

# PTA

POSITIVELY AWARE

THE HIV TREATMENT JOURNAL OF TEST POSITIVE AWARE NETWORK  
SPECIAL ISSUE SUMMER 2015

TRUE TALES  
OF SEX, LOVE,  
AND PEACE  
OF MIND

HOW PrEP IS MAKING  
A DIFFERENCE IN THE  
LIVES OF REAL PEOPLE

DOCTOR 'NO'

I WANT PrEP.  
BUT MY DOCTOR  
DISAGREES.  
HOW TO DEAL

NOËL GORDON  
LIVING FREE AND  
OPEN WITH PrEP

## THE PrEP ISSUE

ONE PILL  
A DAY  
CAN HELP  
PREVENT  
HIV



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"Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare." —Audre Lorde, *A Burst of Light: Essays*

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"It's been a joy working with David on this project. For me the personal stories in this issue of people who are using PrEP are incredibly moving and quite powerful."

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"If we fight PrEP, many new infections will be on us."

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"The fight against HIV requires an 'all of the above' approach. PrEP is part of that strategy."

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# NOT WILLING TO WAIT

**JULY 16TH MARKED** the third anniversary of the FDA's approval of Truvada for pre-exposure prophylaxis (PrEP). That approval marked the first time that the FDA had cleared a technology other than condoms—this time a daily pill—to prevent HIV transmission in the United States.

PrEP's anniversary is something to celebrate in the world of prevention. As a gay teen in the 1980s I remember reading about this new plague that it seemed I could not avoid should I ever choose to act on my desires. Coming out in 1989 and moving to San Francisco, I found myself surrounded by illness and death. With condoms the only thing standing between me and the monster devouring my community I did what most other people I knew did, I joined the army of "safer sex" warriors.

But sex with condoms requires negotiation with a partner who may not be inclined to use them, and the willingness to overcome challenges that some find insurmountable when it comes to sexual pleasure, intimacy, and imbalances in power. With rates of new diagnoses flat for a decade for most groups, and on the rise for young gay and bisexual men (especially African American youth), it is clear that our efforts to combat the epidemic with latex alone may have reached their limit.

When PrEP came along, it was not unlike the dark cloud of the epidemic that started to lift for HIV-positive men and women with the introduction of combination therapy in 1996. Unfortunately, three years after PrEP's approval, we seem to be fighting an uphill battle. More resources are available to PrEP-seekers and more providers are willing to prescribe it now, but we are far from realizing PrEP's promise.

Noted PrEP researcher Robert Grant, MD, reported this past February that if San Francisco could increase the number of at-risk individuals on PrEP by about three times, it could cut new infections by 70% every year. Yet even in a city with tremendous resources, tripling the number on PrEP will be a substantial undertaking.

In putting together this issue, we hoped to offer people an accurate peek at the data indicating how effective PrEP can be, guidance on finding a willing healthcare provider (or advice on how to turn an unwilling provider into a willing one), and things to consider when figuring out how to pay for PrEP.

We also wanted to share with you pictures of activists who are making a difference and the stories of PrEP takers. Our activists demonstrate what can be achieved with passion and hard work, as well as the tasks remaining to be done. Our profiles of those on PrEP represent a diversity of people who see themselves as at risk for HIV, the sense of liberation from fear that PrEP offered them, and the calculations they made in deciding whether PrEP was right for them.

Notable among our profilees, however, is that they were the ones who sought out PrEP. To do this they had to know about it. They had to assess their own risk. And with a few exceptions, they knew how to get their hands on it and how to pay for it, a range of factors rare among those who most need PrEP.

Also notable is that we found people brave enough to openly share intimate details of their sex lives and their choices around PrEP, something that would have been unthinkable just three years ago when the slut shaming around PrEP was on its way to reaching a fever pitch. The shame around PrEP, and the behavior that makes it necessary, remains strong, but coming out is still the best medicine and more people are doing so every day.

It's conventional wisdom that a medical innovation can take 10 years or longer to become common practice, and that it may never reach some. It is my sincerest wish that it doesn't take so long with PrEP. We can't afford to wait.

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—MATHEW RODRIGUEZ  
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NOÉL GORDON, 24, HIV-NEGATIVE AND ON PrEP FOR OVER A YEAR. PHOTOGRAPHED BY JOHN JACK GALLAGHER.

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# MOVING FORWARD WITH

## THE BASICS OF PrEP

BY LIZ HIGHLEYMAN

**H**IV pre-exposure prophylaxis—better known as PrEP—means using antiretroviral drugs to prevent the virus from gaining a foothold in the body from sexual or other exposures.

PrEP is one of the most important advances in HIV science in recent years. While PrEP uptake was slow at first, an increasing number of HIV-negative people are taking advantage of this new prevention option as a growing body of research evidence and real-world experience confirms its effectiveness and puts fears to rest.

Currently the only regimen approved for PrEP is once-daily Truvada, a combination pill containing two antiretroviral drugs: tenofovir and emtricitabine.

The U.S. Food and Drug Administration (FDA) approved Truvada for PrEP in July 2012. In May 2014 the Centers for Disease Control and Prevention (CDC) released guidelines recommending that people at substantial risk for HIV infection should consider PrEP (see CDC recommendations on page 5).

According to leading PrEP researcher Robert Grant, MD, approval of Truvada for PrEP was based on nearly 20 years of data from animal studies, safety information from millions of people using the drugs for HIV treatment, and findings from two pivotal trials of PrEP's safety and effectiveness in thousands of HIV-negative people: the international iPrEx study of men who have sex with men and the Partners PrEP study of mixed HIV status heterosexual couples in Africa.

Studies have shown that daily Truvada PrEP reduces the risk of becoming infected with HIV

by around 90% among people who take it as directed. Some studies have seen no new infections among people with blood drug levels indicating optimal adherence.

But overall PrEP efficacy has varied widely in studies of different populations, mostly due to differences in how often it is used. (See “PrEP Research: Yesterday, Today, and Tomorrow,” for details about the major PrEP studies.)

Evidence for the effectiveness of Truvada PrEP is most extensive for gay and bisexual men. But other groups can also benefit from PrEP, including heterosexuals, women who have HIV-positive partners and want to get pregnant, and people who inject drugs.

### ALLAYING PrEP CONCERNS

**Doubts about PrEP** have come mainly in four areas: side effects, drug resistance, cost and access, and its effect on condom use. While some remain skeptical, most concerns have been allayed by growing evidence from research studies and real-world use.

Truvada PrEP is safe and usually well tolerated. Some people report side effects such as headaches or gastrointestinal symptoms like nausea and diarrhea, but in a number of studies these have been mostly mild and typically lessen over time as the body adjusts to the drugs. Many people on PrEP report no side effects at all.

Although Truvada was approved for PrEP in 2012, tenofovir and emtricitabine have been approved as components of treatment of HIV-positive people since 2001 and 2003, and studies have shown they can safely be used long-term. Among HIV-positive people, tenofovir can sometimes cause kidney problems and a small amount of bone loss after starting treatment.

There is less data on tenofovir for HIV-negative people. Both iPrEx and Partners PrEP showed that people on Truvada PrEP rarely develop serious kidney problems. In fact, in some cases people with mild impairment who stopped Truvada for a while were able to restart without further problems. However, some people with pre-existing kidney impairment should not use Truvada, so kidney function should be tested before starting. A recent study showed that Truvada PrEP causes only minimal bone loss that stabilizes after the first six months.

Likewise, drug resistance has not been a problem for people with good PrEP adherence. But resistance can occur if people already have HIV when they start PrEP, or if they become infected while using it, which is why HIV testing before and during PrEP is so important. Truvada alone is not enough to control an existing HIV infection—people with HIV need combination antiretroviral therapy, usually with three drugs.

Truvada PrEP can be expensive, and cost is turning out to be a barrier for some people who want it. For the most part, health insurers are covering Truvada for PrEP, and many

people have manageable co-pays. But out-of-pocket costs for some has meant giving up on the chance to get PrEP.

Finally, some fear that people taking PrEP will have more risky sex—such as having more partners or not using condoms—which could lead to increased transmission of other sexually transmitted infections (STIs).

Most PrEP studies have not shown an increase in risky sexual practices after people start PrEP (known as risk compensation). In the real world, many people are interested in PrEP because they already are not using or do not want to use condoms, including men who have trouble keeping an erection with a condom, serodiscordant (mixed-status) couples who want to conceive, and anyone who desires a feeling of greater intimacy and pleasure.

The stable rate of about 50,000 new HIV infections each year indicates that many people at risk do





not or cannot use condoms consistently. PrEP offers a new tool as part of a comprehensive HIV prevention and sexual health strategy. Having more choices enables people to take the steps to prevent HIV that work best for them.

## PrEP RESEARCH: YESTERDAY, TODAY, AND TOMORROW

BY LIZ HIGHLEYMAN

**E**vidence for the effectiveness of PrEP comes from several large clinical trials that looked at different populations at risk for HIV.

Before diving into the data, it's important to understand that scientists can examine the data generated by studies in different ways. This helps them assess the likely success of a drug in "real world" scenarios, as well as how it holds up under more ideal conditions.

Not surprisingly, response rates are usually higher when people take a drug as directed, which is the ideal. But the overall response rate (which includes people who took the drug less often or not at all) is also useful, since it shows whether people can use the treatment in the "real world." If

a treatment is too inconvenient or causes too many side effects, for example, many people will not use it consistently and its overall effectiveness will drop.

### PrEP FOR GAY AND BISEXUAL MEN

The first widely reported PrEP data came from iPrEx, a study of 2,499 HIV-negative men who have sex with men, plus a small number of transgender women, at 11 sites in six countries, including the United States.

Participants were randomly assigned to take either Truvada or an inactive placebo pill once daily. Everyone also received a package of prevention services including risk-reduction counseling and free condoms. After the main randomized study ended, participants could continue taking Truvada in the iPrEx open-label extension, or OLE.

The risk of HIV infection was 44% lower overall

in the Truvada group compared to the placebo group. Among people with measured blood drug levels indicating good adherence, the risk decreased by 92%. A mathematical model estimated that PrEP effectiveness could reach 99% for people who took Truvada at least four days a week.

About 1,600 people continued on to iPrEx OLE. Three-quarters chose to keep taking Truvada, while the rest did not and served as a control group. Unlike the randomized trial, OLE participants knew they were getting the active drug and were informed that it reduces HIV risk. This is important, as during the main study participants were warned that they might be receiving a placebo and that even if they received Truvada, it might not work.

The risk of infection in the OLE study was 49% lower overall with Truvada compared to the untreated group after adjusting for risk behavior. Among people with blood drug levels showing they took Truvada at least four times per week, there were no new infections—100% efficacy. But only one-third managed to reach this level of adherence. People who took Truvada two or three times per week had an 84% lower risk of infection, but those who took fewer than two doses saw no significant protection.

At this year's Conference on Retroviruses and Opportunistic Infections, researchers reported findings from two other studies of PrEP for gay and bisexual men. Both were stopped ahead of schedule after an early

peek at the data showed PrEP reduced HIV risk substantially.

The PROUD study included 545 gay and bi men in the U.K. who reported recent condomless anal sex. This study also tested once-daily Truvada, but participants were randomized to start PrEP either immediately or after a one-year delay (there was no placebo).

Men in the immediate PrEP group had an 86% lower overall risk of HIV infection compared to those who waited. However, one man probably already had an early HIV infection at study entry and two others appeared to not be taking Truvada when they became infected.

The second study, called Ipergay, enrolled 400 gay and bisexual men in France and Canada. This trial tested “on-demand” or event-driven PrEP. Participants were randomly assigned to take Truvada or placebo, but instead of taking it every day, they took two pills together up to two hours before having sex, and then two more pills, one at 24 and another at 48 hours after sex.

Men who took Truvada had an 86% lower overall likelihood of HIV infection compared to those who took placebo pills—the same as in PROUD. Again, the two men infected in the first group appeared to have stopped taking Truvada.

Importantly, the men in Ipergay had sex often enough that they took 14 Truvada pills per month on average. This works out to nearly four pills per week—the number found to be highly effective in iPrEx. It is still not clear whether on-demand PrEP will be as effective for men who have sex less often, say once a month.

Because we don't know for sure how much Truvada prior to and after sex is necessary to provide protection, the CDC and



## In iPrEx OLE,

PEOPLE WHO TOOK TRUVADA  
**4 TIMES A WEEK HAD  
NO NEW INFECTIONS—  
100% EFFICACY.**

PEOPLE WHO TOOK TRUVADA  
**2 OR 3 TIMES A WEEK HAD AN  
84% LOWER RISK  
OF INFECTION.**

BUT THOSE WHO TOOK  
**FEWER THAN 2 DOSES SAW  
NO SIGNIFICANT  
PROTECTION.**

## IS PrEP RIGHT FOR ME?

**DECIDING TO USE** PrEP is an individual decision based on many factors, including your sexual practices, choice of sex partners, willingness to use other prevention methods, and whether you can stick to a daily pill regimen. Health care providers, case managers, friends, and others can help you decide whether PrEP is right for you. Online forums of PrEP users can also help you make a decision.

For many people, PrEP will be the right choice at some stages of life but not others—what Dr. Grant and others call “seasons of risk.” For example, couples trying to have a baby may go without condoms while trying to conceive but use them otherwise.

Some people struggle to use condoms all the time or have decided they simply don't want to, even with partners whose HIV status or viral load (if the partner is HIV-positive) they can't be sure of.

Others have a lower risk, but want to consider PrEP to diminish their anxiety. One example is people in a mixed HIV status monogamous partnership with the HIV-positive partner on treatment with an undetectable viral load. In this case, the risk of transmission is very low, but PrEP may reduce fear and increase intimacy.

Some people, after thinking it through, may decide to use other methods for reducing HIV risk. Under any circumstance, PrEP can't prevent you from getting an STI, and condoms do protect against many (although not all) of them. PrEP is best used as part of a comprehensive risk-reduction and sexual health strategy.

others are recommending that people not try this strategy at this time.

## PrEP FOR HETEROSEXUALS

**Partners PrEP** enrolled more than 4,700 mixed HIV status heterosexual couples in Africa. HIV-negative partners were randomly assigned to take Truvada, tenofovir (a component of Truvada) alone, or placebo pills once daily. They also received prevention counseling, STI testing, and free condoms.

The risk of HIV infection fell by 75% for negative partners using Truvada and by 67% for those using tenofovir alone. Among participants with detectable tenofovir blood levels, however, risk reduction rose to 90% and 86%.

Similarly, the TDF2 study, which enrolled more than 1,200 HIV-negative heterosexual men and women in Botswana, saw a 62% risk reduction among participants randomly assigned to take Truvada compared to those taking a placebo.

It is now widely known that when the HIV-positive partner in a serodiscordant couple starts antiretroviral therapy (ART) and achieves an undetectable viral load, their risk of transmitting HIV is close to zero—a concept known as treatment-as-prevention (or TasP). In Partners PrEP however, none of the HIV-positive partners were on treatment at the start of the study and only 20% began treatment during follow-up.

The Partners PrEP team conducted a follow-up study known as the Partners Demonstration Project, which enrolled 1,013 mixed HIV status couples. HIV-negative partners were offered Truvada PrEP until their HIV-positive partner started ART, continuing for the first six months of their partner's treatment. In this case PrEP acts

as a “bridge” to ART, offering protection until treatment fully suppresses viral load.

PrEP adherence was high and the overall risk reduction was 96%. The two women who became infected did so while neither partner was on PrEP or ART with an undetectable viral load—there were no new HIV infections among couples who actually used this combination prevention approach as intended.

## PrEP FOR WOMEN

**Studies of** young heterosexual women in Africa—including VOICE, FEM-PrEP, and FACTS 001—have evaluated oral PrEP using Truvada or tenofovir and vaginal gels containing tenofovir.

The oral tenofovir and tenofovir gel arms of the VOICE trial were stopped ahead of schedule when early data showed they would not be able to demonstrate a protective effect; Truvada also ended up working no better than placebo pills. Likewise, in FEM-PrEP, women assigned to take Truvada were no less likely to become infected than those taking a placebo. More recently, FACTS 001 found no difference in HIV infection rates for young women using tenofovir or placebo gels.

PrEP could not show a significant protective effect in these studies primarily due to low adherence—most of the women did not use the pills or gel often enough for them to work. What's more, actual adherence fell far below self-reported levels. Reasons for not taking PrEP consistently ranged from concern about side effects to fear of stigma.

While the lack of effectiveness in these studies was attributed mainly to low adherence—and both women and men with good adherence were protected in Partners

## CDC'S PrEP RECOMMENDATIONS

**UPDATED GUIDELINES FROM** the Centers for Disease Control and Prevention (CDC) issued in May 2015 recommend Truvada PrEP for people at substantial risk for HIV infection.

The CDC recommends PrEP “as one prevention option” for sexually active men who have sex with men, heterosexual men and women, and injection drug users. PrEP is also “one of several options” to protect the HIV-negative partner in a mixed HIV status couple trying to conceive.

### “SUBSTANTIAL RISK” INCLUDES:

- having HIV-positive sexual partners or drug-injecting partners
- a high number of sex partners
- recent sexually transmitted infections (STIs)
- inconsistent or no condom use
- sex work
- sharing injection equipment

The only FDA-approved PrEP regimen is once-daily Truvada (300 mg tenofovir

plus 200 mg emtricitabine), starting with no more than a 90-day supply (some providers start patients with a 30-day supply and check-in with them about adherence and risk factors before graduating to a 90-day supply). The CDC does not recommend any schedule besides continuous daily use, for example, taking Truvada only before sex or as a “morning-after” pill.

HIV testing should be done immediately before starting PrEP. People with symptoms of possible acute HIV infection (such as fever, sore throat, a rash, or swollen glands) should get a viral load (HIV RNA) test or wait to start PrEP.

Kidney function and hepatitis B status should also be checked before starting PrEP (the tenofovir in Truvada is also active against hepatitis B virus).

People on PrEP should have follow-up visits every three months that include HIV testing, assessment of side effects and STI symptoms, adherence counseling, and pregnancy testing if appropriate. STI and kidney function tests should be done every six months.

PrEP—there may also be a biological reason why Truvada PrEP does not work as well for women having vaginal sex as it does for men having anal sex.

Animal and human studies show that tenofovir takes longer to reach a protective level, and may not last as long, in vaginal compared to rectal tissue. The CDC PrEP guidelines note that while it takes around seven days for tenofovir to reach a protective level in the rectum, this may take around 20 days in the vagina.

## ADHERENCE MATTERS

**The common theme** running through all these studies is that good adherence is crucial for getting the maximum benefit from Truvada PrEP.

As noted, a majority of participants in iPrEx did not take Truvada often enough to see an overall beneficial effect from PrEP. The heterosexual couples in Partners PrEP did much better, while the young women in VOICE and FEM-PrEP did not



## 'PrEPception' AND MIXED HIV STATUS COUPLES TRYING TO CONCEIVE

### ANTIRETROVIRAL THERAPY

in an HIV-positive partner, and PrEP in an HIV-negative partner, have revolutionized the options for mixed HIV status couples trying to have a baby. Previously, such couples had to rely on very expensive assisted reproductive services that were only available in some parts of the country.

Though the CDC does not offer definitive recommendations on the use of PrEP for couples trying to conceive, experts are helping couples that wish to use it as an option. Generally, it is used when the HIV-positive partner is on antiretroviral treatment and has an undetectable viral load. PrEP may add an additional layer of protection to the HIV-negative partner, particularly if condomless sex is limited to the time of the month when the female is most fertile.

Though many thousands of HIV-positive women have used Truvada during pregnancy, there isn't a lot of data on the safety for the baby in HIV-negative women. Studies are ongoing to help answer this question.

Some doctors might have strong negative judgments about serodiscordant couples trying to have a baby without condoms, so education (and in some cases a change of doctors) may be necessary.

There's a great online resource for couples and their doctors at [hiveonline.org](http://hiveonline.org).

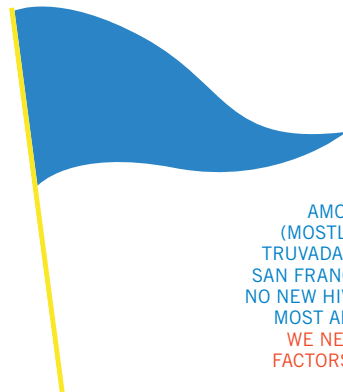
take their pills or use the vaginal gel enough to provide any significant protection.

We know that excellent adherence is possible under the right circumstances. For example, among the more than 500 people (mostly gay men) who have received Truvada PrEP at Kaiser Permanente in San Francisco, so far there have been no new HIV infections, suggesting that most are taking it consistently.

But we need to learn more about what factors encourage good adherence. In early U.S. PrEP demonstration projects, 92% of participants in San Francisco took PrEP at least four times a week, but this fell to 78% in Washington, DC, and 57% in Miami. In iPrEx OLE, adherence was higher among men who reported more HIV risk behavior, but it fell off most among the youngest participants—a group known to have a high infection rate. The Partners PrEP study found that adherence counseling helped participants use PrEP more consistently.

Fortunately, PrEP still offers some protection if people slip up occasionally.

"Having used a condom yesterday provides no protection if you don't use a condom today," Dr. Grant said, but iPrEx OLE showed that "PrEP remains highly effective, even in real-world circumstances in which adherence may not be perfect."



AMONG THE MORE THAN 500 PEOPLE (MOSTLY GAY MEN) WHO HAVE RECEIVED TRUVADA PrEP AT KAISER PERMANENTE IN SAN FRANCISCO, SO FAR THERE HAVE BEEN NO NEW HIV INFECTIONS, SUGGESTING THAT MOST ARE TAKING IT CONSISTENTLY. BUT WE NEED TO LEARN MORE ABOUT WHAT FACTORS ENCOURAGE GOOD ADHERENCE.

## WHAT'S NEXT FOR PrEP?

While daily Truvada is the only regimen currently approved for PrEP, new options are in the works. The Ipergay study suggested that taking Truvada before and after sex, rather than every day, may be enough. Further research and the final results of Ipergay will be needed to guide less-than-daily PrEP, however. Other antiretroviral drugs are also being tested for PrEP, including Selzentry (maraviroc) and a new formulation of tenofovir (tenofovir alafenamide or TAF) that is easier on the kidneys and bones.

Researchers are also testing other PrEP delivery methods. These include long-acting injectable drugs like cabotegravir and implants that release drugs slowly over time. Animal and early human studies suggest that once-monthly or even quarterly injections may offer long-term protection against HIV. Other studies are looking at vaginal and rectal microbicides, or HIV-killing agents in gels, dissolvable films, or slow-release vaginal rings. These new methods will give users more options and help overcome inconsistent adherence—the major barrier to PrEP effectiveness. **PA**

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## PrEP AND BEING TRANS

**THERE IS LITTLE** to guide the use of PrEP in people who identify and/or present with a gender different than the sex they were assigned at birth, or who don't identify with one of the binary genders of male or female.

The only data that does exist—in people assigned male sex at birth, but who identified themselves as transgender in a study—included too few people in this category to reach definitive conclusions.

While there are reasons to suspect that PrEP will offer at least some protection for insertive or receptive vaginal or anal sex, there may be differences in how well it works or how safe it is for transgender people taking sex hormones.

Nevertheless, there are trans persons taking PrEP, two of whom are profiled in this issue. As is the case for anyone, the heart of making the decision about whether PrEP is right for you lies in identifying your risks and what you feel comfortable with.

Fortunately, several demonstration projects have sought to recruit trans persons. What's more, there are grant opportunities for several large demonstration projects devoted exclusively to research on PrEP in trans persons, so hopefully more information will come out in the next two or three years.



# DOCTOR 'NO'

YOU WANT PrEP, BUT YOUR DOCTOR DISAGREES. HERE'S HOW TO DEAL

BY KELLEE TERRELL

**I**f there are two things that we know about PrEP, the first is that it's super effective in reducing one's risk of contracting HIV. The second is that bringing it up at your next doctor's appointment can be particularly stigmatizing, especially for those who are trying to access the little blue pill in a traditional healthcare setting.

So what can you do to make sure that your voice is being heard?

"First things first," says Bryan Bautista-Gutiérrez, PrEP Coordinator for Howard Brown Health Center in Chicago. "You really have to do your research before you set foot into the doctor's office asking for PrEP," he emphasizes.

According to Bautista-Gutiérrez, this work can include:

**ASSESSING YOUR ACTUAL RISK FOR TRANSMISSION:** "I see a lot of clients who come in asking for PrEP, who have boyfriends who are HIV-positive, but have an undetectable viral load, making transmission very difficult." So PrEP is an additional layer of protection that they may or may not want to consider.

**TALKING TO YOUR FRIENDS:** It's interesting that we can talk to our friends about PrEP, but healthcare can still be a barrier. Start a conversation with your friends about whether they are on PrEP, or know of someone who is and who prescribes it to them.

**GETTING ONLINE:** Thanks to the Internet, you can access mounds of trusted information about PrEP including how it works, side effects, follow-up tests, and strategies to combat doctor bias. In addition, depending on where

you live, there are online directories that can tell you where the closest PrEP provider is in your area. So get to Googling. (See a list of resources on page 20.)

**FINDING A LOCAL LGBT/HIV HEALTH CLINIC:** We recognize that in too many areas in our country, such as the rural South, healthcare facilities that specialize in PrEP may seem like a pipe dream. But for those who do have one, opt for accessing their PrEP program in order to increase the odds that you are receiving culturally competent care, although even long-time sexual health providers and community clinics might not yet serve transgender people and people who currently or formerly injected drugs.

And once you get to the doctor's office, Bautista-Gutiérrez, stresses, "There isn't a lot of time in your appointment to beat around the bush, so use this time wisely and advocate for yourself."

**STANDING YOUR GROUND:** Communicate clearly and succinctly that you believe PrEP is an important prevention tool that you need. Don't be afraid to be assertive or ask questions about lab work processes, follow-ups, and prescriptions.

**BEING WILLING TO LISTEN:** While homophobia and other forms of intolerance are real issues, PrEP is relatively new, especially to providers who may have little to no HIV/AIDS experience. What may seem like slut shaming may

also be your doctor demonstrating their lack of knowledge about HIV and prevention. And if that seems to be the case, ask for a referral to a provider who has more experience with PrEP. Referrals are also a good option when providers are medically uncomfortable providing PrEP.

**SPEAKING UP AND OUT:** If you do feel that your doctor is judging you or making assumptions about you, drop them and find a new physician. Remember: You are entitled to respectful healthcare that is culturally competent and empowering.

Granted, when it comes to PrEP, not all of the responsibility should be placed on the patient. Therefore "doctors really do need to get over themselves when it comes to bias," says David Malebranche, MD, MPH, a primary care physician at the University of Pennsylvania's Student Health Center in Philadelphia. "PrEP is not a hard drug to prescribe to patients, nor is the follow up."

But Malebranche stresses that in order to make PrEP a household word in healthcare settings, eradicating bias isn't enough. Doctors, nurses, and other healthcare staff are in dire need of support—both structural support for the logistics of offering culturally competent sexual healthcare and to address barriers in the public health realm.

**KELLEE TERRELL** is an award-winning filmmaker and freelance writer who writes about race, gender, health, and pop culture. Her work has been featured in *Essence*, the *Advocate*, *The Root*, *POZ*, *The Huffington Post*, and [thebody.com](http://thebody.com).




# TRUE TALES OF SEX, LOVE, AND PEACE OF MIND

BY JOSH TAGER

**P**REP CAN BE A SERIOUS COMMITMENT and there may be hurdles along the way. Solid information is key, especially when it's written in language that is friendly to you and your provider. Some people also derive a lot of benefit from hearing the experiences of others. Here are five brave souls who are proud of their decision to start PrEP, and not afraid to explain why.

PHOTO: DAVID TURCOTTE PHOTOGRAPHY





**'PrEP is pretty great for me. It's allowed me to have a better sex life.'**

—MATHEW RODRIGUEZ

## PrEP HAS GIVEN ME PEACE OF MIND

**Mathew Rodriguez**, a 26-year-old queer Latino living in Queens, New York, is the community editor at [TheBody.com](http://TheBody.com), an online HIV/AIDS resource.

### What made you think to start PrEP?

I first heard about PrEP in 2012 while working at Apicha Community Health Center, which does HIV prevention and treatment for LGBT and people of color in New York City.

I didn't think about it for myself, though, until the tail end of 2013, when I started a non-monogamous relationship with a man who didn't always use condoms, and we were having sex without condoms.

Also, I have trouble negotiating condom use when I drink. Drinking is a big trigger for me. I don't always want to use a condom when I drink.

### How did you go about getting a prescription?

I've been super fortunate to have a pro-PrEP doctor who is also my health cheerleader. I didn't need to convince him.

We had two or three conversations about it. He asked me questions about my sex life. I'm living with diabetes, so we talked about that, too. Because I already take daily meds for that, he knew I could adhere to PrEP.

But I'm an atypical case. Accessing PrEP can be much harder for some people than it was for me. Some people have jobs where they can't take a break to call their doctor. And you have to learn the language of the insurance and medical industry—a whole new jargon. Access should be a priority issue.

### What about paying for it?

The first pharmacy I went to told me it was \$1,295 per month. I went to a second pharmacy, and they told me to go through a mail order pharmacy. Then my

provider had to fax information over to them. There were a lot of phone calls to my insurance company.

It took a long time. It took a lot of patience on my part and my doctor's part. It wasn't the hardest thing in the world, but it was a lot of running around.

### Now that you're taking PrEP, what do you think?

PrEP is pretty great for me. It's allowed me to have a better sex life. Most gay men spend their time wondering what are the chances that semen permeated the condom, or how many days until they can get tested again.

I'm stressed out by nature, so PrEP has helped me with my mental health. It allows me to have better sex because my head is more in the game.

### Is your experience different from what you had expected?

It's what I expected. It has given me peace of mind.

PrEP has put me in touch with my own body, and because fear has been taken out of the equation of sex, I have room to do things I may not have done before. I'm more excited about sex, and more sexual.

### Do you ever use condoms even though you're taking PrEP?

I still use condoms when my partner requests it, or if I don't know my partner that well. PrEP is like putting a security system on your house: you still don't leave your door open for everyone.

### Do you have any advice for people who are thinking about starting PrEP themselves?

When it comes to PrEP you are going to be your own best advocate. You need to be vocal with your care provider. Some doctor's offices are frustrating, but they can be advocates for you if you advocate for yourself.

You have options.

## NOT ALONE IN THE JOURNEY

**Brandyn Gallagher, 27, lives in Seattle. He's a trans advocate who was socialized for 25 years as female, but now identifies as non-binary and transmasculine. He's part of a small but growing number of trans people who've decided PrEP is right for them.**

### **When and how did you hear about PrEP?**

It was January 2014, and I was stressing a lot about what it means to be gay, and suddenly starting to have sex with gay men. A friend, who was in a [mixed HIV status] relationship, told me there's a pill now that makes it all kind of irrelevant.

### **How has it been as a trans person to think about PrEP in the absence of good data?**

It's certainly unsettling. But I recognize that PrEP is the best option we've got, even in the absence of confirmed data about how it works in our bodies. Most of us—some studies put the number around 81%—don't use condoms in sexual encounters. There are a number of reasons for this, not the least of which is how hormones affect our vaginal tissue. So for those of us who engage in receptive vaginal sex, condoms are incredibly uncomfortable and arguably more dangerous to use than barebacking.

PrEP is the best option there is, for now, to protect myself against HIV.

### **Has your experience with PrEP been different from what you expected?**

Definitely! It's been interesting to me to see how casually a lot of guys approach sex without giving it much thought. I think maybe some of that comes from [me] being socialized as female for 25 years. The burden of birth control, and for making my partners wear condoms, and for getting tested for STIs, was all my responsibility.

That's just a completely different mindset from what cisgender gay men [those

assigned male sex at birth] have about STIs and HIV testing.

So my experience on PrEP has coincided with my transition into what I call "Fag Space," where visits to bathhouses or sex parties are a pretty normal part of my culture now.

### **Did you have any difficulty accessing PrEP?**

Only a little at first. I went to my primary doctor and asked for it. He said he couldn't prescribe it, but that there was a study going on through Gay City [LGBTQ wellness center offering arts, health, and community-building services] where I could get it, and that when the study was over he'd be able to continue prescribing it.

The researchers make sure the providers get PrEP training in the process so that hopefully in the future they'll feel more comfortable doing it all on their own. Finding competent doctors as a trans person is hard. I ended up leaving that aforementioned primary care doctor because his nursing staff kept emasculating and disrespecting me—and this was at an LGBT clinic. But I'm fortunate to have found a doctor just recently who seems trans-competent, and who is also an HIV specialist.

### **What advice would you give to others who are thinking about PrEP?**

Probably above all else, I would recommend joining the [PrEP Facts] Facebook group, and connecting with people there who know the system and the hurdles that come with being on PrEP. I wish I'd been aware up front that there would be some backlash from guys who think less of people on PrEP. But having the PrEP Facts group gave me a place to find support and camaraderie when those moments happened, and it was great not to feel alone in this journey.

Whatever your method of finding support, I think that's a really important thing to do.





**'I'm fortunate to have found a doctor just recently who seems trans-competent, and who is also an HIV specialist.'**

—BRANDYN GALLAGHER

PHOTO: NATE GOWDY

## FEAR NO MORE

**Julie Lynn** (a pseudonym, as she wishes to remain anonymous), 49, lives in Connecticut. The epidemic hit when she was a teen, but since starting PrEP in September 2014 she's been celebrating her sexuality like she hasn't in years.

### When and how did you first hear about PrEP?

I remember exactly. It was last summer in *New York* magazine. They had a wonderful article about PrEP, and how controversial it was, and it was filled with lots of beautiful photos of gay men. A friend of mine posted it on Facebook. I'd never heard about it and it was really eye opening.

The thing, too—I know it had to be a Tuesday or a Wednesday, because I was in my knitting group—I asked all the women that I knew, "Did you know there's a drug you can take to prevent HIV, and it was approved by FDA two freaking years ago?"

No one believed me.

### How did you decide that PrEP was right for you?

That took a little bit. The morning after I saw the article I talked to one of my lovers, who's a physician. I wanted to know everything he knew about Truvada for PrEP. He said it just never occurred to him to tell me about it.

In a lot of ways I was initially suspicious that PrEP was too good to be true. I did a lot of research. I just couldn't find a reason not to [take it].

I was a college freshman in 1984 when AIDS really broke into the news. It had this really chilling effect on me. Before then I was an adventurous girl, and then that all came to a stop. I decided not to have sex again, because no one died of *not* having it. I kept that up for more than a year, and then science caught up with my fears.

I didn't realize how much fear I still had until I started taking Truvada. I actually started crying. I don't have to be afraid of sex. It was a profound moment for me.

### Has your experience taking PrEP been different than you initially expected?

Some people complain about side effects, but I haven't had them. Of course, you have to go back regularly for tests, but so far there's nothing wrong under the hood so to speak.

### Do you talk to people about being on PrEP?

I originally planned on not mentioning it with new or casual partners—I didn't want to risk a contest of wills over condom use if new folks knew that I couldn't get HIV. I kind of ended up going the other way though.

I do public speaking, and I often share the stage with folks who talk about such serious subjects: HIV in prison populations or HIV and homelessness. My talk amounts to, "Sex is fun, let's have some more of it."

I met a new guy who also does public speaking. Part of how we bonded was talking about our common experiences as speakers, so it was natural to tell him that I'm on PrEP.

When we finally had a conversation about condoms, he asked if we could skip them because I'm on PrEP. Given that he already knows that I speak about sexual health, it was actually easier to explain why we couldn't skip the condom.

### Anything you'd add based on your experience taking PrEP?

Before PrEP there were things I hadn't felt free to do for many years. After PrEP I could have sex with someone without having to know every teeny tiny detail about their sexual health. I was like a kid in a candy store, and I had a lot of adventures.

Now that I've had those adventures, it turns out such casual encounters are less interesting in fact than in fantasy. My behavior may go back to what it's been for several decades, but at this point, if it does, it will be an informed choice rather than an absence of choice.

# A NEW WORLD OF POSSIBILITIES FOR DATING AND LOVE

**Noël Gordon**, 24, is the son of a Panamanian mother and a Jamaican father. He lives in Washington, D.C. where he works for the Human Rights Campaign, an LGBT civil rights organization.

## What made you think to start PrEP?

I read an article about this pill that could prevent HIV a few years ago. I didn't know much about it, though, until I took a quiz, "Is PrEP Right for Me?" on the Stigma Project's website. It suggested that I talk to a provider.

## What did you do next?

I went to my regular healthcare provider. He was very knowledgeable about PrEP, very thorough, and very thoughtful.

He asked me about my sexual habits and history, and about my perceived level of risk. Had I ever taken a daily pill before? He was trying to determine my likelihood of success. We agreed it was the right option for me.

I'm lucky. He didn't judge me. Many LGBT people fail to disclose their sexual identity or sexual activity to their healthcare provider because of real stigma.

## How did you assess your own risk?

It took a really honest conversation with myself. I'm a young gay black man living in Washington, D.C., a city with high rates of HIV, and there are many other young gay black men with whom I'm having sex with, who may or may not have HIV.

There's an old trick in public health. If you ask people, "Do you use condoms?" they'll likely say yes. But if you ask, "Did you use condoms the last three times you had sex?" they might say no. The point is, people often tell healthcare providers and health researchers what they want to hear because of real or perceived stigma.

I accepted that I sometimes engage in so-called high-risk activities, and that there is nothing wrong with me seeking out

tools like PrEP to stay healthy in light of that.

## Now that you're taking PrEP, what do you think?

I feel empowered. I feel less stress now than I did before. I used to constantly worry about whether I was doing enough to protect myself. That's gone by the wayside.

I don't think people talk enough about the mental health benefits of PrEP. I can't emphasize that enough. The number one reason people don't get tested for HIV is that they underestimate their risk. The second most common reason people don't get tested is that they don't want to know the answer.

## Are you open about taking PrEP?

It's one of the first things I tell someone. My mother told me when I came out that she didn't want me to get AIDS and die. I've told her about PrEP and that I will likely not get AIDS and die, and she thinks that's amazing.

And it's something I talk about with sexual partners. Usually I'll ask someone, "When's the last time you were tested for HIV?" And then we talk about PrEP.

## A small, but vocal group of skeptics think PrEP is a bad idea—that it can lead to riskier behavior. What do you say to them?

PrEP has opened up a world of possibilities to dating and love. I would think this is what Larry Kramer [the founder of ACT UP, and PrEP critic] and other advocates are working toward: a world where HIV doesn't have to be stigmatized.

This is the manifestation of the advocacy they're doing. People with HIV don't have to be pariahs, but can be more



**'PrEP is something we should celebrate.'**

—NOËL GORDON

accepted by their husbands, their wives, their families.

[Someone] has called PrEP a party drug. It is, but not in the way that person means. PrEP is something we should celebrate.

## Do you have any advice for people who are thinking about starting PrEP themselves?

It's okay to feel many things about PrEP. It's okay to feel apprehensive, excited, or [have]

conflicting emotions. It's a fraught issue. But I would hope after talking to a knowledgeable, compassionate provider, that no matter what society thinks, or your provider, that you would feel empowered to take PrEP, if it's right for you.

Sex is something we should all be able to enjoy, and PrEP is something that can help us do that.



**'Why not use something that can protect you?'**

—PRUE MENDIOLA

## PrEP IS A BIG DEAL

**Prue Mendiola, 26,** is a proud Latina transgender woman who lives in Hollywood, California, where she works as an HIV prevention counselor for Friends Community Center.

### **When and how did you decide to start PrEP?**

It started out as a bit of a joke early last year when we were planning a PEP and PrEP community forum for the transgender community. We were having trouble tracking down a transgender person taking either, so to help out I said, "Well hey, maybe I should start taking PrEP."

I was married, then, and in a strictly monogamous relationship. I didn't consider myself high risk. But this got me thinking about PrEP and I realized, even if you think you're in a monogamous relationship, there's always a risk.

Since then I've divorced and started dating again. Even with the best intentions sometimes

it's hard to plan when and how I'm going to have sex. Sometimes things just happen.

### **Did you have any problems getting a PrEP prescription, or paying for it?**

PrEP can be difficult to get, but I have the best doctor in the world—Dr. April Soto—who works for Kaiser in Pasadena, California. She's a great transgender advocate.

I shot her an e-mail, I told her I was thinking of going on PrEP, she called me, we talked about it, I went in, I took some tests to make sure I was negative and didn't have any STDs, and got a prescription.

The only problem I encountered was with the pharmacy.

I get help with my co-pays. Usually my prescriptions at Kaiser [Permanente] are \$15, but this was \$50, and when you work for a nonprofit that can be a lot. But I was able to work that out.

### **Is taking PrEP different from what you thought it would be?**

I was concerned about side effects, and hormone interactions, too. But Truvada is a very mild drug [for most]. Sometimes, rarely, people get side effects, but I've had absolutely none.

It's important to take it every day, but for me it's now a habit. It's been like taking a vitamin. I have my little pillbox, so I can see each day that I've taken it. It's not even a thought, now; it's just part of my daily routine.

### **Has it changed the way you feel about sex?**

I feel empowered. I feel inspired to tell people about PrEP. Not just people in my community, but everyone, no matter their risk or sexual orientation. Why not use something that can protect you?

PrEP has given me sexual freedom and a chance to just breathe. I've heard other people say the same thing.

### **Do you still use condoms?**

It depends on who I'm with, or if I'm dating someone seriously. PrEP is a tool, but you can still get other things. Some people carry around gonorrhea or syphilis asymptotically.

Now I think about prevention on a daily basis. With PrEP you get tested every three months. If anything, taking Truvada makes me more cautious.

### **What do you say to people who criticize PrEP, or who say it'll lead to riskier behavior?**

Sex is stigmatized, and stigma is one of the biggest issues we face with PrEP, HIV prevention, and sexual health in general.

There is nothing wrong with wanting to have sex. And there's nothing wrong with wanting to take charge of your own sexual health, no matter what other people say.

PrEP is a big deal, especially for young people. We're looking at a whole new generation who could have a lower rate of HIV.

### **Do you have any advice for people who are thinking about starting PrEP themselves?**

Your sex life is your own. Sex is very personal. **PA**

*If you're thinking about PrEP, know that it's a terrific option. Talk to your provider. Take charge of your sexual health. You're empowering yourself.*

**JOSH TAGER** is a journalist and investigator who has reported on health, personalities, and pop culture for a range of publications including *POZ*, *Out*, *ETonline*, *Glamour*, and *Time Out New York*.

# LOOK WHAT THE STORK DELIVERED

WITH THE HELP OF PrEP, SHANNON WEBER HELPS POSITIVE PEOPLE HAVE A BABY—SAFELY

BY KELLE TERRELL



Depending on who you ask, California-native Shannon Weber just may be the hardest working woman in PrEP.

And depending on which day of the week of it is, you would find Weber at one of her many positions which include being the director of the HIVE clinic and its website, [HIVEonline.org](http://HIVEonline.org), a coordinator of San Francisco's Getting to Zero campaign, and working on-staff at the San Francisco Department of Public Health Capacity Building Assistance program and AIDS Education/Training Center.

But to Weber, who is also a mother of three, this “can’t stop, won’t stop” mentality is worth it because she gets to do what she loves: Link HIV-negative women and men to PrEP to safely conceive babies with their HIV-positive partners.

“Having a baby is such a nuanced decision. And I believe that having HIV, or having a partner living with HIV, shouldn’t change our opinions about who has the right to have a child. People should have their right to foster, adopt, and even have a child in the way that they want and HIV shouldn’t stand in the way of helping make those desires a reality,” says Weber.

But conception among mixed status couples can be complicated and pose many obstacles, including financial ones. Many couples cannot afford expensive procedures such as sperm-washing and in vitro fertilization. Therefore, condomless sex and PrEP (which does pose insurance coverage issues for some) may be the most plausible options. But it’s these latter options that many of Weber’s clients choose and that are often met with opposition from their healthcare providers.

“It’s a shame because PrEP reduces risk of transmission as does having a positive partner on antiretrovirals who is undetectable. And that’s what needs to be emphasized here: Women

PHOTO COURTESY OF SHANNON WEBER



who want PrEP to conceive are not asking for zero percent risk, they just want help to reduce their risk.”

And helping to reduce risk is exactly what Weber does.

Since 2005, Weber has helped more than 250 women around the U.S. find providers in their area who support them in navigating safer conception options. In addition, she works with providers, offers preconception and prenatal counseling, gives webinars and trainings for other organizations, and has even created instructional videos for providers to educate them about PrEP.

And if that wasn't enough, Weber is on the cusp of launching [PleasePrEPMe.org](http://PleasePrEPMe.org), an online directory that will provide a comprehensive list of providers in California who will provide PrEP.

“This has been really exciting because with this tool we are reaching a much broader audience, and it can also help people feel less isolated when it comes to PrEP and know that they are not alone,” she says.

And if it's not obvious, Weber's work is also important because of recent demands that women be a part of the narrative around PrEP, which hasn't been the case given how much media coverage and awareness has been centered on gay and bisexual men. Not to mention, because of the intersections of HIV, gender, and reproductive health, Weber's work could help usher in women's health organizations like Planned Parenthood to incorporate PrEP in their family planning strategies, which is a need.

“Only 12 percent of 500 women's health providers we surveyed believe PrEP is an important part of a family planning visit. Meanwhile women think their gynecology or family planning provider would be an ideal setting to learn about PrEP. So yes, there is huge gap and hopefully in the future by working together we can fill it.”

# MAKING GOOD ON THE PROMISE OF PrEP

## HOW JIM PICKETT IS MAKING PrEP A HOUSEHOLD WORD

BY KELLE TERRELL

**If you look at Jim Pickett's 20-year career, it's hard to believe that this wasn't his intended path.**

Pickett, who is currently AIDS Foundation of Chicago's Director of Prevention Advocacy and Gay Men's Health, is a long-term survivor who has spent the past two decades traveling the country (and the world) raising awareness and pushing for innovative prevention methods, which currently includes his fierce activism around PrEP.

After dropping out of college and moving to Chicago, the Wisconsin native wrote for the now-defunct *GAB*, a tongue-in-cheek weekly zine about gay nightlife. During his tenure there he penned some pretty salacious gossip columns and crafted insanely witty serials, such as “Poop Stain with Miss Margie” and “The Adventures of Bottom Boy.”

And then in 1995, Pickett tested positive and decided that if his life was going to change, so should his writing.

“Two years after my diagnosis, I started the column ‘Sick: A Body of Work in Progress.’ It delved into my own fears and the schizophrenic experience of living with this disease—a disease that so many of us thought we were going to die from.”

He adds, “I felt like if I wanted to be a ‘real’ writer, I had to do something more than ‘Poop Stain.’ I ended up unwittingly becoming an HIV poster child,” he admits.

It was this intensely personal work that catapulted Pickett into public health, working with the Chicago Department of Public

Health on syphilis and crystal meth awareness for gay men and managing the multimedia project *The Faces of AIDS: Living in the Heartland*, before working with the AIDS Foundation of Chicago in 2004 doing policy work. Pickett also penned the extremely popular column “Pickett Fences” in *POSITIVELY AWARE* for nearly a decade.

But over the years, Pickett saw that he was immensely attracted to HIV prevention work.

“I think my writing and how in-your-face it was played a role in why I'm so fascinated with prevention,” he admits. “Prevention is about being taboo and talking about issues such as sexuality, anal sex, and barebacking. You know, the kind of stuff that makes people clutch their pearls and shriek,” he laughs.

Pickett, who is also a staunch microbicides advocate, definitely sees PrEP fitting into that taboo category, given how polarizing the prevention tool has been, especially in the gay community, since its debut.

“Fifteen years ago I was really dismissive of PrEP, but the more I read and followed the science, I got really excited! For so long the only tool we had was condoms and now we have a pill that not only can prevent transmission, but can serve as a gateway drug to get people linked into primary care.”

It's this excitement that helped Pickett become a PrEP tour de force, spearheading AFC's efforts with PrEP literacy trainings, providing PrEP referrals, and amplifying the voices of people on the medication. Most important, Pickett and AFC have been the leaders in fighting against the state's governor



Bruce Rauner, who halted the much-anticipated PrEP 4 Illinois assistance program.

But Pickett points out that his PrEP advocacy is truly about collaborating with others.

One such partnership is the Chicago PrEP Working Group, which Pickett oversees with the Chicago Department of Public Health. This “energetic and great” group of over 100 organizations and advocates works together to help break down structural and cultural barriers that make PrEP hard to access for communities in need. In addition, the working group has collaborated on an online resource listing citywide providers and organizations that provide PrEP, and, with AFC's leadership, has raised almost \$500,000 to increase clinical capacity and launch a comprehensive PrEP awareness campaign set to debut this fall.

**KELLE TERRELL** is an award-winning filmmaker and freelance writer who writes about race, gender, health, and pop culture. Her work has been featured in *Essence*, the *Advocate*, *The Root*, *POZ*, The Huffington Post, and [thebody.com](http://thebody.com).

# YOU SAY 'WHORE' LIKE IT'S A BAD THING



COLLAGE: DAVID DURÁN

# HOW STIGMA FUELS THE HIV EPIDEMIC

BY ENID VÁZQUEZ

**Y**EARS AGO, when a doctor in the Bronx was told that he should test his 18-year-old pregnant patient for HIV, he asked, “Why? What do you think she’s been doing?”

With that story, the effects of stigma became clear to me. If a *doctor* doesn’t understand how HIV is transmitted, what chance does the public have? He seemed to think that you had to be a prostitute to get HIV, a position of ignorance and misinformation. Because that’s what stigma does, it drives misinformation. *You have to be a prostitute to get HIV. You have to be gay. You have to sleep around.*

The most vulnerable communities affected by HIV were dehumanized with stigmatizing words that helped delay research and treatment.

*Faggot.*

*Junkie.*

*Whore.*

Today, stigma remains as alive and well as ever while the epidemic evolves, except that now it’s a pill for HIV prevention that has moralistic panties up in a bunch.

That’s right: A pill to prevent the scariest STI in history is being condemned, along with the people who dare to take it, thereby making a bid for greater sexual freedom. (How dare they!)

You would think that people taking a pill shown to reduce the risk of HIV by 92% or more would be hailed as responsible heroes in the fight against the epidemic. Instead, the Sex Police have labeled them “whores.” After all, Truvada PrEP, just like the birth control pill before it, gives you greater freedom to be a slut. (Never mind that you can be a slut without taking any prevention pills or methods at all. You would just be a slut at higher risk of every STI.)

It is sadly bizarre that we’ve stigmatized having HIV for so long and now we’re stigmatizing a prevention method that helps people stay HIV negative.

What’s even more bizarre is that the stigma towards gay and bisexual men is coming primarily from the last group of people I would have expected to be anti-PrEP: gay men, many of them themselves HIV-positive.

It was an HIV-positive gay male writer who coined the phrase “Truvada whore” to condemn HIV-negative men taking the daily pill to prevent infection. Although he took it back later, the damage was done.

Outreach workers on the West Side of Chicago heard “Truvada whore” over and

over as they promoted a PrEP study to young black gay men, who have the highest rate of HIV in this country. It’s heartbreaking. The neighborhoods where they promoted the study have the highest infection rate in the city and desperately need as many prevention methods as possible.

Later, on Chicago’s North Side, a nurse who had heard about PrEP told his gay doctor that he wasn’t at risk, but would think about it. He went in three months later and found he had HIV. We mislead people into feeling safe if they don’t “whore” around. As with pregnancy, it’s hard to believe you can get it after just one time. Or maybe three times. Or one partner—or three.

And even if someone was sleeping around, wouldn’t that be all the more reason to suggest that they consider using Truvada PrEP to avoid HIV infection if they’re at risk?

Kudos to Adam Zeboski for taking back the term and creating the Truvada Whore educational campaign (with fabulous T-shirts).

Although pretty much any sexually active person is at risk for HIV if they don’t protect themselves, it’s been shown that those at particularly high risk often don’t recognize it. For example, research has found that many gay men who reported not being at risk for HIV were actually already infected.

At any rate, it would be a disservice to lead people to believe that they are safe when that is not exactly how the epidemic works—marriage, monogamy, fewer partners, and so forth are not vaccinations against HIV. On the surface, all of these would seem to reduce risk. Instead, each can lull a person to falsely assume that their partner actually knows their HIV status or is being faithful. In communities where HIV is highly concentrated, particularly the gay and African American communities, these forms of risk reduction are simply too impotent to overcome the odds that a partner is HIV-positive and doesn’t know their status.

All in all, the words “high risk” or “at risk” for HIV are misleading, and even stigmatizing in themselves. Anyone honest enough to recognize a need for PrEP is truly courageous.

We’re also told to “just use condoms,”

which ignores some ugly secrets, such as the fact that sexual assault among many, especially gay men, remains an unrecognized danger, sometimes resulting in seroconversion.

Here’s the irony: PrEP puts power back into the hands of the most vulnerable individuals, notably because unlike condoms it doesn’t require getting your partner to slip on some latex. There are many people at risk who could benefit from Truvada PrEP who are already particularly vulnerable to shame for who they are: trans men and women, people who have multiple partners or partners outside a primary relationship, and people who love someone who has HIV.

Yet, this self-empowerment may bring stigma upon them.

**IT’S SADLY BIZARRE THAT WE’VE STIGMATIZED HIV FOR SO LONG AND NOW WE’RE STIGMATIZING A PREVENTION METHOD THAT HELPS PEOPLE STAY HIV NEGATIVE.**

PrEP taker and advocate Damon Jacobs recalls the backlash against distributing free condoms in gay bars in the 1980s and ’90s, because many people thought it would only

encourage more gay sex, which they considered immoral. For decades, condoms were actually illegal in 30 states. The cure for syphilis in the 1930s was also condemned because many believed that curing people of an “immoral” disease would only make them more immoral, he said.

A small report on the approval of the birth control pill in the *New York Times* on May 9, 1960 quoted an FDA spokesman as saying, “We had no choice as to the morality that might be involved.” The statement seems astounding now, but was clearly the norm then.

There’s a catch phrase going around that says “community is immunity.” It comes from research showing that people who thrive are those who have the closest relationships, including friendships and the tribes they’ve built around them. With others who have your back and want the best for you, you—and your health—will do better.

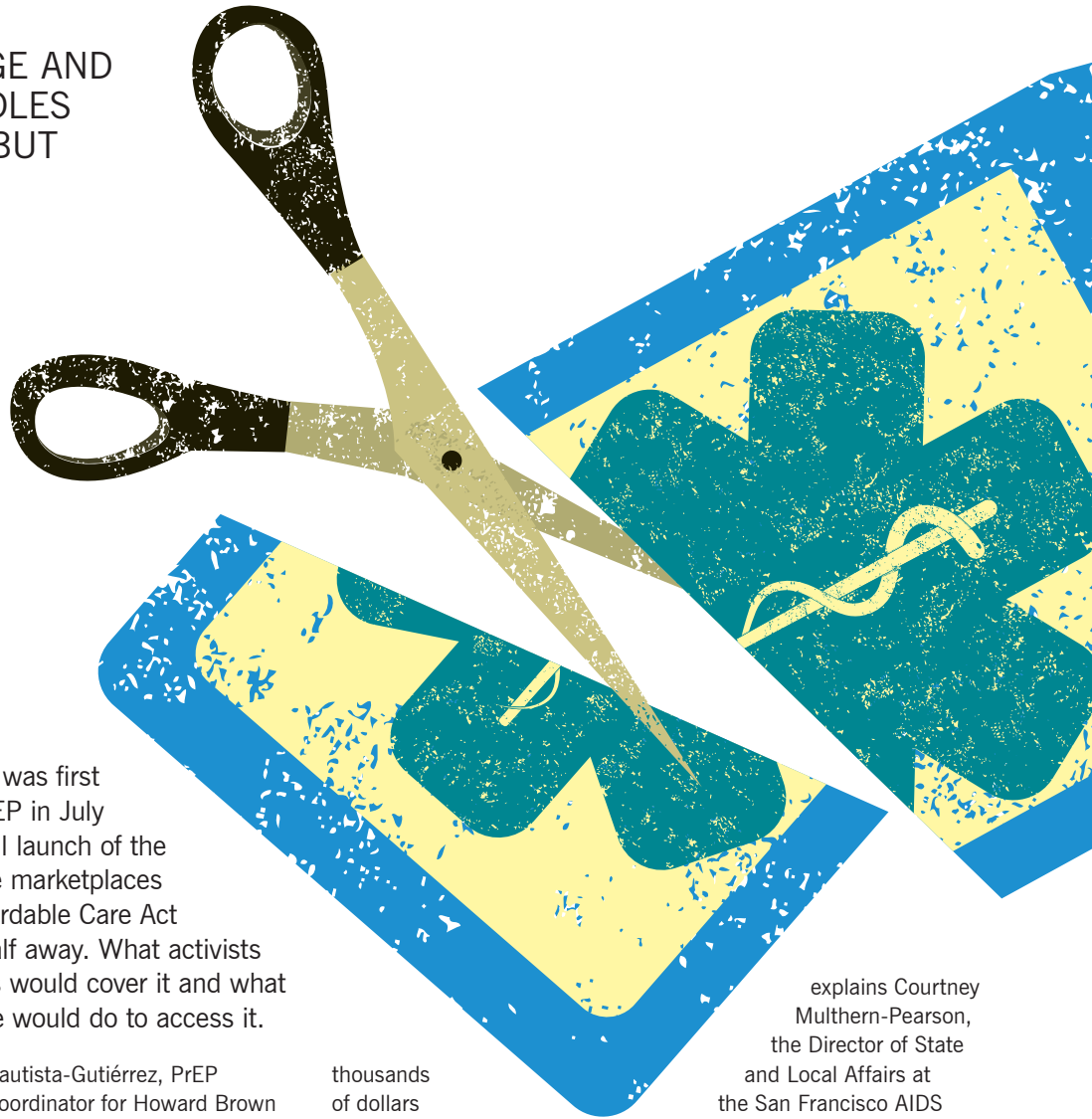
It’s a disgrace that at this point in the epidemic we have to fight for our right to medication and to protect ourselves from HIV. It’s a shame that some of the biggest moralizers in this battle to end the epidemic have come from the group most at risk for HIV themselves, the gay men who have been shamed for their sexuality perhaps more than any other group at risk, even legally prosecuted with sodomy laws. The group, ironically, that has always led the battle to end the epidemic.

Sex shaming is such a shame.

# HOW DO I PAY FOR PrEP?

INSURANCE COVERAGE AND OTHER ACCESS HURDLES CAN BE OVERCOME, BUT IT MIGHT TAKE WORK

BY DAVID EVANS



**WHEN TRUVADA** was first approved for PrEP in July 2012, the formal launch of the health insurance marketplaces through the Affordable Care Act was still a distant year and a half away. What activists wondered was whether insurers would cover it and what people without health insurance would do to access it.

What they learned was that even if someone could get their hands on a prescription for PrEP, there was no guarantee that they would be able to pay for it. Most Medicaid programs picked it up pretty quickly, though some instituted conditions that had to be met before a prescription could be filled. Private insurers also didn't put up too many hurdles.

What slammed the door in peoples' faces, however, were the out-of-pocket costs for those with insurance, and the income limitations on the medication assistance program designed by Truvada's maker, Gilead, to help those without insurance.

"Yeah, that's been a real problem," says Bryan

Bautista-Gutiérrez, PrEP Coordinator for Howard Brown Health Center in Chicago, though he thinks things are getting better now that more people have insurance and that the generosity of and knowledge about the assistance programs has gotten better.

In fact, Gilead's co-pay program went from covering \$200 per month of out-of-pocket costs to \$300 this past October, and the income limit of their medication assistance program for the uninsured went from about \$23,000 per year to about \$58,000. Unfortunately, while Obamacare gave many more people access to health insurance, we learned the hard way that they often had many

thousands of dollars in deductibles before their pharmacy benefits would kick in, something Gilead's program wasn't designed to cover.

It's the sticker shock that really rattles people, says Bautista-Gutiérrez.

"People thought they were getting health insurance and they didn't know what to ask when they signed up," he says. "We have patients who are paying \$300 or \$400 per month [for premiums] and [the plan] is still not covering it."

It's the lowest level plans in the exchanges, called a Bronze plan, that have the largest deductibles and co-pays,

explains Courtney Mulhern-Pearson, the Director of State and Local Affairs at the San Francisco AIDS Foundation. The plans, which range from Bronze to Platinum, have drastically different levels of out-of-pocket costs, but also have varying monthly premiums too. Mulhern-Pearson says that Bronze plans aren't the best option for people wanting PrEP.

Employer-based plans can also let you down, however.

"I remember a young guy who had an employer-based plan and they were out-and-out refusing to cover PrEP," she recounted. "We helped him and he ended up going back to the doctor for an appeal based on medical necessity."

"There was another guy," she adds, "who had an employer

# CHOOSING A PLAN

## DOING YOUR HOMEWORK WILL BENEFIT YOU IN THE LONG RUN

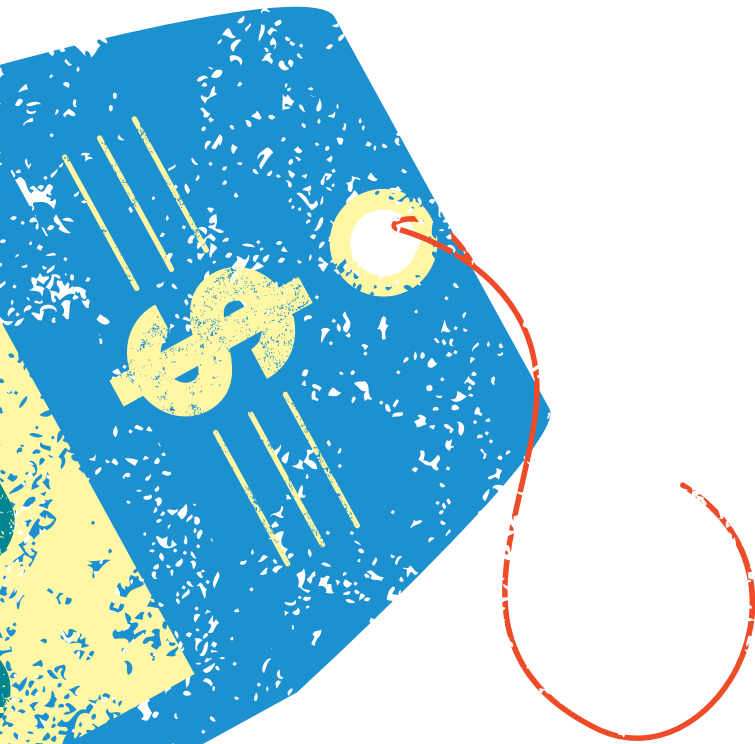
BY DAVID EVANS

**CONSIDER TAKING** this list with you whenever you talk with someone about choosing a healthcare plan from the health insurance exchanges. Tackling these tasks may take some legwork (phone calls, time spent online, etc.), but they are doable, especially if you have access to a professional who can help you.

- Create a list of questions that you need answered.
- Talk to one or more persons (Certified Insurance Agent or Enrollment Counselor, or a PrEP navigator).
- Know what plans are offered in your geographic area or by your employer.
- If you know you want to stay with your current provider, know which plans they take.
- Find out if the pharmacy you want to use is included in the plan you are considering—and that there are no pharmacy restrictions on Truvada for PrEP.
- Review the plan formularies (a list of drugs covered and the price level they fall under). Most formularies are available online from the insurer, but they aren't always easy to find, and might be out of date. Calling the insurer may be the best way to determine this.
- Make a list of other health-care services you are likely to need, and know the out-of-pocket costs associated with them. Truvada PrEP, for example, requires regular HIV and STI testing in addition to other lab work.
- If you are choosing a plan from the insurance marketplace in your state under the Affordable Care Act (aka Obamacare), know what the different levels (Platinum, Gold, Silver, or Bronze) mean, and have an idea of which level might be best for you. You may qualify for assistance with premiums and out-of-pocket costs, but even with this assistance, most people on or considering PrEP should not choose Bronze, the lowest level plan.
- Know whether the plan you are interested in has a deductible, and what the deductible covers.
- If you're considering PrEP, read the special considerations to help in your plan choice and calculating the cost of your health insurance; some plans have occasionally refused to cover PrEP.

### KNOW YOUR RIGHTS

**IT'S IMPORTANT** to understand your rights to health insurance. You have the right to receive a broad range of services, and the ability to protect your rights by challenging decisions in which you and your health provider disagree. The goals of challenging decisions are: 1) getting the health insurance you're entitled to under federal and state law, and 2) getting the care that you need.



plan with insanely high deductibles.” Fortunately, a non-profit foundation called the Patient Access Network now helps some people with high deductibles, though there is an income limit.

For people trying to pick a plan, Mulhern-Pearson says, it's best to turn to an insurance agent or navigator for help, as the various aspects of a good plan are far from transparent and information can be really hard to find. For those who don't have access to a navigator, Project Inform published a plan choice guide last November to help people in California choose an exchange-based plan. Though it is state-specific, most of the information would be useful to people no matter where they live. The AIDS Foundation of Chicago also provides a state-specific but helpful guide. (See Resources on page 20 for the guides.)

Both Mulhern-Pearson and Bautista-Gutiérrez urge people to keep fighting and not give up.

“I can't tell you the number of times people who were at high risk could have been on PrEP way before,” says Bautista-Gutiérrez. **PA**

THERE'S A POSSIBILITY OF OBTAINING FREE TRUVADA PrEP THROUGH A DEMONSTRATION PROJECT. CHECK [PREPWATCH.ORG](http://PREPWATCH.ORG).

**FOR MORE INFORMATION ABOUT ASSISTANCE PAYING FOR PrEP, GO TO:**

**The Fair Pricing Coalition**  
[fairpricingcoalition.org](http://fairpricingcoalition.org)

**Gilead Medication Assistance Program**  
(855) 330-5479

**Gilead Co-pay Program**  
[gileadcopay.com](http://gileadcopay.com)  
or (877) 505-6986

**Patient Access Network**  
[panfoundation.org](http://panfoundation.org)

# PrEP RESOURCES

COMPILED BY ALAN McCORD



## EDUCATIONAL VIDEOS

### Your Life Matters

A series of four videos for young men who have sex with men (MSM), from Project Inform. [vimeo.com/prepvideos](http://vimeo.com/prepvideos)

### What is PrEP?

This video describes how PrEP works inside the body. The page also has links to several resources.

[whatisprep.org](http://whatisprep.org)

### How to Access PrEP

A video for African American and Latino MSM, from the National Minority AIDS Council (NMAC). [youtube.com/watch?v=9o804b9Qt1A](http://youtube.com/watch?v=9o804b9Qt1A)

### Do You Swallow?

A video for African American MSM, from the National Black Gay Men's Advocacy Coalition (NBGMAC) and NMAC. [youtube.com/watch?v=Jud4mpCnqXE](http://youtube.com/watch?v=Jud4mpCnqXE)

### My PrEP Experience video factsheet

Vlogger @kenlikebarbie explains PrEP. [youtube.com/watch?v=KoMFKoup2kA](http://youtube.com/watch?v=KoMFKoup2kA)

### Three PrEP Myths Busted

A video explaining some common misconceptions about PrEP, from the San Francisco AIDS Foundation (SFAF). [betablog.org/video-three-prep-myths-busted](http://betablog.org/video-three-prep-myths-busted)

### HIVEonline

Videos and information for cis-gender and transgender women. [hiveonline.org/for-you](http://hiveonline.org/for-you)

## PATIENT INFORMATION

### AIDS Foundation of Chicago

"I need ... PrEP" is a web page dedicated to finding a medical provider and obtaining insurance access on the marketplace.

Although state-specific, the insurance guide provides useful information.

[aidschicago.org/page/i-need/prep](http://aidschicago.org/page/i-need/prep)

### Project Inform

Educational booklets, videos, point-of-care cards, and other resources are available. Order free copies online.

[projectinform.org/prep](http://projectinform.org/prep)

### PrEP Facts

Information and Q&A for gay men as well as heterosexual men and women, in English and Spanish. [prepfacts.org](http://prepfacts.org)

### PrEP for Women

Information on PrEP for women, from The Well Project. [thewellproject.org/hiv-information/prep-women#sthash.jt63UYUW.dpbs](http://thewellproject.org/hiv-information/prep-women#sthash.jt63UYUW.dpbs)

### U.S. Women & PrEP Working Group

A national advocacy group by and for women about the use of PrEP. [facebook.com/groups/1514070505510245](http://facebook.com/groups/1514070505510245)

### Talking to Your Doctor about PrEP

A brochure from the Centers for Disease Control and Prevention offers questions that you can ask your doctor. [cdc.gov/hiv/pdf/risk\\_PrEP\\_TalkingtoDr\\_FINALcleared.pdf](http://cdc.gov/hiv/pdf/risk_PrEP_TalkingtoDr_FINALcleared.pdf)

### PrEP Watch

Clinical trial research data supporting the use of PrEP and a list of demonstration projects, from AVAC. [prepwatch.org](http://prepwatch.org)

### Center of Excellence for Transgender Health

Lots of useful information for transgender persons and the people who serve them. Though not devoted to PrEP, this link provides a list of support options.

[transhealth.ucsf.edu/trans?page=home-00-00](http://transhealth.ucsf.edu/trans?page=home-00-00)

## COMMUNITY EDUCATION

### Ready. Set. PrEP.

The AIDS Foundation of Chicago offers two education program slide decks—one for providers ([slideshare.net/JimPickett/project-rsp-cdphmarch2015updated](http://slideshare.net/JimPickett/project-rsp-cdphmarch2015updated)) and a community education slide deck ([issuu.com/jimpickett/docs/projectrspttrainingcdphjune2014\\_fina](http://issuu.com/jimpickett/docs/projectrspttrainingcdphjune2014_fina)).

### PrEPare for Life

Education and awareness program by NMAC targeting young gay men, in particular, Black and Latino gay men 18–25 years old. [nmac.org/prepareforlife](http://nmac.org/prepareforlife)

### Is PrEP Right for Me?

A visual, step-by-step introduction to PrEP, from The Stigma Project. [ispreprightforme.com](http://ispreprightforme.com)

## MEDICAL PROVIDER RESOURCES

### Federal PrEP Guidelines

Clinical Practice Guidelines (evidence, prescribing info, etc.) from the CDC, and a Provider's Supplement (checklists, ICD, CPT and LOINC Codes, etc.). [cdc.gov/hiv/prevention/research/prep](http://cdc.gov/hiv/prevention/research/prep)

### National PrEPline

Clinician Consultation Center PrEPline, UCSF, for medical professionals. [nccc.ucsf.edu/2014/09/29/introducing-the-ccc-prepline](http://nccc.ucsf.edu/2014/09/29/introducing-the-ccc-prepline)

### Truvada for PrEP

Manufacturer's website for Truvada for PrEP. Information for educators and uninfected individuals as well. [start.truvada.com](http://start.truvada.com)

## OF SPECIAL INTEREST

### PrEP Facts: Rethinking HIV Prevention & Sex

This rapidly growing (7,020 members and counting) closed Facebook group offers a safe and sex-positive place for people to get advice, support, and information on PrEP. Founded in 2013 by New York City psychotherapist and PrEP user Damon Jacobs, the site not only helps people though challenges such as stigma, disclosure, side effects, and risk reduction, it has also become one of the quickest ways to find a PrEP-friendly provider. Search for the group on Facebook and request to join.

### MyPrEPExperience.com

Long-time HIV prevention advocate Jim Pickett (page 15) launched this blog when the first few people were beginning to take PrEP, and when the stigma toward PrEP users was at its greatest. Founded on the philosophy that sexual health should be rooted in pleasure, the site also offers links to a variety of sources of PrEP information.

### HIVEonline.org

HIVE (see page 14 for a profile of director Shannon Weber) offers information for people contemplating or taking PrEP and for their providers. Weber, a champion for perinatal care for HIV-positive women and reproductive rights for all people living with HIV, pioneered work that provides new options for mixed HIV status partnerships (couples, surrogacy, singles) who want to safely have children.

THE 2015 POSITIVELY AWARE

# PrEP SURVEY



Your confidential responses to this survey will help us to understand the level of community knowledge about PrEP. You can also take the survey at [positivelyaware.com](http://positivelyaware.com). Thank you for your participation!

1. Have you heard of PrEP before this special issue of PA?  
 Yes  No
2. How knowledgeable were you about PrEP before reading this issue?  
 Very  
 Moderately  
 Somewhat  
 Not at all
3. Was there information in this issue that was new to you?  
 Yes  No
4. If you are HIV-negative, are you currently taking PrEP?  
 Yes  No  N/A
5. If you are HIV-negative, would you consider taking PrEP?  
 Yes  No  
Why or why not? \_\_\_\_\_
6. Would you feel comfortable asking your medical provider about PrEP?  
 Yes  No
7. Based on what you currently know, would you recommend PrEP to a friend or partner?  
 Yes  No  
Why or why not? \_\_\_\_\_
8. If you are HIV-positive, based on what you currently know, would you recommend PrEP to an HIV-negative partner?  
 Yes  No  
Why or why not? \_\_\_\_\_
9. If you answered yes to #8, would it change the way you negotiate condoms and other forms of protection with that partner?  
 Yes  No  
Why or why not? \_\_\_\_\_
10. Do you know anyone currently on PrEP?  
 Yes  No
11. Do you know where to find more information about PrEP?  
 Yes  No
12. What would you most like to know about PrEP? (CHECK TWO)  
 How effective is PrEP for someone like me?  
 Who is a candidate for PrEP?  
 What is the dose?  
 What are the side effects?  
 Why is adherence important?  
 PrEP and pregnancy?  
 What does it cost?  
 Other: \_\_\_\_\_
13. What is your age?  
 Younger than 18  
 18–25  
 26–35  
 36–45  
 46–55  
 Over 55
14. What is your gender?  
 Male  
 Female  
 F to M Transgender  
 M to F Transgender  
 Non-gender conforming
15. What is your race/ethnicity?  
 Black/African American  
 White/Caucasian  
 Latino/a  
 Asian/Pacific Islander  
 Native American (American Indian)  
 Multiracial  
 Other: \_\_\_\_\_
16. What is your sexual orientation?  
 Gay  
 Lesbian  
 Heterosexual  
 Bisexual  
 Other: \_\_\_\_\_

MAIL, FAX, OR E-MAIL YOUR RESPONSE TO: POSITIVELY AWARE,  
5050 N. Broadway St., Suite 300, Chicago, IL 60640;  
fax (773) 989-9494; e-mail [inbox@tpan.com](mailto:inbox@tpan.com).  
Survey also available at [positivelyaware.com](http://positivelyaware.com).

# Talk before you...



Protect yourself and your partner. Talk about **testing**, your **status**, **condoms**, and new options like **medicines** that prevent and treat HIV. Get the facts and tips on how to start the conversation at [cdc.gov/ActAgainstAIDS/StartTalking](http://cdc.gov/ActAgainstAIDS/StartTalking).

**Start Talking. Stop HIV.**



**ACT  
against  
AIDS**

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 [@TalkHIV](https://twitter.com/TalkHIV)