Ending AIDS in America: Meeting the Challenge
Pneumocystis Pneumonia — Los Angeles

In the period October 1980–May 1981, 5 young men, all active homosexuals, treated for biopsy-confirmed Pneumocystis carinii pneumonia at 3 different hospitals in Los Angeles, California. Two of the patients died. All 5 patients had lab confirmed previous or current cytomegalovirus (CMV) infection and candidal infection. Case reports of these patients follow.

Patient 1: A previously healthy 33-year-old man developed P. carinii pneumonitis and oral mucosal candidiasis in March 1981 after a 2-month history of fever associated with elevated liver enzymes, leukopenia, and CMV viruria. The serum complement CMV titer in October 1980 was 218; in May 1981 it was 32. The patient’s condition deteriorated despite courses of treatment with trimethoprim-sulfamethoxazole, pentamidine, and acyclovir. He died May 3, and postmortem examination revealed P. carinii pneumonia, but no evidence of neoplasia.
1987

- 41,000 Dead; 71,000 Living with HIV
- AIDS Quilt first time on National Mall
- First Antiretroviral Drug Approved – AZT
- First public Speech by President Reagan on AIDS
- ACT-UP Founded: AIDS Coalition To Unleash Power
Understanding AIDS

What Do You Really Know About AIDS?
HIV & AIDS Over Time: Our Legacy

Introduction of Highly Active Antiretroviral Therapy (HAART)

- People living with HIV
- New HIV infections using back-calculation methodology
- New HIV infections using incidence surveillance methodology
- New HIV infections using updated incidence surveillance methodology
Treatment Costs of HIV

- Lifetime Treatment Cost $379,668
- 50,000 New Infections
- Lifetime Treatment Cost $18.9 Billion

IN 5 YEARS?

= $94.9 Billion

Insurance Coverage of Nonelderly Adults with HIV
2009 Pre-ACA

- Medicaid 167,180 (41%)
- Medicare 25,300 (6%)
- Other Public 22,380 (5%)
- Private 122,390 (30%)
- Uninsured 69,720 (17%)
- Unknown 6,100 (1%)
HIV = A Disease of Disparities
HIV Diagnoses Trends 2005-2014
By Race
HIV Diagnoses Trends 2005-2014
By Mode of Transmission
HIV Diagnoses Trends 2005-2014
By Race among MSM
Lifetime Risk of HIV Diagnosis in the United States (CDC, 2016)
Lifetime Risk of HIV Diagnosis in the United States (CDC, 2016)
There are 1.2 million Americans living with HIV

One of every four is a woman

Two of every three women with HIV is African American
CDC Estimated 2014 New HIV Infections

- Black MSM: 11,207
- White MSM: 9,012
- Latino MSM: 7,057
- Black Hetero Women: 4,657
- Black Hetero Men: 2,113
- Other MSM: 2,105
- Latina Hetero Women: 1,282
- White Hetero Women: 1,115

All subpopulations accounting for 1,000 or more of 2014 infections.
A 2008 meta-analysis of 29 studies focusing on trans women in the United States found:

- 27% MTF tested HIV Positive
- 11% Self-reported knowing they were HIV+

Among African Americans:
- 56% MTF tested HIV Positive,
- 31% Self-reported knowing they were HIV+

“Transgender communities are among the groups at highest risk for HIV infection in the United States.”
Ascertainng transgender status

- Not all under the "transgender umbrella" will self-identify as transgender
  - Anatomy, sexual practices, and sexual identities ≠ gender identity

- Current best practice to ascertain identity is 2-step method
  - Current gender terms vary by context and geographic location

1. What is your current gender identity? (Check and/or circle ALL that apply)
   - Male
   - Female
   - Transgender Male/Transman/FTM
   - Transgender Female/Transwoman/MTF
   - Genderqueer
   - Additional category (please specify):
     - Decline to answer

2. What sex were you assigned at birth? (Check one)
   - Male
   - Female
   - Decline to answer

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**The One- and Two-Step Approaches: Differences in Test Events and Positives**

- Number of Test Events among TG Persons
  - One-Step: 12,485
  - Two-Step: 21,092

- Number of HIV Positive Test Events among TG Persons
  - One-Step: 450
  - Two-Step: 331

GenIUS 2014, Mulatu 2015
Rates of Adults and Adolescents Living with Diagnosed HIV Infection, Year-end 2013—United States and 6 Dependent Areas

N = 950,811  Total Rate = 355.9

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.
Income as well as race predict who is more likely to die from HIV

(Singh, 2013)
NEW
PARADIGM
AHEAD
NHAS Vision:

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.
Projected impact of highly active antiretroviral therapy on expected survival of a 20-year-old person living with HIV in a high-income country consider in different time periods

Source: UNAIDS / Lohse et al / Hoog et al / May et al / Hogg et al
HPTN 052 – Treatment as Prevention

A scientific breakthrough in 2011 showed that HIV treatment not only saves lives, but reduces the risk by 96% of transmitting the disease.
Graphic developed by:

Rodger A et al. HIV transmission risk through condomless sex if HIV+ partner on suppressive ART.
Change in ARV Treatment Guidelines

Based on new research from NA-ACCORD cohort of HIV+ people, life expectancy of HIV+ adults initiating therapy today is approaching the life expectancy of the general population.

**DHHS 2012 Guidelines:** ART is recommended for all people living with HIV to reduce the risk of disease progression.

**WHO 2013 Guidelines:** ART is recommended as priority for individuals at < 350 CD4, for individuals at >500 CDC, and for all people living with HIV and with active TB, co-infected with Hepatitis and evidence of liver disease, and sero-discordant couples.
Stages of Care – The United States Treatment Cascade

1,201,100 HIV-Infected
86% Diagnosed
1,032,800 Linked to HIV Care
61% Retained in HIV Care
40% On ART
37% Suppressed viral load
30%

PrEP is a new prevention method in which people who do not have HIV take a pill a day to reduce their risk of acquiring the virus.

When taken consistently, PrEP has been shown to reduce the risk of HIV acquisition by up to 92%.
• No rescissions, no ability to exclude based on pre-existing conditions;
• Expansion of numbers of individuals with insurance, particularly the poor vis-à-vis states opting in to Medicaid expansion,
• Establishing a base of essential health benefits;
• Expansion of preventative health services, including testing;
• Insurers currently facing challenges linked to placing all HIV drugs in specialty and/or top tiers, increased co-pays and smaller networks – challenges being worked out.
• Transparency of formularies & networks of care.
Current Status of State Medicaid Expansion Decisions

NOTES: Current status for each state is based on KCMU tracking and analysis of state executive activity. *AR, IA, IN, MI, MT, NH and PA have approved Section 1115 waivers. Coverage under the PA waiver went into effect 1/1/25, but it has transitioned coverage to a state plan amendment. Coverage under the MT waiver went into effect 1/1/2016. LA’s Governor Edwards signed an Executive Order to adopt the Medicaid expansion on 1/12/2016, but coverage under the expansion is not yet in effect. WI covers adults up to 100% FPL in Medicaid, but did not adopt the ACA expansion. See source for more information on the states listed as “adoption under discussion.”

American Knowledge & Attitudes
(Washington Post/ Kaiser Family Foundation 2012 Survey)

- 61% of Americans believe Americans don’t have access to HIV treatment;
- 50% of Americans never tested for HIV despite CDC recommendations
- 34% of Americans identify sharing a drinking glass, touching a toilet seat or swimming in pool as risk of HIV transmission
- 20% would be somewhat or very uncomfortable working with someone who has HIV; and 44% similarly would not want an HIV positive person preparing their food.
Not Just Population-at-large, but also Provider Attitudes Limiting Success: Particularly for Trans Populations
Our Asks

AIDSWatch
1. Insurance and Coverage
2. Housing
3. Education
4. Decriminalization
5. Research
Massachusetts: From 2000 to 2011, the number of HIV infection diagnoses decreased by 44% and the number of deaths among people reported with HIV/AIDS decreased by 41%.

ACA + RWP = Faster progress towards an AIDS-free Generation.
The Asks

• Enforce ACA nondiscrimination mandates;
• Enact laws to reduce discriminatory cost-sharing for HIV medications;
• Maintain federal commitment to Medicare and Medicaid, with emphasis on support for late-comer states to expand Medicaid and still garner three-year full coverage.
• Serves an estimated **536,000 Low-Income People Annually** (nearly half of all individuals living with HIV in the U.S.)

• Is a safety net/payer of last reset - critical in covering the uninsured and **elements not covered under insurance** that are needed for engagement & retention in care.

• Last authorized in 2009 & Expired (not sunset) in 2013

• **Reauthorization will be needed**, but more time needed first to see impact/needs related to ACA.
• The Ryan White Program (RWP) is a critical component of the national public health response to HIV infection and disease.

• While reauthorization may not be ready, **full and continued appropriations** are needed.
STABLE HOUSING
The Facts

• A lifeline for people living with HIV

• One of the greatest unmet needs of Americans living with HIV/AIDS

• HOPWA
Enacted 1990
FY16 $335 Million
Modernize Formula –

Rather than current approach of allocating based on cumulative AIDS cases, new formula should be tied directly to number of individuals currently living with HIV, poverty level, and housing costs.

Increase Funding –

Provide a $40 million increase to HOPWA at time of modernization to close gap on need, and to ensure modernization gets more equitable resources to areas with growing epidemics, while other areas are not destabilized.
The Facts

• Less than half of all high schools and only 20% of middle schools in the U.S. provide all of the 16 topics identified by the CDC as critical sexual health education.

• Young people under age of 25 accounted for 20% of all new HIV infections in 2014 and 68% of all chlamydia cases in 2013.
Support continued authorization of the Personal Responsibility Education Program (PREP) for FY 2016-2020, and increased funding for Teen Pregnancy Prevention Initiative (TPPI) and Division of Adolescent & School Health (DASH) in FY 2017.

Eliminate federal funding for abstinence-only programs, as proposed in the President’s budget.

Co-sponsor Real Education for Healthy Youth Act.
The Facts

- 33 states and two territories have HIV-specific statutes that apply only to people living with HIV;
- In U.S., more than 1,000 people living with HIV have faced charges under HIV-specific statutes;
- Long sentences, even where no real risk of transmission has occurred, have been documented.
- Criminalization is limited to those who know their status, and as such, could inhibit some from seeking to learn their status (anti-public health).
Support and/or Co-Sponsor HR 1586 sponsored by Rep. Barbara Lee and S 2336 sponsored by Senator Coons

The Repeal of Existing Policies that Encourage and Allow Legal HIV Discrimination ) REPEAL Act.

- Requires a federal review of state laws, policies, and regulations related to HIV Criminalization. Won’t change state law, but will hopefully influence.
AIDS Budget & Appropriations

- Investment in Research, Care, Prevention and Housing critical to bending the cost-curve of new infections (each prevented HIV infection saves $377k in future treatment costs)

- Ensure Budget Requests from AIDS Budget and Appropriations Coalition are supported

- NIH Budget fall short of $100 million increase promised for HIV research
“We are on scientifically solid ground when we say we can end the HIV/AIDS pandemic,” Dr. Fauci said. “The end of AIDS will not be accomplished, however, without a major global commitment to make it happen. We have a historic opportunity — with science on our side — to make the achievement of an AIDS-free generation a reality.”

- 2012 Int’l AIDS Conference