

## Connecticut Teens May Soon Be Able To Get HIV Prevention Medication Without Parental Consent

By NICOLE LEONARD • JUN 19, 2019

It was during his freshman year of high school when Sam Smith approached his doctor — he had been exploring his sexuality for a couple years.

"I was like, hey, I'm having sex with guys," he said, recounting the doctor's visit. "What do I do?"

Smith hoped that his doctor would suggest pre-exposure prophylaxis, or PrEP, which is a daily pill that can prevent someone from contracting the HIV virus if they're exposed to it. "But he never did," he said, "and I found out after it all that he didn't even know it was a thing, which is kind of a shame."

Before he graduated high school, Smith, who feared coming out to his family as gay and felt he couldn't turn to them for help, would be diagnosed with HIV. And although it's no longer a deadly diagnosis, it's still a costly disease that Smith, now 21 and living in New Haven, will have to manage for the rest of his life.

A bill that was passed in both the Connecticut House and Senate earlier this month would allow minors to get PrEP without parental consent, meaning teens may not have to choose between their privacy and health. Smith hopes this will help teens avoid the lifetime disease.



Sam Smith, 21, of New Haven, supports a state bill that would allow teens to get PrEP, an HIV prevention medication, without parental consent. This way, he said people won't have to choose between their health and the privacy of their sexual activities. NICOLE LEONARD / CONNECTICUT PUBLIC RADIO

"As a young, gay person, there's so many things on your plate — coming out to your parents, coming out to your friends, who's going to find out, who's going to see my Tumblr, what's going to happen, am I going to get HIV," he said. "The medication takes one very big thing off your plate and kind of keeps you safe."

New cases of HIV, which is a chronic disease that damages the immune system, result in many fewer deaths than they did during the 1980s epidemic, but thousands of people in the U.S. still become newly infected with the virus each year.

In Connecticut, 281 people were diagnosed with HIV in 2017, according to the state Department of Public Health. Of those cases, 14 people were under the age of 20. The next age range (20 - 29 years old) accounted for the highest number of new cases that year.

According to the federal data, the virus is most commonly transferred through sex or injection drug use — men who have sex with men are at the greatest risk of contracting HIV.

PrEP has been proven to be more than 90 percent effective if taken as prescribed. The most common side effects to the medication are usually mild and temporary, and serious side effects are rare, according to federal guidelines.

That's why Dr. Krystn Wagner, medical director of HIV and infectious disease at Fair Haven Community Health Center

in New Haven, said she and other colleagues were excited when the U.S. Food and Drug Administration approved the preventative medication for adults in 2012.

"If you think back to the beginning of the epidemic, that we could have had a daily pill that would have prevented it, it wasn't something that we would have thought possible at that time and we would have wished for," she said. "It really has been a tremendously exciting advance in science and an opportunity for at-risk patients."

But despite that opportunity, Wagner said young people who aren't ready to reveal their sexual activity to family may not seek out something like PrEP if they need a parent's consent. And soon, they may not need one. "If parental involvement served as a barrier to their having access to something that would prevent a lifetime infection, I think it's a pragmatic and empowering option to give teens," she said.

In general, minors can't make medical decisions without a parent or guardian's involvement. State and federal laws have made some exceptions, including for the testing and treatment for sexually transmitted disease.

But PrEP is an HIV preventative medication, which is why Jay Sicklick, attorney and director of the medical-legal partnership at the Center for Children's Advocacy, said state laws need to be amended in order to catch up with the advancements medicine.



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Minors' capacity to access preventive HIV services, such as PrEP, without parental or guardian consent, as of 2017. Since then, more states, including New York, have allowed PrEP access without parental consent. CREDIT U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION "The problem was that this area of prophylaxis doesn't easily fall within the definition of care or treatment, because it is not in fact care or treatment for something to prevent the transmission of a disease," he said.

Sicklick worked with Wagner on the legislation, which got strong bipartisan support in the legislature. It also helped that the FDA officially approved PrEP for minors just last year — before that approval, Sicklick said that was a big roadblock for the bill in past years.

People who opposed the bill, like Dawn Jolly, a mother of three, testified against it at a February public hearing. She and others said laws like this would violate the rights of parents to make medical decisions for their children.

"While I understand that children here that don't feel comfortable talking to their parents, I should not be punished, because I have done what I

need to do as a parent to have my children have these types of relationships with me that they're happy to speak with me about such intimate matters as sex and drugs and drinking and things that teens face," she told lawmakers.

But Jesus Morales Sanchez, 24, of New Haven, said those parents are missing the bigger picture.

"By any means, if parents have that kind of communication with their children, they should be involved and their child should be comfortable to say, 'mom, dad, I want to explore PrEP as a preventative measure and I want to ask my doctor about it,' " he said. "That would be ideal. However, what we're talking about with this bill, is for those children who don't have that relationship. . . we're talking about those like me didn't have that communication, that couldn't go and tell their parents, hey, I want to explore PrEP because I'm having sex with other men."

Sanchez migrated with his family to Connecticut from Mexico as a teenager. He said he knew that cultural and religious barriers would prevent his family from accepting he was gay, so he explored his sexuality in secret, in ways that were risky to his health.

"I could have been in a really, really difficult situation," he said. "Not even just HIV, it could have been so many other things and it is unfortunately what happens when teens don't feel comfortable, don't have an adult they can reach out to and say, I'm having these questions, I'm having these doubts, I want to explore my sexuality, and they don't know how to do it in a healthy manner." Sanchez said he now feels lucky that he never contracted HIV or another disease. He hopes this new bill will become law and help other teens who are going through what he did. The bill isn't perfect, because there are still cost and insurance factors for the medication, but he believes it's a good step forward.

"Hopefully we'll see a decrease in the number of youth that are unfortunately being infected every year in Connecticut."

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Jesus Morales Sanchez, 24, of New Haven, is an immigration and LGBTQ activist. He says teens need to be able to access sexual health services like PrEP without the need of parental consent, because their families may not be accepting of their sexuality. CREDIT NICOLE LEONARD / CONNECTICUT PUBLIC RADIO