#### **Evolving Treatment Adherence Paradigm HIV PrEP and Social Media**

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# **Objectives**

- Analyze the validity of HIV prevention claims among users on social media
- Discuss probable effects of HIV prevention advertisements and consumer testimonials on patient adherence
- Distinguish among FDA-approved and non-FDA approved HIV prevention modalities reportedly used by social media participants

### Disclosure

I have no real or perceived vested interests that relate to this presentation nor do we have any financial relationships with pharmaceutical companies, biomedical device manufacturers, and/or other corporations whose products or services are related to pertinent therapeutic areas."

> Kenric B. Ware, PharmD, MBA, AAHIVP September 2, 2020

Ongoing **Discouragement of Participation in Product Sharing/** Educational Interchange Platforms **Medication** Adherence & Compliance Comprehensive **Balanced Marketing /** Assessment of **Advocacy Strategies Medicinal Use** 

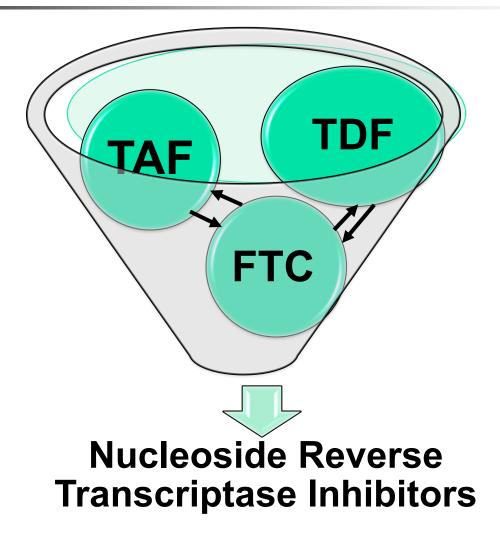
## What is **PrEP**?

 Provision of a fixed – dose combination product (TDF/FTC) & (TAF/FTC) in single daily dose to adults and adolescents weighing ≥ 35 kg

 TAF/FTC: Lack indication for use among individuals likely to acquire HIV from vaginal sex



### **FDA Approved Options for PrEP**



### Social media & HIV PrEP---Supportive & Scientific Interactions



# Shared updates on HIV PrEP advancements/developments

#### Drug Expiration Dates — Do They Mean Anything?

STAYING

HEALTHY

DISEASES &

CANCER

FDA study gets to the heart of expired medicine and safety



Harvard Health Publishing HARVARD MEDICAL SCHOOL Trusted advice for a healthier life

MIND &

HEART

HEALTH

#### Doxycycline for STI Prevention?

- Small studies examined old antibiotic for chlamydia, syphilis in MSM



#### I'm about to switch from Truvada to Descovy.

Pros or cons?

#### At least 28,000 women in the United States have started PrEP

Study shows more women take it in the north-east states, but highest need is in the south

Gus Cairns | 4 July 2020



DAILYMAIL.CO.UK | BY DAILY MAIL

A new bi-monthly injection could replace daily HIV prevention pills



# Should consumers stop HIV PrEP during social distancing?

\*The image comments below were lifted directly from a social media post and were not edited by the presenter for content or grammatical considerations.\*

Should someone stop taking Prep durring lockdown if at zero risk with current partner or celibate durring this time?

& Start back 5 days before any attempt at sex may occur

- When was HIV PrEP initiated? For how long?
- Is the *current partner* living with HIV?
- Is any impression of "zero risk" truly accurate?
- Is there consistent
  evidence for resuming *five days* prior to sex? 9

### Legal Claims of Therapy Harm

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Truvada Lawsuit Information Sponsored · 🕲

Truvada linked to bone density and kidney side effects.

... Continue Reading



- Outcomes distorted by photo setting
- Implies other medications are safer
  - May or may not be true
  - May discourage use
    - Lower HIV PrEP uptake works against community health efforts

### Legal Claims of Therapy Harm

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Truvada Lawsuit Information Sponsored · ③

📕 📕 Truvada linked to bone density and kidney side effects.

Anyone who experienced severe negative side effects due to the medication called Truvada may be eligible for significant compensation.

We help those affected get every dollar they deserve. There is limited time to file a claim. Click below to get a FREE claim evaluation. It only takes one minute.

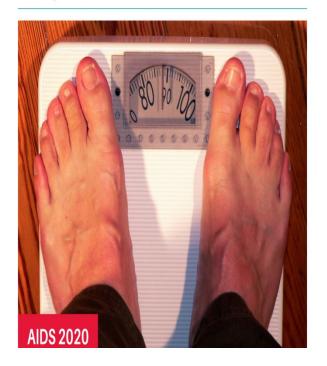


- Side effects may be due to other medications aside from HIV PrEP
- "Kidney side effects" may be too general and difficult to pinpoint
- "Bone density" phrase may be unfamiliar to consumers

# Are TAF formulations leading to extra pounds on the scale?

Rapid weight gain after switching to TAF, regardless of other HIV drugs taken

Keith Alcorn | 4 July 2020



- Changes in weight may be due to other medications taken with TAF among PLWH
- Some findings suggest TDF may be linked to weight reductions
  - Normalization of weight when switched from TDF to TAF
- Suspicion of weight gain may deter patients and providers

### **Trolling HIV PrEP while Traveling**

I am in Brooklyn NY and seeking to borrow PrEP for me and my partner, as we've run out due to changes in provider and insurance and mail order woes. Can anyone assist us? We gave away backstock to others in need.

Guys...

Anyone in the UK can borrow me some prep as my new pills got some delivery issues which I may need to wait another 2 weeks but I only left 5 doses with me...

If anyone can help please DM me.

I don't mind to pay or I can give u back later when I get my refills back? Your help is highly appreciated...

thanks a lot!!! 🙏

Borrowing PrEP pills when poz ---

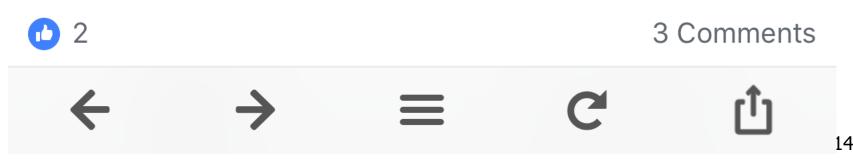
It happens that friends forget their pills and then borrow one. In such exceptional cases, does it make sense to borrow a PrEP pill if they are poz or not at all? Or can it even negative effects? And also vice versa with borrowing HIVmeds when on PrEP. Thanks

### Another Example of PrEP Requests

Yesterday at 4:27am · 💷

Any Seattlites spare one or 2 prep pills. I already missed one dose this week and now because of a car issue i may be here 1 or 2 nights. I can mail you back what i borrow. Feel free to p.m. me

(Please don't give me the <u>4 dose a week</u> thing there is evidence that that might not be true for trans men and is dangerous to imply so).



### Seeking advice about borrowing

\*The image comments below were lifted directly from a social media post and were not edited by the presenter for content or grammatical considerations.\*

I ran out of prep waiting for new order. Can I take triameq instead meanwhile?

- Common consumer question
  - Not specific to a certain HIV medication
- Peer feedback *largely* discouraged alternate use while waiting for PrEP
- Uncertain if safer sex practices observed during period of PrEP absenteeism

# **Conflicting use of Acronyms**



#### **Image Perceptions**

-Viewers may mix up references to PrEP with Post-Exposure Prophylaxis (PEP)

-Further confusion as TDF/FTC may be used as a component of PEP regimens, but not alone

### False Connections between PrEP and Sexually Transmitted Infections



#### **Image Perceptions**

-PrEP indication does not carry a guarantee of "STD – Free"

-Frequent monitoring of STIs should occur while patients are taking PrEP

-False representation of the scope of PrEP may directly and indirectly link to new cases of STIs

-Company owning the rights to PrEP may be viewed as supportive of erroneous claim

# **Messaging in News Media**

### AIDS pill as party drug?

DEC. 19, 2005

"Taking a T." That's what HIV-negative gay men call the growing practice of downing the AIDS drug tenofovir and, with fingers crossed, hoping it protects them from the virus during unprotected sex.

It's being sold in packets along with Viagra and Ecstasy in gay dance clubs -- and even prescribed by physicians, say doctors and AIDS prevention experts. The trend has alarmed public health officials. There is no proof that tenofovir protects against HIV transmission, they say. People who practice unsafe sex while taking the drug could still become infected or suffer side effects from it.

The first time I heard of PrEP was back in 2005, when I read this widelysyndicated article. I was exceptionally skeptical of the idea at the time, mainly because of the idea of an untested drug (tenofovir) being combined so readily with street drug usage struck me as an imminent disaster.

#### <u>Article Analysis</u>

-Synonymous use of AIDS and HIV by author

-Practice of HIV prevention being packaged with erectile dysfunction and illicit drugs still exist in some settings

-TDF/FTC approved for PrEP in 2012. TDF and TDF/FTC for HIV prevention often used interchangeably

#### Purchase-PrEP Online in 3 easy steps...

#### **1** Select your shipping country below & add products to cart.

Please make sure that you are purchasing a product that ships to the country you are wanting delivery to.

#### 2 Checkout.

Please make sure you enter your shipping/delivery address correctly including post code.



#### Mytan A Prescription Drug Emtricitabine/Tenofovir Disoproxil Fumarate Tablets RICOVIR-EM 200 mg/300 mg B0 Tablets

#### Select your shipping country below:

**The Americas** 

- United States of America
- III Canada
- Argentina
- 💿 Brazil
- L Chile
- Colombia
- Venezuela

#### Europe, Middle East & Africa

- United Kingdom
- + Northern Ireland
- Israel
- \* Malta
- Poland
- Switzerland
- Ukraine

#### Asia & Australasia

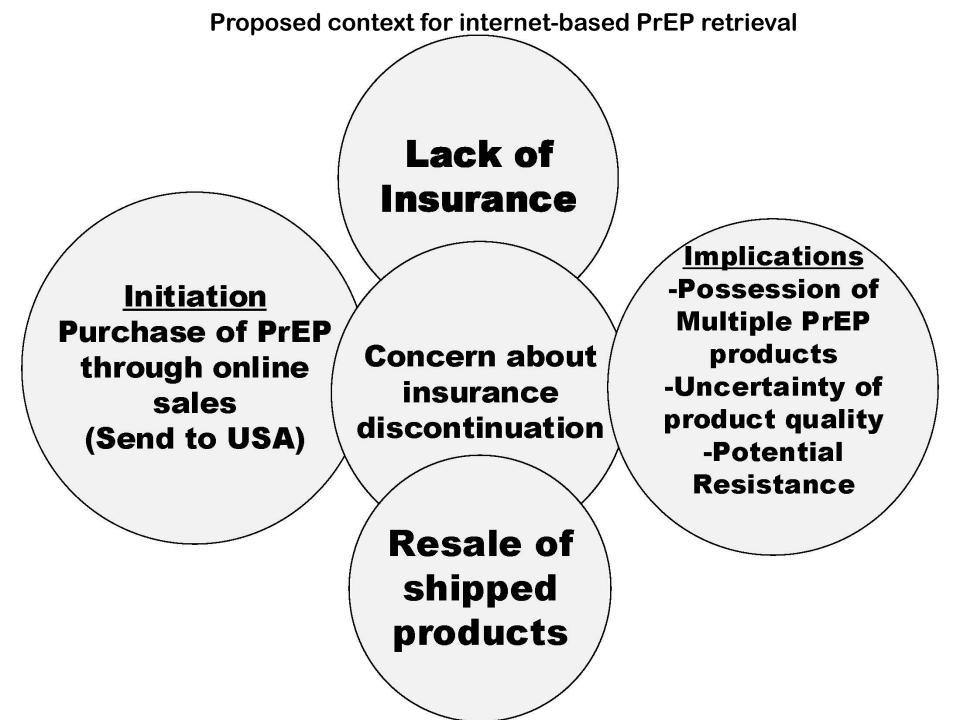
- 👪 Australia
- Japan
- Malaysia
- New Zealand
- Philippines
- Singapore

# \*DISCLAIMER\*

- The medications included in this presentation that are retrievable via online mediums are for discussion points only.
- Patients report increased use of these products which suggests a need for greater awareness of their existence.
- Drug interaction assessments or chronic monitoring of patients using these products does not appear to be uniform.
- Online transactional features may request varying levels of personal information that might lead to privacy issues.
- <u>The presenter does not endorse the use of non FDA-</u> <u>approved products</u> as their utility may not be closely supported by clinical evidence.

### **Cost & Formulation Comparisons**

Truvada ®	Tenvir – EM	Ricovir - EM	Tavin – EM
~\$2,210.70 for 30 tabs	~\$62.29 for 30 tabs ~\$168.17 for 90 tabs	~\$144.00 for 90 tabs	~\$240.00 for 90 tabs
FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg



## **Purchaser's Perspective**

\*The comments provided below were lifted directly from a social media post and were not edited by the presenter for content or grammatical considerations.\*

"I am a social worker and usually visit an orphanage that has children with HIV. Some of these children are being treated using the Tenvir EM tablet. One can buy Tenvir online from ADC, so I usually donate this medicine to the orphanage. This adds to my convenience as I don't have to visit the medical store to buy such medicines. I have heard that it is really effective in improving the immunity of the patient."



ADC: All Day Chemist

# **Limitations of Stockpiling**

 Mr. Justin Times is initiated on Truvada by his physician for PrEP. He later learns from an internet forum that he can purchase cheaper generic versions of Truvada online. Mr. Times then decides to order both Tenvir-EM and Ricovir-EM products since the forum claims that they are equally effective.



### **Public Perceptions of PrEP**





**Questions about PrEP?** 

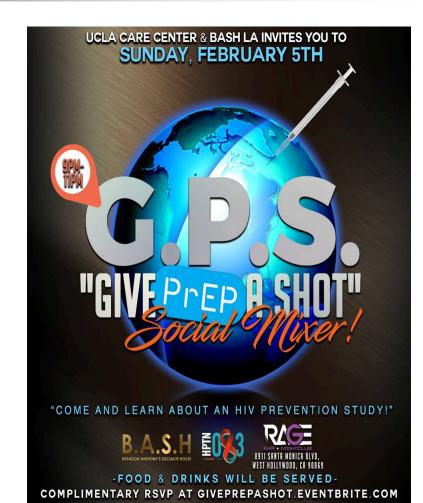
Want to meet guys on PrEP?

Meet Damon L. Jacobs, Therapist and PrEP Advocate



Alibi, Manchester Room February 10th 2017 6pm-8pm

www.PrEPwithPRIDE.com



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### **Public Perceptions of PrEP**



### **Public Perceptions of PrEP**



# **Group chat involving PrEP**

\*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.\*

#### Had an amazing time on a gay cruise and I truly able to enjoy sex thanks to prep

Great post! Thanks for sharing. #Pleasure

Sounds hot!

I'm looking on going on a (gay)cruise Which did you go on? Thank you in advance

It was last week. Altantis

Around the Caribbean? My friends went on that and took PrEP with them ;-)

# **Group chat involving PrEP**

\*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.\*

Yes and prep is a must

I must get in touch and hear how they got on. Looks like I maybe booking a cruise 🤝

is there a lot of sex on these cruises?

Loi a huge boat full of men who like men? Noooo very little sex 🎿

Done Atlantis (and other gay cruises) a few times. You can have as much or as little sex as you want. Take PrEP with you. Just like the boy scouts, you'll always be prepared :)

id be hosting orgies lol

I don't believe you. We need to know the story in graphic detail.

# **Group chat involving PrEP**

\*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.\*

How many men go? I would need ten bottles of prep

Number of men = depends on the particular cruise ship's capacity

damn! i wan na go to one that has a lot!!!

Royal Caribbean's Harmony of the Seas, currently the world's largest cruise ship has a maximum passenger capacity of 6,360. Atlantis used it recently :)

6k men? thats almost enough for me!

that's what the Royal Caribbean's website says the ships passenger max is :)

I went with Atlantis on a smaller Royal Caribbean ship.....3,000+ men. That was more than enough :)

### Implications of PrEP portrayals

- Perceptions of "party drug"
- Prompting of promiscuous behavior
- Concern for STI acquisition(s)
- Medication sharing
- Indiscriminate use

### **Future Considerations**

- Explore perceptions of PrEP across multiple social media platforms
- Restructure healthcare curricula to increase formal orientations to social media messaging
- Legal advice for healthcare personnel responding to medical queries on social media
- Possible institution of social media health care task forces to further explore online dialogues

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