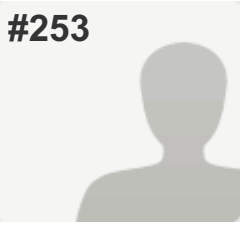


Ending the Epidemic Task Force Recommendation Form

#253



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Q1: OPTIONAL: This recommendation was submitted by (please provide your first and last name, affiliation, and email address)

First Name	Jim
Last Name	Eigo
Affiliation	ACT UP/NY
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Q2: Title of your recommendation

No End of the AIDS Epidemic Until Soaring Drug Prices Are Brought Under Control

Q3: Please provide a description of your proposed recommendation

New York State deservedly touts the fact that in the age of the Affordable Care Act and Expanded Medicaid virtually every New Yorker is eligible for affordable healthcare. Accordingly, the top goal of the Task Force that is drafting a blueprint for Ending the AIDS Epidemic is linking people to affordable healthcare, whether they are living with HIV or HIV-negative members of target populations. But the Affordable Care Act offers no mechanism for keeping drug prices affordable. It expressly forbids Medicare from using its enormous clout to negotiate the price of drugs. The Task Force has the luxury of contemplating an end to the AIDS epidemic only because New York State has secured a major Medicaid rebate for HIV drugs from the four major producers of these drugs.

But this agreement should not distract the Task Force and its Care Committee from considering mechanisms to control drug prices. The secured rebates are only for HIV drugs, and only through Medicaid, not other third-party payors. People living with HIV and people at risk for HIV have many medical conditions that can require many medications paid for by many different mechanisms that fall beyond the comparatively narrow safe zone of the secured rebates.

In New York State, we have a fresh example of the dangers of unregulated drug prices. Sofosbuvir, alone or in combination, is a recently-approved treatment for Hepatitis C that could cure the infection in far more than 90% of the people living with it. Hepatitis C, spread through sharing injection drug paraphernalia and sex, is a health threat to individuals and to the public. Recreational drug use and sex are notoriously difficult-to-regulate areas of human conduct, and Hepatitis C is spreading rapidly among a new generation of injection drug users. CDC says that people living with HIV are at heightened risk for infection through sex. People living with Hepatitis C often advance to chronic liver disease and remain infectious for the duration of their infection. Individual health and public health both argue in favor of treating Hepatitis C as widely as possible, as soon as diagnosed and with the best treatment available. One might think New York State would share this position. After all, in September 2014 Governor Andrew Cuomo signed a law that increased access to Hepatitis C testing.

Instead, many of those newly diagnosed with Hepatitis C will have to wait for treatment until they advance to liver disease. Though the drug is neither difficult to synthesize nor expensive to produce, the drug company that owns sofosbuvir has slapped a thousand-dollar-a-pill pricetag on the drug. Third-party payors have seized upon the cost of the drug to lobby against guidelines that would make treatment with sofosbuvir widely available. And so the Drug Utilization Board of New York State's Department of Health has drawn up restrictive criteria for prescribing the drug. There is no justification for drawing up a hierarchy of patients worthy of treatment with a drug that is cheap and easy to make. All people deserve the best treatment available.

In this sorry charade it's been hard to decide which party's greed has been more sickening to observe: the greed of the drug company or the greed of the third-party payors. But the most disappointing party has been New York State. Its complicit decision to advise withholding the best treatment from whole classes of people will cause much individual sickness and prolong an epidemic. Most people living with HIV who are co-infected with Hepatitis C (about 1 in 4) will be able to obtain sofosbuvir if Medicaid is their payor. But many people beyond that narrow class will not. New York State has missed an opportunity to put a relatively quick end to a growing epidemic that is a particular risk for people living with HIV and many members of target populations at risk for HIV.

Observers of the pharmaceutical industry predict a truckload of medications about to come onto the market that will bear pricetags comparable to sofosbuvir's. Many will be cancer drugs; people living with HIV are especially susceptible to a number of cancers. And there will be exorbitantly priced drugs for other conditions that affect people living with HIV and at risk for HIV—just as there are many payors beyond Medicaid. To ensure the care of people living with HIV or at risk for HIV, the Task Force will have to articulate a policy about the price of drugs that fall beyond the very limited agreement for Medicaid rebates on HIV drugs made with four drug companies.

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Q4: For which goal outlined in the Governor's plan to end the epidemic in New York State does this recommendation apply? (Select all that apply)

Linking and retaining persons diagnosed with HIV to health care and getting them on anti-HIV therapy to maximize HIV virus suppression so they remain healthy and prevent further transmission

Q5: This recommendation should be considered by the following Ending the Epidemic Task Force Committee (Select all that apply)

Prevention Committee: Develop recommendations for ensuring the effective implementation of biomedical advances in the prevention of HIV, (such as the use of Truvada as pre-exposure prophylaxis (PrEP)); for ensuring access for those most in need to keep them negative; and for expansion of syringe exchange, expanded partner services, and streamlined HIV testing by further implementing the universal offer of HIV testing in primary care, among others. The Committee will focus on continuing innovative and comprehensive prevention and harm reduction services targeted at key high risk populations, as well as grant-funded services that engage in both secondary and primary prevention.

Care Committee: Develop recommendations to support access to care and treatment in order to maximize the rate of HIV viral suppression. The Committee will promote linkages and retention in care to achieve viral suppression and promote the highest quality of life while significantly decreasing the risks of HIV transmission. Recommendations will also ensure a person centered approach is taken and that access to culturally and linguistically appropriate prevention and health care services is available.

Q6: Does this recommendation require a change to an existing policy or program, or the creation of a new policy or program?

Unknown

Q7: Would implementation of this recommendation be permitted under current laws or would a statutory change be required?

Unknown

Q8: Is this recommendation something that could feasibly be implemented in the short-term (within the next year) or long-term (within the next three to six years)?

Unknown

Q9: What are the perceived benefits of implementing this recommendation?

Affordable drugs for all.

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Q10: Are there any concerns with implementing this recommendation that should be considered?

Respondent skipped this question

Q11: What is the estimated cost of implementing this recommendation and how was this estimate calculated?

Respondent skipped this question

Q12: What is the estimated return on investment (ROI) for this recommendation and how was the ROI calculated?

Respondent skipped this question

Q13: Who are the key individuals/stakeholders who would benefit from this recommendation?

Every person living with HIV or at risk for HIV who uses any expensive medication other than an HIV medication made by one of four producers of HIV drugs

Q14: Are there suggested measures to accompany this recommendation that would assist in monitoring its impact?

Respondent skipped this question

Q15: This recommendation was submitted by one of the following

Ending the Epidemic Task Force member