Ending the Epidemic Task Force. However, we also recognize effective progress will rely on greater inclusion by New Yorkers of color in the processes by which policies are made and funds allocated, on state and local levels.”

C. Virginia Fields - President and CEO, National Black Leadership Commission on AIDS (NBLCA)



“Nobody understands the disparities that we have to overcome within organizations, businesses, and corporations. That’s why being a transgender woman of color who holds the position of program director is very uplifting and empowering. It allows me to set the stage for others to do the same because we are here to stay, and we belong here.”

Gykyira Shoy - Program Director
New York Transgender Advocacy Group



“New York State is leading the nation, by coming together to end AIDS by 2020. It’s implementation time! And we need to follow recommendations coming from diverse voices representing English and non-English speaking communities. The giant task ahead is to ensure that our communities are reached with effective and culturally sensitive programs. The messenger matters when we try to reach communities at most risk, such as our gay/bi men, our youth, our transgender women, our intravenous drug-using communities, and women of color. Ending AIDS and eradicating health disparities can be accomplished by bringing together research, communities at risk, policy, advocacy efforts, and government.”

Guillermo Chacón - President
Latino Commission on AIDS (LCOA)

1986

CDC reports that AIDS cases are disproportionately affecting African Americans and Hispanics.

2016

Thirty years later, this is still the reality for men, women, youth, transgender women, gay men and MSM of color. In NYC, 81% of new HIV diagnoses and AIDS-related deaths are among African Americans and Hispanics. In NYS, approximately 70% of new infections were among African Americans and Hispanics.



Carlos N. Molina © 2014

A New York State without AIDS

by Doug Wirth - President and CEO, Amida Care

Governor Cuomo’s Blueprint to End the AIDS Epidemic in New York by the year 2020 is a groundbreaking initiative that positions New York as the first state to end HIV/AIDS as an epidemic. We can serve as a model for the nation. Today, more than ever before, we have the tools to combat HIV. However, the populations that are most impacted by HIV – those who are homeless, people of color, young men having sex with men, and transgender individuals – are also the communities facing the most barriers when it comes to accessing quality health care. Health care is a right, not a privilege. It’s time to break down the barriers to HIV treatment and prevention so underserved and at-risk communities can access the comprehensive care they need. This is critical to help people living with HIV become virally suppressed and reduce the rate of new infections. This is about saving lives. This is about ending HIV/AIDS. And through saving millions of dollars in avoided health care costs, this is a win-win for the people, for the city, and for the state. Together, we can achieve an AIDS-free New York by 2020.

Together,
we can achieve an
AIDS-free New York by 2020.



Carlos N. Molina © 2016

ACKNOWLEDGMENTS

Amida Care would like to express our profound gratitude to the contributors from across New York State who made this EtE publication possible, with special thanks to:

Eli Cahmi, VP, SelectHealth, VNSNY Choice

Guillermo Chacón, Latino Commission on AIDS

Barbara Cicatelli, Cicatelli Associates, Inc.

Michael Czaczkes, Gay Men's Health Crisis

Demetre Daskalakis, MD, Bureau of AIDS/HIV Prevention & Control Mental Hygiene, NYC DOHMH

Sharen Duke, ASCNYC

C. Virginia Fields, National Black Leadership Commission on AIDS

Mark Harrington, Treatment Action Group

Mary Jones, Trillium Health

Jacquelyn Kilmer, Harlem United

Charles King, Housing Works

Kelsey Louie, Gay Men's Health Crisis

Jarrett Lucas, Stonewall Community Foundation

Valerie Reyes-Jimenez, Housing Works

Gykyira Shoy, NY Transgender Advocacy Group

Kimberleigh Smith, Callen-Lorde Community Health Center

Paul Vitale, President/CEO, Brightpoint Health

Reed Vreeland, Housing Works

Amida Care contributors: Doug Wirth, Jerome Ernst, Lyndel Urbano, Eric Leach, Lee Garr, Terry Leach, J. Smith, and our **Communications and Publications team:** Teri Wade, Carlos N. Molina, and Susan Ruel, with Glenn McFall, Shakira Croce, LeRon Stevens, and Hannah Erickson.

Amida Care would also like to convey our deep appreciation for members of the Community Coalition to advance the EtE initiative — and other community organizations who support this effort.

RESOURCES

For additional background, including a timeline of the AIDS epidemic in New York State, go to Amida Care's website at: www.amidacareny.org

For more information on the history of Treatment and Advocacy and the history of the PWA (People With AIDS) self-empowerment movement, read the Denver Principles (1983) online at: <http://bit.ly/2fD8p9J>



1-855-GO-AMIDA (1-855-462-6432) • www.amidacareny.org

Follow us on    