The (Alarming) State of (AIDS in) The Union

February 3, 2011 By Regan Hofmann

President Barack Obama

I listened to President Obama's recent State of the Union address with both ears cocked wondering if his commentary on health care reform would indicate what may be in store for people, like me, who are living with HIV in America.

I was particularly attuned in light of the GOP-proposed budget cuts for HIV/AIDS programs because we are starting to see proof that taking the scalpel to AIDS funding constitutes real and imminent, "death panels" for people with HIV.

As I write, there are currently more than 5,550 Americans living with HIV/AIDS on waiting lists for the Ryan White AIDS Drug Assistance Program (ADAP) in 10 states. ADAP is a federally subsidized, state-run program that covers the cost of antiretroviral treatment for 165,000 low-income Americans with HIV.

Temporary solutions have been found to ensure that, to date, people living with HIV placed on ADAP waiting lists have not gone without their drugs: the federal government and the pharmaceutical companies who manufacture the drugs have come to the rescue. In 2010, when the ADAP crisis began, Congress passed a resolution in support of $126 million in emergency funding; Secretary of Health and Human Services Kathleen Sebelius freed $25 million in emergency funding from the Department of Health and Human Services and the president's midyear budget request called for an additional $30 million. As a result, to date, most of those on ADAP waiting lists have not had interruptions in their lifesaving treatment. That may change as early as this week.

The convergence of more effective HIV testing efforts, the recession -- which has left many jobless and without health insurance -- AIDS budget cuts, rising drug prices and the fact that people with HIV are living longer thanks to treatment, have dramatically increased patient burden on ADAP.

While the right-wing media would have its "FOX Nation" believe that the Democrats's health care reform is designed to "kill grannies," the truth is, GOP-proposed budget cuts will ensure the United States is no longer the safest place in the world to have HIV/AIDS. Because soon, even in the United States, if you have HIV you could die because you can't get your pills. Unchecked by medications, HIV can progress to AIDS, and eventually, kill you.

For three decades, America has led the world by example with its bipartisan generosity while fighting the AIDS pandemic. But the United States is about to join the ranks of the developing nations we have provided emergency support to through programs like the Global Fund to Fight AIDS, Tuberculosis and Malaria and The President's Emergency Plan for AIDS Relief (PEPFAR).

Lack of state funds and impending further budget cuts in Florida, Michigan, North Carolina, Ohio, Virginia, Washington state and others may soon raise the number of people on ADAP waiting lists (or kicked out of the program altogether) to nearly 20,000 -- and there is no emergency plan in place to cover the cost of treatment for so many. It's important to note that the figure of 5,550 people currently on waiting lists is deceiving because some states reduced their formularies and changed eligibility criteria to disenroll patients from ADAP, making their ADAP crisis seem less dire. But whether a person is technically disenrolled from ADAP or is on an ADAP waiting list matters little when, in either case, the person can't afford the medicines that can save his or her life.

House of Representatives Speaker John Boehner

One of the prime battlegrounds where people are fighting for access to care is in House of Representatives Speaker John Boehner's own backyard of Ohio. There are 1,000 people on Ohio's ADAP waiting list, many in Boehner's district. The local HIV-positive community's fight to save lives in the heartland may well set the standard for battles to come nationwide.

In the face of all this, certain members of our federal and state governments are saying we need to spend less money on HIV/AIDS.

In his State of the Union address, the president said, "I recognize that some in this chamber have already proposed deeper cuts, and I'm willing to eliminate whatever we can honestly afford to do without. But let's make sure that we're not doing it on the backs of our most vulnerable citizens." (Here, I felt a flicker of hope that our Commander-in-Chief was promising to protect us.) He continued, "And let's make sure that what we're cutting is really excess weight. Cutting the deficit by gutting our investments in innovation and education is like lightening an overloaded airplane by removing its engine. It may feel like you're flying high at first, but it won't take long before you feel the impact."

Had I been his speech writer (a girl can dream!) I would have revised the line thus: "gutting our investments in innovation, life-preserving health care and education is like lightening an overloaded airplane by removing its engine."

Butchering HIV/AIDS budgets now would have a similar effect to ripping the Pratt & Whitney out of a flying 747. But rationing support for HIV/AIDS today could kill a lot more people than a single downed plane -- and it's likely to cost our nation a lot more money in years to come.

I understand that we all must tighten our belts to survive. But as expensive as it is to treat HIV infection (a Johns Hopkins study found it can cost as much as $600,000 over a person's lifetime in the United States), it's a far costlier proposition if treatment is not given and the person progresses to AIDS. Because before people die of AIDS, they become very sick and require often

exorbitant end-of-life care.

Beyond the argument that untreated HIV results in higher health care costs, there's another very good reason to consider funding treatment: treatment can prevent the spread of HIV. Antiretroviral treatment can lower a person's viral load thus diminishing the chances that HIV can be spread to others. The one-two punch of effective treatment (keep a person alive; keep others from getting it) brings enormous cost savings. When treatment is stopped, as could happen due to the ADAP crisis, people can develop resistance to medications and their available arsenal of effective treatment options is reduced.

Treatment is efficacious enough as a prevention tool that global research is exploring its use to prevent HIV-negative people from contracting HIV (an approach known as "PrEP" for "pre-exposure prophylaxis").

Given the efficacy of treatment, possibly for both HIV-positive and HIV-negative people, and the resulting cost savings, I struggle to understand why some in the GOP are championing budget cuts that will force people off drugs.

Representative Dave Agema

One answer is that by doing so, they advance their own political agendas. For example, Michigan GOP state Representative Dave Agema (R-Grandville) has proposed rerouting HIV/AIDS funding to airports in his state. Agema introduced a bill to eliminate state funding for HIV prevention, testing and care, proposing the elimination of the Michigan Health Fund Initiative (MHFI), a $9 million budget used to fund HIV services in the state. Agema proposed channeling the MHFI money into the Michigan Aeronautics Fund, a move he said will help pay for upkeep and expansion projects at state airports, will create jobs and keep fuel taxes down.

It is not fiscally responsible, let alone humane, to increase the likelihood HIV could spread. Doing so undermines public health and could cause HIV care costs to skyrocket. Which, in turn, could mean more people who can't afford care. And when the word on the street is you won't be able to get drugs to save your life, why would you get an HIV test? And, since people who are unaware of their status are more likely to unwittingly pass HIV to others and are more likely to have higher viral loads and be relatively more infectious, anything that blocks testing and care for HIV leads directly to potentially more cases, and the need for more money.

There's no question there are very sound economic arguments for continuing to spend money to fight HIV: in short, pay now, or pay a lot more later.

I fully appreciate the grim economic reality of our country and accept that sacrifices must be made. But where do we draw the line? Shouldn't it be argued that when budget cuts put thousands, maybe tens of thousands, of Americans' lives on the line, the cuts are too deep?

Okay, so where do we get the money?

An organization of AIDS advocates known as the Fair Pricing Coalition (FPC) working in concert with the National Alliance of State and Territorial AIDS Directors (NASTAD) have negotiated with the pharmaceutical companies who manufacture antiretroviral HIV drugs; as a result, drug pricing has dropped sufficiently in some states struggling to afford care for their people on ADAP.

The pharmaceutical companies have stepped up further by expanding their own patient assistance programs (PAP) to people with incomes up to 500 percent of the federal poverty level. The FPC has also successfully persuaded most of the pharmaceutical companies to participate in Welvista's program that streamlines treatment access for people living with HIV on ADAP waiting lists. Welvista is a pharmacy that delivers AIDS medicines within a day to a person who has been wait-listed by ADAP. Based in North Carolina, Welvista is licensed to distribute AIDS drugs in any state where people are unable to access treatment through ADAP.

It was feared that lack of funding would lead the state of Florida to announce -- this week -- the termination of access for the majority of its 10,000 ADAP clients -- possibly more than 6,500 people -- from February 1st (when ADAP funding runs out) until mid-April (when emergency funds kicks in) to offset a $14.5 million budget deficit. The FPC and Welvista have assured for now those patients will be covered.

The FPC, NASTAD and Welvista have worked with the pharmaceutical industry to bridge that gap, but even with the help of the pharmaceutical companies who have agreed to participate (as we go to press: Abbott Pharmaceticals, Bristol Myers-Squibb, Gilead Sciences, Merck, Viiv Healthcare), the fix in Florida is a) temporary and b) very clearly intended as a one-time emergency solution that the drug manufacturers are not looking to replicate across the nation.

The Florida-Welvista deal is just a Band-Aid. And it means shifting the burden of care for thousands of people with HIV from the state and federal government to pharmaceutical companies. Which means the lives of people on Florida's ADAP waiting list depends on the largesse of for-profit businesses. It is a legitimate, and arguably understandable, concern that the pharmaceutical companies may one day decide not to subsidize ADAP.

Are the pharmaceutical companies worried that if they bail out Florida, other states may expect similar treatment? It's a fair question.

Access to affordable care aside, there is also great concern that Florida's existing health care infrastructure is incapable of making a seamless migration of 6,500 people from ADAP to the pharmaceutical PAPs via Welvista. And those who fall through the cracks in the system are likely to cost the state more money.

Florida State Senator Joe Negron

In the midst of this situation, Florida State Senator Joe Negron (R-Stuart), chairman of Florida's Senate Budget Committee's subcommittee on Health and Human Services Appropriations said, "There needs to be a transfer in priority in revenue from health and human services to education."

He added, "I'd like to see several billion less in HHS."

According to reports, Negron said he thought "health care lobbyists had done a better job making their case over the years than education lobbyists, pointing out that health care lobbyists are good at painting 'apocalypses' as results of health care budget cuts."

Well, Senator Negron, I'm a journalist, not a lobbyist. We deal in facts. And the fact is, the lives of 10,000 Floridians hang in the balance of your state's unbalanced budget. If you don't think AIDS Armageddon America Part II is a real possibility, think again.

Negron claims deficit reduction is his highest priority. But help me with the math here. Where will Florida find the money in the future to pay for people with HIV who end up in emergency rooms and in hospitals or get transferred to Medicaid because they became too sick to work and pay for their own health insurance if Florida doesn't even have the much smaller sum of money needed to keep them healthy today? Isn't Negron's willingness to cut millions now from state funding for AIDS merely a political stunt that will ensure his tax payers will be left holding the bag for millions more later? Is this intelligent, responsible, conservative fiscal policy?

Don't get me wrong. I think Negron's idea of bolstering education is key. Had Florida, and our nation as a whole, done a better job teaching comprehensive sex education, America's HIV caseload would likely be far lower than it is today. Nearly 34 percent of all new HIV/AIDS cases in America occur in people under the age of 30. The AIDS epidemic in Florida can be tied, at least in part, to Florida's lack of a statewide minimum standard for sex education and, as a result, its programs fail to be culturally competent and are restricted, unable to teach anything other than "abstinence-only until heterosexual marriage" -- an approach that has been well-documented to increase, not decrease, risk to sexual health. However, I don't think Negron is talking about funding comprehensive sex education.

The critical questions are: Who can, will and is responsible for funding the survival of low-income Americans with HIV? The federal government (by tapping HHS stimulus dollars)? State governments? Pharmaceutical companies (by dropping drug prices or offering higher rebates)? All of the above? While the various groups duke it out, people with HIV are at risk for getting sick and dying.

Maybe we should apply for international aid.

Here's an idea: If the GOP leadership wants to appeal to their fiscally minded constituents (thus bolstering their chances for re-election), perhaps they should consider supporting the FPC's and NASTAD's efforts to negotiate with pharmaceutical companies to make AIDS medicines affordable to states and individuals. What about providing tax incentives to pharmaceutical companies that agree to participate in the Wellvista program and support people on ADAP wait lists?

We should look hard and deep into programs like those provided by the Ryan White CARE Act and see what efficiencies can be realized and how we can do more with what we have. We should also scrutinize states' administration of AIDS funding to ensure it's being handled in the most impactful way. And, we must analyze state's contributions to ADAP. Over the years, they have declined

significantly, furthering the problem.

There's no easy answer to how we pay for AIDS in America. But there must be a solution. If we had the drugs to cure cancer and people were having trouble accessing them, don't you think we'd fix the roadblock? Yes.

So why is AIDS different?

In a word: stigma.

Representative Larry Brown

2011 marks the 30th anniversary of the first reported cases of HIV and we've made progress on the scientific front of AIDS. But deadly stigma prevails, evidenced by the fact we still have people like Representative Larry Brown of North Carolina, who said, when discussing legislative priorities, he does not condone using taxpayer money to treat HIV/AIDS patients if they contracted the illness because they were "living in perverted lifestyles." He has agreed to fund health care for babies born with HIV and those who contracted the disease through "no fault of their own" but apparently no one else.

We're in a most challenging position: In one of the most economically constricted times in our country's history we are asking rich, mostly white, socially conservative people who will assure their political futures by slashing budgets to increase funding for the care of poor people, largely people of color, who have a disease most of them contracted through sexual contact or the sharing of needles.

Talk about an uphill battle.

Yet it's high time to answer once and for all whether this nation will rise above discrimination and stigma and a selfish desire for political power on the part of some politicians to honor what should be every American's unchallenged right regardless of their color, gender, socioeconomic status or sexual orientation: access to life saving health care.

In short, we must balance the budgets, yes. But not, as President Obama so compassionately put it, "On the backs of our most vulnerable citizens."

Here's hoping we see bipartisan leadership from our nation's government to solve our AIDS funding crisis. If our leadership steps up, we will show the world that the state of our union is such that in America we won't let you die when we have a way to save your life.

Click here to read an AIDSmeds interview with the Fair Pricing Coalition.

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