Who Wants to Be an AIDS Advocate?

The moment is ripe for us to collectively change our futures—but to do so, we must add our voices to the national discussion. With this special feature, and the launch of our new online Advocacy hub (at poz.com/advocacy), POZ heralds in a new era of AIDS activism. It is vital that we all get vocal—and viral. (Trust us, it feels good to take action.) Welcome to the future of your health care. Welcome to AIDS Advocacy 2.0.

November 1, 2009 By Regan Hofmann

The tipping point for AIDS advocacy has come. After more than a decade of denial about AIDS in America, a crisis of complacency within our government (with a handful of notable exceptions), infection rates that are higher than previously reported and levels of domestic funding for AIDS that are far from meeting the community's needs, it is time for all people living with and affected by HIV/AIDS to voice our concerns to those who will determine the health care of our futures.

Not in years have we had such an opportunity to make such a significant difference in our own lives—and the lives of millions of others. President Barack Obama is making health care reform a priority. And no matter what your take is on the specifics of his recommended plan, there is little dissension that the current health care system is badly broken and in need of a big Band-Aid (did you know that 50 percent of all people in the United States are without health insurance?). The president's proposed plan of health care reform will likely provide a health insurance option for people who are currently unable to afford or qualify for health insurance, and it will allow those who currently have coverage to stay with that coverage.

We have President Obama's promise to develop and implement a national AIDS strategy. We have Jeffrey Crowley, MPH, the new director of the Office of National AIDS Policy, who is traveling around the country to talk to people living with HIV/AIDS and to those who care for us to ensure that the national AIDS strategy is developed with our needs in mind. Our Secretary of State, Hillary Clinton, has voiced her support for the President's Emergency Plan for AIDS Relief (PEPFAR) at the current pledge of a whopping $48 billion to combat HIV/AIDS around the globe (which is a good thing as only one third of all those who need treatment around the world are receiving it). We have Eric Goosby, MD, newly appointed as PEPFAR's global AIDS coordinator; his resume for fighting AIDS and his dedication to those living with the disease are legendary.

We have Thomas Frieden, MD, MPH, in the position of director of the Centers for Disease Control and Prevention (CDC). As the former health commissioner of New York City, Frieden well understands the intricacies of battling AIDS.

We also have Kevin Fenton, MD, PhD, the director of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention for the CDC, overseeing the launch of "Act Against AIDS," a five-year, $45 million AIDS awareness, prevention and testing campaign designed to help identify (and, hopefully, link to affordable care) the 21 percent of the estimated 1.1 million Americans living with HIV who don't know they have the virus. "Act Against AIDS" marks the first time in nearly 20 years that the American federal government has earmarked funds at this level for AIDS awareness and prevention stateside. The campaign is designed to address communities hardest hit by AIDS, including men who have sex with men (MSM), gay men and African Americans.

That's the good news.

Yet, as we go to press, despite President Obama's pledge to honor evidence-based approaches to public health, legislators have yet to green-light needle exchange. An amendment to a bill that removes the ban on needle exchange contains restrictions that would make it logistically impossible to implement needle exchange programs, particularly in the inner cities of Baltimore; Washington, DC; and Oakland, California, where they are most sorely needed. And while there's talk of rolling out comprehensive sex education programs in our kids' schools, there is much to do to address the aftermath of eight years of abstinence-only sex education that led to widespread ignorance among America's youth on the subject of HIV/AIDS. Witness the fact that 34 percent of all new HIV infections are among people younger than 25.

Homophobia and racism continue to get in the way of our ability to speak plainly and clearly about and to gay men, MSM and people of color so that they are aware of their risk and how to prevent getting HIV. We barely address the issue of HIV/AIDS among lesbians and transgender people, and the stigma surrounding HIV continues to make people afraid to get tested, to disclose their status and to seek medical treatment and the emotional support that would help them save their lives. We refuse to acknowledge that people have sex in prison and need access to condoms. People in prison who are living with HIV often lack access to care and treatment, which increases the chance that HIV will spread both inside and outside prison walls.

We've never had to address HIV as a nation in the context of an economy as weak as our current one. Recently announced budget cuts in many states (notably, and dramatically, in California for example) means more people have barriers to lifesaving care. People are unable to afford the antiretroviral medicines and other treatments that save their lives; some are forced to go on waiting lists for federally funded AIDS drug assistance programs (ADAP); meanwhile, AIDS service agencies are closing their doors around the nation. The Ryan White CARE Act—federal funding specially earmarked for people living with HIV—is up for renewal, and there's no guarantee it will continue. Budgets for ADAP, Medicaid and Medicare (which together provide tens of thousands of HIV-positive people with health care and prescription drugs) are too low to meet the current need.

That's the bad news.

By the time this issue of *POZ* hits the streets, Housing Works and the Campaign to End AIDS will have staged a (hopefully, massive and impactful) national AIDS rally on the Ellipse by the White

House. And *POZ* will have launched its Advocacy hub, a whole new section of our website (poz.com/advocacy) dedicated to giving you direct access to each other, to all of the AIDS advocacy groups around the country—and to those on Capitol Hill who shape policy and vote on the legislation that affects us.

This past August, I spoke at the opening plenary session of the CDC's prevention conference. I've spoken many times around the country and the world, but the fervor and enthusiasm I felt in the audience that day among people living with and affected by HIV/AIDS, including those who work tirelessly in AIDS service organizations, the health care arena and federal and state governments, made me feel that there is a new urgency—and a new energy in the air. Many people are scared, mad, sad and bewildered that we are failing to stop the spread of HIV and save more lives of people who have the virus. But they are also hopeful that we may have the chance to do something about it. We unquestionably do.

I've spent time in Washington, DC, lately, talking to members of Congress and the people leading the fight against HIV/AIDS in our government. I was present in the House chamber on September 10 when Obama spoke of his plan for health care reform. The dissension and tension present in that room, juxtaposed with Obama's deep desire to save American lives, showed me one thing: We do have a chance to affect what happens to us, but in order for things to change we have to support the people, including our president, who are trying to change them. It may seem obvious to say, but the people who sit in House and Senate seats work for us. And it is our responsibility to educate them about and sensitize them to our needs so when they cast their votes, they do so with our concerns factored in-—and with the knowledge that we'll be watching them.

At the beginning of the epidemic, six gay activists in New York coined the phrase "silence equals death." Soon after, it became the slogan for ACT UP, and it has been the battle charge of the HIV community ever since. When former President Ronald Reagan refused to even mention the word "AIDS," people had to act up—or die. Today we not only have a president who is well-educated about AIDS and willing to speak about it; we also have a president who has expressed his desire to hear from us directly.

With more than 25 million people in the ground and an estimated 33 million people walking the planet with HIV/AIDS, it is officially one of the worst and deadliest pandemics ever to hit Mother Earth. In the recorded history of humanity, only one other has resulted in more deaths: the black plague. But at the current rate, AIDS is soon to take over as the single deadliest pandemic in human history. Effective antiretroviral treatment has been a wonder, a blessing and, in some ways, a curse as the fact that HIV no longer has to be a death sentence has resulted in a false sense of calm around the virus.

So, as I mentioned in my editor's letter, I want every one of you to do me a favor and visit the POZ Advocacy hub (poz.com/advocacy) and post a comment about what issues you think our national AIDS strategy should address. Tell your story. Speak your piece. (It's fine to post anonymously; we will protect your privacy.) By the time this issue of *POZ* comes out, the CDC will have already held five town hall meetings (in Atlanta; Washington, DC; Minneapolis; Albuquerque; and Houston).

Nine more town hall-style community discussions are scheduled across the United States (and in Puerto Rico and the U.S. Virgin Islands). Seating, and the number of people given airtime at the microphones, will be limited at each town hall. But there is no limit to the capacity *POZ* has for fielding your comments, concerns and life stories on our website.

When I told people in government that *POZ* was launching an Advocacy hub, there was some concern that we'd incite the community to flood governmental e-mail in boxes and phone lines. (After all, we reach 75 percent of all people who know they are living with HIV in America, or nearly three quarters of a million people.) I say: Let's do exactly that!

The change that Obama has spoken of must start with us. Engaging in the discussion and taking action to save your own lives and those of others have been clinically shown to be good for your health. And wait until you see how good you feel when things do shift for the better—and you know that you were part of the reason why.

Obama referenced a Hopi saying during his campaign. The saying is: "We are the ones we've been waiting for."

I say, let's prove him right.

The Whens and Wheres of National AIDS Strategy Town Halls

We wrote our recommendations for the national AIDS strategy in the October 2008 issue of *POZ*. Now, it's your turn. Attend one of the remaining meetings. If you're not near one of these cities or can't travel to one, visit poz.com/advocacy and post a comment in the "National AIDS Strategy" section. You can make a request, voice a concern, tell your story or relay information for someone who doesn't have a computer or know how to use one. You can also visit or call your local AIDS service organization (find one on poz.com/directory) and write in on its behalf. Don't have a computer? Send a letter to *POZ* at 500 Fifth Avenue, Suite 320, New York, NY 10110. This is your chance to influence the agenda and the format of the town halls—and a way to shape the future.

San Francisco	Oct. 16
Oakland, CA	Oct. 17
Los Angeles	Oct. 18
Columbia, SC	Oct. 26
Puerto Rico	Nov. 6
U.S. Virgin Is.	Nov. 9
Jackson, MS	Nov. 16
Ft. Lauderdale	Nov. 20
New York City	Dec. 4

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