Privilege and Profit Corrupt the PrEP Access Debate

August 13, 2018 By Peter Staley

"I am going to fight them, my patients are going to fight them, and you goddamn well better fight them!" —Dr. Suzanne Phillips in a clip from How to Survive a Plague

It was August 1994, and TAG, the Treatment Action Group (I was a cofounder), had become the most hated AIDS organization in the country, while TAG member Spencer Cox had become the most hated AIDS activist. Hated by other AIDS activists. The "them" in Suzanne Phillips's rallying cry above were TAG's activists, and she was railing against "the boys" during a weekly ACT UP meeting after we had shocked "AIDS Inc." with a letter to the Food and Drug Administration (FDA) asking them not to grant accelerated approval to saquinavir, one of the first protease inhibitors.

We felt that Hoffmann-La Roche, its manufacturer, was abusing the accelerated approval process by rushing saquinavir to market before showing how it could be used in combination with previously approved drugs to extend lives. But by this time in the crisis, the status quo of AIDS patient advocacy, driven by the demands of HIV-positive gay white men (often with their gay doctors) in San Francisco and New York, was "just give us the drugs now and we'll figure out how to use them."

While this approach undoubtedly prolonged the lives of many proactive patients with expert docs who attended all the AIDS conferences, it was bound to be a long-term public health fiasco, offering little guidance on best practices for the vast majority of people living with HIV outside of these white gay enclaves.

When TAG challenged this status quo, demanding that answers on how to use the drugs were just as important as access, all hell broke loose. We were vilified by ACT UP and many other AIDS advocacy groups (although GMHC, the AIDS Action Council—now AIDS United—and AIDS Action Baltimore stood with us), with Roche fanning the flames. Spencer was especially eloquent at making our case and thus featured in multiple news outlets that covered the debate. He deftly handled the community scorn thrown his way with sound ethical arguments focused on the greatest good for the greatest number.

Thankfully, the FDA listened to TAG. The pharma companies racing to develop protease inhibitors enlarged their trials to collect real-world data on the various drug combinations. Saquinavir was approved 16 months later, around the same time that far superior protease inhibitors (like

Crixivan) were released, and the government had enough data to publish HIV treatment guidelines that could be widely implemented. The death rate from AIDS in the United States crashed by 60 percent in just two years.

Fast-forward to today, and we face yet another debate in which drug access, profit and privilege collide. In this current debate, PrEP4All is playing the TAG role, and its 27-year-old cofounder, James Krellenstein, is playing Spencer's role.

Today's debate is about access to Truvada as PrEP, the once-a-day drug that prevents HIV infections. Originally approved in 2004 as an antiviral for people with HIV (and priced accordingly), it became the only drug approved as PrEP in 2012. Its patent holder, Gilead Sciences, had no involvement in this new indication (beyond supplying the drug for free for the government's clinical trials). Instead of lowering the price to reflect its use as a preventive, the company has been jacking it up ever since, charging over $1,600 a month. That's a 25,000 percent markup over the $6 a month generic cost paid by PEPFAR (the U.S. President's Emergency Plan for AIDS Relief) and other international programs that provide free access to HIV treatments.

So what is today's status quo regarding PrEP access in the U.S.? The Centers for Disease Control and Prevention (CDC) says approximately 1.2 million Americans would benefit from PrEP. Estimates vary, but the most recent data suggests that a half decade later, less than 10 percent of those are currently taking the drug. Gay white men, most over 25 years old, make up the vast majority of current PrEPsters. The most at-risk groups—especially younger gay men, and gay men and trans women of color—make up a small fraction of current users.

Our status quo involves an exorbitant price, filtered through our byzantine health care system and cosmetically patched up with Gilead's patient and copay assistance programs (which it runs solely to buttress Truvada's obscene price). It's a system that works fairly well for those who seek out PrEP and have the agency to navigate a web of health care options that bring their out-of-pocket cost down to zero. It's a demand-driven system almost entirely for those who already see a doctor.

One thing is for sure—our status quo is not a proactive public health program. It bears no resemblance to coordinated efforts that ramp up proven preventives like vaccines, birth control, anti-smoking campaigns, etc. Imagine if we only provided birth control through pharmacies for women armed with prescriptions and made no effort to hand out free, confidential and stigma-free contraceptives at school clinics (still the sad norm in many of our red states). That's where we are with PrEP today.

We don't have to imagine what a national PrEP access program would look like. We already have a local example, run by the New York City Department of Health and Mental Hygiene (DOHMH). New York's DOHMH brings PrEP to those who most need it by providing same-day access at their sexual health clinics. The first time a 22-year-old black gay man in Brooklyn might engage with the health care system is to take care of that drip he's developed after that great sex he just had. He wants to avoid lectures and stigma, so he gets an STD checkup at one of the city's anonymous sexual health clinics. He's offered an HIV test. If it comes back negative, he gets stigma-free counseling

on all his options, including PrEP. And here's the kicker—he can walk out with a free 30-day supply (along with an appointment for ongoing health care visits).

It is no coincidence that New York City, one of the best-funded health departments in the country, is the only one offering this proactive public health program. The city is spending millions of dollars for these PrEP starter packs, and it's busting its budget because Gilead won't cut it a break.

Now imagine if the U.S. government offered HRSA (Health Resources and Services Administration, which manages the Ryan White Program) or CDC grants to health departments that had the highest rates of HIV transmission (the top 50 to 100 health departments would cover most of the epidemic) to set up stigma-free PrEP clinics within STD clinics and AIDS service organizations targeting the most at-risk communities. Such a program would cost at least $8 billion a year if those health departments paid the same price New York City is paying for its Truvada starter packs. If the National Institutes of Health used its march-in rights to set up a generic supply for this national PrEP access program, the total annual cost would fall below $1 billion a year—and possibly well below that (these are back-of-envelope estimates based on discussions with various public health officials).

Couple that with the estimates of Medicaid/Medicare savings from preventing thousands of HIV infections and your program could be paying for itself within a few budget cycles. If you don't think AIDS activists can get a program of this size off the ground (probably with federal and state funding split 50/50), then you are sorely underestimating our record and resolve in fighting this disease.

But we can't begin to imagine these programs with Gilead's current pricing. Either Gilead plays ball (provides free Truvada starter packs and all health care navigation services to a national program), or we will continue to push on multiple fronts to break its Truvada patent.

Enter PrEP4All, a group of mostly millennial HIV prevention activists that has dared to threaten the status quo on PrEP access. We launched a #BreakThePatent campaign, including an op-ed in the New York Times, and released a detailed national plan for universal PrEP access at the International AIDS Conference in Amsterdam last month.

To win this fight, we'll need all hands on deck. History will not look kindly on the sniping from community members defending a privileged status quo. I've heard from a gay AIDS journalist that PrEP4All is ignoring all the good news on PrEP uptake—that use in New York City is "excellent," that the recent small drop in national HIV incidence is "remarkable" and that maybe "PrEP is not a good fit for certain parts of the at-risk population."

I'm sorry, but when PrEP usage among those deemed at high risk of becoming HIV positive hovers around 14 percent among whites but falls to 3 percent among Latinx people and a paltry 1 percent among African Americans, then you can't slap a happy face sticker on such an inequitable turd. PrEP uptake is a national disgrace.

A recent Logo NewNowNext article by Mike Miksche questions PrEP4All's central focus on the need

for generic PrEP. In what amounts to a collective shrug, extensive quotes from PrEP educator Damon Jacobs state that “between their insurance, Gilead’s assistance programs and Patient Advocate Foundation support, most people in the U.S. can afford PrEP.”

“My Facebook Group, PrEP Facts: Rethinking HIV Prevention and Sex, has been helping people learn how to navigate insurance systems and fight obstructive bureaucracy for five years,” Jacobs says. “We haven’t ever lost someone due to cost.”

I’m a big fan of Damon’s work and think PrEP Facts has been transformative. But it would be silly to suggest that a closed Facebook page, even one with 21,000 members (with only a small fraction of them ever having posted), is adequately meeting the needs of the approximately 1 million Americans who would benefit from using PrEP. PrEP Facts is just scratching the white gay surface and is no substitute for robust public health programs (made affordable by free or low-cost Truvada). Besides, I read every post on the page, and almost half of the handful of access issues members raise each month are not resolved, by which I mean these members don’t come back and say their issues have been overcome and they are now on PrEP. They all get tons of useful advice (the page is amazing at this), but we often don’t know if they’ve successfully jumped through every hoop to gain access.

Even that is beside the point. For every proactive Facebook user who seeks out and finds PrEP Facts and has the courage to publicly admit to trying to start PrEP, there are dozens of nonmembers who give up as soon as their pharmacist tells them that their first bottle of Truvada will cost $1,600 to meet their health plan’s deductible (Gilead will pay this cost, but most folks don’t know that), or who give up after their doctor lectures them about condoms, or who don’t have a doctor to begin with, or who haven’t even heard about PrEP as an option to keep them HIV-free.

These are the real barriers, and many of them fall away with dedicated PrEP-on-demand services at STD clinics and AIDS service organizations. We need these PrEP clinics now, and we need free or cheap Truvada to set up hundreds of them nationwide. Please join us in advocating for the greatest good for the greatest number.

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http://beta.docker.poz.com/blog/privilege-profit-corrupts-prep-access-debate