RECORD TYPE: PRESIDENTIAL (TRP NOTES MAIL)

CREATOR: ACT UP ("ACT UP/NY c/o Housing Works, Inc." <hworks@dti.net> [UNKNOWN])

CREATION DATE/TIME:16-MAR-1998 19:17:39.00

SUBJECT: DEMONSTRATE AGAINST DEMONIZATION 3/26/98

TO: Supporter (Supporter <hworks@dti.net> [UNKNOWN])
READ:UNKNOWN

Todd A. Summers (CN=Todd A. Summers/OU=OPD/O=EOP [OPD])
READ:UNKNOWN

TEXT:
THEY WANT YOUR NAME ON A LIST

New York State says it wants to know how many people have HIV and where the

AIDS epidemic is going. It wants to do this by COLLECTING YOUR LAB AND HIV

TEST RESULTS. Your name will be put on a government list.

But we've known for years where the AIDS epidemic is going:

IT'S STILL HERE AND RAGING OUT OF CONTROL.

Why doesn't the State know this? Probably for the same reason there's still

no condom education in schools, still no needle exchange, still no

universal healthcare, and still no cure: MURDEROUS, CRIMINAL NEGLIGENCE.

More data, no action. Money lining the wallets of AIDS professionals.

People with HIV demonized and criminalized.

IS THIS ANY WAY TO FIGHT AN EPIDEMIC?

For eleven years, people have taken to the streets demanding an end to the

AIDS crisis. IT'S TIME TO DO IT AGAIN.

No names. No numbers. No lists.

No excuses. Fight AIDS!

TRACKING ISN'T TREATMENT.

MAKING LISTS ISN'T PREVENTION.

COLLECTING NAMES ISN'T A CURE.

DEMONSTRATE AGAINST DEMONIZATION.

TELL NY TO GET ITS PRIORITIES RIGHT.

Thursday, March 26

8:30 AM

NYS HIV Advisory Council

FIVE PENN PLAZA

W 34TH ST @ EIGHTH AVE

FOR MORE INFO CALL 212.966.4873

WE DIE. THEY COUNT BODIES. ACT UP.

ACT UP/NY * 32 Bleecker Street, Suite G5, NYC 10014 * General Meetings:

Every Monday @ 7:30 pm at the Lesbian & Gay Community Services Center 208

W. 13th Street, NYC (bet. 7th & 8th Aves.) actupny@panix.com *

http://www.actupny.org * ACT UP is a diverse, non-partisan group of

individuals united in anger and committed to direct action to end the AIDS

crisis.

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NO NAMES. NO NUMBERS. NO LISTS.

ACT UP/NY'S POSITION ON IDENTIFIED HIV CASE REPORTING

ACT UP/NY opposes identified HIV case reporting to government health departments.

This includes reporting the names of people who test positive for HIV as well as reporting individual cases through so-called "unique identifier" codes ("UIs"). Both reporting systems as currently discussed in New York state would require the creation of a centralized registry. As a result, these systems pose considerable risks for people with HIV, raise doubts about the data they might collect, and distract from the implementation of proven HIV prevention methods.

Identified HIV case reporting will not yield good data.

Studies show that many people with HIV will not seek testing if their names enter government lists. Other studies suggest that UIs will also deter testing. With such a skewed picture of the epidemic, how do health officials expect to monitor sero-prevalence? How will collecting names give useful information about at-risk behaviors, prevention efforts and treatment access?

Identified HIV case reporting is not the only, or even most effective, way to gather data.

ACT UP/NY continues to support the collection of accurate data about the epidemic. Cohort studies collect information about the epidemic without coercion. Several databases already exist with records for hundreds of

thousands of people with HIV: Statewide Planning and Research Cooperative System, ADAP/ADAP+, Welfare Management System, NYS and NYC TB Case Reports, AIDS Intervention Management System, Medicaid, NYC Division of AIDS Services and the NYS Cancer Registry--all of these in addition to anonymous testing sites.

Identified HIV case reporting will not bring people earlier into the treatment process.

The advent of combination therapies suggests that people with HIV may wish to consider treatment as early as possible. But the deterrent effects of identified HIV case reporting systems means more people will not seek treatment. For example, poor people, IV drug users and people of color have historical reasons to fear their names on government lists. Immigrants who lack social security numbers and/or are worried about their residency status will be shut out from the healthcare system entirely.

Identified HIV case reporting will not guarantee security.

In Florida, over 4,000 names were released to newspapers. With information readily available on the internet, UIs can be cracked by anyone with access to databases, a computer and the encryption algorithm. Further, access to these lists can be granted through legislative acts. Illinois legislators wanted to identify HIV-positive healthcare workers using their registries. Discrimination against people with HIV still exists and may not be remedied through the Americans With Disabilities Act.

Identified HIV case reporting will not increase efforts to end the AIDS crisis.

A considerable amount of data has already been gathered regarding at-risk populations. Yet the government record on implementing proven prevention and education methods is a dismal failure. There are no guarantees that counting HIV cases will concomitantly occur with an increase in funding or the political will to enact these life-saving programs. Counting cases only guarantees the reallocation of the same funding pie. In fact, with the risk of deterrence, it is quite likely that heavily affected areas will get even less funding.

Identified HIV case reporting will lead to other, more insidious AIDS policies.

Many proponents of names reporting also want to implement mandatory partner notification. Several bills in Albany would criminalize HIV transmission. The Coburn Bill in the US Congress would create a national HIV registry unparalleled among other diseases. Collecting names of people with HIV will only make it easier to implement these policies. Centers for Disease Control and Prevention is behind this latest push for names reporting. Should identified HIV case reporting be implemented in New York, many people will avoid testing, some will see their behavior criminalized, and still others will face deportation. AIDS service organizations will be pitted against each other for shrinking budgets as Congress falsely perceives a declining epidemic. People with HIV/AIDS will be forced to chose between their privacy and not knowing their sero-status. It is time for government bureaucracies to stop creating diversions and divisions and implement proven strategies to stop the AIDS crisis.

In consideration of all of the above, ACT UP/NY believes that the

implementation of identified HIV case reporting systems in New York is backward, sinister, and will hinder efforts to combat the AIDS epidemic effectively. INSTEAD, WE DEMAND:

1. NO IDENTIFIED HIV CASE REPORTING OF ANY KIND. The need for more data on the epidemic is a real one. However, discrimination on the basis of HIV is likewise a very real possibility. Names reporting and UIs will deter people from getting tested for HIV. In this instance, the needs of scientists, public health officials and people with HIV are not at odds: the interests of everyone involved are best served by opposing identified HIV case reporting.

2. NO CRIMINALIZATION OF HIV. NO MANDATORY PARTNER NOTIFICATION. AIDS is not a criminal act. It is a disease, and should be treated accordingly. People with HIV/AIDS have the same right to privacy and dignity that is afforded people without the virus. Any changes to the current AIDS confidentiality law must not put people with HIV in a compromising position.

3. EXPANSION OF ANONYMOUS HIV TESTING SITES. Although New Yorkers have a right to anonymous HIV testing, testing sites are few and far between, resulting in abysmal waiting periods for people who wish to get tested. Anonymous HIV testing sites must be free, accessible and immediately available for all New Yorkers. Modifications of testing questions should include questions about repeat testing and techniques of statistical

analyses should be developed to provide a correction for current sero-prevalence figures.

4. REDOUBLED EFFORTS FOR HIV PREVENTION. Safer sex information, condom availability, needle exchange programs and prevention programs for prisoners all save lives. Yet such programs remain woefully inadequate as a result of government inaction. Tracking people once they contract the virus is too late in the process. Efforts must be focused on keeping people HIV-negative.

5. ACCESS TO STATE OF THE ART TREATMENTS. FINDING A CURE FOR AIDS. The most current advances in AIDS treatments remains a considerable financial burden to most. Funding for programs like ADAP and Medicaid must be increased to ensure that people with HIV/AIDS are not turned away from potentially life-saving treatments because of economic concerns. And while these advances are important, they still do not constitute a cure for AIDS. Finding a cure must once again be a top priority in the fight against the disease.

Adopted: February 23, 1998

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Web Site:www.actupny.org

RECORD TYPE: PRESIDENTIAL (TRP NOTES MAIL)

CREATOR: Treatment-access forum (Treatment-access forum <treatment-access@hivnet.ch> [UNKNOWN])

CREATION DATE/TIME:19-NOV-1998 15:11:24.00

SUBJECT: [257] Suggestions for ACT Up Philadelphia?

TO: treatment-access (treatment-access@hivnet.ch [UNKNOWN])
READ:UNKNOWN

Todd A. Summers (CN=Todd A. Summers/OU=OPD/O=EOP [OPD])
READ:UNKNOWN

TEXT:
ACT UP Philadelphia is interested in getting involved with activist work

regarding drug pricing and drug access in developing nations.

I have not been doing work on this topic, but am interested in formulating

demands that are specific and potentially winnable. What campaigns are

activists already working on? Who are the appropriate targets? What are

the most sensible demands? How can we be most effective is this daunting

arena?

Thanks,

Asia Russell

ACT UP Philadelphia

asia@critpath.org

(215) 731-1844

Julie Davids

jdavids@critpath.org

Philadelphia PA

- A posting from treatment-access@hivnet.ch

- For anonymous postings, add the word "anon" to the subject line

- To join or leave this forum, add the word join or leave to the subject line

- Browse postings at: http://www.hivnet.ch:8000/treatment-access/tdm

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RECORD TYPE: PRESIDENTIAL (TRP NOTES MAIL)

CREATOR: Treatment-access forum (Treatment-access forum <treatment-access@hivnet.ch> [UNKNOWN])

CREATION DATE/TIME:20-NOV-1998 13:22:14.00

SUBJECT: [258] RE: Suggestions for ACT Up Philadelphia? [257]

TO: treatment-access (treatment-access@hivnet.ch [UNKNOWN])
READ:UNKNOWN

Todd A. Summers (CN=Todd A. Summers/OU=OPD/O=EOP [OPD])
READ:UNKNOWN

TEXT:
With regard to the message from ACT UP Philadelphia about getting involved with activist work regarding drug pricing and drug access in developing nations.

While the desire to take action to make anti-retrovirals available at low prices is understandable the issues are complex. In some countries where fully functioning primary care systems exist such action may be appropriate. But in many if not all African countries the problem is not having access to simple effective antibiotics including TB drugs, antifungals, antiseptics, analgesics, gloves, disposeable syringes etc as well as basic diagnostic equipment. Obviously non HIV patients also suffer as a result of these shortages but HIV patients suffer more because of their frequent illnesses.

So I would suggest that in countries without fully functioning essential drugs programs which ensure full access to all essential drugs, that should be the first priority. When this is achieved or in countries with full access, then taking action to make ARV's available at a reasonable price becomes a reasonable action to take.

But if ARV's were reduced in price by 90% and countries without full essential drugs access were encouraged to purchase them, the overall situation could get worse!

So campaigning for reduced prices may not be the way to go for many countries. For some South American and possibly Asian counties it may be useful, but I would caution against trying to have a one solution fits all response.

Richard Laing
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RECORD TYPE: PRESIDENTIAL (TRP NOTES MAIL)

CREATOR: Treatment-access forum (Treatment-access forum <treatment-access@hivnet.ch> [UNKNOWN])

CREATION DATE/TIME:20-NOV-1998 13:22:27.00

SUBJECT: [259] RE: Suggestions for ACT Up Philadelphia? [257]

TO: treatment-access (treatment-access@hivnet.ch [UNKNOWN])
READ:UNKNOWN

Todd A. Summers (CN=Todd A. Summers/OU=OPD/O=EOP [OPD])
READ:UNKNOWN

TEXT:
I support you in your efforts to become better educated on this issue. It is certainly an important one. At the current prices very few individuals with HIV are able to purchase these medications. There are, however, a number of other issues that you need to be aware of that influence the use of medications in most of the developing world.

The problem is bigger then pricing and access. Not only do the drugs need to be affordable and physically located in cities, towns, villages, but there are bigger issues that impact drug efficacy. Many regions are so remote that current medication supplies run out before they can be restocked, an issue of developing resistance. Some medications must be stored in specific ways and many areas do not have access to electricity and if they do they may not have refrigerators. Many areas do not have enough trained medical providers to be able to monitor patients' health. Who will be measuring toxicity levels? Who will monitor CD4 counts and viral loads? There are stories of people from the developing world who were able to get medications from well meaning friends in the developed world. These folks took their medications and died because of the toxic effects of the drugs. Without the proper and sufficient monitoring of

patients these medications are dangerous.

This is not a simple problem of price and access. The issues are far more complicated then you may be aware of. Keep moving forward and keep your minds open to taking on different issues then you may be historically use to. There is a need for many voices in the struggle to improve health in the developing world. Walk with an open mind and an open heart and your role will be shown to you.

Thanks for all that you have done in the past, are now doing and will do in the future.

Joshua

Email: jvolle@mailhost.tcs.tulane.edu
