

Oakland clinic working to end HIV among young gay men of color with HIV prevention pill

The young lives at greatest peril of HIV infection are also the hardest to protect: Healthy gay men of color, who often distrust the traditional health care system.

But they're so comfortable at the [East Bay AIDS Center](#) that they congregate in its waiting room, watching TV, hanging out with friends and chatting with caregivers. And - along the way - learning about a prevention pill that could someday save their lives.

"You feel at home here," said Nadji Dawkins, 28, of East Oakland. "They know some of the things you've been going through, and there's no judgment."

At the Center, Dawkins and other young men of color are participating in an innovative [California HIV/AIDS Research Program](#)-funded research project called [CRUSH](#), which seeks to understand how to best educate and engage this high-risk population about an approach using an HIV prevention pill called PrEP, short for pre-exposure prophylaxis. PrEP is over 90% effective in preventing HIV infection when used daily.

If successful, the project could serve as a model for other cities striving to reduce HIV transmission rates so dramatically that the epidemic is effectively ended. This would be a stunning reversal for a disease that once seemed uncontrollable.

The long-sought dream of ending AIDS has been hindered by this reality: marginalized populations - such as young men of color who have sex with men - are not getting the services they need.

So while the rate of new infections has plummeted in some populations, in others it continues its inexorable march.

Among white gay and bisexual men, new diagnoses of HIV infection dropped steadily between 2005 and 2014, decreasing 18 percent. But new diagnoses climbed 24 percent in Latino men and 22 percent in black men. The steepest increase was seen in young black gay and bisexual men ages 13 to 24, with an 87 percent increase in new diagnoses.

The strategy behind the [CRUSH](#) ("Connecting Resources For Urban Sexual Health") project is yielding resounding results: More than 255 men - almost all of them in this high-risk target population - have enrolled in the project, far more than expected.

They're young: 24 years old, on average, although ages range from 18 to 29. Many are visiting a doctor for the first time in their young adult lives. About 35 percent are Latino, 20 percent are African-American, 15 percent are Asian and the rest are mixed race or white.

Their first visit is often casual and incidental; they may just be accompanying a friend to the Center, which serves approximately 1,500 East Bay residents living with HIV or AIDS. Or they're stopping by to get tested and treated for other sexually transmitted infections.

And while researchers predicted that fewer than half of HIV negative young men coming in to the Center would ask for PrEP, so far nearly everyone asked for PrEP, said Dr. Jeffrey Burack, co-medical director of the East Bay AIDS Center at Alta Bates Summit Medical Center in Oakland and co-investigator of the research project.

In fact, so many young men are participating in the study, funded by a \$6 million grant from CHRP, that more supplies have been ordered from drug manufacturer Gilead Sciences of Foster City, which is donating the drug product (Truvada, the HIV prevention pill).

There's another important finding: Young men are adhering to PrEP's rigorous daily regimen as well as older adults, researchers found. This contradicts traditional assumptions that young adults can't handle the discipline of daily medication.

There isn't enough data yet to reveal whether the young men are taking greater sexual risks because of PrEP, which could boost their rates of syphilis, gonorrhea or other infections.

Dawkins said that he's paying closer attention to his health since joining the study. "Even though Truvada has made the risk of HIV less of an issue for me, I actually wear condoms more now than I used to. I do it because I'm more aware of protection."

"It changes the game," he said. "I believe that it is the first time that we can take more an active appropriation of our sexual health - not just play Russian Roulette."

The science behind PrEP is easy. The pill, called Truvada, is made of two antiretroviral drugs that essentially coat certain cells of the immune system, blocking HIV from gaining a foothold.

The hard part is getting healthy high-risk young men of color to use it, especially as part of a research study.

"It is tough to convince them it is safe to get care - especially when there is nothing wrong with them," Burack said. "The most effective way is having their peers trust us."

There's a cloud over research volunteerism in some communities due to the abuses of the U.S. Public Health Service's "Tuskegee Study," when a large group of rural black men went untreated for syphilis between 1932 and 1972, even after penicillin had become the standard of care, said Dawkins.

And there are lingering allegations that HIV was concocted by the federal government to destroy people of color, a conspiracy theory promulgated by post-apartheid South African President Thabo Mbeki and preacher Rev. Jeremiah Wright.

"Historically, people of color have distrust with the medical field, in general," said Dawkins. "People still think certain things are government implemented - that AIDS is a government thing to kill people off."

There is also worry over cost, loss of time from work or the stigma of being identified as gay, he said.

That's why the message of the CRUSH project is one of personal empowerment: "Take Charge Of Your Sexual Health And Have Fun," its [website](#) asserts. And it includes PrEP as part of a much larger package of helpful preventive services.

Their approach is working for subtle, but profound, cultural reasons: young men in this community - whether HIV positive or not - have many close and trusting ties within their wide social networks. They exchange ideas, information and experiences. So when one person has a good experience with CRUSH, their friends get curious.

"Young people travel in packs," said Ifeoma Udoh, co-investigator and project director. "The appointment will be for one patient but they'll bring in five friends and hang out."

Accompanying friends will often ask: "'What's this clinic about?'" said Michael LaCorte, CRUSH Retention Coordinator. "They end up becoming patients."

At first, the CRUSH project wasn't too inviting. So it got a facelift. Staffers took down gloomy wall posters and redesigned its website.

"It was horrendous," said Udoh. "We had stock photos on the website that were these sad, disheartened faces - young men with their hands on their cheeks - 'Oh, no, I have a Sexually Transmitted Infection!'" It was depressing. Horrible. So they came down."

Added Dawkins: "The wording was cheesy," he laughed. "Who would actually say this stuff? Maybe 'back in the day,' but not now."

The new site features an image of a strong, muscular man, gazing out to sea; think retired NBA basketball player Jason Collins, ESPN's LZ Granderson or singer-songwriter Frank Ocean.

Its logo is fun and edgy: "Your pleasure is our pleasure."

"The face of HIV is not how it was 30 years ago, with somebody looking like they're near death," said Dawkins, who serves on the project's Community Advisory Board and

recommended the changes. "That was the reality of it back then, but now it is "Yeah, you have it. But you could still live a long and prosperous life. You're still, like, normal."

Other changes were implemented, as well. Appointment scheduling is flexible. There's greater use of texting and social media to remind patients when it's time for a visit. The youth have their own 'check-in' section, separate from older adults.

"Young people can come through the door and not be negatively seen if they don't make appointments on time. The idea was to reduce the formality," said nurse practitioner Jessica Horwitz, the project's clinical director.

A youth-focused team - including a nurse practitioner, social worker, peer mentor and advocate - provides the care. PrEP doesn't stand alone as an HIV prevention method - it's delivered as part of other general sexual health care and intensive counseling about sex risk education. These so-called "wraparound services" - an approach pioneered by the program Downtown Youth Clinic, part of the East Bay AIDS Center - support young people to stay in care, the team says.

"The idea is to prove and demonstrate that this particular model of 'wrapping' PrEP into other sexual health care services is viable, so that other clinics are incentivized to do these kinds of things in their communities," said Udoh.

There's national debate over whether PrEP is better delivered by primary care providers or HIV experts like those at CRUSH. This team is convinced that their HIV experience gives them a special advantage: they're already skilled in managing the health issues of at-risk populations. Many of the staff are gay men of color. One provider is openly HIV-positive, an experience he shares with clients. Another lost his partner to HIV. There's 24-hour access to a doctor. The team knows the medications, and they're skilled counselors.

"Since we're already set up to serve this population, it is easy to extend what we do to the at-risk population," said Horwitz. "The hard part is already in place. Our staff is devoted to this - which wouldn't happen in a primary care center."

"You can't just have people show up for a doctor's visit and leave - that doesn't keep this population engaged," she said.

Each time a young man enters the door, LeCorte tries to quickly build rapport. "I'll get their back story. Make small talk," he said. "Then I'll explain every step of the visit and introduce them to every person they'll interact with, so there's more trust. I'm not shocked at the stuff they say. I'll say 'That's OK' and applaud them for coming in. If they're scared and vulnerable, I tell them 'You're not the only one to go thru this stuff.' "

The tone is what staff proudly call "sex positive." They assume that young people are having sex, rather than assuming they're not. "This makes it easier to ask what they are doing and with whom they are doing it. It is not a judgment - but an appropriate concern," said Horwitz.

Words matter. Young men are not asked "Do you use condoms?" but "Tell me about your condom use." You get more information that way, said Horwitz. "It makes it far easier for them to say: 'Sometimes I do and sometimes I don't.' "

They take time to empower men to care about their own health - something as simple as, say, teaching them how to do a self-rectal swab. " 'You can do it yourself,' Horwitz tells them. " 'You don't need to have me, who you just met, do it.' That makes people want to come back."

Most importantly, they resist blame and finger-wagging. Questions are posed about "condomless" sex, not "unsafe" sex. And they steer clear of categories or labels, instead asking about specific behaviors. They don't ask "Do you consider yourself gay?" but rather "Who do you have sex with?"

Preventive medication is just part of this long and thoughtful conversation. It's just an option - maybe not right now, but perhaps later, they say. They answer the usual questions: Side effects? How long does it take to work? What kind of follow-up is needed?

"I tell them that PrEP is like HIV birth control," LeConte said. "The light goes on. They say 'That makes sense.'"

"They keep it in their mind as an option. And more than likely, later along the line they'll follow up. They'll say: "I am at a place where I can commit to a pill every day," he said.

Added Udoh: "One pill a day has become so normalized in reproductive health care. But it's got a long way to go before being normalized in HIV prevention."

The goal isn't to get everyone on medication, they add. Instead, they aim to give everyone access to general sexual health care - and then include medication, if appropriate, said Burack. He believes that PrEP's Truvada pill isn't something that should be offered uncritically to a large group of people. Rather, there are "seasons of risk" - times when people are at lower risk due to celibacy or stable monogamous relationships, and times of higher risk.

The average participant takes Truvada nine out of 12 months, the study has found. For instance, a young man may take it for three months, then quit, then resume for another six months.

"It is not a failure if they start, but don't stay. There is nothing magical about 12 months," said Burack. "They should take it when they are at risk and should not be taking it when they are not at risk. It depends on what is going on in their life. We try to support that."

"What's important is knowing it is available for them - and how to access it, so if things change, they can go back on it," he said.

Dawkins used to spend a lot of time anxiously waiting for a phone call to hear his HIV test results, he said. Now, in charge of his own health, he feels less stress and more confidence.

He's built his PrEP medication into his daily routine, taking it when he comes home from work at United Parcel Service or promptly after awakening from a post-work nap. It's like setting an alarm or brushing his teeth, he said - such a normal part of life that he doesn't need reminders any more.

"I'll get off it when I find Mr. Right," he said. Until then, he's grateful for the CRUSH team's support. "They actually know my name. I'm not just a number on their papers. You want to feel important. They're really good about making you feel OK."

[He encourages friends to learn more about PrEP](#), he said. I tell them: 'It's an empowering move. You have the power to get that knowledge, to make that choice to protect yourself, as long as you take it consistently every day.' "

"The word is spreading like wildfire," he said, "that it definitely works."

The California HIV/AIDS Research Program (CHRP) fosters outstanding and innovative research that responds to the needs of all people of California, especially those who are often under served, by accelerating progress in prevention, education, care, treatment, and a cure for HIV/AIDS. CHRP was founded by the California state legislature in 1983 to respond to the HIV/AIDS crisis in the state. Since the program began, CHRP has funded more than 2,000 research projects and distributed and monitored more than \$275 million in state funds for HIV/AIDS research.