

# AIDS TREATMENT NEWS

**Issue Number 367**  
**June 29, 2001**

Published twice monthly by  
John S. James  
AIDS Treatment News  
1233 Locust St., 5th floor  
Philadelphia, PA 19107  
800-TREAT-1-2  
Email: [aidsnews@aidsnews.org](mailto:aidsnews@aidsnews.org)

## Contents

**AIDS Vaccines and Activism: Interview with Jon Cohen ..... 2**

Like most people, we had assumed that with all the talk about AIDS vaccines, any obvious holes in the research and development effort to produce a vaccine were being addressed. In fact, serious problems persist, often with no one handling them. Freelance writer Bruce Mirken asked Jon Cohen, who for years reported on AIDS research for *Science* magazine and has recently published a book about the problems in AIDS vaccine development, to discuss what is happening today, what has changed since his book went to press, and what people can do now to help get effective AIDS vaccines developed and tested faster.

**United Nations AIDS Meeting: Observations..... 4**

The recent 3-day United Nations General Assembly Special Session on HIV/AIDS produced unanimous approval of a surprisingly strong document -- weakened only slightly to keep conservatives on board when they objected to wording on sex or human rights. We note some of the major areas of agreement -- and also controversies including listing vulnerable groups, and the three-hour fight over whether to seat a representative of a gay organization. We also note the denial of U.S. visas to some civil-society delegates who should have been at the session -- and what can be done about this for future meetings.

**Global AIDS Epidemic: Getting Things Done ..... 7**

The world has plenty of resources, and plenty of good will, to effectively control AIDS, tuberculosis, malaria, and other major health problems. What, then, is lacking? We believe the key is to organize social roles allowing those who want to help to do so.

**Names Reporting: Pennsylvania, California Activists Change the Momentum..... 8**

Many AIDS activists and others are uncomfortable with the government having their names on a list of people who are HIV-positive; others are concerned that such lists will cause persons to avoid being tested. Public health experts do need case reporting to get accurate information on the incidence of HIV in order to devise properly targeted control strategies. Cases can be reported by unique identifiers instead of names to reduce confidentiality concerns; however, several years ago the Federal government decided to favor names reporting, and most states have gone along. In Pennsylvania, activists recently began what first seemed a hopeless effort for a system of HIV reporting by unique identifiers instead of names. While the outcome is not yet determined, activists have changed the political momentum in favor of unique identifiers.

## AIDS Treatment News

Published twice monthly

### Subscription and Editorial Office:

AIDS Treatment News  
Philadelphia FIGHT  
1233 Locust St., 5th floor  
Philadelphia, PA 19107  
800-TREAT-1-2 toll-free U.S. and Canada  
fax: 215-985-4952  
email: [aidsnews@aidsnews.org](mailto:aidsnews@aidsnews.org)

**Editor and Publisher:** John S. James

**Associate Editors:** Kate Krauss, Tadd T. Tobias

### Statement of Purpose:

*AIDS Treatment News* reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations which work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

### Subscription Information: Call 800-TREAT-1-2

Businesses, Institutions, Professional offices: \$325/year. Includes early delivery of an extra copy by email.

Nonprofit community organizations: \$150/year. Includes early delivery of an extra copy by email.

Individuals: \$140/year, or \$80 for six months.

Special discount for persons with financial difficulties: \$54/year, or \$30 for six months. If you cannot afford a subscription, please write or call.

Outside the U.S., Canada, or Mexico, add air mail postage of \$20/year, or \$10 for six months.

Back issues, and discounts for multiple subscriptions, are available; contact our office for details.

Please send U.S. funds: personal check or bank draft, international postal money order, or travelers checks. VISA, Mastercard, and purchase orders also accepted.

To protect your privacy, we mail first class without mentioning AIDS on the envelope, and we keep our subscriber list confidential.

ISSN # 1052-4207

Copyright 2001 by John S. James. To assure accuracy, *AIDS Treatment News* requires permission for republishing articles. Readers may make up to 20 photocopies for persons with AIDS or HIV; if you want to reprint more, call or write to us. Bulk orders and bulk subscriptions are available. Our address and phone number must be included in any reprint. Brief passages may be quoted for review.

## AIDS Vaccines and Activism: Interview with Jon Cohen

by Bruce Mirken

Longtime *Science* reporter Jon Cohen has earned a reputation as one of the most perceptive observers of HIV/AIDS research. In his recent book, *Shots in the Dark: The Wayward Search for an AIDS Vaccine*, (Norton and Co., 2001) he analyzed the disorganization and lack of coordination in the AIDS vaccine research effort. He argued for creation of a "March of Dollars," an entity that would play a role similar to that of the March of Dimes in developing a polio vaccine: keeping an eye on the whole field and making sure that gaps are filled.

*AIDS Treatment News* spoke with Cohen on June 20, after he spoke at a University of California San Francisco-sponsored event marking the 20th year of the AIDS epidemic:

**AIDS TREATMENT NEWS:** In light of your suggestion for a March of Dollars, how do you look at developments since you wrote the book?

**COHEN:** There have been some big changes. Merck has revealed the details of their AIDS vaccine program, and it's a substantial program. I think it is the first time a big pharmaceutical has really revealed a serious, large program to find an AIDS vaccine, and that's all for the good. But it would be great to see some competition, still, and I don't see any really hot competition similar to the competition to develop antiretrovirals.

IAVI (the International AIDS Vaccine Initiative) has more money than ever, with Bill and Melinda Gates pledging an extra \$100 million a year ago. And I think the world's attention towards the problem in Africa is a major shift that I hinted at at the end of my book, but that has continued. I think as people concentrate on the real magnitude and scope of the epidemic and do see that more people have now died than died from the Black Plague, it increases the sense of urgency to find a vaccine.

Scientifically there haven't been any really dramatic insights into how to make a vaccine, but there have been several publications in the past year that show more and more solid protection in monkeys. That's good.

**ATN:** Obviously nobody has stepped forward to create a March of Dollars, but do you see any progress toward fulfilling the functions you envisioned for such an organization?

**COHEN:** I hear hallway whispers. My idea for a

March of Dollars really was meant to be provocative. It's not that I believe there has to be a March of Dollars. I believe more is needed, and outlined a fantasy organization that I would like to see.

I see no organization attempting to fill gaps, to analyze what could be enriched, if you will, in the basic research arena. That could help. I still think it would be good for a smart group of people to meet four times a year and to freely distribute money to laboratories that they think could stimulate progress. That's not happening anywhere.

As far as a master monkey study [Cohen described at length in his book how studies of candidate vaccines using monkeys and SIV are not standardized, making it virtually impossible to compare results from tests of different products done in different labs], I don't see real momentum for it. I have heard hallway whispers of some people trying to organize such things, but have not seen it happening -- certainly not with the agenda I laid out, which is: After [candidate vaccines] work in monkeys better than others, move them into humans with the intent of taking them to efficacy trials, unless safety problems emerge.

And THAT would be a shift in the way that everything moves forward now. Everything moves forward based on immune responses in humans. Fine, let people do things that way. In addition, let's cover the other base; let's also move forward more empirically. It worked in monkeys, that's the rationale. It's not the levels of cytotoxic T-lymphocytes in human volunteers, nor levels of neutralizing antibodies; it's not all these fancy immunologic measurements. It's simply, this vaccine worked in monkeys.

ATN: You talked about the need for activism. What issues should activists be looking out for right now?

COHEN: I think it's very analogous to the drug activism arena. Activists existed when there were no drugs on the market. And what did they do? Well, they hounded the companies: 'Where are you now? What's your progress now? What'd you do last week? What'd you do last month? What'd you do last year?' They wrote report cards on researchers. They kept track of where the money was moving between different people. They scrutinized the field and they followed the money. And they issued reports and were relentless. They shut down Wall Street, they shut down the NIH (U.S. National Institutes of Health). They did dramatic moves in San Francisco on the streets during the [6th] International [AIDS] Conference.

All that brought attention to the drug search and put the companies on notice that every move they make would be scrutinized, and they would be yelled at to move faster at every turn. And I think it helped.

None of that is happening. None of it. Yes, the AIDS Vaccine Advocacy Coalition is writing reports and they are good, but that is a small group of activists. And they are not employing street theater tactics. They're not receiving the type of attention that ACT UP once enjoyed, or that TAG [Treatment Action Group] enjoyed.

ATN: For people who are interested in vaccine development and where pressure might be applied, what should they be looking at?

COHEN: There are AIDS conferences that happen all the time. There are probably 3 or 4 big AIDS vaccine conferences a year. At one of them I was the only journalist--that was at Keystone. At one of them I don't think there were any journalists there because I didn't go, the AIDS vaccine conference in Puerto Rico that was sponsored by IAVI. It was an important conference, and I don't think there was a single journalist there. I mean, hello? If this were drugs there would have been a hundred or a thousand journalists there.

And there's a big AIDS vaccine conference coming up in September in Philadelphia, and then there's another one in France. All of these conferences have a tremendous amount of information, and they should be monitored. There should be activists there. And there often are; Bill Snow [of AVAC] goes, but there are one or two activists. It is nowhere near the level warranted. [For lists of upcoming AIDS conferences, see links at: <http://www.aidsnews.org/#conferences>]

So that's one place to start. Another is to read the literature, follow the journals, follow the papers that come out, and follow the companies that have programs and check in with them regularly the same way activists have done with drugs: Write reports, create documents for journalists to build on. I don't mean to be self-serving, but read my book. I say that because it's the only book out there on this topic.

ATN: What other sources of information would you recommend?

COHEN: You can look on the Web, too, at the NIH's Web site (<http://www.niaid.nih.gov/d aids/vaccine/default.htm>), and at IAVI's Web site (<http://www.iavi.org>). The IAVI newsletter is tremendous. It's an excellent source to keep up with what's going on.

ATN: There has been a shift away from looking for "sterilizing immunity" (complete prevention of infection) and toward looking at preventing disease. What does that mean for vaccine efficacy trials--how big they'll need to be, how long they'll need to run?

COHEN: There are two schools of thought. I think it has profound implications. One school of thought is that

it's not a big deal for efficacy trials, that enough people will become infected and will not opt to take [antiretroviral] drugs that you'll be able to get a clean answer.

Certainly, though, there's a numbers game going on. The problem is this: If people start taking drugs shortly after becoming infected, you're going to have a very hard time seeing a vaccine's impact on delaying or preventing disease because the drugs are going to confuse that. But if many people opt not to take drugs, statistically speaking you might have enough people to make an evaluation of whether the vaccine works.

Logically I would think the trials would have to become larger or they would have to go on for longer periods of time, one or the other. Any way about it, it becomes more expensive and more difficult.

And then you also have ethical issues that arise because of this that are really thorny. In poor countries that have no access to drugs right now you can get a cleaner answer. Is it ethical to stage a trial there--even if people volunteer--without offering the people who become infected treatment? Some people say you have to offer them treatment, it's the only ethical thing to do. Others counter, "Well, there's the principle of undue influence." Would it be unduly influencing someone's decision to join a trial if they knew that they would get treatment?

I think those are real issues. I don't have any pat answers for them. I think it's certainly a more complex picture today than it was before the advent of drugs.

ATN: Is there anything else that we should particularly watch out for in the next few months or years?

COHEN: I think one thing that's interesting now is how the line is blurring in the very definition of a vaccine. The simple way to describe a vaccine is "something that you take and then you never have the bug in you." Well that's clearly not the way that AIDS vaccine researchers are thinking about things now. A vaccine might do one of three things: It might prevent infection, it might prevent or delay disease and allow you to be infected, or it might be used after you become infected to bolster your immune system.

In the third category, that's an idea that's been around for years--since the very first AIDS vaccine in 1986 was tested as a therapeutic, the Zagury trial. And it's still unclear that it's ever benefited anyone. But as these acutely infected studies begin to show auto-vaccination in essence--people who go on and off drugs have their virus return [and] their immune system seems to actually benefit from a short exposure to the virus again, because when they go off drugs the next time they're more likely to contain the infection for a longer period of time. It argues very strongly for a therapeutic vaccine used in an

acute infection setting with strategic treatment interruption. That's yet another version of what an AIDS vaccine might do.

It's also possible that AIDS vaccines used in conjunction with drugs will reduce the emergence of resistance. That could be another parameter that you could look at. So I think there's some much more fluid definitions of what a vaccine is or might be today than there ever has been--by mainstream thinkers, not fringe thinkers. It's no longer fringe to think about therapeutic vaccination. It's now mainstream. It was very fringe for years.

## United Nations AIDS Meeting

### Observations by John S. James

The 189 member states of the United Nations General Assembly met June 25-27, 2001, and unanimously approved a document that can be an important tool around the world for urging governments and others to take responsibility for helping to control the global epidemic. Almost everyone agrees that the meeting was largely a success, though only time will show its results. Here are some of the key issues:

\* The central question is whether governments around the world will find the political will to be serious about AIDS, and take measures to end the epidemic and meanwhile reduce its destruction and suffering. For many reasons governments have avoided acknowledging or dealing with the disease. Yet everyone knows that the epidemic will not go away by itself but will become incomparably worse, with many parts of the world affected as severely as southern Africa, where as much as a third of the entire adult population is HIV-infected, and half of teenage boys and girls are likely to die of AIDS.

About a dozen heads of state came to the meeting, all from developing countries, almost all from Africa. No heads of state came from any rich country -- nor from any of the Eastern European or Asian countries where the epidemic is rapidly spreading. Most countries sent their health minister instead. (The U.S. sent both its health minister, Secretary of Health and Human Services Tommy Thompson, and Secretary of State Colin Powell, a leader on global AIDS.)

One African head of state who did not attend was Thabo Mbeki of South Africa -- even though he was in Washington at the time, and traveled to West Point, Pennsylvania to visit a Merck AIDS research lab on the last day of the meeting. His absence illustrates one factor keeping governments away from AIDS -- embarrass-

ment. Almost everyone sees Mbeki's handling of the epidemic in South Africa as disastrous.

But the meeting produced good news as well on government political will. All the countries accepted a strongly worded Declaration of Commitment (see below). The United Nations session brought AIDS to the attention of government officials who otherwise have not dealt with it. It clearly changed the tone of some of the discussions in the U.S. Congress (and probably as many other governments as well), at least for now.

\* Many new donations, commitments, and programs were announced at this special session on HIV/AIDS. Many of these were donations to the Global AIDS and Health Trust Fund now being developed (which will also fund programs for tuberculosis and malaria, where relatively little money can have great importance in saving lives and improving human health). Also important were other donations, such as offers to help train thousands of doctors and set up medical clinics. Many people believe that what is important is the total level of funding (including appropriate in-kind contributions), not only cash for the Fund.

\* The General Assembly unanimously adopted a strong Declaration of Commitment, including detailed timetables and goals for achieving results, such as reducing mother-to-child and other new infections. The Declaration emphasizes women's rights (women are often infected because they do not have the power to refuse sex or negotiate safe practices). It notes that "stigma, silence, discrimination, and denial, as well as lack of confidentiality" undermine prevention, treatment, and care, and must be addressed. It names prevention as the mainstay of response, and also notes that "prevention, care, support and treatment for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response and must be integrated...." It recognizes the importance of access to medication, notes the need to reduce the cost of drugs and related technologies, and outlines ways of doing so.

In discussing resources, it sets a goal of \$7 to \$10 billion per year by 2005, and urges developed countries to try to meet the target of 0.7% of their GNP for development assistance, as they have previously committed to do (only a handful have so far). (In April of this year, African countries agreed to a target of 15% of their national budgets on health-sector improvements to help address the epidemic.) The Declaration of Commitment includes a fairly weak section on debt relief.

It has a major section on research and development, "including biomedical, operations, social, cultural, and behavioral research and in traditional medicine...." Research infrastructure, research cooperation, ethics of human research, drug side effects, the female condom,

and of course vaccines and microbicides, are all explicitly addressed.

What is most remarkable about this document is that all countries in the United Nations accepted it -- after fairly minor compromises which weakened it only slightly.

The Declaration of Commitment is available at <http://www.un.org/ga/aids/>

## **Controversies at United Nations AIDS Session**

### **\* Removal of naming vulnerable groups**

Some mostly-Islamic countries, and also the U.S., did not want to name vulnerable groups, especially men who have sex with men, or sex workers and their clients. So the following language (from the May 11 draft Declaration of Commitment) was replaced:

"By 2003, develop national strategies, policies and programmes, through a participatory approach, to promote and protect the health of those most vulnerable to, and at greatest risk of HIV infection, such as: children in especially difficult circumstances, men who have sex with men, sex workers and their clients, injecting drug users and their sexual partners, persons confined in institutions and prison populations, refugees and internally displaced persons and people separated from their families due to work or conflict;"

The entire section on vulnerable groups was rewritten, and in many respects strengthened; the following paragraph (number 62 in the final document) includes the replacement for the language listing groups some countries did not want named:

"By 2003, in order to complement prevention programmes that address activities which place individuals at risk of HIV infection, such as risky and unsafe sexual behaviour and injecting drug use, have in place in all countries strategies, policies and programmes that identify and begin to address those actors that make individuals particularly vulnerable to HIV infection, including underdevelopment, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, all types of sexual exploitation of women, girls and boys, including for commercial reasons; such strategies, policies and programmes should address the gender dimension of the epidemic, specify the action that will be taken to address vulnerability and set targets for achievement;"

### **\* Removal of reference to the United Nations HIV/AIDS and Human Rights International Guidelines**

Many of the same countries wanted no mention of this document, the result of the Second International Consultation of HIV/AIDS and Human Rights, a meeting organized jointly by the Office of the United Nations High Commissioner for Human Rights and UNAIDS. The guidelines were described as follows by ICASO, the International Council of AIDS Service Organizations, in email on World AIDS Day (December 1, 2000), before the current controversy had emerged:

"There are 12 guidelines in all, each containing action-oriented measures. For example, they call upon states to: provide political and financial support to ensure that community organizations are able to carry out their activities effectively; review and reform public health laws to ensure that they are consistent with international human rights obligations; enact or strengthen anti-discrimination and other protective laws to protect vulnerable groups, people living with HIV/AIDS, and to provide for speedy and effective remedies when the laws are broken; enact laws and regulations to ensure safe, effective and affordable medications, and adequate prevention and care information."

The 58-page document is available at:  
<http://www.unaids.org/publications/documents/human/>

Apparently these conservative governments wanted to remove any reference to this document because it could support the human rights of gays and lesbians (although gays and lesbians are not mentioned in the 12 guidelines). Although far from a majority, these countries had leverage because of the great desire of most countries to have unanimous agreement of all UN member countries on the Declaration of Commitment. After long negotiating sessions lasting until 2:30 or 3:00 a.m. each night, agreement was reached to drop this reference, as well as the listing of vulnerable groups, from the document. In return the conservatives agreed to approve the document, even though they did not get other changes they wanted.

### **\* Allowing International Gay and Lesbian Human Rights Commission at Human Rights Roundtable**

The entire General Assembly spent almost three hours on the morning of the first day on whether a representative of the International Gay and Lesbian Human Rights Commission (IGLHRC, based in San Francisco and New York) could sit on a round table on human rights -- after about nine governments, apparently led by Egypt, objected because she represented a gay organization. Some of these governments did not want to be identified, and were not publicly known when we last checked. Perhaps coincidentally or perhaps not, Karyn Kaplan, the

speaker they tried to ban, is also a leader in the movement to make medications more affordable in poor countries.

As we understand the procedure, any country could veto a non-government representative from the round table; even one country would have been enough, and their veto could not be appealed. But a representative could be added to the round table by a two-thirds vote. So Ms. Kaplan was added back by a vote of 62 in favor, none opposed, and 30 abstaining -- with the countries most opposed not voting at all, in a failed attempt to deny a quorum and prevent the vote from counting.

The U.S. delegation voted in favor of her speaking, and also was helpful in the negotiations.

While it may seem unreasonable that the General Assembly spent almost three hours to allow a short speech on human rights, there was a bigger issue involved. A decision the other way could have been a message and precedent that gay organizations (and perhaps gay individuals) were not accepted as equal partners in the United Nations fight against global AIDS.

Not all of the governments that tried to block the quorum, or were less than supportive by abstaining, were necessarily against a gay representative, as there were also procedural issues involved. In addition, the General Assembly is divided into blocks of nations that usually vote together, so it is likely that some votes were cast in block solidarity, or traded for votes on other issues, or represented reluctance to offend Egypt or other countries that were upset that Ms. Kaplan was being voted back on the roundtable after they thought they had her removed.

So far no one has been able to fully explain to us what really happened here, or why. It is not clear what Egypt or the other countries that objected expected to gain, even if they had won. It seems that the attack on equal gay participation was largely used to pursue other ongoing issues at the UN -- issues sometimes difficult for an outsider at that institution to understand.

### **\* Visa denials**

Many AIDS organizers who should have been at the United Nations AIDS session were not allowed to participate. Most, apparently, were vetoed by their own governments, some of which do not like AIDS organizations. No reasons were given for these denials, so it is not known how many were barred this way.

Some were stopped by U.S. officials at U.S. embassies in several countries, who would not give them the waiver required for an HIV-positive non-citizen to enter the United States. Apparently some were also stopped by U.S. officials because they did not have enough money -- as if they were tourists instead of AIDS experts attending

a major United Nations meeting. It is our understanding that U.S. policy was to give the HIV waivers, but that by law the final decision to give visas is up to each embassy. There are many countries and therefore many U.S. embassies, and it seems that not all of them took the AIDS meeting seriously.

While it is too late for a remedy for this meeting, something can be done about the larger issue of irrational travel restrictions and gross discourtesy or worse to international visitors. These problems happen because the travelers are not citizens of the countries they are entering, so they have no political power there, and the usual checks and balances which would otherwise offer some protection do not exist. So irrational restrictions and harassment of even routine visitors can grow with little restraint.

What is needed is an international movement on behalf of travelers, and probably immigrants as well, which could function like the ACLU does in protecting political liberty in the U.S., by fighting test cases within each country. It could and should improve on the ACLU model by picking cases for their public-relations appeal as well as their legal or procedural value. It would attract citizens of any country by helping to protect them in their own travels -- and also appeal to national pride, organizing those who want to make their own society more hospitable to business travelers, workers, tourists, customers, relatives, refugees, and any other visitors who are not excluded for legitimate reasons.

## **Global AIDS Epidemic: Getting Things Done**

Comment by John S. James

We cannot wait for governments to find the political will to deal with AIDS just through their own bureaucratic processes. The initiative must come from people in all areas of life -- including government, industry, the professions, and the general public. The world has more than enough resources to deal with HIV/AIDS (and also tuberculosis, malaria, and other infectious diseases); and there are millions of people who care and can help. The big shortage is of attractive, workable opportunities for channeling this concern into effective action.

For example, we heard from one U.S. HIV physician that he wanted to donate his vacations for several years to go to Africa or wherever he was needed, to train doctors in diagnosing and treating HIV disease. But he could find no program that had set up arrangements for doing so. (Some U.S. HIV doctors and researchers already work in

Africa, but usually full time; we also need opportunities for doctors who want to maintain their current practice but could donate vacations, or work during other special occasions.)

For a different example, consider the great change in the worldwide discussion of treatment access and prices of medicines. Three years ago, almost everyone took antiretroviral prices of about \$10,000 per patient per year, even in the poorest countries, for granted -- along with the death without treatment of almost everyone with HIV in Africa and other poor regions. The change could not have happened without the work of a fairly small number of activists around the world -- in ACT UP in the U.S. and France, Treatment Action Committee in South Africa, the Health GAP Coalition in the U.S., and other organizations. How did workable opportunities for involvement in this activism come into being? We do not know.

As key issues now move toward infrastructure, there will be more need than ever for both volunteer and professional involvement. Not everyone need work abroad. For example, if HIV doctors cannot find suitable programs through which to volunteer vacation time, then activists could find out why. Perhaps some organization already has such a program but is not well known. Or maybe someone needs to bring together funders with organizations like Doctors Without Borders, which already do this kind of work. Perhaps some medical organization already sends physicians abroad but has never worked in HIV before, and might be willing to start now. Volunteers need to research such possibilities and start bringing people together.

And of course almost all countries need lots of work in generating public pressure so that governments will have the political will for serious commitment in AIDS and other infectious diseases, and will develop the large-scale programs that require governments involvement.

We greatly need the work of determined activists, volunteer or professional, with "people" skills or organizing skills, as well as those with medical or other technical training and experience. But this need does not automatically translate into workable roles that people can choose for themselves. Clearly we already have the need, the resources, and the people willing to help with AIDS and other infectious diseases. The big challenge is how to develop the human structures so that the resources get used and the work gets done.

[Note: This writer has a personal Web site, <http://www.communicationpractices.org>, to explore the development of self-education practices for improving human relationships. We believe this work can contribute to the conscious development of social roles, helping to improve institutions as well.]

# Names Reporting: Pennsylvania, California Activists Change the Momentum

by Jim Straub

This past April the Pennsylvania State Legislature proposed using a names-based reporting system to track HIV infection in Pennsylvania. Many in the HIV/AIDS community oppose such an approach, since the collection of HIV-positive individuals' names and personal information may cause fewer people to seek testing and threaten the safety and privacy of those who do. Activists in Pennsylvania, who maintain that a coded system called unique identifiers could track HIV adequately without the risks of names reporting, had spent a great deal of time in the past several years trying to persuade the state legislature to adopt a non-names based HIV reporting system. However, the Pennsylvania Department of Health finally dismissed the unique identifier system as being too expensive and unwieldy, and the state moved ahead with a public comment period that would precede the adoption of names reporting.

At the point that the public comment period began, many veteran activists and advocates felt that the battle had been lost. "A lot of us felt like we had lost and were stuck with names reporting now," said Julie Davids of the Critical Path AIDS project in Philadelphia. "We had advocated for unique identifiers for a long time, but when the Department of Health said they wanted names, me and a lot of other people felt like throwing the towel in then."

Feeling defeated, many of Pennsylvania's important AIDS advocates began moving on to other battles. However, a handful of HIV-positive people who felt deeply opposed to names reporting's potential impacts on their lives picked up the issue. Barry Busch, a member of ACT UP Philadelphia, describes his initial efforts: "A lot of bigwigs had given up, but I just kept pestering them to take a stand and make a big stink about this. I and some other people started calling ASOs (AIDS service organizations) around the state, and also informed some journalists about this."

Busch's efforts struck a chord, and before long the lost momentum around names reporting was more than regained. Several newspaper articles described the potential problems with the names reporting system the state was considering, and activists from ASOs began calling each other across the state to plan a lobby day in the capitol. Before long the trickle became a flood, with first Philadelphia's City Council, and then Mayor,

coming out against names reporting and even suggesting that Philadelphia might refuse to comply with a names-based reporting system.

"That really got them talking in the capitol," said Busch of City Council's threat to refuse to comply with names reporting. "A similar thing happened in California, when that state was considering names reporting. Basically, San Francisco's department of health said it wasn't giving up any names to the state, no matter what. Thanks to their stubbornness, California now has a safe, efficient system of HIV reporting that doesn't report names. And I think Pennsylvania might be joining them soon." Indeed, many of the state legislators who initially favored names reporting have changed their stances since the recent furor over the issue.

While AIDS activists who oppose names reporting concede the battle is hardly over, it is certain that the momentum around the issue has changed dramatically. On the brink of defeat, some of the most powerful voices of AIDS advocacy in Pennsylvania had fallen silent. It took, instead, a handful of people who felt deeply about the issue's impact on their lives calling to ASOs statewide to spark a sudden grassroots resurgence of debate about names reporting. With several other states also now considering enacting names-based HIV reporting systems, perhaps Pennsylvania's lesson can be useful elsewhere.

[Jim Straub is a member of ACT UP Philadelphia.]