

Civil society advocacy as a prerequisite for the implementation of oral PrEP and other ARV-based prevention

Cindra Feuer, Kevin Fisher, Emily Bass, Deirdre Grant

Controlling the HIV Epidemic with Antiretrovirals: Avoiding the Cost of Inaction

September 19, 2014

Global PrEP Advocacy

- Advocacy for research; preparing for results (2004–today)
 - Daily oral PrEP efficacy
 - Intermittent; alternatives to tenofovir-based
 - Other delivery methods, e.g., rings, injectables
- Advocacy for approval (normative or regulatory) (2010–today)
 - US FDA approval; CDC Guidelines
 - WHO guidance on PrEP demo projects (2012); recommends PrEP for MSM (2014),
 - South Africa and Quebec provider guidelines
- Advocacy for implementation targeted access (2012–today)

Throughout – this advocacy and activism has embraced combination prevention

PrEP Trials, Advocacy Beginnings



- 2004–2006 Controversy over PrEP research ethics and meaningful engagement of community

Readying for PrEP Results in the US

USCA PREP ROUNDTABLE BE CAREFUL WHAT YOU WISH FOR: WHAT IF PREP WORKS? PREPARING FOR PREP POLICY, PRACTICE AND ETHICS

Saturday, Oct. 31, 2008, 8:30-10:30 am
Union Square 13, 4th Floor, Hilton San Francisco

Participants: Grant Colfax, San Francisco Department of Health;
Nichole Little, Sexual Health Education Resources & Outreach;
Dawn Smith, Centers for Disease Control; Vinya Sysamouth, Asian & Pacific
Islander Wellness Center; Steve Wakefield, HIV Vaccine Trials Network;
Facilitators: Kevin Fisher, AVAC; Cindra Feuer, AVAC



for PrEP

Does PrEP work to reduce the risk of HIV?
We'll find out soon!

USCA PrEP Workshop

The poster features a central image of a person's back and buttocks, with their hands held out to the sides. The text is overlaid on the image. The word 'for' is in blue, and 'PrEP' is in red. The question and answer are in blue. The bottom of the poster has a blue banner with the text 'USCA PrEP Workshop'.

Advocacy for PrEP Approval



AVAC PxROAR Member Matthew Rose speaking at the FDA hearing.

“I ask you to give my community another option. . . Give people options and choices that will work for them, things science tells us will give us a chance.” *New York Times*, May 2012

US Advocacy for PrEP Access

- National civil society coalition
- PrEP Watch: prepwatch.org
- My PrEP Experience: myprepexperience.blogspot.com
- PrEPFacts: prepfacts.org
- US Women and PrEP Working Group
- PrEPception
- PrEP @ 2 Years, social media campaign
- ASO Sign-on letter in support of US PrEP Guidelines (300 signatures)
- Gilead community grants
- Media engagement

US Media: PrEP Inculcated

The New York Times

Advocating Pill, U.S. Signals Shift to Prevent AIDS

By DONALD G. McNEIL Jr. MAY 14, 2014

THINKPROGRESS

The Obscure Federal Policy Change That Could Transform The Way We Fight AIDS



It's time to bring HIV prevention drugs out of the closet

NEW YORK

Sex Without Fear



HEALTH, LIFE & HIV

New Advocacy Group Wants to Improve Feasibility of PrEP for US Women

The BAY AREA REPORTER

Serving the gay, lesbian, bisexual and transgender communities since 1971

Does PrEP = a new gay sexual revolution?



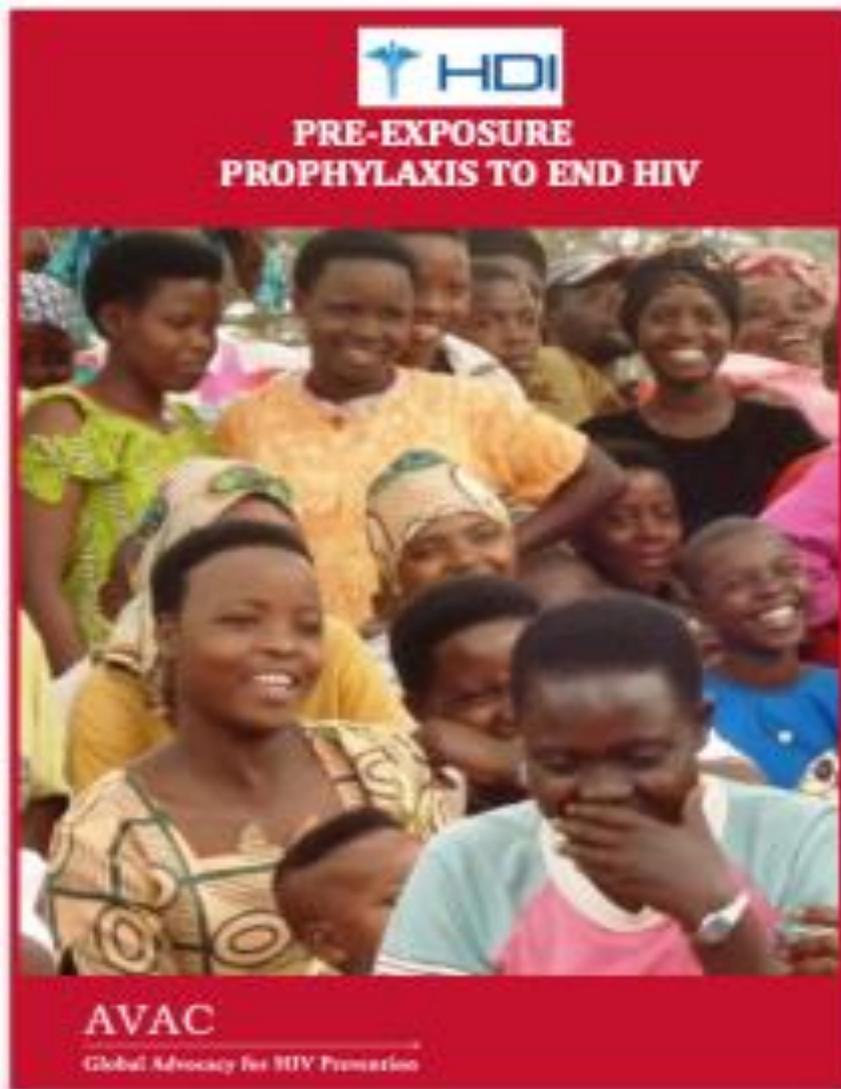
THE BODY PRO

The HIV Resource for Health Professionals

I'm an HIV Physician. And I'm Starting PrEP.

By Howard Grossman, M.D.

Readiness/ Approval/Guidance



PrEP Campaigns, alongside VMMC, TasP, condoms, rights – combination prevention

Uganda (IDI, IAA)

Kenya (BHESP, PHRD, KEMRI, GEM)

South Africa (TAC, DTHF, JHHSA)

Rwanda (HDI)

France (AIDES, Sidaction)

Germany (GSSG, GM)

UK (NAM, NAT, THT, UKCAB, etc.)

Peru (IRMA-ALC, Epicentro)

Kenya PrEP Access Wins

- MoH Prevention Revolution Roadmap, launched August
 - Combination interventions include PrEP for sex workers, MSM, women and truck drivers
 - Priority political actions:
 - Proactively **develop guidelines** that facilitate efficient translation of research into policy (PrEP, Treatment for HIV Prevention, Microbicides) by 2015
- Kenya AIDS Strategic Framework
 - **Pending: 2 PrEP pilot projects planned**
- Global Fund
 - Pending: Funding for PrEP tied to KASF

Now: Implementation advocacy

- Demonstration study coordination and continued research for additional options
- Coalition-based work to amplify demand for daily oral tenofovir based PrEP
- Educate policymakers about PrEP and emerging tools (rings, gels, injectables) and to champion supportive policies.

Lessons Learned

- Prepare communities, policy makers and media before, during and after trials.
- Initial PrEP skepticism is overcome with correct information
- PrEP advocacy by a few, eventually spreads on its own – especially when it is integrated into combo prevention
- Delayed translation of research findings into policy and practices, even in the best of situations, e.g., Kenya, US
- Patterns arise, predicting where troubled spots will be for forthcoming interventions
- Science is the easy part

“If it exists among scientists, we can’t assume policymakers will implement it “

Nikos Dedes

Yesterday, IAPAC, London