



**POSITIVE WOMEN'S NETWORK**  
USA

# Eliminating Stigma from the Language of HIV Communications

## **Presenters:**

Vickie Lynn, MSW, MPH

Valerie Wojciechowicz

Olivia Ford (Introductions / Moderation)

*February 3, 2015*



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***WELCOME!***



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# Moderator: Olivia Ford

As Communications Director at PWN-USA, **Olivia Ford** coordinates the organization's communications strategy while working with PWN-USA's members to build their capacity to engage in media and communications work. She previously worked at TheBody.com, a comprehensive Web-based HIV resource. There she conducted interviews and developed materials on such topics as the intersections of trauma, gender-based violence and HIV; health care access in transgender communities; the rollout of PrEP for US women; criminalization and stigma; as well as many aspects of becoming a parent while living with HIV. Olivia has co-presented workshops to diverse audiences at conferences throughout the US.





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# Who We Are

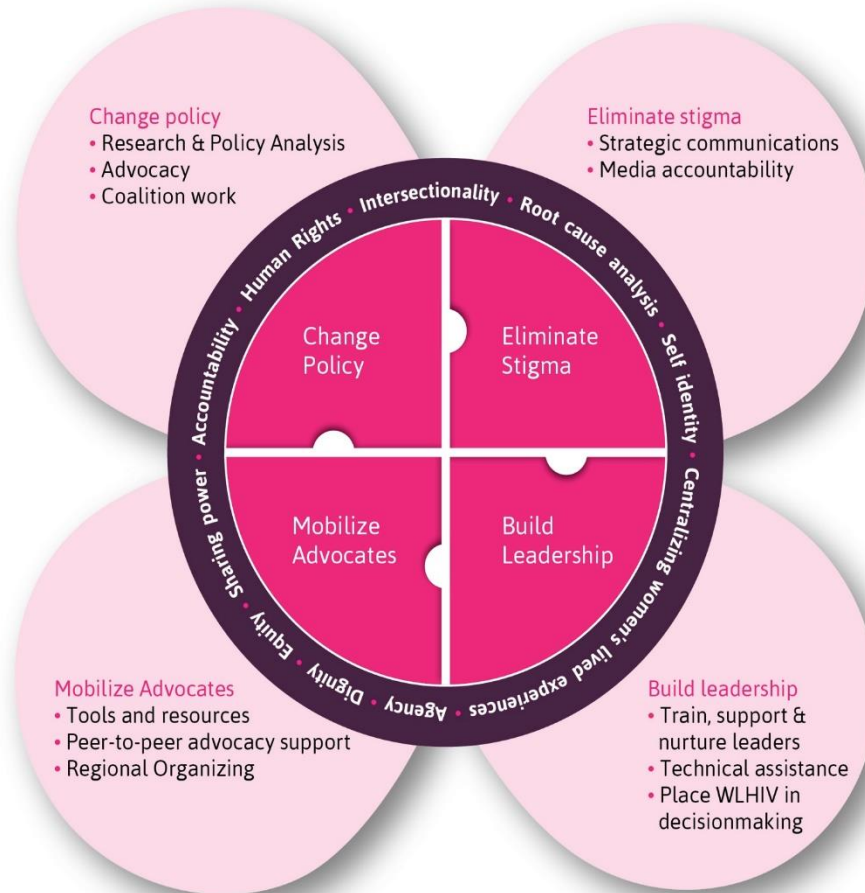
*Positive Women's Network - United States of America (PWN-USA) is a national membership body of women living with HIV working to prepare and involve all women living with HIV, in all our diversity, including gender identity and sexual expression, in all levels of policy and decision-making to improve the quality of women's lives.*

*PWN-USA applies a gender equity and human rights lens to the HIV epidemic to achieve federal policies grounded in the reality of women's lived experiences.*





# *Eliminate Stigma:* PWN-USA Strategic Plan





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# Intersectional Stigmas



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**Transgender Law Center**  
*Making Authentic Lives Possible*



WOMEN WITH A VISION

## **Intersectionality, HIV Justice, and the Future of Our Movement** **Part 1: An Introduction to Intersectionality**

*"If we aren't intersectional, some of us, the most vulnerable, are going to fall through the cracks." - Kimberlé Williams Crenshaw*

HIV thrives in conditions of structural inequity - where the workings of poverty, patriarchy, and other overlapping systems of injustice render community members vulnerable to acquiring HIV. Who is "most vulnerable" and who "falls through the cracks" is not static. *We do not all experience these vulnerabilities in exactly the same way.* However, the differences in our experiences - the learning edges of power and oppression, privilege and vulnerability - can, for our extraordinarily diverse HIV community, be sources of strength themselves.

### *Who We Are*

We stand together as a group of HIV activists of color. We are Black lesbians. We are Black gay men. We are heterosexual. We are immigrants and descendants of immigrants. We are people living with HIV and people

# Responding to Stigma



COMMENTARY : VIOLENCE

## What's HIV Got to Do With It? New York Post Violates Alleged Victim's Rights in Strauss-Kahn Case

by USA Positive Women's Network  
May 18, 2011 - 6:54 pm

The Positive Women's Network has

[rhrc.us/LG8jNS](http://rhrc.us/LG8jNS) COPY

## Tyler Perry's *Temptation* Sentences People With HIV to a Lifetime of Stigma and Isolation

From Positive Women's Network of the United States of America

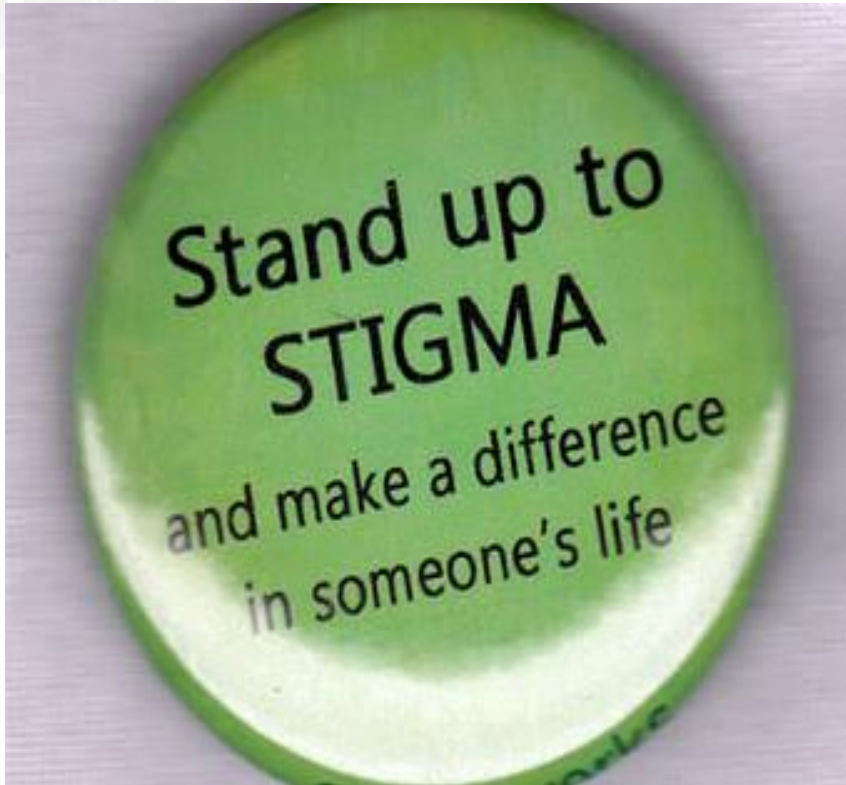
April 16, 2013

"Tyler Perry's *Temptation* left me emotionally pained, angry and disappointed. Mr. Perry, a filmmaker, missed a genuine opportunity for honest and accurate community education around HIV. Instead, *Temptation* perpetuated HIV sensationalism and stigma. It demonized people living with HIV and portrayed women who acquire HIV as an undesirable, reclusive, sub-species of people destined to live out their lives in suffering," commented Waheedah Shabazz-El, a woman living with HIV.





# *#StandUpToStigma*



- All of us – including those with the “power of the pen” – have a role to play in eliminating HIV stigma

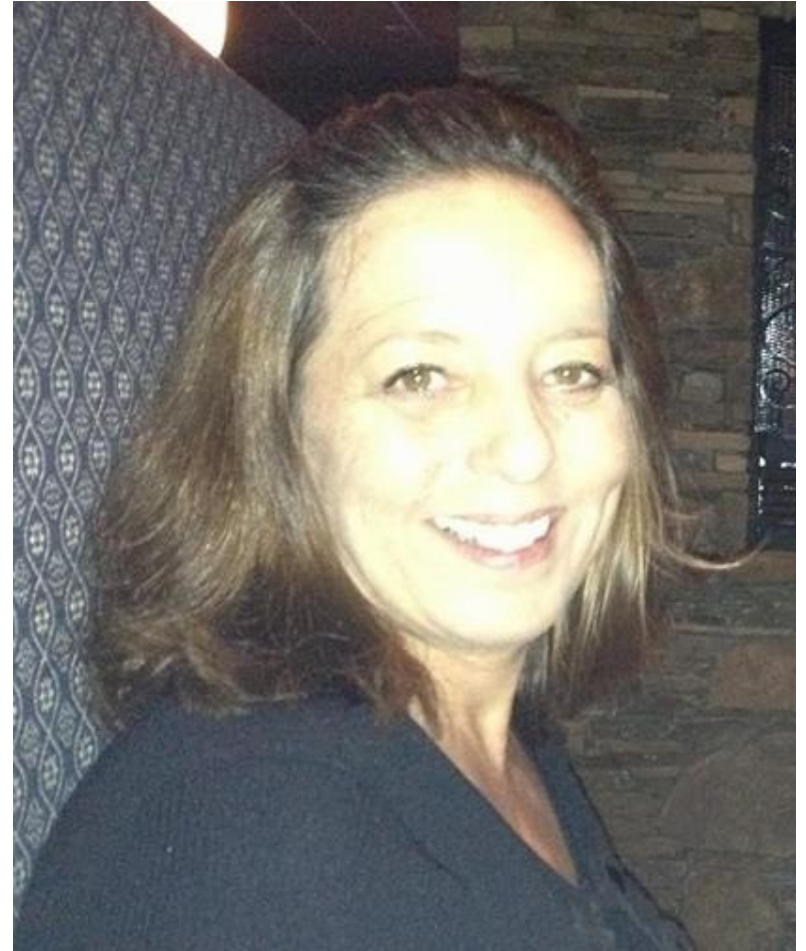




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# Presenter: Vickie Lynn, MSW, MPH

**Vickie Lynn** is a third-year doctoral student at the University of South Florida (USF), College of Public Health (COPH), Department of Community and Family Health (CFH), with a focus in Behavioral Health. Her research interests include examining behavioral health integration into primary care for people living with HIV, as well as other issues affecting access to care and treatment. A long-term survivor living with HIV since 1985, surviving an AIDS diagnosis, homelessness, and drug addiction, Vickie Lynn has spent the past few decades being an advocate for HIV issues.





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# Presenter: Valerie Wojciechowicz

**Valerie Wojciechowicz** has overcome many obstacles in her life, including addiction and obesity. These challenges and living with HIV (and its related stigmas) for 29 years have given her the determination to make a difference. Valerie uses her experiences to educate and empower others. In addition to providing services as an HIV testing counselor, Peer Navigator, Speaker, Trainer, and Fitness Professional, she has been instrumental in implementing Peer Programs in Florida. She works tirelessly to eliminate stigma and help improve the quality of life for others living with HIV and AIDS.



A close-up photograph of a woman's hand holding a red HIV awareness ribbon. The woman's face is partially visible in the background, out of focus. The ribbon is wrapped around her index finger and held taut. The background is a soft, out-of-focus white and light pink. A semi-transparent red banner with a white floral pattern is overlaid on the right side of the image, containing the title and authors' names.

# **Eliminating Stigma from the Language of HIV Communications**

Vickie Lynn, MSW, MPH  
Valerie Wojciechowicz

# Objectives

- Understand how language shapes our world
- Understand the history of language in relation to HIV.
- Explain the differences in stigmatizing and empowering language.
- Identify “people first language” and its importance.
- Explore the use of empowering language when talking or writing about self and others.



# Language

- Focusing on use of language may be the first place to start in order to address stigma, social exclusion, and discrimination against people living with HIV.
- Language
  - helps to shape our world
  - it describes and gives meaning to our lives
  - it persuades and changes minds
  - It can destroy or empower



# Empowerment

- *Empowerment* “is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people, in their lives, their communities, and in their society by acting on issues that they define as important (Page & Czuba, 1999)



## Reporting on HIV and AIDS

“Because reporting on HIV and AIDS ultimately deals with matters of life and death, and because many people will form their understanding of HIV and AIDS through the media, the story must be approached with clarity, precision, and sensitivity”

Kaiser Family Foundation. Reporting Manual on HIV/AIDS





**HISTORY OF LANGUAGE USED IN THE HIV  
COMMUNITY**



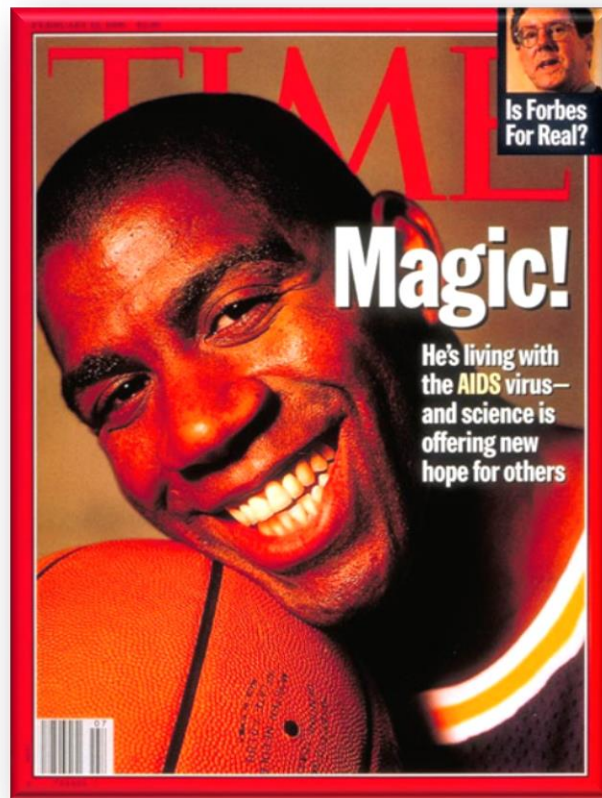


# Terminology

- GRID (Gay Related Immune Deficiency)
- *AIDS* (Acquired Immunodeficiency Deficiency Syndrome)
- *ARC* (AIDS-Related Complex)
- Full-blown AIDS
- HIV - Human Immunodeficiency Virus
- Late stage HIV, end stage HIV, or Stage 3 (US) or Stage 4 (WHO)



# Media



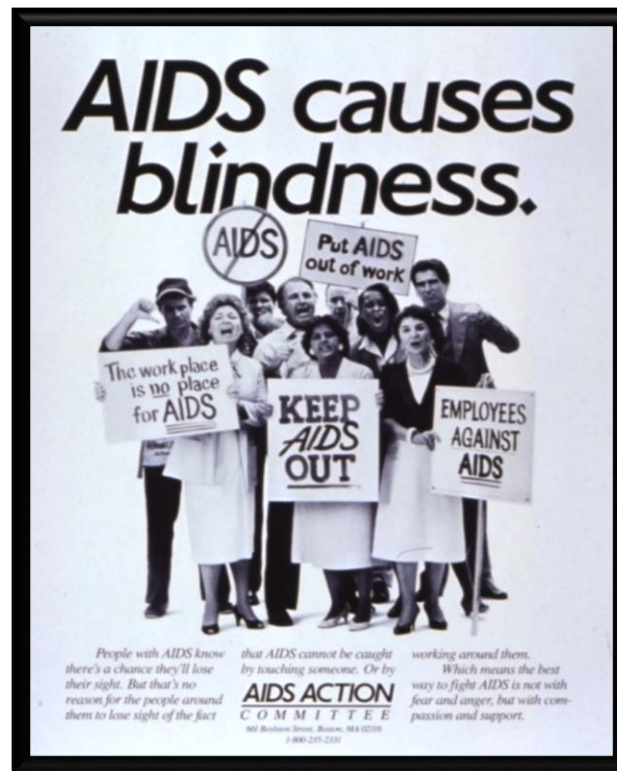
Something is not correct on this magazine cover. What is it?



# Media



# Media



**AIDS causes blindness.**

Put AIDS out of work

The work place is no place for AIDS

KEEP AIDS OUT

EMPLOYEES AGAINST AIDS

People with AIDS know there's a chance they'll lose their sight. But that's no reason for the people around them to lose sight of the fact that AIDS cannot be caught by touching someone. Or by working around them. Which means the best way to fight AIDS is not with fear and anger, but with compassion and support.

**AIDS ACTION COMMITTEE**  
102 Boston Street, Boston, MA 02108  
1-800-215-2331



# Media



# Media



**A man who shoots up can be very giving.**

**He can give you and your baby AIDS.**

Most babies with AIDS are born to mothers who shoot drugs or who sleep with men who have AIDS. And if your man shoots drugs, he'll give you AIDS. If you're thinking of having a baby, you and your partner need to get tested for AIDS. Only get pregnant when you're sure both of you aren't infected. Until then, help yourself and your partner by using condoms. And if your man shoots drugs, help him get into treatment now. It could save them from AIDS. Only babies with AIDS are born to mothers who shoot drugs or who sleep with men who have AIDS. And if your man shoots drugs, he'll give you AIDS. If you're thinking of having a baby, you and your partner need to get tested for AIDS. Only

**STOP SHOOTING UP AIDS.**  
CALL 1-800 662 HELP.

**A man who shoots up can be very giving.**

**He can give you and your baby AIDS.**

Most babies with AIDS are born to mothers who shoot drugs or who sleep with men who have AIDS. And if your man shoots drugs, he'll give you AIDS. If you're thinking of having a baby, you and your partner need to get tested for AIDS. Only get pregnant when you're sure both of you aren't infected. Until then, help yourself and your partner by using condoms. And if your man shoots drugs, help him get into treatment now. It could save them from AIDS. Only babies with AIDS are born to mothers who shoot drugs or who sleep with men who have AIDS. And if your man shoots drugs, he'll give you AIDS. If you're thinking of having a baby, you and your partner need to get tested for AIDS. Only

**STOP SHOOTING UP AIDS.**  
CALL 1-800 662 HELP.

**"If he doesn't have a condom, you just have to take a deep breath and tell him to go get one."**

It's not the easiest thing in the world to say. But these days, you have to. If you're dating someone who doesn't use condoms, talk before having sex. Explain how you feel. Offer to help during the condom moment. And if this doesn't work, ask yourself, is it worth the risk? For more information on condoms and AIDS, call 1-800-342-AIDS to answer your own questions.

**PREVENTING AIDS**

**"If he doesn't have a condom, you just have to take a deep breath and tell him to go get one."**

It's not the easiest thing in the world to say. But these days, you have to. If you're dating someone who doesn't use condoms, talk before having sex. Explain how you feel. Offer to help during the condom moment. And if this doesn't work, ask yourself, is it worth the risk? For more information on condoms and AIDS, call 1-800-342-AIDS to answer your own questions.

**PREVENTING AIDS**

**\*Warning for next slide**



# Media



# Street slang

- Dirty
- The bug
- Bug catchers
- Monster
- Ninja
- The germ
- Diseased
- Are you *clean*?





## Slang in Africa

"Language can neither be separated from our thoughts and feelings, nor from the social context in which it is used. Words and images create different conceptual realities of the phenomenon." – Felicity Horne

Felicity Horne studies AIDS and language at the University of South Africa.



# Slang in Africa

- Amesimamia Msumari | “**Standing on a nail**”; euphemism for being skinny ... referring to AIDS-related weight loss. (Tanzania, Kiswahili.)
- **Departure Lounge** | A person living with HVI is in the departure lounge awaiting death. (Zimbabwe.)
- **F.T.T.** | “Failure to thrive” (adapted from the medical phrase, now used to describe children living with HIV). (Zimbabwe.)
- Udlala Ilotto | “**Playing the lotto**” / ubambe ilotto – “won the lotto” (said of someone suspected of living with HIV; Lotto is the national lottery).

<http://www.irinnews.org/report/78809/africa-mind-your-language-a-short-guide-to-hiv-aids-slang>



# People First Language

- Rather than using labels to define individuals with a health issue, it is more appropriate to use terminology, which describes individuals as being diagnosed with an illness or disorder.



# Empowering Images





# Using Language



# Language



Stigmatizing	Preferred
PLHA or PLWHA	People living with HIV or Person with HIV
HIV patient, AIDS patient	Person living with HIV
Positives or HIVers	
AIDS or HIV carrier	
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications or end stage HIV



# Language

Incorrect	Preferred
AIDS virus	HIV
HIV virus	This is redundant use HIV
HIV or AIDS	HIV AIDS (only when referring to AIDS) HIV and AIDS
Risk group	Risk
Risky or unprotected sex	Be specific on what you are saying. Condomless sex, condomless sex with PrEP or without PrEP



# Language



Stigmatizing	Preferred
Victim	Do not use
Sufferer	
Contaminated	
Innocent (victim)	
AIDS orphans	Children orphaned by loss of parents or guardians who died of AIDS related complications





# Language



Stigmatizing	Preferred
HIV infected mother	Mother living with HIV
Mother to child transmission	Vertical transmission
AIDS Orphans	Children who lost both their parents
Bodily fluids	Be precise on which fluid you are referring to blood, semen, vaginal fluid or secretions, breast milk, amniotic fluid, pre-ejaculate



# Language



Stigmatizing	Preferred
Intravenous drug users	Person who injects drugs or person who uses drugs
Sharing (needles, syringes)	Use of non-sterile injecting equipment
Prostitute or prostitution	Sex worker, sale of sexual services
Promiscuous	This is a value judgment and should be avoided. Use - Having multiple partners



# Language



Stigmatizing	Preferred
Fight against AIDS	Response to AIDS or AIDS response
HIV/AIDS (HIV slash AIDS)	Use HIV when appropriate and use AIDS when appropriate.
AIDS test	HIV test
To catch AIDS To contract AIDS To catch HIV	An AIDS diagnosis, developed AIDS To contract HIV
Compliant	Adherent



# Self Talk



## Infected



# Self Talk



Positive



© Penny Lane dpchallenge.com





# Intro to Activity



## Example

- I was infected with HIV when I was a teenager.
- I contracted HIV when I was a teenager.



## Example

- Women are most likely to be infected with HIV through heterosexual contact.
- Women are most likely to contract HIV through heterosexual contact.





## Example

- Cardiovascular disease has become a major concern among **HIV-infected individuals**.
- Cardiovascular disease has become major concern among **people living with HIV**





# Activity

## Your responses . . .



## What is Next . . .

What can we as advocates, activists, and other professionals do to help reduce the stigmatizing language?

- Use appropriate terminology
- Use empowering terminology
- Use non-stigmatizing language and images
- Portray people with HIV living positively, not depressed or ostracized
- Empower yourself and others



**I AM NOT**  
“**DYING**  
**HELPLESS**  
**SICK**  
BEING PUNISHED  
**GUILTY**  
*OR DIRTY*”

← →  
**I AM**  
**HIV**  
**POSITIVE**

UPDATE YOUR THINKING.  
END THE STIGMA.

LIVE HIV NEUTRAL

THE  
**S+IGMA**  
PROJECT



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<http://www.kff.org/hivaids/7124-02.cfm>
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# Questions?





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# Keep in Touch with PWN-USA

[www.pwn-usa.org](http://www.pwn-usa.org)

fb: [tinyurl.com/pwnusafacebook](https://www.facebook.com/tinyurl.com/pwnusafacebook)

tw: @uspwn ~ #pwnspeaks

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