Bearing Witness

Several people living with HIV recount tales from past AIDSWatch events and explain why it's important to speak directly to Congress about the needs of the community.

April 1, 2009

POZ asked several people living with HIV to recount tales from past AIDSWatch events and to explain why it's important to speak directly to Congress about the needs of the community. They also address whether such advocacy is influential and whether the new administration will be more responsive. Here is a sampling of their answers:

Shirlene Cooper
New York, NY
As a grandmother living with HIV/AIDS, I say it is urgent that we all step up and speak directly to the people in our communities. We have to educate them, rather than sitting back and watching them fail. New generations suffer from a lack of information.

The HIV/AIDS community plays a valuable role in influencing policy. I'm quite optimistic that this era will be different. The epidemic has gone through four presidents (Ronald Regan, George Bush, Bill Clinton and George W. Bush). We need today's politicians to support the development of a national AIDS strategy.

My favorite AIDSWatch moment is being among those who never give up.

Elizabeth Lancaster-Shepherd
Washington, NC
I feel that the presence of our bodies, spirits and personalities will help end this thing. If the representatives don't listen, I will sneak into their houses at breakfast every day and take my pills in front of them until they do. I sincerely believe a change is here, and it feels good to dream big now. I am willing to go to any length to help the issues come to the surface in Washington, DC. I believe it will all work out for the best.

My favorite part of AIDSWatch was talking to Congress members and seeing they were actually interested in our concerns. Today, I see a light perhaps at the end of a long tunnel.

Patrick Archer
Redding, CA

I hope that our new president understands our needs and will be open to meeting with HIV-positive people, like myself, who have survived 22 years and have seen the prejudice and hate that he may have also seen as a African-American person—such a background may have given him an understanding of what a person living with HIV/AIDS experiences.

I want to deliver an "in your face" message that HIV/AIDS has not been cured and millions still live with this disease. AIDSWatch offers hope and support to those in the HIV community who are afraid to have their voices heard. Perhaps it provides peace of mind to know that AIDSWatch is watching out for them.

Herbert Hodge
Dallas, TX
It is very important to attend AIDSWatch and let Congress know that people are still getting infected with this disease today and that we need to stop it. I don't think that the community is able to influence AIDS policy at this point because many people are afraid to speak out and disclose their status; this is where the changes need to start.

We might have a chance for change since we have a new president. I think if the representatives listened openly, we would have funds to help with this disease and be able to put a national AIDS strategy in place. Our administration isn't looking at this epidemic strongly enough. This disease is just like cancer and diabetes. It's a major health issue.

Robert Felix
Detroit, MI
No one knows what it is like to battle HIV unless he or she is infected. The gay community and the African-American community are constantly discriminated against and told that funding is cut for essential services. If the community isn't making sure Congress is aware of the needs for HIV/AIDS care, treatment, research and prevention, how will they know what policies to create and which policies/programs are effective?

When you are advocating and speaking to Congress on behalf of individuals infected and affected by HIV, the lawmakers see and feel the urgency and they are willing to allocate and fight for more funding. I feel that President Obama understands the urgency and what is needed to respond to HIV/AIDS in the United States. Unaddressed issues will continue to threaten our country's health programs and resources. HIV/AIDS must be part of the president's focus to reform health care.

Scott Daly
Schenectady, NY
If our congressional leaders do not see a large presence of the community in Washington, DC, discussing the importance of our issues, they will assume that we are happy with the status quo. The most powerful message is the one told by those living with this disease—the individuals affected by the lawmakers' legislative and funding decisions.

I cannot express or measure the beneficial effects I get from the feeling of self-

empowerment—both physically and mentally—while advocating before my legislative leaders. There is an incredible sense of accomplishment each and every time I have gone to DC to participate in AIDSWatch.

Without our personal stories, and the faces to associate them with, our pleas for change in policy are only words on a page to our legislative leaders.

Charlene Bowen
Jacksonville, FL
My husband died four years ago of AIDS. He needed continuous care, but he didn't know where to get the services he needed and there was no one to advocate for him. When he did find people to help, they never really listened to what he needed, which made him feel depressed and isolated. HIV/AIDS is not just a disease of the body; it affects the mind and the spirit as well. After my husband died, I decided I needed to fight for what I needed. I have a family to care for, and I need to be around for them. I needed to make my voice heard, not just for me but also for those who can't speak for themselves.

Anyone can go before Congress and speak about an issue, but a person who has lived and breathed this disease every day can truly speak with a passion and fire that make the powers that be understand how important it is to make changes that will save our lives. We are more than just statistics, and the only way for Congress to see that is for them to see us and hear our stories.

Waheedah Shabazz-El
Philadelphia, PA
We always hear people say, "We must put a face on AIDS." The face of AIDS must also have a voice. I attend AIDSWatch because it is important for our representatives not just to hear us speak but also to recognize we can speak for ourselves.

During our visit to the Hill, several of us requested water to take our antiretroviral medicines. It was a powerful strategy to break down the stigma. We went from being perceived as "people with at-risk behaviors" to "people who have a medical condition and lack the resources to live a quality life." The representatives and their staff were moved by compassion—they had never seen people with HIV/AIDS take their drugs.

It was refreshing to know that I'm not working in a vacuum. It was a rich experience connecting with other people living with AIDS from across the nation who also want to be a part of the solution. AIDSWatch gives me the opportunity to fight on the front line for myself and to advocate for the needs of a community who has loved and supported me unconditionally.

This article is from our AIDSWatch 2009 primer, which also includes:

Go Tell It On the Mountain: Let's speak our truth together—and rewrite HIV history—at AIDSWatch 2009.

The Holy Grail: What we're asking for on the Hill

Dear Congress: A letter to your representatives in Congress

Uniting With Might: Strategies for an effective Hill visit

The Glory and the Power: Who's who in HIV/AIDS on the Hill

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