Suppression Superheroes

A super new program at New York City's Housing Works helps participants get and keep their viral loads undetectable with incentives and without superpowers.

August 11, 2015 By Tim Murphy

Click here to read a digital edition of this article.

A year ago, London Gray was very depressed—and, consequently, not regularly taking her HIV meds. Sure, this 30-year-old transgender Brooklynite, a former staffer at the harm-reduction center Positive Health Project, had been diagnosed with HIV nearly a decade ago—but she'd never really made peace with it. "I had trouble with the thought of being positive, so I didn't really stay focused on my health," she says. "I'd stop and start my meds, and sometimes I'd sell them to make ends meet."

Sure enough, her CD4 count fell, and her viral load rose. "I don't remember the exact numbers," she says, "but it was sky-high. I didn't care about myself or anybody else. I'd stay in the house all day. I hated having to go to the doctor every three months—I hated being around other people who also had HIV and were always talking about their struggles—so I started skipping appointments."

Eventually, she says, she started to feel physically sick. "Moody, lazy, no energy, no appetite. I had no one around to say, 'Here, take your meds like you're supposed to.'"

But Gray was a member of Housing Works, the pioneering New York City nonprofit that serves homeless and low-income people with HIV/AIDS. And last year, Vaty Poitevien, MD, Housing Works' chief medical officer, asked Gray if she wanted to be part of a unique and exciting new program called the Undetectables, an agency-wide effort to get 80 percent or more of HIV-positive people in the Housing Works community to take their meds consistently and thus have undetectable levels of virus in their blood. (Undetectability not only promotes long-term health and longevity, it also keeps positive people from transmitting the virus to others.) To reach that goal, Housing Works' care teams would help clients look at their whole lives to identify roadblocks to taking meds consistently. Then the team and the client would work together toward removing those roadblocks.

The program included something to sweeten the deal: Every time participants proved undetectable on lab tests, at three-month intervals, they would receive a gift card for $100 to spend however they wanted. "Dr. Vaty made it seem like it was exciting to be part of the program," Gray says. "I wanted to take care of myself. But there was an added incentive, too. It was like, 'Woo, how much do I get for taking care of myself?'"

So Gray signed on, embarking on an amazing journey with the entire Housing Works community—and potentially even with New York State, which is looking to the Undetectables as a model of how to become

the first state to essentially end its AIDS epidemic by 2020.

According to Poitevien and her Undetectables co-director, Ginny Shubert, who is also Housing Works' senior adviser on research and policy, 700 community members have signed on since the program began in May 2014—and 85 percent of the ones who've been enrolled for six months or more have undetectable virus levels on their latest labs. In conjunction with Toorjo Ghose, PhD, Housing Works' research and program partner at the University of Pennsylvania, the agency wants to present data showing the effectiveness of the Undetectables program in 2016, possibly at the 21st International AIDS Conference—a.k.a. AIDS 2016—in Durban, South Africa.

How did it all begin? According to Shubert, Housing Works wanted to put its money where its mouth was in terms of ending the AIDS epidemic in New York State—something the agency, with other local activists, has been urging state lawmakers to prioritize the past several years. "We felt that we needed to do our part by achieving a community rate of viral load suppression [undetectability] of 80 percent or more," Shubert says. "We had to figure out how to get our community members to understand the role of taking care of your own health as part of the overall end of the epidemic."

To reach that goal, Housing Works did three things. First, it undertook a major, agency-wide public relations campaign to make sure that the whole community understood the link between meds adherence, undetectability, good health and stopping HIV's further spread. "We wanted to destigmatize talking about viral-load suppression and make it a heroic act, something to be proud of," Shubert says. The agency asked Berlin-based illustrator Rafa Gonzalez to create a comic book about a group of Housing Works superheroes called, natch, the Undetectables, who fight shame, stigma and hopelessness in New York's HIV-positive population, empowering folks to get the support they need to take their meds and keep themselves—and their communities—free from AIDS.

"The term 'Undetectables' just sounded like superheroes to us," says Juan Astasio, Housing Works' creative director, who wrote the comic book's storyline with an in-house team. They even created a pin that the heroes wear, now also worn by countless real-life folks around the agency, such as co-founder Charles King. "Charles wears his pin everywhere to start a conversation about being undetectable," says Astasio—including in meetings with New York governor Andrew Cuomo, who has thrown his weight behind the state's End AIDS campaign.

Secondly, Housing Works looked at previous results of programs that used financial incentives as part of a meds-adherence program. Ghose had experienced earlier success with that element in India, where he was involved with a program that involved giving HIV-positive sex workers free condoms and rooms to work in if they adhered to meds and maintained undetectability.

But Housing Works took a key conclusion from the India program and other previous efforts: Financial incentives worked best when they were part of a holistic effort to help patients identify and fix deep underlying factors that affect people's adherence to their meds, such as not being stably housed or having enough money for food; experiencing depression and other mental illness; and substance abuse. So the agency created a tiered program, which would begin with an in-house team of health care providers and caseworkers meeting with enrollees to examine their lives and complications.

And once they did, says Poitevien, they started peeling back the layers behind some enrollees' seeming reluctance to take their meds. "I had a longtime patient, a grandmother in her early 50s, who's only been undetectable once," she says. "Her T-cells had dropped to 12, but she wasn't fazed." Yet after a few

visits, the grandmother's team realized that "she was overwhelmed with so many issues," Poitevien continues. Not only was the client distraught over grandchildren who were in jail or being abused, but she also had very bad neuropathy in her legs that made it painful for her to cook or clean, or even get to her doctor appointments. The Housing Works team connected her to rides to her appointments, a home attendant to help with chores and reminders on her phone about her meds.

"She became undetectable," says Poitevien. Prior to the Undetectables program, she adds, she would have told this patient and others like her simply to divide up their meds for the week in pillboxes. "But she said to me, 'I'm not a child; I know how to take my medication.'" The reasons blocking her adherence were unique to her and needed unique fixes, which is just what the program provided.

If that first tier of intervention isn't enough to help participants, the program offers two more. One is overseeing a support group where enrollees meet to talk through their adherence issues and derive help from one another. And for the most challenged enrollees—the ones often struggling with mental illness or intermittent or heavy drug use—the program employs directly observed therapy, in which a Housing Works staffer comes to the enrollee's residence daily with meds and watches the enrollee take them.

According to Ghose, the Housing Works approach is offsetting prior studies (particularly a large New York City study released earlier this year) that showed decidedly mixed results when it came to offering people financial incentives to take their meds. Why? Because, says Ghose, the Undetectables provides "incentives married to several other interventions, [and] case managers connecting you up to" key needs like housing, food, and mental-health and substance-use treatment. "It's not just financial incentives floating free, which has been tried before."

And both Shubert and Poitevien insist that a major reason for the Undetectables' success so far is that Housing Works has made the program a big, splashy community-wide effort, not just something discussed privately between a health care provider and patient. "Case managers talking to patients about viral suppression had been going on, but it had never been articulated organizationally as a shared goal," Shubert says. "Even though it was supposed to be a team effort, it wasn't really happening."

But now, it seems like it is happening—and the team effort is making a big difference in the lives of myriad Housing Works community members. Take Adonis Porch, a 29-year-old childcare provider and volunteer at an HIV youth drop-in center. Diagnosed with HIV nearly a decade ago, he'd long had trouble adhering to his meds, often missing them as much as five days a week. "Every time I looked at those pills, it made me feel bad about myself," he says. He also suffered depression from being harassed in college after coming out with his HIV status, not to mention rejections from potential love interests because of it.

Then the folks at Housing Works gave him the Undetectables comic book, and asked him again and again if he'd join the force. "If one more person asked me, I was gonna scream," Porch recalls, laughing, "so finally I said, 'Where do I sign up?'" He freely admits that the financial incentive is what initially hooked him, "but once my doctor told me the first time, 'You're undetectable,' that motivated me to continue." That, he says, and the fact that his caseworker cared enough to call him every day to ask if he'd taken his meds.

"I feel great," Porch says. "Being undetectable is letting me know that I'm finally doing something right with my life."

Then there's Ervin Rogers, 54, a Housing Works peer educator and needle-exchange counselor. Diagnosed with HIV in 2002, he was occasionally skipping meds because they required that he take them in the morning with food—something he didn't always have. Then he joined a Housing Works day program that came with breakfast, which helped him become adherent. (Shortly thereafter, his Housing Works doctor helped him switch to a once-daily regimen that doesn't require food.)

Rogers was soon asked to join the Undetectables. "My reason for staying undetectable is because I want to live," he says. "But the money is an incentive, I'm not going to lie. Who couldn't use an extra $100 every three months?" He's also on the program's board. "I find enjoyment in helping others," he says. "I love seeing the light bulbs go off in people's eyes when they realize that if they take their meds, they're gonna live longer. They're battling addiction, hep C, HIV. Sometimes taking meds is not very high on their totem pole, so I'm an ear for them."

Certainly, taking HIV meds regularly wasn't priority No. 1 for Benjamin Ball, 38, who lives in one of Housing Works' residences. Diagnosed with HIV in 1999, he'd struggled for years to take his meds. "Fifteen pills a day was too much for me to wrap my brain around," he says of those days. Over the years, he continued to miss meds and became deeply depressed. He got very sick, with his CD4 count dropping to zero.

Last year, he was asked to join the Undetectables. "I wanted to be a part of it because I wanna live," he says. Ball is in the most intensive tier of the Undetectables, those who have a staffer come to their home every day to watch them take their meds. "I'm not a great morning person, but the person who comes here doesn't feel like a stranger," he says. "We have great conversations." He also attends a monthly Undetectables support group.

Since becoming an Undetectable, Ball has seen his CD4s climb to 44 and his viral load fall to about 1,500 (technically, being "undetectable" means lab tests can't detect HIV in your blood, but the Housing Works program focuses first on lowering your viral load). He's feeling good about his life—which makes it all the easier to enjoy his favorite TV show, Empire. His favorite character? Cookie, of course. "She reminds me of my mother," he says, "outspoken, brash and sassy." Perhaps Cookie could be his next adherence manager? He laughs. "She'd say, 'Get up off your ass and take these meds!'"

Housing Works is very proud of the fact that the Undetectables is now being considered as a model for statewide viral suppression by New York's campaign to end AIDS by 2020. "They're really behind our concept of eradicating HIV," Toorjo Ghose says, adding that he believes multitiered programs like the Undetectables will be "the next wave of intervention."

Of course, addressing the deep underlying issues that contribute to non-adherence—such as lack of access to stable housing, food, and mental-health and substance-abuse treatment—is easier in a contained agency environment like Housing Works than it is across the whole city or state.

According to Undetectables co-director Shubert, New York City could help with a huge piece of the puzzle by finally passing a long-demanded expansion of housing assistance to all income-qualifying people with HIV, not just those with an AIDS diagnosis (defined as 200 or fewer CD4s or at least two opportunistic infections), which has long been the rule in the city. That's especially important, she says, now that we know definitively that it's best to start HIV treatment immediately after infection.

But of course, that and other systemic fixes will take political will and a reallocation of city and state

funds. “It’s challenging any time people have to consider a reshuffling of existing resources,” Shubert says.

Meanwhile, the Undetectables continues to make everyday superheroes out of folks in the Housing Works community. According to Shubert, 83 percent of those who signed up for the program a year ago are still involved.

And one of them is London Gray. The Undetectables team helped her realize that she had untreated depression. “I didn’t believe in antidepressants,” she says. “I was so ignorant about them.” So she started them and began attending support groups. “Since then I’ve been feeling really good,” she says, which, in turn, has helped change her attitude about meds.

With the help of daily phone alerts, she’s been undetectable now for months—and she’s earned the bucks for it. “I got my hair and nails done and bought new summer sandals,” she says. But the biggest rewards, she knows, can’t be found in a store: her improved health.

Go to liveundetectable.org for more information.

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/article/suppression-superheroes-27628-3266