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# Social Media and Implications of Online HIV PrEP Retrieval

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# **Evolving Treatment Adherence Paradigm Intersection of PrEP and Social Media**

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## Disclosure Information

I **do not** have any conflicts of interest to disclose and I **do not** intend to discuss off label use of any drug or treatment during this discussion.

# Presentation Objectives

- ❖ Evaluate social media comments from consumers regarding Food and Drug Administration (FDA) approved and non-FDA approved therapeutic options for HIV pre-exposure prophylaxis (PrEP)
- ❖ Design an educational initiative to assist with addressing patient care dilemmas in an online environment
- ❖ Construct a multi-disciplinary task force to monitor and intervene, when appropriate on misleading and/or inaccurate comments provided in cyber world



# Social media outlets



# What is PrEP?

- Provision of a fixed – dose combination product (TDF/FTC) in single daily dose to healthy **adults** at risk of acquiring HIV (HIV – negative individuals)
  - ❑ Recommended in these populations:
    - Men that have sex with men (MSM)
    - Transgender population
    - Heterosexually active men and women
    - Injection drug users (IDU)

# Selected Conversations

## Excerpts from social media posts:

I need some advice! I've hardly missed a dose of PrEP the last year I've been on the medication, but I forgot to take it this past Saturday and Sunday (two doses). I had sex on Saturday night and now I'm experiencing some anxiety. I took the pill this morning. Should I be worried? PreP stays in your system right? And how many doses can you miss and have the medication still be effective?

So of course my fear happen. New doctor new insurance and my doctor had no clue on what prep was. And of course I had to educate my doctor on prep so getting tired of explaining this medication

Just filled my first PrEP RX for a 16 y/o patient.



# Conversation analysis

- I need some advice! I've ***hardly*** missed a dose of PrEP the last year I've been on the medication, but I ***forgot to take it this past Saturday and Sunday (two doses)***. I had ***sex on Saturday night*** and now I'm experiencing some anxiety. I took the pill this morning. Should I be worried? ***PreP stays in your system right?*** And ***how many doses can you miss*** and have the medication still be effective?
  - “Hardly” reconciled with “two doses” within past two days
  - How many sex acts occurred on Saturday night? How many people?
  - Confirm medication history to determine exact number of doses missed

# Conversation analysis

- So of course my fear happen. ***New doctor new insurance*** and my doctor had no clue on what prep was. And of course I had to ***educate*** my doctor on prep so getting tired of explaining this medication
  - Continuity with patient
  - Coverage options
  - Patient's current educational level about PrEP

# Conversation analysis

- Just filled my first PrEP RX for a **16 y/o patient**
  - Clinical trials surrounding targeted age indications
  - Sexual orientation of the patient
  - Number of reported sexual partners
  - Consistent insurance coverage long term

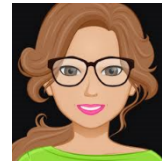
# Confidentiality concerns

- Level of confidence that the people interacting and providing healthcare advice are the real representations of themselves?
- Assurance of any medical training???
- Meet Susie Black and James Bond who provide PrEP advice
  - Are we sure these people are actually James Bond and Susie Black?
  - How can we prove it?
  - Should we trust the “advice” received?



# Appeal of social media “avatars”

- Reduced perceptions of external judgement
- Less constraints on questions posed
- Opportunities to identify as preferred gender
- Limited accountability for suggested claims
  - Informal exchanges
    - Unintended consequences
      - Therapy interruptions
      - Unanticipated adverse events
      - Furtherance of false claims



Brunskill D. Social media, social avatars and the psyche: is Facebook good for us? *Australas Psychiatry*. 2013;21(6):527-532.

Vasalou A, Johnson A, Banziger T, Goldie P, Pitt J. Avatars in social media: Balancing accuracy, playfulness and embodied messages. *Int J Hum Comput Stud*. 2008;66(11):801-811.

## \*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 can merit 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 may compromise one's identity.
- **The presenter does not endorse the use of these products** as their utility is not closely supported by clinical evidence.

## Other TDF-FTC (Besides Truvada®)

- Tenvir-EM
- Ricovir-EM
- Tavin - EM



**CAUTION!**



- ❖ These medications are currently UNAVAILABLE in the United States.
- ❖ We as practitioners do NOT support individuals ordering these medications as they are NOT FDA approved in the United States.

# Cost Comparisons

Truvada ®	Tenvir – EM	Ricovir - EM	Tavin – EM
~\$2,010.90 for 30 tabs	~\$62.29 for 30 tabs ~\$168.17 for 90 tabs	~\$144.00 for 90 tabs	~\$240.00 for 90 tabs



## CAUTION!



- ❖ **Tenvir – EM, Ricovir – EM, and Tavin - EM** are currently **UNAVAILABLE** in the United States.
- ❖ We as practitioners do NOT support individuals ordering these medications as they are NOT FDA approved in the United States.



# Dose Comparisons

Truvada ®	Tenvir – EM	Ricovir - EM	Tavin – EM
FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg	FTC 200mg TDF 300 mg



## **CAUTION!**



- ❖ **Tenvir – EM, Ricovir – EM, and Tavin - EM** are currently **UNAVAILABLE** in the United States.
- ❖ We as practitioners do NOT support individuals ordering these medications as they are NOT FDA approved in the United States.

# Participating countries (PrEP via postal mail)

**AUSTRALIA**

**CANADA**

**FRANCE**



**GERMANY**

**ITALY**

**MEXICO**

**NETHERLANDS**

**PERU**

**THAILAND**

**PORTUGAL**



**UNITED KINGDOM**



# Customer Testimonial

\*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.”

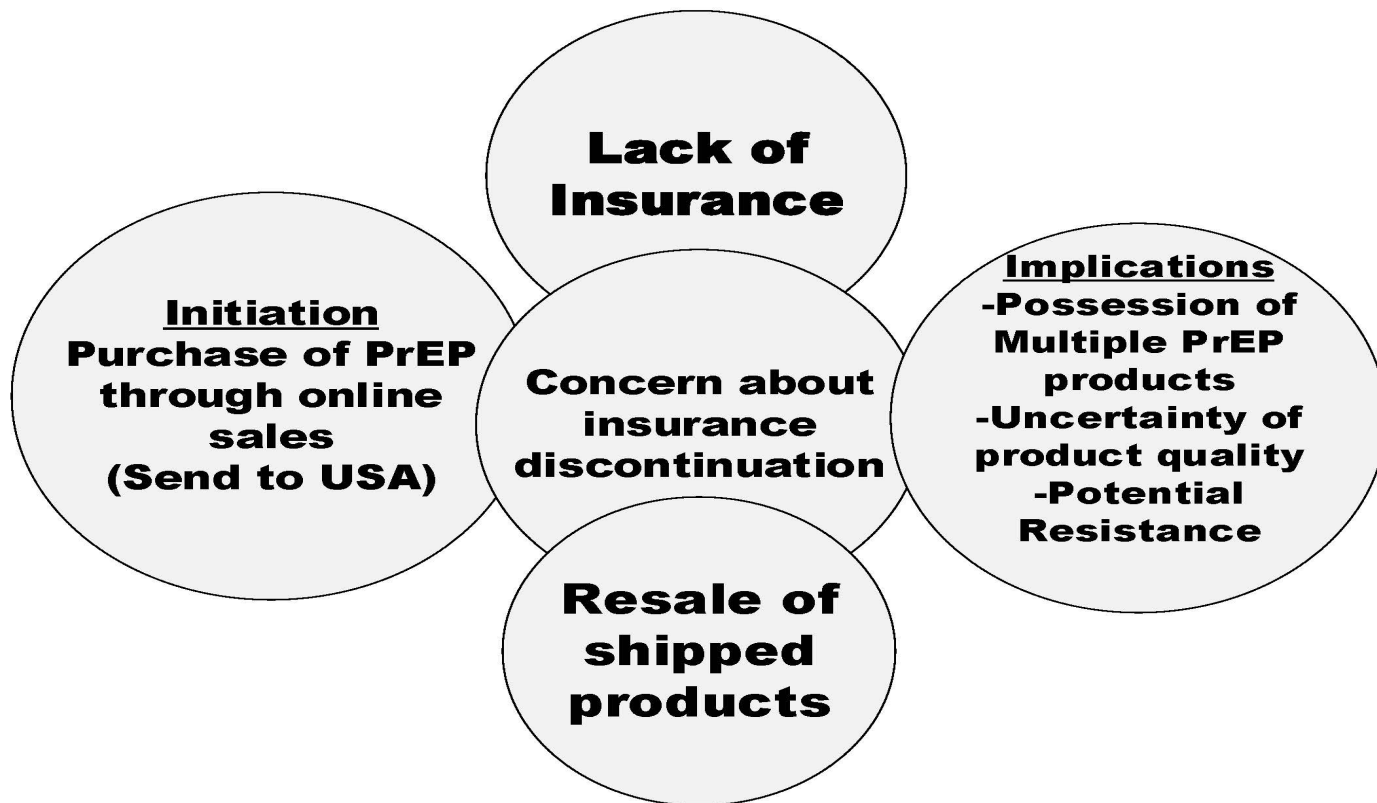


# Case Study


- 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.



# Proposed context for internet-based PrEP retrieval



# Community Outreach



THE PRIDE CENTER

**PREVENTION YOU CAN GET BEHIND!**

**PrEP Social Night**

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

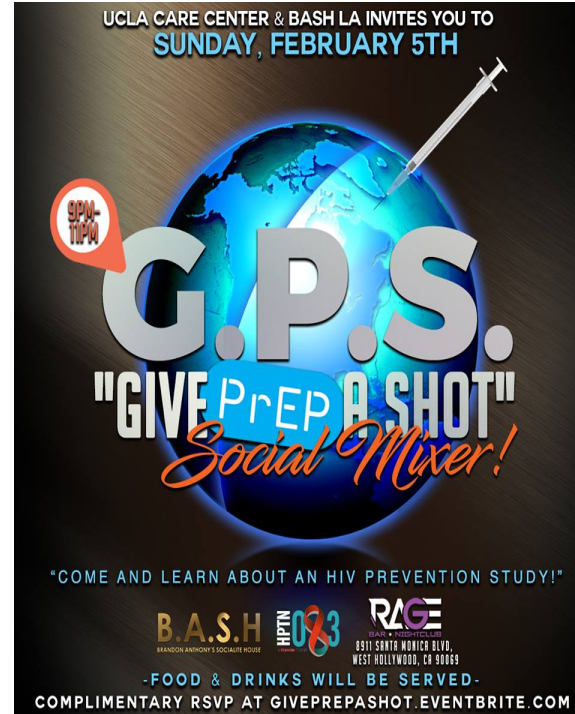
[www.PrEPwithPRIDE.com](http://www.PrEPwithPRIDE.com)  
[prep@pridecenterflorida.org](mailto:prep@pridecenterflorida.org) • (954) 463-9005, Ext. 210

**ALIBI**  
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FT TOWN

**PrEP**  
with PRIDE

Condom  
with PrEP

UCLA CARE CENTER & BASH LA INVITES YOU TO  
**SUNDAY, FEBRUARY 5TH**



**G.P.S.**  
"GIVE PrEP A SHOT"  
*Social Mixer!*

"COME AND LEARN ABOUT AN HIV PREVENTION STUDY!"

**B.A.S.H.** **HPTN 083** **RAGE**  
BRANDON ANTHONY'S SOCIETY HOUSE HPTN 083 RAGE  
8511 SANTA MONICA BLVD, WEST HOLLYWOOD, CA 90069

-FOOD & DRINKS WILL BE SERVED-  
COMPLIMENTARY RSVP AT [GIVEPREPASHOT.EVENTBRITE.COM](http://GIVEPREPASHOT.EVENTBRITE.COM)

# Perceptions around PrEP





# Perceptions around PrEP





# Group chat around 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 around 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 around 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 wanna 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 :)

# Request to share PrEP



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 4 dose a week thing there is evidence that that might not be true for trans men and is dangerous to imply so).

## Points of Consideration:

- Recent evidence has further explored effectiveness of 4 tablets/week
- Dosing schedule of 2:1:1
  - Sample regimen:
    - 2 tabs of TDF/FTC 2 – 24 hours before sex on Day 1
    - 1 tab of TDF/FTC 24 hours after sexual event on Day 2
    - 1 tab of TDF/FTC 48 hours after sexual event on Day 3

Saag MS, Benson CA, Gandhi RT, et al. Antiretroviral drugs for treatment and prevention of HIV infection in adults: 2018 recommendations of the International Antiviral Society-USA Panel. *JAMA*. 2018;320(4):1-18  
Molina JM et al *N Engl J Med* 2015;373:2237-46  
<http://www.cdc.gov/nchhstp/newsroom/2015/IPERGAY-2015-Media-Statement.html>

# Implications of PrEP portrayal

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

# Suggestions moving forward...

- Restructure healthcare curricula to increase formal orientations to social media messaging
- Remind patients not to share personal medical information on social media sites
- Restrict or prevent healthcare personnel from responding to individual medical queries
- Recommend or revitalize social media – inclined healthcare task forces to further explore online exchanges

# Questions / Answers

# Thank You

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