



PrEP
PRE-EXPOSURE PROPHYLAXIS

TRANSCENDING BARRIERS FOR SAFER PLEASURE



a publication for transgender women

Table of contents

- 1 Using this booklet ...
- 2 Strengthening your community, strengthening yourself
- 5 Quick facts about PrEP ...
- 6 What is PrEP?
- 7 Is PrEP right for you?
- 8 Some reasons not to use PrEP might be if you:
- 9 What are Truvada's side effects?
- 10 How well does Truvada prevent HIV infection?
- 10 Why test for hepatitis B before starting PrEP?
- 11 What tests will you need done?
- 12 What might you want to talk about with your provider?
- 13 When do you start/stop taking PrEP?
- 14 Why is it important to take PrEP every day?
- 15 What if you get HIV while taking PrEP?
- 16 Do you still have to use condoms?
- 17 Should I keep it a secret that I'm taking PrEP?
- 18 How do you get PrEP and how much will it cost?
- 19 What else is helpful to know?
- 20 Resources that may help

TERMS FOUND IN THIS BOOKLET

“MSM” in this booklet refers to cisgender and transgender men who have sex with men, and does not refer to women or trans people who were assigned male sex at birth.

“Cisgender” or “cis” refers to either men or women whose current gender is the same as was assigned to them at birth. Cisgender is the opposite of transgender.

Using this booklet ...

Project Inform and Outshine NW partnered to write this PrEP resource guide for women who are transgender and for other trans/gender-variant people who were assigned male sex at birth.

We believe that everyone is beautiful and deserves to have a sex life that is loving, consensual, passionate, pleasurable and free from concern about HIV. Because of that, we want to share information with you about an HIV prevention strategy known as PrEP, or *Pre-Exposure Prophylaxis*. Unlike condoms, PrEP doesn't require the cooperation of your sex partners, so it puts the control over your health in your own hands. We believe that you deserve to know the facts so you can make the most informed decision for yourself. PrEP is an exciting and effective prevention tool, though it's not for everyone.

By the end of this book, you will:

- 1) know how to find more information about PrEP;
- 2) know how to find an accessible healthcare provider;
- 3) know how to ask for PrEP;
- 4) know where to get support to advocate for yourself if you run into any hurdles along the way; and
- 5) have a better idea whether PrEP is an HIV prevention tool you want to use.

PROJECT INFORM RESOURCES

If you are a cisgender or transgender man who has sex with men, read our other publication, *Is taking PrEP the right choice for you?*

If you are a cisgender woman who has sexual relationships with men, read our publication, *A new option for women for safer loving.*



HIV vulnerability: strengthening your community, strengthening yourself

Let's get the simple stuff out of the way first: HIV is a virus that attacks the immune system, and without treatment it is almost always fatal. It's spread through contact with blood, semen, breast milk, and vaginal fluids. If you never have sex with anyone, if you always use a condom correctly for every sexual encounter, or if you never share syringes or other injection equipment with anyone else, then you probably don't need to worry about HIV.

If your sex life is a bit more complicated than that though, which is true for most women, this booklet can help you achieve more control over your own health. PrEP for HIV prevention means taking a pill every day that in the past was used only to treat HIV. In 2010, a study called iPrEx was published; it included 339 trans-feminine people for a total of 14% of the study's sample.

About 28% of transgender women in the US are living with HIV. One study suggests that 73% of HIV-positive trans women don't know they have HIV. Simply being a trans woman does not automatically put you at risk for HIV, but risk factors for getting HIV seem more common in trans women, so it may be more important to take an honest look at those and how they can affect your HIV status.

Let's look at some things that affect women's HIV risk. As you read through these questions, consider whether any of them seem to apply to your life or to a situation you're likely to be in:

- Do any of your sex partners have HIV? Many of us start relationships with HIV-positive people that are wonderful, loving and satisfying. Sometimes in relationships, condoms feel like a barrier to intimacy and people would prefer not to use them.

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- Do you find using condoms to be a challenge? Do you have a partner who refuses to use condoms at least some of the time? Do you sometimes feel like you have no choice whether a condom is used? Lots of women deal with this, so you're not alone. You have options for protecting your health though, even if you can't change other aspects of your situation right now.
- Are you African American, Latina or Native American? Trans women of color are more likely to get HIV in the US, largely because of barriers to health care access. White trans women also have high rates of HIV – because finding competent doctors isn't easy for any of us – but trans women of color are far more impacted.
- Do you live in a part of the country with very high HIV rates? These include, but are not limited to, Washington DC, Baltimore, Atlanta, New York City, Los Angeles, and much of the South. Even if you don't live in one of these areas you could still be at risk for HIV, especially if other factors listed here apply to you.
- Do you have more than one sex partner, even if it's only once in a while? This is true for many women and may increase your chances of getting HIV.
- Does your partner ever have other sex partners, or do you suspect they might? This is true for lots of women and may increase your chances of getting HIV.
- Have you or your partner(s) recently been treated for an STI such as syphilis, gonorrhea, chlamydia or herpes? This may be a sign that you're more likely to get HIV.
- Have you used PEP (post-exposure prophylaxis), a strategy where you take medications for a while after an HIV exposure to stop an infection, more than once in the past year?

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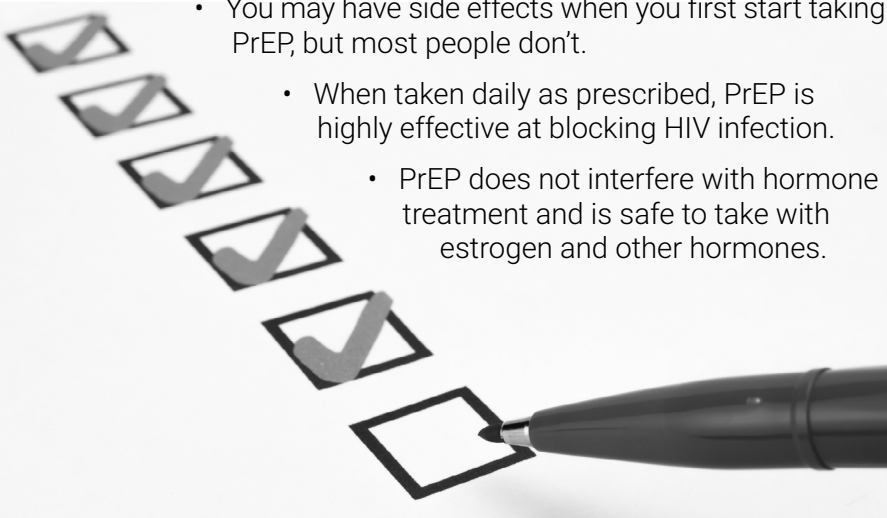
- Have you experienced sexual assault or other types of violence in your life? Does your partner verbally threaten you or say things that cause you to feel bad about yourself? About one in three women, cis and trans alike, experiences this type of difficulty in a relationship at some point in their lives. Unfortunately, people who experience abuse as children or adults are much more likely to become infected with HIV.
- Does your partner use injection drugs, or have they ever used injection drugs? This could put them at higher risk for HIV and make you more vulnerable as well. However, PrEP can help lower your risk even if you share injection equipment.
- Have you or your partner ever been to jail or prison? This can increase your risk of HIV.
- Do you struggle with depression, low self-esteem or anxiety? All of these can impact your risk for HIV, and may make it harder to negotiate using condoms the same as if you felt more confident.
- Have you or your partner(s) ever exchanged sex for money, housing or other kinds of assistance?

Do any of these factors apply to you? They apply to many women, both cisgender and transgender. At first glance, it might not seem like good news to realize this about your circumstances, but it can actually be very empowering. It means you've taken the first step in knowing your risk for HIV. Now you have the power to do something to protect yourself.

It's up to you to determine the best way to preserve your own health: Do you think you can always use condoms 100% of the time with every partner? Are you monogamously partnered with someone who is already on successful HIV treatment or who has recently tested negative for HIV? Do you never have sex? If any of these are true, you might not need PrEP. However if those aren't options for you or if you feel like you need an added layer of protection, PrEP is a tool you can choose that will protect you from HIV regardless of your partner's status.

Quick facts about PrEP ...

- PrEP uses a single pill called Truvada, which is two drugs combined, taken once a day to prevent HIV infection. Other forms of PrEP, including long-acting injections, are being studied.
- PrEP can take a while to build up in the tissues of the parts of the body that are exposed to HIV. This is why you need to take it continuously, and not just over a weekend.
- PrEP is recommended along with other prevention methods, such as condoms and ensuring that any HIV-positive partners are on treatment with their virus under control.
- PrEP requires a prescription and is not safe to take without medical supervision.
- Some providers may not know about PrEP or may not be comfortable discussing your sexual health. Resources are listed later in this book to help you advocate for yourself.
- PrEP includes regular medical visits and routine blood tests, about every three months.
 - You may have side effects when you first start taking PrEP, but most people don't.
 - When taken daily as prescribed, PrEP is highly effective at blocking HIV infection.
 - PrEP does not interfere with hormone treatment and is safe to take with estrogen and other hormones.



What is PrEP?

PrEP stands for Pre-Exposure Prophylaxis. It means taking a medication before you are exposed to HIV to keep yourself HIV-negative. Studies have proven that PrEP works across a broad range of body types. The US Food and Drug Administration (FDA) approved Truvada for PrEP in July 2012 for adults at risk for sexual transmission of HIV.

Truvada is a pill made up of two drugs — Viread (tenofovir disoproxil fumarate) and Emtriva (emtricitabine). Currently, it's commonly used together with other pills to treat HIV infection in HIV-positive people. Viread is also used to treat hepatitis B.

Truvada prevents HIV from replicating in the body. If you are exposed to semen, pre-cum, vaginal fluids or blood from a person living with HIV, Truvada can help to keep the virus from turning into a chronic infection. (Watch this video at www.whatisprep.org.)

PrEP differs from *Post-Exposure Prophylaxis*, or PEP. PEP means starting HIV medications within 72 hours after you have been exposed and taking it for a month. If you are prescribed PEP, talk with your doctor about continuing a prescription for PrEP without a break in between. This can maximize your ongoing protection.

Is PrEP right for you?

Now that you've considered your HIV risk factors, you might be wondering what to do next. Is PrEP one of the right HIV prevention options for you? Here are some things to keep in mind as you answer this question for yourself:

- PrEP can be used with condoms. In studies, people who used condoms before starting PrEP generally continued to use them. People who did not use condoms before PrEP generally continued not using them — but were at very low risk for HIV. Actually, in studies so far, no one who was confirmed to be HIV-negative before starting Truvada and who took their pill consistently has become infected.
- Unlike condoms, PrEP is something that you have control over taking daily at a time that's convenient for you. Condoms require agreement from both parties in the heat of the moment. This alone makes PrEP the most empowering HIV prevention tool available.
- PrEP requires ongoing care from your provider, including an office visit with lab work every three months. This can be a great opportunity to check in about other healthcare questions you have as well, such as regular hormone testing. Many trans people find that these quarterly visits improve their happiness and quality of life beyond just HIV prevention. If you need help finding a trans-competent provider, keep reading — we have resources for you!



Some reasons not to use PrEP might be if you:

- Don't know your HIV status. Your doctor will test you for HIV before prescribing PrEP to make sure you're safe.
- Don't know your hepatitis B status. Your doctor will test you for hepatitis B before prescribing PrEP to make sure you're safe.
- Are HIV-positive. Truvada is not a complete treatment for HIV.
- Can't find a medical professional or clinic to provide HIV and STD testing and prevention counseling along with Truvada.
- Can't or won't keep up with a daily pill regimen.
- Just plan to take it for short periods at a time, such as for a weekend when you think you need it.
- Have kidney disease or reduced kidney health.



What are Truvada's side effects?

Most people who take Truvada don't experience side effects. In fact, some people have remarked that they wonder if the pill is working at all because they haven't felt anything change.

With that said, the short-term side effects noted in PrEP studies included headaches, weight loss and stomach problems like nausea, diarrhea and stomach ache. These occurred in about 1 out of 10 people, and usually subsided after a few weeks on the pill.

Around 1 in 200 people have had minor problems with kidney health, which got better when Truvada was stopped. They were usually able to take PrEP again after a short break. Some people also experienced a minor decrease in bone density, though this was not a cause for concern. As for longer-term side effects, our best information about Truvada right now comes from more than a decade of experience among people who are HIV-positive.

Some people worry about other side effects they've heard about from other HIV drugs, like changes in fat distribution. Taking Truvada is not associated with those types of side effects. It was chosen for PrEP because it has so few side effects and it's much safer than other HIV medications. This is one reason it's better to prevent HIV, to avoid needing more medications in the future that might have harsh side effects.

One "side effect" that's rarely mentioned is that many people end up feeling less anxious about HIV. They have more time to organize their thoughts, which leads them to make healthier choices that can help stabilize their relationship, income, housing or any other issues that might have been harder for them when they were worrying about HIV. You may find that PrEP gives you the mental and emotional space to become more proactive around your sexual health.

How well does Truvada prevent HIV infection?

Estimates based on clinical studies suggest that people who take Truvada every day as prescribed can expect a 99% reduction of HIV risk. In the iPrEx study (which researched PrEP's effectiveness among transgender women and cisgender men who have sex with men), researchers found that the people who contracted HIV during the study were not taking the pill regularly. Those who took the pill each day did not contract HIV.

That same study found that only 18% of trans women took PrEP consistently as prescribed, but among the women who took the pill daily or near-daily, none of them contracted HIV. There were no HIV infections among study participants who took Truvada four days per week or more. People who take the pill every day are well-protected from HIV regardless of their partner's status.

Why test for hepatitis B before starting PrEP?

Both drugs in Truvada also work against hepatitis B. Therefore, it's important to know if you currently have hepatitis B before starting PrEP. If that test shows that you haven't been exposed to hepatitis B, then get the routine vaccine. It's covered by most health insurance plans.

You can take PrEP at the same you're taking hepatitis B meds. In fact, you may be given Truvada to treat hepatitis B as well as prevent HIV. However, if you have active hepatitis B disease and stop PrEP suddenly, it can cause dangerous liver problems. Work with your medical provider on the safest way to stop PrEP if you also have hepatitis B disease.

What tests will you need done?



BEFORE YOU START PREP, you'll need:

- An HIV antibody or antibody/antigen test and possibly a test to detect HIV directly
- Tests for hepatitis B, kidney function, and STDs.

WHILE YOU'RE TAKING PREP, you'll need:

- Routine HIV testing after 1 month on PrEP and every 3 months after that to make sure you remain HIV-negative.
- Routine lab work to monitor your kidney health for very rare but possible side effects. If that becomes a concern, your doctor may ask you to take a short break from PrEP for a little while.
- An honest conversation with your provider about side effects, how to take it every day, and your sexual or drug use activity. You'll also need STD tests every 3-6 months depending on your risk level.

What might you want to talk about with your provider?



- Are they knowledgeable, willing and ready to support you being on PrEP? If not, are they willing to learn? Resources are provided at the end of this booklet to share with them.
- How often do they want you to test for HIV? (At least every 3 months.)
- Do you have hepatitis B? If not, is your vaccination still active?
- What STIs do you need to get tested for, and how often? Are all sites of exposure being swabbed/tested?
- What is your kidney health? Is it safe for you to start PrEP?
- Do you feel safe at home? Do you have any concerns about a partner finding out you're on PrEP?
- Are there any reasons you're afraid you might not be able to take a pill every day, such as unstable housing, no insurance coverage or struggling with finances for survival? Ask if your doctor can help connect you with resources to ease some of this stress to make taking PrEP every day a little easier.

When do you start/stop taking PrEP?

It depends.

Generally, people use PrEP over a period of time when they are at a risk for getting HIV. Some may quickly adopt different sexual behaviors and only use PrEP for a few months. Others may choose to take it over years. Still others may take it for a few months or years, stop for a period of time if they're not at risk, and then restart if that changes again. Making this decision — when to use PrEP as well as when not to use it — is best done with help from your provider.

It's also okay to stop for other reasons. You might simply want to stop. You may find that your risk for HIV has changed, or that you don't like the side effects, or you have trouble taking the pill every day. Whatever your reason, it's important to talk to your provider first to make sure you're doing whatever else you can to keep from getting HIV. Remember: if you get HIV, you're going to end up taking this pill every day as treatment anyway, combined with other medications which are more likely to have side effects than Truvada alone.

One very important thing to remember is that if you have hepatitis B, you'll need to stop PrEP carefully. This will help avoid a dangerous “flare up” in your liver, which can occur when Truvada is stopped all at once.

Right now experts recommend that people whose primary risk is through anal sex take Truvada daily for at least 7 days prior to exposure. For all other forms of exposure, it is best to take daily PrEP for 20 days before exposure.

As for stopping PrEP, the guidance until recently has been to continue the medication every day for 28 days following your last risky sexual encounter before you stop. Recent data from the IPERGAY study suggest that you might not need to take it for so long, but there isn't yet a strong consensus.

Why is it important to take PrEP every day?

Simply put: if you don't take it, it doesn't work.

Trans women have one of the highest rates of HIV infection in the US. Yet, in the iPrEx study, only 18% of these women took PrEP consistently as prescribed. The women who did not take the pill were not protected. Many of them contracted HIV, which could easily have been prevented. It is much easier to take one pill for PrEP every day now than to take HIV treatment medications every day for the rest of your life.

PrEP is currently prescribed only as a daily pill, which offers the most reliable protection. If you accidentally miss a dose once in a rare while, or if it's not at the same time every day, it's not a big deal, but you want to do your best to take one pill each day.

Some people find it fairly easy to take pills every day, like taking a daily vitamin. This can be easier if you take the dose at the same time that a routine activity occurs, like eating breakfast or brushing your teeth before you go to sleep.

It can also help if the pill bottle is in plain view like on a night stand or bathroom shelf. Some people use a cell phone alarm, pill reminder app, or texting service that sends messages or email reminders to help them to take their pills on time. MediSafe is a free app that many people have found helpful for remembering to take all their medications.

If you forget to take a pill one time, you can take it the next day as soon as you remember and still have a high degree of protection from HIV. By contrast, if you forget to use a condom one time and are not on PrEP, you will have zero protection during that encounter, and there is no way to go back and change it after the fact.

What if you get HIV while taking PrEP?

In order to control the virus, HIV-positive people take at least three drugs altogether. Taking only two drugs (Truvada is two drugs) is not enough to control HIV infection in someone who is infected. Taking too few drugs lets the virus to continue to replicate and develop strains that the drugs can no longer control. In other words, the virus becomes “resistant” to those drugs.

Therefore, if you get HIV while on PrEP and don't realize it until resistance has developed to both drugs in Truvada, then you probably won't be able to use them later as HIV treatment. Since Truvada is preferred over some other HIV medications for its low risk of side effects, not being able to use it would really limit your treatment choices. Almost all of the small number of people who have developed drug resistant virus on PrEP turned out to have been infected when they started it, but were incorrectly diagnosed as being HIV-negative because their infection was so recent.

There are 2 things you can do to help prevent drug resistance:

- 1** Before starting PrEP, make sure you're HIV-negative. If you are very recently infected, your antibody test could say that you're HIV-negative when in fact you're HIV-positive. This is because your body hasn't developed enough antibodies to HIV to show up on that test. For this reason, report your recent sexual activity and any flu-like symptoms or rashes to your provider before starting PrEP as they could be symptoms of acute infection.
- 2** While on PrEP, get tested after 1 month, and then get routinely tested for HIV every 3 months. Also, let your provider know if you miss doses and then develop flu-like symptoms or unexplained rashes in between tests.

Do you still have to use condoms?

Condoms work great when they're used. They are the cheapest way to avoid getting HIV and they protect against some STDs, while PrEP does not. However, PrEP is also great for some people, especially if you struggle with using condoms, if you simply choose not to use condoms, or if you don't have an option to use condoms.

Using condoms is not always possible. Your partner(s) might refuse to use them. If you're depressed or using alcohol or drugs heavily, condoms may seem impossible. You and your partner might see using condoms as a sign that you don't trust one another, or that you love each other less. Many people struggle with condom use; there's no reason to feel ashamed if you don't use them.

In nearly all of the PrEP studies so far, people have stated that their condom use improved while they were on PrEP.

Many people choose to use condoms as much as possible while taking PrEP.

PrEP won't prevent most other STDs, but it will strongly reduce your risk of HIV, and it will help you remember to get tested every 3 months so that if you contract another STD you'll be able to treat it right away. Getting other STDs is not necessarily a problem; it's not getting tested and then getting cancer or going blind because you don't know about the STD that's a problem. PrEP will help you take care of yourself in more ways than just preventing HIV, regardless of whether you use condoms alongside it.



Should I keep it a secret that I'm taking PrEP?

That's up to you.

One of the things that you may not think about before starting PrEP is what might happen if anyone finds out that you're taking Truvada. Some of your friends or family may know what that pill is used for and may assume you're HIV-positive. They may not be aware that it can be used as PrEP. Even if they know about PrEP, they may still have a negative opinion about it.



Take some time to think about how you'll take your pill every day, where you'll store it, and who may be around to see you. Many people won't find this to be an issue, but for others this may cause them some unnecessary social problems.

Also, many medical providers are still not aware that Truvada can be used for PrEP. If you find yourself in a situation where you need to tell a medical professional the list of meds you take, make sure you tell them that the Truvada you take is for PrEP. Otherwise, they may assume you're HIV-positive. You may also have to explain what PrEP is, and even refer them to clinician resources to read.

OUR BOTTOM LINE: If you're taking PrEP, you're taking charge of your health. You've carefully thought about it and are acting more responsibly by preventing HIV – for yourself and your community. That's something to be proud of. If you ever hear others disapproving of your choice to use PrEP, it may provide you a chance to educate them, if you want to go that route.

How do you get PrEP? How much will it cost?

Since Truvada is approved by the FDA, it is covered by health insurance. It should also be available through government programs like Medicaid. If you have difficulty accessing PrEP or your insurance tries to deny coverage, consult our resource list at the end of this booklet. Where there's a will, there's a way!

Your insurance should cover Truvada and both your doctor's visits and lab tests, with little money out of your own pocket. Some insurance plans require your doctor to fill out a prior authorization form before you get the medication.

If you have a co-pay with private insurance, Gilead Sciences, the maker of Truvada, will cover up to \$3,600/year (www.gileadadvancingaccess.com), so most people only need to cover co-pays for medical visits and labs.

Some insurance plans are not generous at all, and may have very high out-of-pocket drug costs, or co-insurance that requires you to pay a percentage of the cost rather than a flat co-pay. The Patient Advocate Foundation (www.patientadvocate.org) and PAN Foundation (www.panfoundation.org) may be able to help you with these high costs, especially if they are combined with Gilead's co-pay program.

For people with no health insurance who aren't eligible for Medicaid, or for people with insurance without prescription coverage, Gilead's Medication Assistance Program offers free drugs to those with low to moderate incomes.

To learn more about the co-pay programs, visit the Fair Pricing Coalition's website (www.fairpricingcoalition.org/projects). For a step-by-step guide on how to pay for PrEP, read Project Inform's PrEP Chart at www.projectinform.org/prep-chart.

What else is helpful to know?

- It is safe to take hormones and PrEP together. Many women use Truvada either as PrEP or as treatment for HIV, and there are no observed issues with using Truvada and hormones at the same time.
- DO NOT take PrEP on your own. Only take PrEP as prescribed from a health provider who can monitor your health and any possible side effects. You need specific initial and ongoing tests. If you don't know the results to these tests, your health could suffer. Do not share your medication with others, as they need to be monitored regularly for their safety also.
- DO NOT take just a few pills over the course of a weekend or just when you have sex. Although the IPERGAY study found that "sex-based" dosing was relatively safe and effective, few people in the study took PrEP less than four days per week. Therefore, taking it less often may not offer the same level of protection as trying to take it every day.
- Although other HIV drugs are currently being studied, no other HIV pill besides Truvada and Viread has been shown to prevent HIV infection. Therefore, it is not reliable to use any other HIV pill in place of Truvada.
- Taking PrEP can be a major change in your life and can affect your sexual and other close relationship(s). Consider talking about PrEP (and other prevention methods) to your partner(s) to continue to promote open dialogue about the choices you make.

Resources that may help

PATIENT INFORMATION ...

Pre-exposure Prophylaxis

www.projectinform.org/prep

My PrEP experience

<http://myprepexperience.blogspot.com/>

What is PrEP?

www.whatisprep.org

The HIVE (reproductive health & HIV)

www.hiveonline.org/for-you/transgender/

PrEP Facts: Rethinking HIV Prevention and Sex

(Online support group that can answer any of your questions)

www.facebook.com/groups/PrEPFacts

ARTICLES ...

Fenway Health policy brief:

Transgender women and pre-exposure prophylaxis for HIV prevention: What we know and what we still need to know

<http://tinyurl.com/fenwaytrans>

PrEP Works for Transgender Women, According to New Analysis

<http://tinyurl.com/betatrans>

Truvada PrEP appears to work for transgender women, but only if used consistently

<http://tinyurl.com/aidsmaptrans>

HIV pre-exposure prophylaxis in transgender women: a subgroup analysis of the iPrEx trial

<http://tinyurl.com/lancettrans>

CONTINUED ...

RESOURCES FOR CLINICIANS ...

Clinician Consultation Center

(This free resource will walk your prescriber through everything they need to know to safely prescribe Truvada for you.)

800-933-3413, <http://nccc.ucsf.edu/>

Truvada for a PrEP indication

<https://start.truvada.com/>

CDC Fact Sheet (PrEP: A New Tool for HIV Prevention)

www.cdc.gov/hiv/prep/pdf/PrEPfactsheet.pdf

CDC Guidance on HIV PrEP for Various Populations

www.cdc.gov/hiv/prevention/research/prep/

Clinical studies resources

www.avac.org/ht/d/sp/i/262/pid/262

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Our appreciation to the following
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www.projectinform.org/prep