Civil society advocacy as a pre-requisite 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
  – South Africa and Quebec provider guidelines

• Advocacy for implementation targeted access (2012–today)

Throughout – this advocacy and activism has embraced combination prevention
• 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 Smitt, Centers for Disease Control; Vinya Sysamouth, Asian & Pacific Islander Wellness Center; Steve Wakefield, HIV Vaccine Trials Network; Facilitators: Kevin Fisher, AVAC; Cindra Feuer, AVAC

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

USCA PrEP Workshop
Advocacy for PrEP Approval

“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

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

POZ
Sex Without Fear
New Advocacy Group Wants to Improve Feasibility of PrEP for US Women

Bay Area Reporter
Does PrEP = a new gay sexual revolution?

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

The Body Pro
I'm an HIV Physician. And I'm Starting PrEP.
By Howard Grossman, M.D.
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 the 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