

INSIDE

FROM STRATEGY TO REALITY: WHAT WE NEED TO KNOW TO MAKE THE NHAS WORK 6

The National HIV/AIDS Strategy states that HIV prevention and treatment research is needed, but it doesn't define the research challenges.



THE ADAP CRISIS: WAITING FOR MEDS 8

There are 8,230 people waiting for HIV meds on ADAP waiting lists in 13 states.

NEW HOPE FOR A CURE 11

Finding a cure won't be easy, but with a real effort it could be a reality sooner than we think.



Personal Perspective: THE CHANGING FACE OF HIV TESTING 14

Due to the changes in HIV testing laws, more people will access HIV testing without written consent.

THE NATIONAL AIDS STRATEGY: AN OPPORTUNITY FOR ACTIVISM 16

After 30 years, why do the same groups continue to dominate new HIV infections?



EDITORIAL 19

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A New Era for HIV Health Care

by Robert Greenwald and Amy Killelea

In March 2010, the Patient Protection and Affordable Care Act was signed into law. It is the most important piece of health care reform legislation since Medicare and Medicaid were created in 1965. Health care reform presents a great opportunity to increase access to affordable care, treatment, and prevention services. But the devil is in the details, and its potential depends on reform being implemented in ways that truly meet the needs of people with HIV. In addition, there are shortcomings in the law that the HIV community must address.

The health care reform law means major changes are on the horizon for our entire health care system, and for HIV care in particular. We must begin an open and honest discussion about what these changes mean for those living with HIV. In this changing environment – one in which thousands of people with HIV will

have access to public and private insurance for the first time – the role of Ryan White programs will change dramatically. Ryan White programs have been the primary providers of HIV care, treatment, and services for over 20 years. Yet in recent years funding has fallen far short of demand, and people are increasingly unable to get the care they need. Health care reform will greatly help to address the problems caused by inadequate funding and increased need.

The future of HIV care must include integration of Ryan White services into newly created health care systems. This is no small task and will involve difficult decisions and changes to the current order. We must work to make sure these newly created opportunities work and that the inevitable challenges are addressed so that all people with HIV get the care they deserve.

continued on page 3

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ACRIA Trials in Progress

BMS-663068

People with HIV who are 18 and older and who have become resistant to more than one HIV medication will take BMS-663068 (an experimental HIV attachment inhibitor) or Reyataz for up to 96 weeks. Everyone will also take Isentress and Viread.

Cenicriviroc (TBR-652)

People with HIV who are 18 and older and who have not taken HIV meds will take either Cenicriviroc (an experimental CCR5 inhibitor) or Sustiva for a year. Everyone will also take Truvada.

BI 201335

People aged 18 to 70 who have hepatitis C virus but not HIV, and who have not taken interferon, will take BI 201335 (an experimental HCV

protease inhibitor) with peg-interferon and ribavirin for 12-48 weeks.

Ibalizumab

People who are HIV negative will receive four weekly injections of ibalizumab (a monoclonal antibody) to study its safety and effect on the immune system.

Selzentry

People with HIV who are 18 and older and who have not taken HIV meds will take either Selzentry or Truvada for 22 months. Everyone will also take Prezista with Norvir.

For more information on these trials, contact us at 212-924-3934, ext. 130.

Compensation is available for some studies.

ACRIA Launches Hepatitis C Studies

For the first time in its 20 year history, ACRIA will begin conducting trials for hepatitis C virus (HCV), an infection that affects up to 4 million people in the U.S. and about 30% of people with HIV. It is the leading cause of death for those with both viruses.

The first trial, of an experimental HCV protease inhibitor, will begin enrolling at the end of June. It will compare two different doses of the drug to a placebo in people who have HCV but not HIV. Everyone in the study will also take standard HCV therapy (a combination of pegylated interferon and ribavirin).

The second trial, scheduled to start in September, will study an experimental HCV protease inhibitor taken with interferon and ribavirin, in people who have both HCV and HIV. This study will be open to people who have never taken any HCV treatment and to those who have.

Additional studies are being considered in the hopes of finding more effective treatments for this serious condition.

What Does Health Care Reform Mean for People with HIV?

Medicaid Expansion

Nearly 30% of people with HIV are uninsured, and up to 59% are not in regular care. Medicaid's requirement that a low-income person with HIV be disabled by AIDS to be eligible for the program has been a huge barrier. The single most important piece of health care reform for people with HIV is the elimination of this cruel "catch-22."

Starting in 2014, low-income people with HIV will no longer be forced to wait until they are disabled by AIDS to be eligible for Medicaid. Instead, most people who make up to 133% of the federal poverty level (FPL; about \$14,000 for an individual and \$29,000 for a family of four) will be eligible based on income alone. In addition, people newly eligible for the program will be entitled to a benefits package that includes, at a minimum, the same "essential health benefits" required for all health plans sold in the private insurance exchanges created by the health care reform law.

Medicare Part D Reforms

Uninterrupted access to medication is essential for the treatment of HIV. Currently, Medicare Part D has a funding gap known as the "doughnut hole" (people are responsible for paying \$4,550 for their meds after Medicare has paid \$2,830) leaving many unable to afford lifesaving medications. The following reforms will help people with HIV:

- ADAP contributions can now be used to help people get out of the doughnut hole faster and will count toward their out-of-pocket spending. (*Already in effect.*)
- People on Medicare receive a 50% discount on all brand-name prescription drugs, reducing out-of-pocket payments for most people with HIV from \$4,550 a year to approximately \$2,100. (*Already in effect.*)
- The doughnut hole will be phased out and ultimately eliminated by 2020.



Photo: Jonathon Berliner

Access to Private Insurance

People with HIV (as well as millions of others in the U.S.) will be able to purchase private insurance more easily. Starting in 2014, every state will be required to put in place an exchange that will serve as a marketplace for people to purchase individual and small group health insurance plans. Subsidies will be available to people who earn up to 400% of the FPL (about \$43,000 for an individual) to make private insurance more affordable. Plans sold through the exchanges must include "essential health benefits," the details of which will be determined by the federal government.

Elimination of Discriminatory Insurance Practices

Because of harmful insurance practices, it is currently not possible for a person with HIV to buy individual private insurance. In addition, the private coverage available is often limited and does not cover the HIV services needed. Health care reform eliminates many of these harmful practices.

- Health plans are prohibited from excluding children due to a preexisting condition. (*Already in effect.*) Starting in 2014, plans will also be prohibited from excluding adults who have preexisting conditions. In addition, beginning in 2014 no one

can be denied coverage based on HIV status or charged higher premiums because of HIV or other disabilities.

- Health plans are prohibited from placing lifetime limits on coverage. (*Already in effect.*) Beginning in January 2014, they will not be allowed to place annual limits on coverage.
- Insurers are prohibited from cancelling coverage when a person gets sick, except in cases of fraud. (*Already in effect.*)

Prevention and Public Health Investments

Millions of new dollars invested in prevention initiatives, community health centers, and expansions of the health care workforce will mean that people with HIV will have access to comprehensive care from a variety of new sources. Community health centers, for instance, will receive \$11 billion over the next five years to expand. This will allow some Ryan White clinics to become Federally Qualified Health Centers and provides an opportunity to ensure that existing community health centers provide necessary HIV care, treatment, and prevention services. New investments also mean that many newly insured people with HIV will gain access to HIV prevention services and that there will be more health care providers available.

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The Way Forward

Health care reform represents a huge shift in both the health care system and the philosophy behind it. The emphasis on prevention and wellness, community interventions, and integrated models of care has major implications for HIV services and providers, particularly with regard to the Ryan White program. For many people with HIV, care has been provided by distinct programs in separate health care settings. Through these programs, we have developed expertise in coordinated and “whole patient” care, creating a blueprint for the “health home” models that feature prominently in the health care reform law.



But the health care reform train is out of the station. Even the greatest supporters of HIV care and Ryan White programs in the administration and Congress are telling us that the current separate approach to HIV care is no longer tenable. They insist that it will be in the best interests of the thousands of people with HIV who will have access to public and private insurance for the first time for us to put our efforts into making sure that health

care reform works for people with HIV.

We know that even after health care reform is implemented, there will continue to be a need for the specialized HIV care, treatment, and support services provided through the Ryan White Program. So we must begin thinking about what the future of HIV services in general, and Ryan White in particular, should look like. This is especially important given the fact that Ryan White funding has not been enough to meet demand. Moreover, if the HIV community continues to rely solely on Ryan White to ensure that the needs of people with HIV are met, we will have missed an important opportunity to gain access to the billions of dollars in new funding streams included in health care reform. Further, we will have missed an opportunity to integrate the coordi-

nated service delivery model that is the hallmark of the Ryan White Program into the new, larger-scale reforms.

The Top Six Actions Every HIV Advocate Should Take

1. Defend Health Care Reform

Despite the significant strides that health care reform offers in combating HIV (increasing access to Medicaid and pri-

ivate insurance, eliminating harmful and discriminatory insurance practices, increasing prevention efforts), the reform that members of Congress courageously passed last year is in danger of repeal. We cannot let the promise that reform holds for millions of Americans fall victim to a partisan attack.

2. Ensure that HIV Services and Ryan White Infrastructure Are Integrated into Health Care Reform

The Ryan White program has been an essential source of care for thousands of people with HIV, and will continue to provide important services even after some of the major health care reform provisions go into effect. Given the funding difficulties that Ryan White faces and the changes brought about by health care reform, however, we cannot rely on Ryan White alone to ensure that HIV treatment needs are met. We must think creatively about how to integrate its comprehensive services and skilled providers into broader systems.

Ryan White programs offer an important blueprint for the kinds of services needed by people with chronic illnesses. In many ways, Ryan White programs serve as a best-practices model for complete and cost-effective care. We must ensure that these models are integrated into broader health care systems. This means starting conversations with providers, advocates, and lawmakers about how the services that people with HIV depend on can be integrated into community health centers, Medicaid, and private insurance.

3. Ensure that the “Essential Health Benefits” Package Meets the Needs of People with HIV and Other Chronic Illnesses

The health care reform law requires that all plans sold through insurance exchanges, as well as the benefits offered to people newly eligible for Medicaid (those who were not eligible for Medicaid on the date the law was enacted), include “essential health benefits.” This package must contain ambulatory and emergency services, hospitalization, maternity and newborn care, mental health and substance use services (including behavioral health treatment), prescription drugs, rehabilitative services and devices,

laboratory services, preventive and wellness services, chronic disease management, and pediatric services (including oral and vision care). Because the U.S. Department of Health and Human Services must define the specifics of the package, advocacy is needed to ensure that the benefits meet the wide-ranging needs of those who will be entitled to them, including people with HIV.

4. Address the Current ADAP Crisis

We are in the midst of an unprecedented AIDS Drug Assistance Program (ADAP) funding shortage (see article on page 8). The result has been an access-to-care and public health crisis, with over 8,000 people currently on ADAP waiting lists throughout the country. States have also enacted other cost-saving measures such as limiting the drugs covered by ADAP. We must put pressure on state and federal lawmakers to ensure full funding of ADAP, now and through 2014, when the Medicaid expansion will offer prescription drug coverage to most low-income people with HIV.

5. Support Implementation of the National HIV/AIDS Strategy

In July 2010, President Obama announced a National HIV/AIDS Strategy (NHAS), detailing goals and priorities to address the AIDS epidemic in the U.S. and pro-



supporting state applications for “1115 waivers,” which are needed to immediately expand Medicaid to people with HIV who are not disabled.

6. Defend Medicaid

Today, Medicaid is an essential lifeline to care and treatment for many people

The health care reform train is out of the station. Even the greatest supporters of HIV care and Ryan White programs in the administration and Congress are telling us that the current separate approach to HIV care is no longer tenable.

viding a roadmap for drastically cutting the number of new HIV infections, increasing access to care and treatment, and reducing health disparities. As a community, we fought hard for the NHAS, and we must be prepared to continue to fight for its full implementation. Advocates should work with federal agencies, state health officials, and community-based organizations to implement NHAS provisions, such as

with HIV. Starting in 2014, Medicaid will become an even more important source of care for thousands of currently uninsured people with HIV who will be eligible for Medicaid because of health care reform. To make sure that Medicaid is able to meet this need, HIV advocates should join forces with others outside the HIV community to protect against harmful cuts to the Medicaid program at both the state and federal levels.

Conclusion

There are many unknowns regarding health care reform, and the HIV advocacy community must be ready to respond to setbacks. Whether Congress, the President, or state governments have the political conviction to fulfill the promise of health care reform in ways that most benefit our community is an open question.

That being said, now is not the time to ignore the tremendous opportunities presented by the new funding and innovative service delivery initiatives provided through health care reform. Instead, we should be working to defend the law and to ensure that Ryan White services, providers, and models of care are integrated into health care reform initiatives. The role of Ryan White in health care reform is a complicated issue, and the HIV community will benefit from an open dialogue about the best way forward. ■

Robert Greenwald is the Director of the Legal Services Center of Harvard Law School's Health Law and Policy Clinic and Director of the Treatment Access Expansion Project (TAEP). Amy Killelea is a clinical fellow and attorney with the Clinic and TAEP.



From Strategy to Reality:

What We Need to Know to Make the NHAS Work

by Stephen F. Morin, PhD., Raymond A. Smith, PhD,
and Robert H. Remien, PhD

The White House released the first National HIV/AIDS Strategy in July 2010 to provide “a concise plan that will identify a set of priorities and strategic action steps tied to measurable outcomes.” Accompanying the Strategy is a Federal Implementation Plan that outlines the steps to be taken by Federal agencies.

Both the Strategy and the Plan recognize that new research activities will be needed to advance HIV prevention, treatment, and care. For example, “the Strategy cannot succeed without continued and sustained progress in biomedical and behavioral research...current approaches to preventing HIV must be coupled with research on new and innovative prevention methods that can have a long-term impact.” But neither document provides an overview of the main research challenges.

Early Testing

Existing evidence suggests that a voluntary “test and treat” approach could dramatically reduce new HIV cases within a decade. Some think it could even halt the pandemic. But before this approach can begin, it will be necessary to carry out research to study its feasibility, effectiveness, benefits to individuals vs. benefits to society, and cost-effectiveness.

The CDC estimates that over 200,000 people in the U.S. have HIV but are unaware of it. The percentage of those who don’t know is higher in certain groups, such as young men of color who have sex with men (MSM). CDC guidelines from 2006 call for screening all patients for HIV, unless the rate of HIV infection in their risk group is extremely low. People in high-risk groups, such as MSM,

injection drug users, sex workers, partners of people with HIV, and heterosexuals with more than one partner, should be screened at least once a year, as should people being treated for TB or sexually transmitted infections.

Knowing your HIV status provides significant individual and social benefits, and also helps to advance the goals of the Strategy. Early detection allows people to begin treatment at the best time. People who know they have HIV are much less likely to have unprotected sex. And those who are on treatment are also less infectious. Treatment also has an impact on reducing “community viral load” (the average viral load of people living in a certain area).

Social marketing campaigns in Washington, DC, and the Bronx are highlighting the importance of getting tested. In Washington, the number of publicly funded HIV tests increased from 19,766 in 2004 to 72,866 in 2008, and there was a 17% increase in the number of HIV diagnoses reported from 2004 to 2007. Between 2004 and 2008, there was also a significant increase in the length of time people took to progress to AIDS and a significant improvement in the time between diagnosis and entry into care.

But reaching much larger numbers of people will require a greater “routinization” of testing. This means the HIV test must be automatically offered in a variety of medical settings—doctors’ offices, clinics, emergency rooms, etc. Early evidence suggests that more extensive routine screening programs are likely to be cost effective only when focused on groups with a higher risk of HIV. For example, one large study of routine testing in six health centers in the South offered HIV tests to 16,291 adults. Over 11,300 agreed to be tested, but only 17 tested positive. That may not be the best use of precious HIV dollars.

Given current budget limitations, the Strategy must be mindful of costs. Research is needed to determine when and where routine testing should be done. One early finding in San Francisco found that a high percentage of people who received an HIV diagnosis late in their disease did so in emergency rooms. This reveals a lost opportunity for early diagnosis. Important research topics include how to develop protocols for routine HIV testing in different settings, and studying how the offer of HIV testing is affected by what condition brought the patient there, language barriers, or even time of day.

To achieve the Strategy's goals, research is needed on how to identify more people earlier in their infection. Community mobilization and outreach strategies could be promising ways to increase the frequency of testing. These could include text messaging and incentives (like bus fares or snacks) for regular screening, and making testing more of a norm within communities. Although a great deal is already known about community mobilization, more research is needed on community preparedness, the involvement of community leaders, linkage to other community goals, and outreach strategies like testing at events.

Promising approaches to diagnose HIV-positive people earlier include improved testing technologies, awareness campaigns for providers and for people at risk, and counseling protocols for use when people test positive. One study at the University of California, San Francisco followed a high-risk, mostly homeless group of drug users and found that more frequent testing (every three or six months) was more acceptable than testing based on symptoms. It also found that it's best to bundle HIV testing into other services, make the process quick and convenient, and offer incentives. This could help to advance the Strategy's second goal of increasing access to care and improving the health outcomes of people with HIV

Linking To Care

HIV infection is a lifelong disease, and testing is only the first step of a long relationship between patients and providers. It requires regular check-ups and management of treatment regimens. "Treatment engagement" is defined as the patient seeing the provider at least once in a six-month period. Using this definition, one study found that those who were highly engaged had an average viral load below 17,000, while those not engaged had an average over 28,000.

Previous guidelines recommended HIV treatment for people with CD4 counts below 350, but that number has now been revised upward to 500. Some providers and public health experts recommend treatment for all people with HIV, regardless of CD4 count, for improved health outcomes and public health. Mathematical modeling suggests that more widespread treatment could result in many fewer infections. This would greatly assist in advancing the goals of the Strategy.

But linkage to care and retention in care are distinct processes. Engagement in care is vital for HIV treatment success, especially for members of groups with a high rate of HIV infection. Additional services, such as mental health and substance abuse care, play a crucial role in engagement and retention. Research has shown that missed visits in the first year of care are associated with increased mortality, but there have been no controlled trials or even a consistent definition of retention. Is it measured as one visit in three months or in six months? Data are also not linked to the content of the visit, making it difficult to assess the reasons people don't return for follow-up.

There are few studies on linkage and retention in care. One study sponsored by the CDC, however, found that five case management sessions resulted in increased linkage to care. At six months, 78% of those receiving the intervention kept an HIV provider appointment, compared with 60% of those who did not receive the intervention. At 12 months, 64% who were in the intervention arm kept an HIV provider appointment versus 49% of those who were not. Additional research in this area is needed.

Another major obstacle to retention in care is medication adherence. Research shows that adherence approaches should include practical tools like pill boxes, alarms, calendars, etc. We should also address complex barriers like stigma, access to care, cultural beliefs, economic problems, and depression. Further research is needed in all of these areas, as well as on the impact of various approaches, such as cognitive, behavioral, and social support; contingency management; home visits, and directly observed therapy.

There is also a need for mental health and substance abuse care for people with HIV. Short computer-based screening in waiting rooms could be combined with risk assessment, and more innovative use of electronic medical records could also offer benefits. This is yet another area where more research is needed.

Conclusion

As President Obama noted in the opening statement of the National HIV/AIDS Strategy, "researchers have produced a wealth of information about the disease, including a number of critical tools and interventions to diagnose, prevent, and treat HIV." With solid evidence based on rigorous research, the National HIV/AIDS Strategy finally provides an opportunity to get ahead of the epidemic. But that will only be possible with more evidence and further research, to build on prior successes. ■

Stephen Morin is Director of the Center for AIDS Prevention Studies at UCSF. Raymond Smith and Robert Remien are Research Scientists at the HIV Center for Clinical and Behavioral Studies, NYS Psychiatric Institute, and Columbia University.

To achieve the Strategy's goals, more research is needed on community preparedness, the involvement of community leaders, linkage to other community goals, and outreach strategies like testing at events.



The ADAP Crisis: Waiting for Meds

by Lanny Cross

AIDS Drug Assistance Programs (ADAPs) provide access to life-saving medications for low-income, uninsured, and underinsured people with HIV. ADAPs began in 1987, when Congress approved funds to help states purchase the only approved HIV drug at that time, AZT. They have since become the “payer of last resort” for thousands of people with HIV whose incomes are too high for Medicaid but who lack private health insurance. With more than 210,000 enrollees last year, ADAPs cover over a third of all people with HIV receiving care in the U.S.

To provide this access, ADAPs must balance the available resources and demand for services. This has become increasingly difficult in the past two years, as thousands of new people applied due to the recession and growing unemployment rolls. At the same time, federal funding for ADAPs has stagnated and states have not increased their contributions. A crisis has developed, affecting access to HIV medications for thousands of people across the country.

The Current Crisis

As of June 9, 2011, there were 8,230 people on ADAP waiting lists in 13 states. Eighteen ADAPs, 11 with waiting lists, have insti-

tuted additional cost-containment measures in the last year. In addition, 13 more ADAPs are considering new or additional cost-containment measures.

This is not the first crisis for ADAPs. The programs were overwhelmed by demand when highly active antiretroviral therapy (HAART) was introduced in 1996. This treatment breakthrough and the resulting increase in costs had not been anticipated during that year’s federal budget process. But strong advocacy from the HIV community and irrefutable evidence of the cost-effectiveness of HAART resulted in an infusion of federal funds and several years of large budget increases, which enabled the programs to expand enrollment and formularies (the list of drugs they cover). By 2000, however, the federal focus on ADAPs waned and later increases were inadequate. Once again, ADAPs began to struggle.

This time it was the states that came to the rescue. In 2003, a group of AIDS Directors and ADAP Coordinators formed the ADAP Crisis Task Force and negotiated with the drug industry for lower drug prices and bigger rebates. This has resulted in more than \$1 billion in savings for ADAPs in the past seven years. States also dramatically increased their contributions to ADAPs, almost doubling from \$171 million in 2003 to \$328 million in 2008. ADAPs also benefited from the new Medicare Part D drug program in 2006, which allowed them to shift some clients to that federal program. The combination of lower drug costs and higher state funding allowed most ADAPs to struggle but survive.

But today, a convergence of factors has led to another crisis. Due to the recession that began in 2007, thousands of people with HIV have lost employment, and along with it their health insurance. Also, dramatic increases in health care costs in recent years have resulted in higher health insurance premiums, causing some

As of June 9, 2011, there were 8,230 people on ADAP waiting lists in 13 states. Eighteen ADAPs, 11 with waiting lists, have instituted additional cost-containment measures in the last year.

employers to drop health insurance. These national problems have increased the number of people relying on ADAP. At the same time, Federal funding increases have remained inadequate, and state contributions to ADAP were reduced in 2009 as states grappled with their own budget woes. Public health initiatives, such as the national effort to expand HIV testing and linkage to care, and new HIV treatment guidelines calling for starting HAART earlier, have also contributed to pushing ADAPs to the tipping point.

Cutting Back

There are three basic ways to reduce ADAP costs: who is covered (eligibility); what is covered (formulary); and how much is paid for drugs. After years of lean times, ADAPs have trimmed and refined their programs so that only minimal savings can be found by lowering administrative costs, meaning there are no easy answers. Cost containment options are considered with input from consumers and health care providers, and implemented only after a lengthy process that struggles with conflicting goals (access and savings), the ethics of various options, and the potential for unintended consequences.



ADAPs were created for people with low incomes, so a frequent response to a lack of funds is to lower the financial entry criteria. There are two problems with this approach. First, the vast majority of ADAP clients already have low incomes – 89% make less than 300% of Federal Poverty Level (FPL): \$32,670. So lowering eligibility from 400% to 300% has only a limited impact. Second, drug company patient assistance programs (PAPs), which are the final safety net after ADAPs, often require an income of 300% FPL. So, people in “higher” income brackets can be left without any form of assistance, unable to afford close to \$2,000 a month for HAART. Waiting lists for enrollment, with case managers helping people apply for a PAP, has therefore become the option most frequently used by ADAPs.

Reducing an ADAP’s formulary has similar problems. Antiretrovirals are the highest priority for ADAPs and con-

sume on average 89% of their budgets. The remaining 11% is primarily spent on essential drugs for opportunistic infections, leaving only a small amount for drugs that treat HIV-related conditions and the side effects of HAART. Formulary reduction is at best a minor cost saving and may have serious implications for the quality of life of clients.

Negotiations between the ADAP Crisis Task Force and drug manufacturers have reduced the cost of antiretrovirals for ADAPs to the lowest prices for any payer in the U.S. ADAP prices for these drugs are currently below those achieved in Canada and the European Union through their universal health care systems and government pricing regulations. Further efforts to reduce costs could focus on the drug distribution system, but that can lead to tradeoffs between modest savings and limiting the ways clients receive their drugs – with serious implications for adherence and drug resistance.

Moving Forward

There are some encouraging signs for the future. The Affordable Care Act, enacted in March 2010, aims to provide healthcare to all Americans. It takes several steps toward national health care reform over the next four years. Included are provisions that further reduce drug costs for ADAPs, as well as enabling them to take advantage of the Medicare Part D drug benefit. The drug pricing provision of the Act provided a springboard for a series of new ADAP Crisis Task Force negotiations with drug companies, which resulted in further price reductions. Beginning in 2011, ADAP payments for co-pays and deductibles for clients who are covered by Medicare Part D will count toward the client’s cost-sharing requirements. This will allow them to reach the Part D “catastrophic coverage” level sooner and reduce costs to both the individual and ADAP. Previously, Part D clients had to pay more than \$4,500 a year of their own money to reach this level. That was unaffordable to most people, so it was necessary for ADAPs to cover most of their HIV drug costs.

Temporary high-risk insurance pools have now opened, and ADAPs will attempt to move clients into them – but they will most likely fill up very quickly. Beginning in 2014, health insurance exchanges will begin (see cover story). Most ADAPs already help certain clients pay their insurance premiums, so they will be able to move additional clients into private health insurance and assist with the costs. In 2014, the law expands Medicaid eligibility – tens of thousands of ADAP clients will move to Medicaid.

These reforms all bode well for the long term prospects of ADAPs. Ultimately a rebounding economy will provide increasing tax revenues, but state government revenues tend to lag and it may be several years before states are in a position to willingly direct more money to ADAPs.

Fighting for Funding

HIV advocates constantly monitor the health of ADAPs and mobilize when access is threatened, at both the state and national level. Advocacy can take many forms and have varied goals, ranging from a national solution to the ADAP crisis to brokering stopgap measures.

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The ADAP Coalition brings together national HIV advocacy organizations and drug manufacturers to work together for increased federal funding of ADAPs. These efforts had significant success from 1996 to 2002, but since then advocates have been unable to persuade Congress or the President to provide increases that meet the growing demand. This work has kept ADAP in the spotlight, however, and provided some increased funding, even when other health programs were flat-funded. In the summer of 2010, as ADAP waiting lists grew, President Obama redirected \$25 million to ADAPs in crisis. This led to hundreds of clients being removed from waiting lists, but the amount was inadequate and waiting lists have rapidly grown.



The Fair Pricing Coalition (FPC) is a group of community treatment activists advocating for fair and sustainable pricing of HIV and hepatitis drugs in the U.S. The FPC also works with drug companies to ensure that adequate co-pay and patient assistance programs are in place. In January, the FPC brokered agreements that will allow approximately 6,500 Floridians to continue to receive their HIV medications during that state's budget crisis. Florida's ADAP was expected to exhaust all available funds and shut down in early February if an emergency solution was not found. The agreement between Welvista (a non-profit pharmacy), drug companies, and Florida's ADAP provided uninterrupted medications to 6,500 people, who switched to Welvista until April 1, 2011, when new federal ADAP funds became available. The transfer enabled Florida's ADAP to provide drugs to its remaining 3,500 clients for the rest of the fiscal year.

A strong and well organized advocacy effort was initiated in California in October 2009, which was able to turn back a pro-

posed devastating reduction in state funding in the state's ADAP. Despite California's overwhelming fiscal crisis, \$56 million in new state funds were appropriated for ADAP. In North Carolina, a similar grassroots effort resulted in an increase of \$15 million. In New Jersey, advocacy reversed the governor's plan to remove 500 clients from ADAP. On the other hand, South Carolina reduced ADAP funding by 60% in 2010, and Minnesota's 2009 contribution of \$4.5 million was eliminated in 2010. Despite budget deficits estimated to be more than \$142 billion, state governments generally responded generously to the ADAP crisis, increasing the national state contribution level to \$346 million, a 57% increase from 2009 to 2010. As shown by the setbacks in Minnesota and South Carolina, however, advocacy efforts must never be allowed to rest on past successes.

The Politics of ADAP

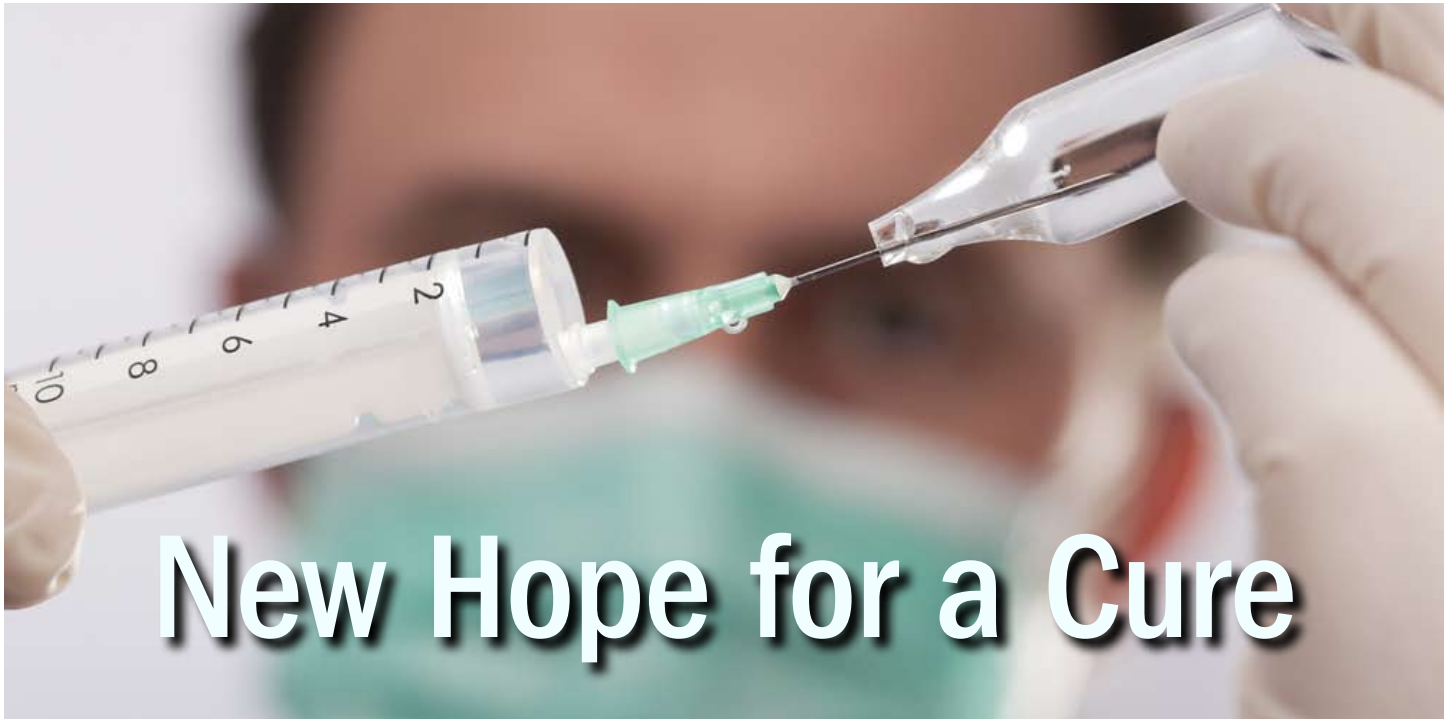
The recession and the 2010 elections turned the tone of political discourse very nasty. Radio and television pundits railed against government spending and taxes, vilifying government programs that serve the needy. Many of those who escaped the worst impacts of the recession are still suffering from financial anxiety and have turned to a political ideology that puts self-interest ahead of the general good and the needs of those less fortunate. Racism, bigotry, and homophobia are increasingly being exploited for political gain and are reflected in calls for devastating budget cuts to health and human services for low income and minority populations.

This political environment may seem overwhelming, but the HIV community must continue to advocate for essential care and services. Advocates must become more effective in their tactics and stand united against those who would slash and burn public health programs like ADAP. The HIV community can assist in efforts to keep ADAPs open by becoming involved with local AIDS service and advocacy organizations. These organiza-

tions must keep local communities informed about the status of their state ADAP and find ways to work with others to increase ADAP resources. Letter-writing campaigns and visits to elected officials make a real difference in funding levels, and coordinated efforts have the most impact.

On an individual level, if someone needs access to HIV medications he or she should apply to ADAP, even if there is a waiting list. While the idea of being on a list can be discouraging, it documents the need for additional funding and will position the person for eventual enrollment. The application process should bring a referral to an AIDS service organization and a case manager to help with applying to PAPs for medications. These programs can provide support and access to other services, as well as opportunities to participate in advocacy efforts. ■

Lanny Cross served as the NYS ADAP Program Director for 15 years and is a consultant on ADAP issues to state and national organizations.



New Hope for a Cure

by Mark Milano and
Donna M. Kaminski, DO, MPH

Since the earliest days of the epidemic, people have hoped for a cure and a vaccine. In 1984, when the discovery of HIV was confirmed, then-Secretary of Health and Human Services Margaret Heckler famously announced that a vaccine would be ready for testing within two years. Over 27 years later, we're still waiting. Likewise, David Ho estimated in 1996 that highly active antiretroviral therapy (HAART) could eradicate HIV from a person's body after two years – a cure. As many suspected, that was somewhat optimistic – the actual time on HAART needed to rid the body of all HIV has been estimated to be as long as...78 years!

Eradication

The reason? Well, we now know that HIV “seeds” certain reservoirs in the body very soon after infection: the gut, brain, genital tract, and an important part of the immune system known as “resting memory CD4 cells.” These cells have been a particular target of cure research. Unlike most CD4 cells, which live only a week, memory CD4 cells live for decades. They do this by shutting down – going into hibernation – to be reactivated only when the infection they were created for reoccurs. HIV infects about one in a million memory CD4 cells,

and attempts to purge them of HIV have so far proven futile. But efforts are continuing. Over 20 HDAC inhibitors (cancer drugs that may be able to activate the latent virus in these cells) are being studied. IL-7, a growth factor found in the body, can activate cells and is moving forward into clinical studies. There has even been talk

Four years after the treatment, researchers can find no trace of HIV in Tim's body. So it appears that at least one person has been cured of HIV.

of destroying all these cells, but that would wipe out all the “immune memory” a person has spent a lifetime building. It also wouldn't solve the problem, since there are other places in the body HIV can hide, and other cells (dendritic cells, monocytes, macrophages, etc.) that act as reservoirs.

The good news is that the low-level replication in these reservoirs usually does not create resistant virus if a person's viral

load remains undetectable. The bad news is that HIV is still there and once HAART is stopped, viral loads quickly rebound.

The First Cure

So the possibility of finding a treatment that could eliminate every particle of HIV from the body remains slim. Hopes for a cure got a boost in 2008, however, when researchers reported on Timothy Brown, the “Berlin Patient.” He had failed treatment for leukemia, so a risky bone marrow transplant was attempted. But instead of searching only for a bone marrow match, scientists looked for a donor who also had the “delta 32” mutation. It was discovered in the early 1990s that some people have a natural mutation that eliminates a receptor HIV uses to enter cells: the R5 receptor. Studying these rare individuals led to the development of Selzentry, which blocks R5. But Tim's case was different – an attempt to replace his CD4 cells with ones that completely lacked the R5 receptor.

Happily, it seems to have worked. Four years after the treatment, researchers can find no trace of HIV in Tim's body, even using the most sensitive tests. So it appears that at least one person has been cured of HIV. Unfortunately, the treatment used is not only life-threatening, it's also expensive – about \$250,000.

Could there be other ways to achieve a cure? That depends on how you define

continued on next page

New Hope for a Cure *cont. from previous page*

“cure.” In his regular updates on the possibility of a cure, Dr. Anthony Fauci, head of NIAID, talks about the search for both a “sterilizing cure” and a “functional cure.” The former refers to the removal of all HIV from the body – something Fauci thinks is unlikely in the near future without a major scientific breakthrough. But the latter is something we may live to see. A treatment for a functional cure would “reprogram” the immune system to control HIV with-

manent residence in the human body as soon as someone is born. We just live with them. Could there be a way to do the same thing for HIV?

Recent Efforts

Just recently, two studies presented at the 18th Conference on Retroviruses and Opportunistic Infections (CROI) in Boston presented treatments that may be able to do just that. Both used gene therapy, a process in which a portion of a person’s blood is removed and CD4 cells are separated

They had an average CD4 count increase of 200 just two weeks after receiving the infusion, and sustained it for a year without any further infusions. The great news is that for some, CD4 counts increased by as much as a 1,000 and that a year later, the increase was still over 900. All of the men tolerated the infusion well, without any serious side effects. Some less serious side effects included chills, fever, headache, sweats, dizziness, fatigue, and a short-lived “garlic” body odor. All of these were easily managed. One man did not respond, which the researchers think may be due to his lower CD4 count before receiving the infusion.

When the investigators looked closely at what effect the infusion had, they found that 25% of the reinfused cells had no CCR5 receptor, and after three months, up to 6% were still missing the receptor. It also appears that the modified cells reached many different parts of the body, including the gut. This suggests that a single infusion may lead to a supply of modified CD4 cells lasting at least a year if not longer.

The trial is continuing and will look at the effect of gene therapy on several groups of people. Jay Lalezari at UCLA will study as many as 21 people with less than 500 CD4 cells who have never been on HAART therapy respond to the gene therapy. Trials will also expand to include a total of 18 participants in Philadelphia and New York City in the upcoming months. These studies will look at how the therapy works in three groups:

- People who have not responded to HAART (viral loads over 2,000 and CD4 counts above 200)
- People who have responded to HAART and have undetectable viral loads
- People who have responded to HAART, but have CD4 counts below 500

Other approaches

Researchers are studying several approaches to curing HIV. A wide range of drugs is still being researched in the hopes they could purge latent HIV from memory CD4 cells and other reservoirs. Enhancing the ability of the immune system to kill HIV is being studied, as is “epigenetic regulation” – the genetic signals that enable HIV to remain in hiding. If these are understood, there may be a way to force



out any medication. We know there are people who can do this (long-term non-progressors) and they are being studied by Bruce Walker in the International HIV Controllers Study (hivcontrollers.org).

It’s actually quite common for the immune system to rely on a functional cure when a systemic cure is not possible. For example, varicella zoster virus, which causes chickenpox, is never eliminated from the body. It remains in the spinal fluid for life, but a healthy immune system can control it. This is the case for many pathogens. In fact, if all the microbes in the body are counted, 90% of them are not human. An incredible number of bacteria, viruses and other pathogens take up per-

out and modified by treating them with a “zinc finger” nuclease that blocks the R5 or X4 receptors. With a now changed set of genes, the CD4 cells are reinfused within 20-30 minutes. Two investigators reported using this technology, the first being Jay Lalezari of Quest Clinical Research in San Francisco, and the second Craig Wilen of the University of Pennsylvania.

In the Lalezari study, six men who had CD4 counts between 200 and 500 (despite having been on HAART for at least two years with undetectable viral loads) received the gene therapy SB-728T. After having had their blood removed and treated with the drug, five of the six men responded well to the modified CD4 cells.

HIV out into the open where medications can attack it.

While most strains of HIV use the R5 receptor to enter a CD4 cell, some use the X4 receptor. An ideal therapy would block or delete genes for both the R5 and X4 receptors, and one group is studying a gene therapy targeting the X4 receptor. Craig Wilen, a biomedical graduate student at the University of Pennsylvania, reported on efforts to design a therapy that knocks out the X4 receptor. Using the same zinc finger nuclease approach, the team disrupted the X4 receptors on human CD4 cells, and then injected them into mice which were then exposed to HIV. The gene therapy seemed to protect the mice from HIV infection. These studies are still in their earliest stages and have a long way to go before we will know if these therapies are safe and well-tolerated.

“Whether a cure is going to come from one approach or some combination, I do think it’s possible that in our lifetime we’ll be curing HIV.”

Another new approach is being pursued in a drug called KP-1461, which works by increasing HIV’s rate of mutation. HIV has a very high mutation rate, allowing it to become resistant to many of the medications that fight it. But this may also be its weakness. KP-1641 has been shown to cause “viral decay acceleration” in the lab. In the presence of the drug, HIV mutations accumulate over time and eventually the virus mutates until it is no longer viable. While the test tube results are promising, clinical trials are needed to prove its efficacy in people, and are under way.

When?

That’s the \$64,000 question. Most researchers have stopped trying to predict when a cure might be available, especially after learning from the many wrong pre-

dictions regarding a vaccine. Years ago, the standard line was, “We’ll have a vaccine in ten years.” After numerous missed deadlines, no one makes such predictions any more. But Jay Lalezari recently told the Bay Area Reporter, “Whether a cure is going to come from one approach or some combination, I do think it’s possible that in our lifetime we’ll be curing HIV.”

Funding the Cure

The question surrounding a functional cure may not be “if” but “when?” The bigger question is how quickly will the needed research get done? In 2009, NIAID spent \$40 million on AIDS cure research. But its total AIDS budget was \$1.5 billion, meaning that less than 3% was spent on cure research. Worldwide, less than 1/3 of people with a CD4 count below 500 are receiving HAART. Without a functional cure, millions will be dependent on world leaders and international charities to pay for the drugs they need to stay alive. Meanwhile, even those with access to excellent treatment still suffer from diseases of premature aging or heart attacks and kidney problems as a result of a persistent virus that causes long-term inflammation.

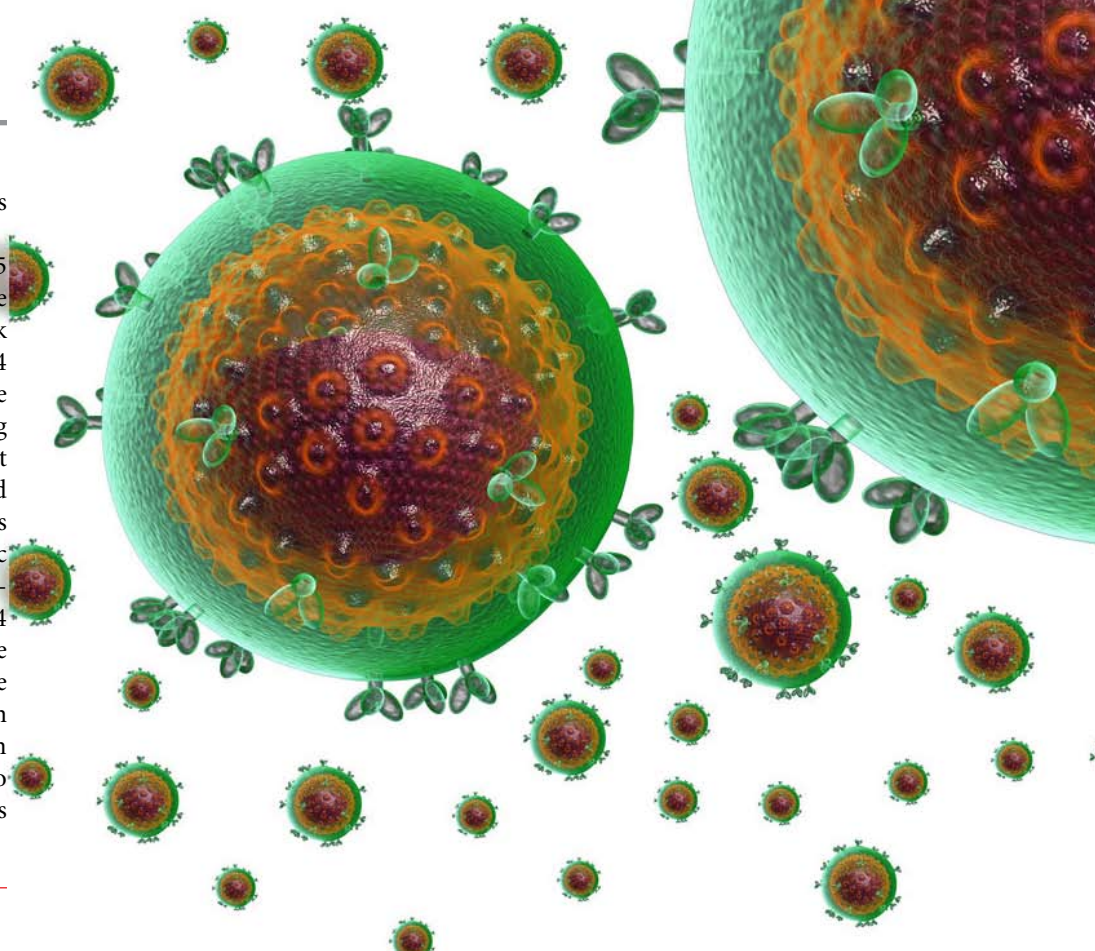
There have been only 12 clinical trials at the NIH’s Division of AIDS focused on a cure since 2005. Of those, three are enrolling, three are in development, and three are “pending.” This means that there is little translation of basic science into producing cures that could be used by people. So far, there have been trials of gene therapy, intensifying HAART, therapeutic vaccines, and the efforts to purge HIV reservoirs, but much more work is needed.

Community action is needed to push Congress and the NIH to make a cure for AIDS a top funding priority. The AIDS Policy Project (aidspolicyproject.org) is calling for a funding increase to \$240 million. They’re also helping researchers cut through red tape, encouraging them to work together and share information, and advocating for new treatments to be tested in people as soon as it is safe to do so.

Finding a cure won’t be easy, but with a real effort it could be a reality sooner than we think. ■

Mark Milano is an HIV Health Educator and the Editor of Achieve.

Donna Kaminski is a resident physician at Somerset Medical Center.



The Changing Face of HIV Testing

by Nelson Villegas

As an AIDS service provider, I was always told that the need for written informed consent for HIV testing couldn't be stressed enough. But I also experienced first-hand the difficulty of getting clients to discuss their very personal risky behaviors. And once that challenge was overcome – once they felt comfortable enough to discuss risk reduction and the need for HIV testing – I then had to re-establish enough rapport to get written consent before we could actually move forward with an HIV test. Sound complex? It was.

Too many medical providers have been hesitant to provide adequate information and HIV testing. The HIV stigma that we battle every day (ingrained even in medical providers) hinders early detection.

But due to the recently amended HIV Testing Public Health Law in New York State, more people will have access to HIV testing without having to give written consent. The new law states that consent can be given orally, as long as the person understands the test is for HIV, the routes of transmission, and the meaning of the test results.

The amendment also makes it mandatory for health providers to offer HIV testing to all of their patients

between the ages of 13 and 64, and to younger people if risks are present. This can only help us fight AIDS, as it is a huge “small step” that will help to normalize and destigmatize HIV. Too many medical providers have been hesitant to provide adequate information and HIV testing in our communities. The HIV stigma that we battle every day (ingrained even in medical providers) not only prevents information from authoritative figures like doctors from reaching those who need it, but also hinders early detection – one of the most important components of defeating HIV.

I remember meeting one young man who at the age of twelve had engaged in more HIV risk behaviors than most adults I've met. He shared that he had tried to get an HIV test after attending an “HIV 101” workshop that I presented at his school. He went to see his pediatrician, who checked him for “everything.” When he returned to get his results, he discovered that “everything” did not include an HIV test. He received a physical examination with bloodwork, but to this day is unsure exactly what that included. He lost faith in his doctor and decided to research some nearby community-based organizations, who also refused to test him for HIV because of his age. He then realized that he had my contact information and reached out to me for support. Since I was an Adolescent Health Education Specialist with the youth department of my organization, I worked to make sure he was educated, counseled, tested, given his results, and linked to necessary care. I hope that with the newly amended law, HIV testing will be a lot more accessible to young people like him, who need it the most.

I also recall counseling a young woman who never believed she was at risk for HIV until she was diagnosed. She shared her thoughts about her relationship with her doctor, saying that if he had discussed HIV testing during any of her many visits, perhaps she would have realized its gravity and taken greater steps to protect herself. At the very least, she could have found out her HIV status at a much earlier stage of the disease. Again, this dem-

onstrates the need for greater integration of HIV awareness and testing into our everyday lives. The message should start at home and flow all through the media, which has such great influence in our society. And we need accurate information, of course!

I hope that with the newly amended New York State law, HIV testing will be a lot more accessible to young people, who need it the most.

I've met many people who feel like the amended testing law will have little to no effect on their lives, or the process they follow to test for HIV and other STIs. They talk to me about their lack of access to medical providers due to poverty, lack of insurance, and immigration status. They tell me that all they have left are the community-based organizations, which can provide them with free and confidential services.

Other clients have told me during counseling sessions that they have health insurance and medical providers, but still choose to go to community-based organization for services, including regular HIV and STI testing, education, safer sex and harm-reduction materials, and supportive services. Their reasons range from the bias-free and nonjudgmental environment that these organizations offer to the availability of multiple services available at one place – something we call “one-stop shopping.” It's about establishing a comprehensive and well-rounded model of care that engages community members about overall health and wellness.

I guess there are no shortcuts to education and awareness yet, but that's for another article and another day. Perhaps



it'll be when we as society are ready to truly integrate HIV education in all aspect of our lives: real information accessed through school education, faith-based settings and even our day-to-day peer conversations.

As a society, we need to truly integrate HIV education into all aspects of our lives, including comprehensive information in school programs, faith-based settings, and even in our day-to-day peer conversations. I'm not saying that our leaders don't care about HIV, because throughout my years as an HIV educator I've met many teachers, organizers, and faith leaders who take a direct role in spreading HIV awareness. But at the end of the day, we can always learn and improve our efforts to defeat HIV. We can always do more. ■

Nelson Villegas is the Program Coordinator of Counseling, Testing, and Referral Services at Harlem United.

THE NATIONAL AIDS STRATEGY

An Opportunity for Activism

by John Hellman

In July 2010, the White House Office of National AIDS Policy released the first National HIV/AIDS Strategy to address the epidemic in the U.S. It outlines an agenda for reducing new infections, increasing access to care, and reducing HIV-related health disparities. The goal of this strategy is expressed in its vision statement:

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.

This statement mentions the many different factors that AIDS advocates have been talking about since the beginning of the epidemic. Although this first national AIDS strategy was not announced until 30 years later, it does represent a breakthrough.

For advocates, it is important to understand how the Strategy understands “the problem.” In 1982, the CDC stated that homosexuals, hemophiliacs, heroin users, and Haitians were most at risk for HIV. Almost 30 years later, similar groups of people – African-Americans, Latinos, and men who have sex with men (MSM) – continue to be at the center of the epidemic. Also emphasized in

the Strategy are people struggling with addiction, injection drug users of all kinds, and people located in certain “hot spots” such as the Northeast, the South, Puerto Rico, and the Virgin Islands. The Strategy notes that “by focusing our efforts in communities where HIV is concentrated, we can have the biggest impact in lowering all communities’ collective risk of acquiring HIV.”

The Strategy acknowledges that there have been significant medical advances in HIV treatment that enable people with HIV to live longer lives. So what prevents all affected groups from getting them?

After 30 years, why do many of the same groups continue to dominate new HIV infections? The Strategy acknowledges that there have been several significant medical advances in HIV treatment and care that enable people with HIV to live much longer lives. So what obstacles prevent all affected groups from getting them?

High-Risk Groups

First, the Strategy outlines a plan to reduce new HIV infections, particularly among “gay and bisexual men of all races, Black men and women, Latinos and Latinas, people struggling with addiction, including injection drug users.” Along with this, the Strategy states in bold that “not every person or group has an equal chance of becoming infected with HIV.” In fact, gay and bisexual men of all races are the only group where HIV infections are increasing.

The Strategy notes that gay and bisexual men made up the largest portion of the epidemic in the 1980s and in the U.S., they still do.

It is clear that African Americans overall and gay and bisexual men (irrespective of race or ethnicity) continue to bear the brunt of HIV infections in the United States.... Blacks comprise the greatest proportion of HIV/AIDS cases across many transmission categories, including among women, heterosexual men, injection drug users, and infants...the United States cannot reduce the number of HIV infections nationally without better addressing HIV among gay and bisexual men.

Second, the strategy aims to increase access to care and improve health outcomes for people with HIV. Although there have been significant medical advancements in HIV treatment, many obstacles to care remain. People with HIV must also deal with other conditions, such as heart disease, mental health problems, and substance use. Social factors like poverty, unemployment, domestic violence, homelessness, hunger, and lack of access to transportation are also listed as barriers. Finally, race, gender, and geography are significant factors that influence the outcome of treatment. The Strategy notes that

HIV-positive African Americans and Latinos are more likely to die sooner after an AIDS diagnosis compared to HIV-positive whites; HIV-positive women are less likely to access therapy compared to HIV-positive men; and access to care and supportive services is particularly difficult for HIV-positive persons in rural areas, as well as other underserved communities.



Third, the Strategy outlines a need for a reduction in HIV health inequalities. For example, HIV diagnoses among Black males are the highest of any group, a figure seven times higher than that for White males. Diagnoses among Latinos are three times higher than among White males. The Strategy notes that although overall deaths have declined due to new treatments, not all groups have benefited equally:

Racial disparities in HIV-related deaths also exist among gay men, where Black and Latino gay men are more likely to die from AIDS compared to White men, and among women, with Black women and Latinas at greater risk for death compared to White women. Gay and bisexual men comprise the majority of people with HIV who have died in the United States.

In order to support this bleak reality,

discrimination and stigma are cited as co-factors. The Strategy recognizes that certain people, particularly African-Americans, Latinos, and MSM, face a much more difficult reality than others. Discrimination in housing, employment, health care, and other social services presents an obstacle to reducing health disparities. To this end, the Strategy boldly claims that:

Working to end the stigma and discrimination experienced by people living with HIV is a critical component of curtailing the epidemic. The success of public health policy depends upon the cooperation of the affected populations.

To clarify what kind of discrimination the Strategy is referring to, the Implementation section specifically refers to “discrimination based on HIV status.”

The Strategy’s Significance for Advocates

It is clear that the disproportionate impact of HIV on African Americans, Latinos, and MSM is a priority for the Strategy. The statistics are shocking and the acknowledgment is welcome. But the expectation that the Strategy will end the epidemic or provide significant changes to the U.S. response to HIV is misguided. After all, the Strategy doesn’t provide any additional funding, only a guide for the use of already existing funds – funds that are threatened by recent budget-cutting moves at all levels of government.

It’s tempting to praise any instance where co-factors are mentioned by government agencies, since they have been ignored in the past. But to grasp the impact of the Strategy, we must understand the overall political landscape. In 2010, the Latino Commission on AIDS released a report titled *New York State Responds to the Latino HIV/AIDS Crisis and Plans for Action*. It approached the issue of HIV and Latinos in New York by acknowledging the issues that affect transmission, testing, and treatment in the Latino community.

For example, fear of deportation often prevents undocumented immigrants from seeking services. One of the sources of this problem comes from

continued on next page

“Secure Communities,” a U.S. immigration policy that calls for “the U.S. Department of Homeland Security and the Department of Justice to quickly and accurately identify aliens who are arrested for a crime.” As long as states continue to comply with this policy, HIV services targeted at immigrants will face obstacles. The Strategy makes no mention of this problem or any solution, nor does it address the other issues cited as creating disparities. The Strategy recognizes that disparities in treatment, infections, and deaths exist, but it fails to consider their causes.

U.S. budget cuts will disproportionately affect the same communities already most affected by HIV. As a result, the most vulnerable people will face even harsher realities, as their government has decided that adequate services for certain groups are too expensive. This issue is not outside the scope of the Strategy – if the U.S. cannot support basic human needs, the HIV epidemic will continue to grow, regardless of advancements in medical care.

Using the Strategy

This does not mean the Strategy is useless or unimportant. It provides a tremendous opportunity for advocates, who have long understood that the fight against HIV is more than just a matter of treatment options. Fortunately, there are signs of increasing awareness of other issues. Almost a year after the release of the Strategy, there have been several reports released by federal agencies that raise concerns about the realities of health disparities:

- In January, the CDC released the report *CDC Health Disparities and Inequalities in the United States – 2011*, which pointed to “ongoing racial/ethnic, economic, and other social disparities in health”.
- In March, the Institute of Medicine released *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, which pointed to health disparities along the lines of sexual orientation.

- In April, the Department of Health and Human Services announced the *HHS Action Plan to Reduce Health Disparities*, an outline of goals and actions to reduce health disparities among racial and ethnic minorities.

This research and information, confirming what advocates have been saying for years, is a step in the right direction. Health is political. As advocates, we must politicize our agenda. We must move

Homophobia, transphobia, racism, poverty, etc., are complex issues that cannot be adequately addressed simply by acknowledging their existence. They are serious social forces that penetrate our society in deep ways and fundamentally implicate our legal and governmental system.

beyond words like “co-factors” to ask more critical questions about what that term really means. Homophobia, transphobia, racism, poverty, etc., are complex issues that cannot be adequately addressed simply by acknowledging their existence. They are serious social forces that penetrate our society in deep ways and fundamentally implicate our legal and governmental system.

Fortunately, continuing research that acknowledges the existence of inequalities opens the door for these forces to enter the conversation, leading to greater understanding of their importance. It is our role to push the conversation further toward reality and to pressure the government to seriously address the conse-

quences of co-factors. If discrimination affects HIV transmission and care, we must address it at all levels.

Understanding state and local agendas is vital to understanding the nuances of how the epidemic operates. Local organizations, service providers, people with HIV, and activists must collaborate and take the lead in creating responses that address the relevant local issues. The Strategy has opened the door, but it is up to us to walk through it. By creating approaches that acknowledge the inequalities driving the epidemic in our communities, we can hold government accountable to the Strategy, no matter its shortcomings.

Conclusion

Let’s return to the vision statement of the National HIV/AIDS Strategy:

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.

The Strategy cannot fully answer the question of how to address the HIV epidemic because it misunderstands the nature of the problem, even in its vision. If the government is serious about its commitment, it must consider the relationship between HIV and other co-factors. Disease may always be a reality, but the unequal impact on different communities can be stopped. Based on this, I offer a vision statement that truly reflects the problems behind the epidemic:

The United States will become a place where ageism, sexism, racism, homophobia, transphobia, and poverty are rare, and people who become HIV positive will have unfettered access to high-quality, life-extending care, free from stigma and discrimination. ■

John Hellman is Director of Advocacy for the Latino Commission on AIDS.

Congressional Forecast: Proceed with Caution

After the 2010 elections, it was clear that the 112th Congress would be heading in a drastically different direction from the previous session, during which Democrats held a majority in both Houses. Running on a platform of drastic budget cuts and lower taxes, a new, fiscally conservative House of Representatives has convened. Many HIV advocates, who had seen significant gains for HIV care and prevention from the 111th Congress, worry that this will mean a reverse. To understand our challenges, we must examine the differences between the two Congresses, and which policies and legislation may be affected.

In 2010, the 111th Congress passed the Patient Protection and Affordable Care Act (ACA), popularly known as health care reform, which promises to benefit people with HIV in several ways. Insurers will no longer be allowed to deny coverage based on pre-existing conditions (including HIV) or impose lifetime caps on benefits. The “doughnut hole” in Medicare Part D prescription drug coverage will be closed, and substantial funds will be set aside to address health disparities by community.

Several elected representatives, however, are making repeal of health care reform a top priority. The “Repealing the Job-Killing Health Care Law Act,” aiming to stop implementation of the ACA and remove all funding, passed the House by the wide margin of 245 to 189. This assault on a law that provides a comprehensive approach to care and prevention of HIV was a symbolic act, since the Senate leadership did not bring the bill to a vote, but it is an unmistakable indication of the fierce opposition ACA faces in the House.

Other troubling initiatives have been introduced this year. One bill seeks to give governors greater control over their states’ Medicaid programs by repealing the sections of the ACA that require states to maintain current eligibility requirements for Medicaid until 2014. Many people with HIV who depend on Medicaid for their health care could become suddenly ineligible. If this bill were to pass, as many conservatives in Congress hope it does, it would deal a heavy blow to HIV care in the U.S.

Comprehensive sex education is another area that is threatened. Until recent years, abstinence-only sex

education programs received significant federal funding. These programs teach children to “save” themselves for marriage, pressure them to take virginity pledges, and are rampant with anti-gay rhetoric. They typically teach nothing about protection and often give blatantly false information. All the while, rates of sexually transmitted infections were rising dramatically among teens over the last decade.

Fortunately, the 111th Congress defunded the largest funding stream for abstinence-only programs, and both Houses passed the Consolidated Appropriations Act of 2010, which removed federal funding for abstinence-only education. Unfortunately, as a bargaining chip to gain conservative support, \$50 million in abstinence-only funding was included in health care reform. With the greater numbers of socially conservative members of Congress, this funding will likely grow.

AIDS Drug Assistance Programs, which help more than 200,000 people access HIV medications, are another concern. 2011 has seen the worst program shortages in history. State funding for ADAP in recent years has also seen the sharpest drops since the program began. Florida was set to discontinue ADAP for the rest of the fiscal year until activists and drug companies stepped in and ensured people could get their drugs free through a non-profit mail-order pharmacy. More than 8,000 people with HIV are on waiting lists across the country. Although this year’s budget proposals include an increase in federal funding for

ADAP, it is not nearly enough to keep up with increasing demand. Because HIV care and medication double as prevention by reducing viral load and thus transmission risk, this funding shortage and the consequent waiting lists may result in additional HIV infections.

After a comparatively progressive 111th Congress and the promising legislation that it passed, we are starting to see conservative push-back in the new session. Attempts to repeal legislation that provides HIV-positive people with greater care and allows for more robust prevention efforts are frightening. If the critical gains that have been made to fight HIV are not going to be lost, we must make it clear to the current, more conservative Congress that Americans won’t compromise on saving lives. ■



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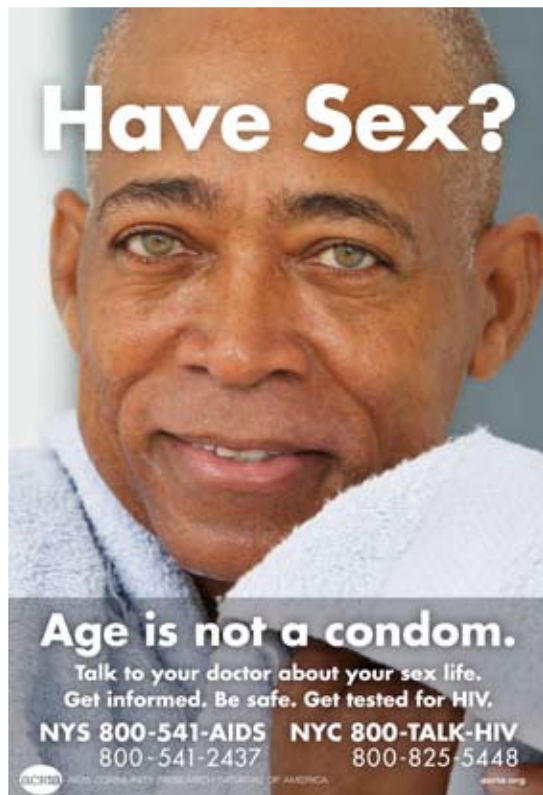
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A CALL TO ACTION

The Personal Responsibility Education Program (PREP) is the only state grant program that funds initiatives to reduce the rates of unintended pregnancy and sexually transmitted infections, including HIV, among young people. Just over \$55 million of its funding over five years would be used to provide evidence-based information on both abstinence and contraception.

But House Republicans have introduced HR 1215, a bill that would make PREP funding no longer automatic. If it passes, Congress would be forced to fund PREP through the annual appropriations process, which could lead to drastic cuts or even complete defunding of the program.

Call your U.S. Representative at 202-224-3121 and ask for a "no" vote on HR 1215. Congress must preserve automatic funding for PREP and continue to give young people the tools they need to make responsible decisions about their sexual health.