POSITIVELY PACHA

February 4, 2010 By Regan Hofmann

This past Tuesday, I was in Washington, DC to cover the announcement and swearing in of the 24 new members of the Presidential Advisory Council on HIV/AIDS (PACHA). Headed by Dr. Helene Gayle, the council of experts represents a diverse group of researchers, service providers and community leaders from around the United States. Several members of PACHA are living with HIV. The council also includes people who work in community based organizations that address the medical, legal or mental health issues of HIV-positive people.

The goal of the council is to advise President Obama, through the Secretary of Health and Human Services (Kathleen Sebelius) on domestic and global issues pertaining to HIV/AIDS. It is also designed to support the Office of National AIDS Policy (ONAP, headed by Jeffrey Crowley) achieve their policy goals. It will also help in the development (and implementation) of the National AIDS Strategy. (For the full skinny on PACHA click here or here). For POZ's coverage and for links to POZ stories of PACHA members, click here.

Okay, so, I have to confess: I'm still getting the press drill down at the White House. After getting up at 4:30 am to catch the Acela out of Trenton, and watching the sun rise hotly pink over a silver, flat body of water somewhere between Philly and Baltimore (and managing not to spill my tea all over me while navigating the aisles of a train moving at nearly 200 mph), I was very proud to be early for the press conference. I marched up to the gate at the corner of the OEOB (Old Executive Office Building) where the press conference was being held and where the VP and much of the executive branch of the federal government has their offices. But alas, I was in the wrong place. The last time I'd visited OEOB was to attend a meeting of "Women and Girls" gathered to help inform the folks developing the National AIDS Strategy about the needs of those of us of the female persuasion. On that day, I was an invitee to a meeting. Last Tuesday, I was wearing my journalist's hat and therefore, was supposed to go to another entrance.

To this New Yorker, an uptown/downtown block can be covered in 30 seconds of brisk walking. A crosstown block can happen in a New York minute. But rounding the horn of the OEOB (in heels) takes nearly ten minutes. And it's uphill. On a sidewalk not made for stilettos. So, I arrived at the right gate, breathing loudly into the speaker that is answered inside the bullet-proof hut at the edge of the White House driveway. Especially in this post-Salahi era, getting inside the White House gates - even after you've provided credentials, photo ID and probably nuked all your unborn kids by passing through the metal detectors - is not easy. After you get your pass and are released inside, you still have to travel a good ways to get to your meeting. But it is such an honor to walk freely down the driveway toward the White House and each time, I still move slowly, enjoying the

view. I've only been several times, but each time, I can't quite believe that I am allowed to walk that close to our President's home without Secret Service flanking me. Of course, I know they are everywhere around the grounds. I can't see them, but they can certainly see me! I always wonder what would happen if I touched a toe to the White House lawn (or pulled out a single blade of grass for my scrapbook). But not wanting to tempt fate and wanting to respect protocol, I walk straight to the press area near the West Wing and await direction for where we are to gather.

It's quite a scene inside the press area. Journalists from all over sit and chat waiting for their escorts to the room where their respective press conference is being held. The last time I visited the White House was to watch President Obama sign the re-authorization of the Ryan White Care Act and to mention that the travel ban on HIV-positive people coming to the United States was to be lifted. On that day, we were escorted into a room where we stood behind velvet ropes until the President and group of politicians and AIDS advocates came in for the signing.



It was an incredible day - and being that close to President Obama and watching his eyes carefully as he spoke about his commitment to fighting HIV/AIDS overseas and in the U.S. was incredible. I believe he understands and cares about the issues impacting people with HIV. I believe he knows how disproportionately hard hit the African American community is by HIV. I'll never forget watching him embrace Jeannie White as she burst into tears after he signed the bill into life again. It's easy to get swept up into the feeling that this time, things will be different and that finally we have leadership in Washington that truly cares about HIV not only internationally but domestically. But even as I see the barriers to care fall (e.g. the passing of legislation that allows for needle exchange), I know too well that saying we'll do something and being able to pay for - and effectively implement - it is a whole other thing. As I stood there that day relieved that many people's link to lifesaving treatment was perpetuated by President Obama's pen, I couldn't help but think also of the people who lay sick in their beds watching the hands of a clock spin, terrified, while they desperately hoped that there will be enough money to enable the AIDS Drug Assistance Program to help them get lifesaving meds. (According to the National Alliance of State and Territorial AIDS Directors, the average monthly growth for ADAPs in 2009 was 1,271 clients - an 80 percent increase versus year ago.) ADAP is funded by the Ryan White Program. As more people with HIV lose their jobs and can't afford health insurance, and as more people become positive, more people will depend on the same limited resources to save their lives. It's gonna get Darwinian. According to the AIDS Institute, we need an additional $126 million in FY10 funds to support ADAP. And that's based on the current estimations of the total number of people living with HIV in America. And if you ask many of the experts, they'll tell you that HIV surveillance efforts have been underfunded at the CDC and that therefore, we really truly don't know how many Americans are living with HIV. We estimate that about 21 percent of people with the virus don't know they have it. The absolute count of people, and therefore the percent who are unaware of their status could be mich higher.

We've had several celebratory moments in AIDS history in the last several months. And the administration should be applauded for the steps they've taken to improve the lives of people

living with HIV/AIDS in America. I was proud to be an American when we elected President Obama, and I was proud to be an American woman living with HIV when we said to the world, “You may come visit us, even if you bring your HIV with you.” In 2012, for the first time in more than 20 years, the United States will again host the International AIDS Society’s International AIDS Conference. That’s amazing. It’s also horrifying that we were one of the last nations to eliminate the deeply stigmatizing HIV travel ban.

The fact that the administration has reinstated the Office of National AIDS Policy, that there is dedication to developing a National AIDS Strategy and that PACHA has been re-upped with an incredible roster of people with remarkable track records fighting HIV/AIDS is all good. And I remain very hopeful that these steps indicate a recognition of and dedication to solving the problem of the HIV/AIDS pandemic.

But all of this good intent will only be as good as the ability of the people tasked with running ONAP, developing the National AIDS Strategy and serving on PACHA to implement the brilliant ideas they hatch. And that will take their relentless pressure. Political capital. A lot of money. And some help from us.

The federal government has said it will not spend in one area unless it can save in another. I think the AIDS community should also look hard at realizing efficiencies and I hope that part of ONAP and PACHA’s focus will be on flushing out redundancies and inefficiencies in the AIDS world. If the National AIDS Strategy does one thing, it should be able to evaluate those groups that are getting it done, and those groups that aren’t, and reallocate funds to the people who are making the greatest impact most efficiently. We have no shortage of talent, will and insight. In many of the meetings I’ve attended intended to help those who are shaping policy understand what’s happening on a grass roots level in the community, it is said over and over that people living with HIV must be at the table. And we now have HIV positive people assigned to tell Secretary Sebelius and in turn, our President, what they need to know to stop AIDS and to save and improve the lives of those of us living with the virus. But we can’t rely solely on them to do our work for us. Many of you have spoken up in the town halls-style meetings hosted by ONAP. Many of you voiced comments on the POZ.com advocacy hub. Many of you posted comments on AIDS.gov’s website.

We need to keep it up.

The process has just begun and for any of the current efforts to work, they will need the support of and feedback from the community.

As I walked away from the White House this week, I contemplated the duality that I face every day. I am a journalist, reporting on HIV/AIDS. But I am also a woman, fighting for my life against the very virus I write about daily. And it is this reality that fuels me with a vengeance to use the power of my pen to help ensure that the needs of the HIV community are heard by those who need to hear them.

The president changes history and saves lives when he lays down ink on a bill.

We at POZ hope to do the same. So please continue to share your stories, concerns, dreams and insights with us and we will be sure that they make their way inside the gate, down the driveway and into the hallowed halls of the White House - one way, or another.

Below, some pictures from DC - the group shot is of PACHA plus Secretary Sebelius. That’s Dr. Gayle and Chris Bates, PACHA’s Executive Director, at the podium.





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