POZ Q&A: Senator Kirsten Gillibrand

POZ editor-in-chief Regan Hofmann sits down with Senator Kirsten Gillibrand (D-N.Y.) to discuss the state of the epidemic in America and her commitment to HIV/AIDS advocacy.

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What specific events or people led to your involvement in HIV/AIDS advocacy?
My first introduction to the issue came through the gay community because I have a lot of friends who are gay. I learned about their worries and concerns and [heard stories about] their friends who had lost their lives to the virus. Growing up in upstate New York, I had a close friend of my mother's die, so I've been aware of HIV/AIDS since I was very young. And when I was a lawyer in New York City, my sister worked with a charity that helped children living with HIV. She described how hopeless and how sad these young kids were and how nobody wanted to give them any affection. [HIV] has always been an issue that has influenced my life. But [the epidemic] is changing, and I don't see us making the progress that we should be making.

As a senator, I became [personally] involved when I read the statistics of who is now being affected by HIV/AIDS. About 26 percent of all new infections are among women, and 66 percent of those new cases are African-American women. [Those numbers] are really troubling because it means young girls and women are not getting the kind of information they need to protect themselves. And when you look at the rates of how many people don't know they have HIV [an estimated 21 percent], it's startling. We should be able to do more to reduce, to combat and to fight [this disease] worldwide, and yet we see these growing statistics. Part of my interest now is to increase the information that is available to families all across America. And to create programs to tackle the challenges of today. We need programs in place that can really combat the [hardest hit] areas. We need to come up with solutions to address different populations. There is so much more we need to do.

Can you talk a little about HIV-related stigma?
When I was younger, there was an enormous stigma toward people who were gay and HIV positive. For a while people forgot about AIDS—it was such a big thing in the '80s—but in the '90s President Clinton reminded the world we needed to do more to help people living with HIV/AIDS continue to live their lives. But [attitudes] have begun to change. I think having President Clinton take on HIV/AIDS eradication worldwide and the funding of lifesaving drugs was very eye-opening. It made people realize we need to combat this disease. And President Bush continued [to remind us] by being the first Republican president to say HIV/AIDS is a disease we have a moral obligation to address worldwide. [Through the President's Emergency Plan for AIDS Relief (PEPFAR)], he

pledged $48 billion of funding toward HIV/AIDS worldwide. I remember listening to his State of the Union address and thinking, “Wow that’s pretty progressive for a Republican president to care about the eradication of HIV.”

I think over time stigma has diminished, but awareness has also been diminished—and that’s a problem because people are not aware of the level of HIV/AIDS we still have in this country and how many families are being affected. The other side of acceptance is complacency. The biggest challenge we have is to inform the public that this is still a grave health crisis. We need to have the ability to educate children and the ability to test anyone who wants to be tested. And we need to make sure voluntary universal testing is always covered [by insurance] and is affordable and available. Those are things I am working on in the Senate. I want to start to take this on as an issue we support, and change the current dynamic. We need to protect the young women who are not aware [of the risks] and who are not worried like they should be.

How important is it for you as a senator to hear directly from your constituents, and how much of an impact does an individual’s personal story have?
Real-life stories are invaluable. When you put a face on any problem, it helps you focus and understand the depths of the problems [that people face]. The testimony of any person who lives with the virus helps prevent others from contracting it and helps others live with the disease. It makes a huge difference and inspires people to be productive, to be healthy and to have the social networks around them to get the support they need.

This seems to be a new era for HIV/AIDS advocacy. Is it?
I think you definitely have an ally in the White House, and you certainly have an ally in me. And so this is definitely a time for beginning a new debate on what we as Americans should do to combat AIDS and to raise the level of awareness and create new policies that can actually be effective.

If you have one goal related to HIV/AIDS in the next year, what would you like to see?
One of the bills I put forward was Senate Bill 1446 to provide incentives to increase HIV testing for all Medicaid recipients. If we can start by testing all Medicaid recipients who would like to be tested and have it be covered, then we can go a long way in beginning to [address] the people who don’t know the risks of the disease, and those that don’t know they have it. So that’s one piece of legislation I think we actually have some hope in passing. I want to do much more about awareness. I am very concerned about the growing numbers of young women who are being infected with HIV and don’t know it. That has to change. If we can increase access to testing and begin to have a national debate about the issue and get the statistics out, we can really warn parents and say, “You need to teach your children about risks and what actually can happen to them.” And we need to work on access to treatment. Getting low cost medicine to anyone who wants it—it should be affordable, and they should have access to it.
