

# **KQED MORNING FORUM: HIV/AIDS REPORTING**

*KQED Public Radio, San Francisco, CA*

Wednesday, July 27, 2005

**Michael Krasny (MK):** From KQED Public Radio in San Francisco, I am Michael Krasny. Coming up next on this morning's opening hour of Forum: reporting on HIV infection. We will discuss the debate about whether or not to keep names coded or to report patients' names. As much as \$50 million in federal aid to California for prevention and treatment of HIV could be at stake. Forum is next with your calls and e-mails after this.

*-Intermission-*

**MK:** From KQED Public Radio in San Francisco, I am Michael Krasny. Good morning and welcome to this morning's Forum. The Ryan White CARE Act Reauthorization in 2000 calls for AIDS data to be standardized by the year 2005, or at the latest 2007. In 2002, California began using codes instead of names to protect privacy. But even some former supporters say the use of codes is too cumbersome and bureaucratic. It was supposed to be the way to keep tabs on the spread of HIV without any compromising of civil rights or patient privacy. The system, however, seems riddled with serious problems, and the US Centers for Disease Control and Prevention does not consider codes accurate enough. Federal officials have warned of withholding the funding—which in California could mean the loss in as much as \$50 million in federal funds for treatment and prevention of AIDS.

This morning's opening hour of Forum: we want to focus on reporting attention on HIV infection. We are going to have a whole panel here. But, first, we want to talk to State Senator Carole Migden—who is, of course, California's Third Senate District senator, which includes parts of San Francisco, Marin and Sonoma Counties. Good morning, Carole.

**Carole Migden (CM):** Good morning, Michael. How are you?

**MK:** I am okay. Glad to have you here. I would like to begin by just getting your response to this: the response that we keep hearing about this is a bureaucratic nightmare . . . that the code system is a bureaucratic nightmare. Is it time to switch to names?

**CM:** Well, it is certainly time to very strongly consider those steps and to find ways that we can still ensure patient protection. But, what a lot of people haven't been aware of, California using these identifiers—along with five other states—for many years have not been counted in the national stats, since the CDC will only count the names of reported HIV and AIDS cases. So, in many respects, we get a very skewed national picture, and that has been a great loss.

**MK:** Because . . . ?

**CM:** Because it incorrectly projects cases or cases of infection, it appears as if the cases of gay male conversion to seropositivity is declining, when in fact it is not. California's cases are more gay-related, although there is a surge among African Americans that are HIV—which are IV drug users.

**MK:** There was a Senate Bill that your colleague, Senator Nell Soto, put forward—(SB) 945—that essentially would have required healthcare providers and labs to report cases of HIV to local health officers that would use patients' names. What happened to that bill?

**CM:** The bill was killed. In 1999, I offered a bill which said we would install this unique identifier system. And Michael, many states of the union did so as well. And, then it was a credible alternative to name reporting. Moreover, we also want to make sure that gay men or other at-risk populations get tested, so there was other . . . a rationale, a strong rationale to use numbers instead of names. Over time, it has turned out to be expensive . . . difficult to track . . . You and your listeners should know partner notification always happened, 100% (of the time). It was just the names of the people with HIV (that) were concealed.

**MK:** So, if there isn't another system used—then the present one: are we looking at the loss of \$50 million or is Congress . . . ?

**CM:** I think we will act before that, and there has been movement (around) different parts of the state, and this is increasingly been a national demand. I don't think California stands prepared to lose \$50 million. Some of us have just wanted to convert slowly as, again, Maryland, Illinois, Massachusetts, Rhode Island, Vermont, Hawaii. These states also use unique identifiers, so I don't want to stand out as a special problem child nationally. When we first began tracking, we were also concerned about testing people, to not have them lose jobs, to not have them face discrimination, to always notify partners, but also to encourage testing. It seems that worked well enough, and at this point it looks like we will face national consequences. And, moreover, we admit that the unique identifier system is more unwieldy and more difficult to enforce.

**MK:** Is it true that every other reportable disease, including full-blown AIDS, is tracked by name in the confidential database?

**CM:** The only . . . everything else is counted by name. But, all partners are identified with any sexually transmitted disease. The only disease is cases of AIDS, frankly, and those are the names that are converted to unique identifiers.

**MK:** We are talking to State Senator Carole Migden, from California's Third Senate District, which includes parts of San Francisco, Marin and Sonoma Counties. So at this point, Carole, you would say that the State will come up with something, and it will come up with something that can perhaps ensure privacy and confidentiality?

**CM:** I (*inaudible, phone breaking up*), and frankly, Michael, (*inaudible, phone breaking up*).

**MK:** Carole, you are breaking up. We are not hearing you clearly as we would like to. I am getting a sense from you that—I think it is your cell phone—but I am getting a sense from you that we are going to move forward on this, and we are going to actually move forward and talk with some others...

**CM:** That is right . . .

**MK:** We got you, okay?

**CM:** We want to ensure patient protection. Hello?

**MK:** I can hear you now. Go ahead.

**CM:** We want to ensure patient protection, (and) at the very same time, comply with (the) national—increasingly changing national—demands on the money. Moreover, over time we have found that the unique identifier system was a good safeguard, and there were not the abuses of patient identity issues that we anticipated.

**MK:** So you sound fairly confident that is the way we will move?

**CM:** Yes.

**MK:** Senator, than you so much for joining us.

**CM:** Thank you, Michael.

**MK:** That is Carole Migden, State Senator. And, we are going to talk with some other folks who we have rounded up for a discussion on this subject—an important subject—not only because \$50 million is at stake, because also there are all kinds of issues about confidentiality and the like. I ought to mention, in fact, that, at present, an estimated one-quarter to one-third of those who are infected with the HIV virus don't know it. The difference is probably not entirely a result of reporting flaws.

Also joining us is Michael Montgomery. He is Chief of the California State Office of AIDS, Department of Health Services, in Sacramento. He joins us from the State Capitol this morning. Good morning.

**Michael Montgomery (MM):** Good morning. Thank you for having me on your program.

**MK:** Glad to have you here. Also, glad to have Michael Weinstein—who is President of the AIDS Healthcare Foundation in Los Angeles—joining us this morning as well. Good morning to you.

**Michael Weinstein (MW):** Thank you.

**MK:** Thank you for being here. With us in the studio is Fred Dillon—who is Deputy Director of Public Policy and Communications for the San Francisco AIDS Foundation. Fred Dillon, welcome.

**Fred Dillon (FD):** Good morning. Thanks for having me.

**MK:** As far as the AIDS Foundation is concerned, Fred, you don't need names to improve this data, I guess?

**FD:** We have a long standing position of supporting a unique identifier policy for the State of California, and that has been for several main reasons. One, is we felt a unique identifier system could give us the data we need, give us the information we need on the case counts in California, and give us a sense of what is happening with the epidemic without requiring people to put their names forward. The reasons we have had concerns about that is that we have been afraid that some people, many people say if they knew their name was going to be reported to the government, they wouldn't come forward for testing. Our absolute . . . one of the things we are most focused on is making sure people get into the system and get tested and get into treatment, so we don't want to erect any barriers that might stand in the way of people getting tested. So that has been a big concern of ours.

At this point, though, with what the federal government is essentially requiring—in terms of the funding following HIV cases reported only by name—California is really backed into a corner, and is really going to have no choice, but to make a switch to a name-based system.

**MK:** You are resigned to that almost?

**FD:** At this point, it looks like that is inevitable. I think California is going to have to look really carefully at how we structure that law, and how it looks to make sure it is absolutely safeguarded in terms of confidentiality, and that we do everything we can to promote testing and make sure people still feel comfortable getting tested and seeking care.

**MK:** What are you thinking of in terms of safeguards to ensure what you are talking about?

**FD:** A host of things: like what sort of parameters should be built around how the data is used—making sure the data is the data only used for epidemiological purposes as one possibility. What sort of penalties should be imposed, if there were ever a confidentiality breach. I think we need to look at that, and just make sure that there is as high (a standard) as possible. So, those are sort of the questions that we want to look at, and really analyze in putting forward a bill that makes this work. Another piece is to make sure anonymous testing remains in place. Even in states that have name reporting, there is still anonymous testing, so people can—if they are not comfortable with their name being reported—can go get tested without ever putting a name forward, and we want to make sure that remains in place as well.

**MK:** But you would have preferred for the present system to be maintained?

**FD:** We would have. We feel it would give us the data we need without the risk of possibly driving people away, without the risk of possible breaches in their confidentiality, and without the risk—once these lists are created, once name reporting is in place—it is always possible, something else could happen politically with those names, the legislature could do something with them. So that has been a concern of ours.

**MK: There in Florida, where about 6,500 names of AIDS and HIV-infected were inadvertently sent out to about 800 healthcare workers, but Michael Montgomery—if I go to you—we haven't had a breach in security on this in California since 1987, and you feel pretty strongly that this system is a system that is not working.**

**MW: Yeah, on several levels. We have had over 138,000 AIDS cases reported in this office without any breach of security, as well as almost 38,000 HIV cases reported by code. But, what we are finding is, I want to respond to a couple of things that Fred said. One, is that I know that there is widespread concern about discouraging people from being tested, but all of the research in the United States, including research in those states that have converted from a code-based reporting system to a name-based system, supports that there has been no reduction in testing on the part of the populations we want to get in for testing. Even the study that the University of California in San Francisco recently completed, that showed a strong preference for code-based reporting, shows that the people really were unaware of what sort of reporting system was in place. So we really don't see this as a factor in discouraging people from being tested. But we have many layers of security in place, and our computer system within our Office of AIDS is not on a network, it is separate from any outside network. Information off of that database could not be e-mailed out of the office. We have many layers of security and . . .**

**MK: We will send it to some of the credit card people, of course.**

**MM: Well, (the problem with) the credit card people seems to be that the problem there has been people have been hacking into their system, and that is not possible on a network that is not hooked up to the Internet.**

**MK: Michael Montgomery is Chief of California State Office of AIDS, Department of Health Services, with us from Sacramento. What about the necessity to change the statutory language? Right now, it is a criminal offense to divulge names of those who have AIDS, but not HIV.**

**MM: Correct. Well, I am sorry: it is a criminal offense to divulge either a person's name who has, with AIDS or with HIV, but the protection with AIDS doesn't extend to public health offices reporting in the State of California. What we need is legislation that would allow public health officers to report to the State Office of AIDS for the purpose of epidemiology, not for the purpose of any further reporting.**

**MK: Anyone carrying that legislation that you know of, Michael?**

**MM: No, the one bill that was in the Senate—as you mentioned with Senator Migden—was held in the Judiciary Committee.**

**MK: California was kind of late in reporting HIV cases, I mean 2002 . . .**

**MM:** Well, it has been a very politically controversial issue, and I think the comments that both Senator Migden and Fred were making are reflecting the concerns that are in the State of California. We are dealing with populations that are highly stigmatized. So I don't criticize people for wanting to assure the safety of those people or the privacy of the people involved, but we believe that we have protections in place that we can assure the confidentiality.

**MK:** **Michael Montgomery, again, is Chief of the California State Office of AIDS, Department of Health Services. Michael Weinstein is President of the AIDS Healthcare Foundation in Los Angeles. Those who support the code, Michael Weinstein, are arguing that the possibility of a leak would again keep people from being tested for HIV. We have heard Michael Montgomery say that he feels pretty confident that that is not likely to be a concern. What do you feel?**

**MW:** Well, in all the other states that have name-based reporting, which is most states in the union, there has been no decline in people going for voluntary testing, and this is not a concern that is shared by most people. I think that they are really harkening back to a different time when AIDS was not treatable and when the stigma was much greater. I think it is time to take a public health approach to treating AIDS as we do with other communicable diseases. It is interesting to hear Senator Migden and Fred Dillon (agree to) this when it was only a few weeks ago that they participated in killing a piece of legislation by Senator Soto that would have done this.

Michael Montgomery has pointed out that we have no time to lose, because it is going to take a considerable amount of time to implement this new system and the federal deadline is looming very closely. I am standing right now in the lobby of the Health and Human Services Building, where there is going to be an unveiling of the principles that the administration is going to support for the re-authorization of Ryan White and one of them says that there will be no extension of the deadline of 2007 for implementing funding based upon names reporting and 2007 is not very far away. That is only a year from this October. So, if we move immediately on an urgent basis, we will still have difficulty implementing this in time.

**MK:** **What about those who are saying that Congress is going to have to decide and maybe it won't be the case that this money is going to be withdrawn?**

**MW:** Well, as I said, I am standing in the lobby of the Health and Human Services Building in Washington right now being briefed by the Secretary of Health and Human Services, Mr. Levitt. He is saying the White House is adamant about this. I think that we have already heard from Senator Coburn, who is a leader on this issue in Congress, and I don't think we can play a game of "chicken". I think that there is too much at risk here. We have the lives of tens of thousands of people with HIV who need services that would be risked. And, the downside risks that are, or fears that are, being inflamed do not equal the damage that can be done by the loss of these funds. Plus, I think the public health community believes that this is the right thing to do and that it is overdue and that we need—you can't track a disease, you can't fight a disease without tracking it properly. We are not tracking it properly now.

**MK:** Let me also get a sense from you about the problems with the codes. I mean certainly those who are arguing against them—who want name-based reporting—say that they make it difficult or impossible in some places for county health officials to exchange information with doctors or eliminate duplicative reports—who, for that matter, link HIV with reports of other diseases. In other words, there is a lot of interference on that score, and essentially you would agree with those kinds of criticisms?

**MW:** We have 10,000 uninvestigated cases in Los Angeles. Those include cases of AIDS where we are already being penalized, because those cases are not being counted. Yes, I mean when you take fragments of information and make it into a code and then you have to go into a doctor's office and try to decipher whether those numbers pertain to this particular patient—it takes hours, if not days to do that on a single case. Whereas, if you are comparing names to names, then it is not as difficult and you cannot register a name until you are sure that it is not a duplication.

**MK:** Michael Weinstein, again, is the President of the AIDS Healthcare Foundation in Los Angeles. Fred Dillon is here with us in the studio—who is Deputy Director of Public Policy and Communications for the San Francisco AIDS Foundation. Fred, would you concede that the present system does hamper follow-up and present the kinds of problems we are hearing? Also, we should add, I suppose, nullifies the option of tracking sexual partners.

**FD:** As Senator Migden said, we do partner notification now without a name-based reporting, and that is able to be done now. People are encouraged when they get tested—when they test positive—to talk to their partners or to contact the Health Department to get help with contacting their partners. So, that is already standard practice. Most of the public health officials I talk to (agree that) if we had name reporting, it is unlikely they are going to have the resource to contact every single person and follow-up with them on partner notification. That doesn't happen with even most other STDs. So there just (aren't) the resources to even make that happen. So, partner notification that is happening, there is standard practice of it right now.

**MK:** What was the problem, from your perspective, with the bill that we mentioned that was authored by Senator Nell Soto—Senate Bill 945—that would have called for names to be used? I mean it died in Committee and that was back in May, why? Why were you opposed to it?

**FD:** Again, that was over two months ago. What we were hoping for, is we were really waiting to see what the federal government came out with. We have been really pushing for the CDC—the Centers for Disease Control and Prevention—to incorporate our data, California's HIV data, into the national dataset, so that we wouldn't be faced with these problems of our data not being included and us losing federal funding. We have been hoping all along that ultimately they would have to do that. Increasingly, it has become clear—and the CDC just put out a letter in the last month—basically recommending that all states move to name reporting and essentially making it clear they are never going to put data from code-based states into the system. So, we were waiting to see what the federal government did.

The other thing that should be noted is we have been waiting for the Ryan White CARE Reauthorization legislation to move forward. We expected a bill in Congress much sooner in the process than this. We thought it was going to come out in March/April and give us a signal of what the federal government was going to require. And, it hasn't been put forward, so that is what we have been sort of waiting for.

**MK:** Let me go back to Michael Montgomery, who is Chief of California State Office of AIDS, Department of Health Services in Sacramento. Michael, what would this \$50 million loss mean? I mean, can you kind of give us a picture of worst case scenarios of what it would mean?

**MM:** Well, yeah. California—under the current formulas that allocate Ryan White CARE Act funds—which fund the drugs for people living with HIV, as well as medical treatment, is based upon a formula that already discriminates against California. It uses estimated living AIDS cases, and it underestimates California's living AIDS cases by as much as 30%. So this to me, in my mind, this would really compound that, and every year the California legislature and the Governor have moved aggressively to support our AIDS Drug Assistance Program to make sure that we had enough funding, not to turn people away. A loss of \$50 million would be enough to prevent us from being able to serve the people who come onboard annually, and would limit the number of drugs we could have on the formulary. \$50 million is a lot of money, and it would severely hamper our ability to not only provide drugs, but (to) assure people have access to medical treatment.

**MK:** Michael Weinstein, do you want to comment on this, too?

**MW:** Yes, I want to emphasize that we are already experiencing a loss of funds, because of the reporting system. That (became clear) when we started putting names into the system from labs. When we adopted the unique identifier system, we found a lot more AIDS cases than we knew about. But, we can't have all those cases identified, because we have to investigate them, and we have a backlog in LA County of almost 10,000. So, we already are losing millions of dollars.

As I said, I am at the briefing on Ryan White and there is a definitive word now that they will not extend the deadline. So, I would urge Senator Migden to support us in immediately re-introducing this bill, and having it active during this current session as an urgency measure—so it can go into effect immediately and we can begin the planning process to actually implement name recording as quickly as possible.

**MK:** Would you support the bill now, Fred Dillon, as it was written and as it died in the committee back in May?

**FD:** Again, I think what we are going to be doing as a community in San Francisco, with our local Department of Public Health and other stakeholders that are concerned about this, is really looking at this legislation, and looking at if there is going to be a names reporting bill in California, what safeguards would we want to make sure are a part of that. And, looking at the bill that was introduced, as well as others, and trying to figure out other model laws that may be in place

in other states and coming up with the best provisions possible for California. And, we are going to work on that in a very timely fashion. I mean, that is our goal.

I do want to say about this \$50 million, in terms of what the real loss would be—I think there have been a number of estimates of what that could be, and the one thing that should be pointed out is there is what is called the “hold harmless” clause in the Ryan White CARE Act that protects the State from losing more than “X” percent per year. So, at this point it is about 1½% to 2%, the State couldn’t lose more than that. So, I think the \$50 million is at the very highest end of what could possibly be lost.

**MK:** I am sorry—Michael Weinstein, I think I heard your voice there, didn’t I? No, I guess I didn’t, okay. Well, we are coming up on a break and we are going to have to say goodbye to Michael Weinstein. We are going to get somebody else from the AIDS Healthcare Foundation. He has to leave us, but we will continue our discussion with Michael Montgomery and Fred Dillon and you, in fact, you are cordially invited to participate. What do you think? Using names instead of codes? The present system here in California unique identifier system? Let’s hear what you have to say. In fact, let me invite you to join us now at 866-733-6786. That is toll-free from wherever you are listening to us or however—radio, Internet, Sirius Satellite. 866-733-6786 is the number for your calls or you can join us by e-mail, our e-mail address is [Forum@KQED.org](mailto:Forum@KQED.org). I am Michael Krasny.

*-Intermission-*

**MK:** You are listening to Forum. I am Michael Krasny. We are talking about whether California should use names instead of the present system of using codes to identify HIV-infected patients. Michael Montgomery is with us, who is Chief of the California State Office of AIDS, Department of Health Services. He is with us from the State Capitol. Fred Dillon is with us in the studio. He is Deputy Director of Public Policy and Communications for the San Francisco AIDS Foundation. And, we are going to go right to your phone calls here. Let’s begin with Ray. Hi, Ray.

**Caller #1:** Good morning. You know, there are a couple of things that hit you right away about this—and maybe I missed something—but to me it seems like if I go to the clinic and I fill in my status and get a test and I come up with a positive, how are you going to verify who I am? One thing that occurs to me immediately is, of course, everyone is concerned about the identity. Identity theft is a big issue and privacy is a big issue, but this cuts from the other side too, how do we verify the names? And, what happens to people who are incarcerated who come up with a positive?

**MK:** Some good questions there. Fred Dillon, I am going to go first to you.

**FD:** Sure, I mean I think that has been a problem in states—even with name reporting—that there are a number of people that turn in names of “Nancy Reagan” or “Mickey Mouse”, or a variety of things, so ultimately those people aren’t ultimately counted in the system, because it is realized they are not verifiable. Michael Montgomery, our other epidemiologist, may have a better sense of that.

**MK:** **Yeah, let me hear from Michael Montgomery. And, also Michael Montgomery, what comes to my mind is case history. I read about a false positive—talk about loss of identity that just remained a false positive in the records and was never rectified.**

**MM:** Well, on the point of using false names: I think that is always a problem with surveillance, and that is why we have disease investigators who try to make sure that the reports are accurate. But, certainly there is not a lot we can do when somebody gives a false name at the point of testing. However, most people eventually end up in treatment, and they depend upon public programs to pay for their treatment, and, in that way, eventually a correct name is going to show up.

**MK:** **That does sound like coercion.**

**MM:** Pardon?

**MK:** **That does start to sound like coercion, and what happens to people who don’t know their status, who are incarcerated? Those people are definitely going to be discouraged from wanting to participate in any program.**

**MM:** Yeah, well, testing is voluntary. It has always been voluntary, no question about it. The correctional facilities do cooperate with the confidential reporting systems.

**MK:** **Ray, I thank you for the call. I am going to get as many of you on here as I can. Let’s go next to Brian. Hi, Brian.**

**Caller #2:** Hi. Thanks for taking my call.

**MK:** Sure.

**Caller #2:** A quick question, and then a comment. The question is when you are talking about security leaks with a name-based system: I am guessing you are referring just to the insurance companies or employers, or are there other potential dangers for people with HIV or AIDS with the security leak like that?

**MK:** **Michael Montgomery—what are the dangers for security leaks?**

**MM:** Well, I think that historically people with the heavy stigma attached to HIV and AIDS, and some of the causes are fears of discrimination in employment and insurance and in housing and those sorts of things. But, we have many laws in place now to protect people from those forms of discrimination.

**Caller #2:** Yeah, and my comment was just as an American living with a chronic illness. I am a Type 1 Diabetic, have been for quite a long time. I just think it is too bad that in our society we can't/we aren't at a place yet where names attached to a disease doesn't change who a person is, doesn't change their rights and their ability to function in society. I really think a name-based system is the way we should go. I think we should turn our society to a point where we don't have to discriminate just because of diseases. Thanks for taking my call.

**MK:** All right, Brian. We thank you for your comments, and we thank you for your call, and on we go. Kim, good morning. You are on Forum.

**Caller #3:** Morning, Michael. Michael (Weinstein) is off the air now, but I want to thank Michael and Fred. I am with the Santa Clara HIV Planning Commission, and we had a debate on this very issue two weeks ago, and we decided to go along with names reporting. Most of California—except for San Francisco—have agreed to go along with names reporting.

CDC has been insisting on data being reported in a certain format. The State Office of AIDS in California is refusing to send the data in that format. They don't even open the envelope, which California sends, so our data is not being combined at CDC, and we are at risk of not being funded. But, San Francisco and the legislature in Sacramento continue to be obstinate and strong-headed on this issue—when the writing is on the wall. All of California has gone along with this except for San Francisco. So, we just need to stop being obstinate.

**MK:** What about that, Fred Dillon?

**FD:** Well, I would say a number of things. One, there are a variety of folks that have opposed this bill, not just San Francisco. The ACLU, for example, opposes this bill—as have people living with AIDS groups throughout the state, including Being Alive, which is based down in Southern California. So, there has been a range of folks that have had concerns about this. And, State Senator Sheila Kuehl was one of the main opponents of the bill when it was before the Committee, and she is based down in Los Angeles.

So, I think there are concerns throughout the State about these privacy concerns and the concerns about potentially deterring people from testing. Again, California is now between a rock and a hard place. It is really clear the federal government is not going to give California any other option, but to make us switch to name reporting. And so I think . . .

**MK:** Which kind of affects the obstinacy, doesn't it?

**FD:** Absolutely. But, I do think most of us believe a code-based system is best for the constituents of California, and wish the federal government would let us have that choice.

**MK:** Let me thank the caller, Kim. And, by the way, if you would like to join us, our toll free number is open to you. It is 866-733-6786. That is the number for your calls: 866-733-6786 or join us by e-mail— [Forum@KQED.org](mailto:Forum@KQED.org). Chris, good morning. Welcome to Forum.

**Caller #4:** Hi, Michael. You are putting on a great a show.

**MK:** Thank you for that.

**Caller #4:** My question is: how is it possible for legislators and healthcare workers to bridge the gap on an issue like AIDS or HIV? It seems the main complaint—or the main objection—to a name system would be to—whether it is a security leak or whether anyone else—to know that you as an individual by name have AIDS. It seems like it is less of an issue with cancer or other long-term, you know, terminal illnesses perhaps, but what can be done? It seems to me that using a name system, like I said, speeds it up—it makes things a little more streamlined. How can we address, I mean, we have been living with the disease in our society for long enough now—barring any kind of discrimination like the gentleman was saying—how can we help people feel like they are participating in addressing and controlling the disease, rather than just being singled or put on a list that someone is going to refer to to keep you from joining a gym?

**MK:** Do you have some thoughts for Chris, Michael Montgomery?

**MM:** Well, I think Chris is pointing to a real issue—(in) particular that affects us when we are trying to address prevention of transmission of HIV—that there is a huge stigma attached to the illness and the behaviors that are associated with transmitting the virus. So it makes it very difficult for communities to discuss this openly. And, it is not only the gay community, it is communities (that) are really struggling on how to deal with it. So, I absolutely agree that stigma is a huge issue. Certainly in our prevention efforts, we are trying to find ways to counteract stigma.

**MK:** But, you had said before, Michael, that—certainly with protease inhibitors and with the education that has been going on since AIDS became the plague it was and, to a great extent, still is—that things have changed on the stigma front.

**MM:** I think that certain communities have addressed stigma and other communities are struggling to address stigma. We know that around the United State—and California is not excluded from this—that the African American community is significantly over-represented statistically among people who are HIV-infected, and that community is really struggling with finding ways to address it directly and finding the kind of language that is needed to talk about a heavily stigmatized disease. So, no, I don't think stigma is gone, I think we have made progress, but we certainly have a long way to go.

**FD:** Most of the studies . . .

**MK:** (This is) Fred Dillon (speaking).

**FD:** . . . on this topic have confirmed that. I mean there is still, unfortunately, discrimination and stigma. There still are people, for example, who don't want to drink out of a cup or drink out of a water fountain that a person with HIV has used, or use even a toilet that a person with HIV has used. There are still these misconceptions about how HIV is spread—even after all these years. So, I think we have to continue to educate the public about this to minimize those sort(s) of practices.

**MK:** Let me thank Chris for the call, and go to more of your calls. Angie is joining us from where? You are in Kansas, Angie? Where in Kansas are you?

**Caller #5:** Right now I am in Garden City, Kansas.

**MK:** You are listening to us on Sirius I take it?

**Caller #5:** Yes, I am.

**MK:** Glad to have you onboard.

**Caller #5:** My question is, you know, I understand the stigmatism (*sic*), and I don't mean to the way I am feeling. But, if you write a bad check, your name is on a list, so the banks are protected and merchants are protected. If you are a sexual predator, you are on a list and the public is protected. There is a small percentage of people that have AIDS—and I have deep sympathy for them and I know there are various ways they get it—but what about the protection of the general public—the majority of the people? Them being quiet, there are a lot of people that can't deal with it or they don't tell their partners. What about our rights?

**MK:** Michael Montgomery, the public's rights here or other people's rights?

**MM:** Well, I think we need to separate issues. One is this HIV surveillance system is not meant to identify people for the purposes of identifying them in the public. And, in fact, we want to maintain confidentiality.

**Caller #5:** Well, of course, you do. But the thing is, what about me? If a guy lies to me, I have sex with him, he says he is clean and everything, where are my rights protected here, you know? He knows he has got it, he is going, "Well, I am not telling anybody, there will be a stigmatism," and he doesn't open up to anyone, and he spreads it and hurts other people. What about our rights?

**MM:** I think that—the way I view it in my own life is—that I am responsible for myself and if I am not aware of the status of my partner, then I have to take responsibility for protecting myself. I think that what we are trying to do is teach people about how this disease is transmitted, and to take the protections you need to take to protect yourself.

**MK:** Thanks, Angie, for the call. Fred Dillon, you wanted to add?

**FD:** Our big concern, too, is that if those sort of policies were put in place where people could quickly identify if their sexual partner is HIV-positive or not, then people would be just driven underground and people at risk for HIV just would not get tested at all. Many people would just choose—if there was even a chance that their name could be put out there on a list that other people could view—then we would completely drive this epidemic underground, and people would not even want to know their own status—which is absolutely the opposite of what we want to try to do. So, from a public health perspective, getting people tested—making them feel comfortable with that, making sure they know their status—we believe is the best way to protect the public, because then people know their status and, hopefully, are not infecting others.

**MK:** **Whitney Onjerion (*sic*) is co-chair of the Public Policy (Committee) for Los Angeles County Commission on HIV, and joins us. We welcome you, good morning.**

**Whitney Engeran (WE):** Thank you, good morning. Engeran (correcting pronunciation).

**MK:** **Engeran, excuse me. Let me bring you into this discussion: have you decided at the LA County Commission on HIV to pretty much go ahead with name-based reporting at this point? I mean it seems likely that that is going to be the way we are going to have to go in California.**

**WE:** Yes, we did. And when we took our vote, we convinced the LA County Board of Supervisors also that that is what we should do, and they are co-sponsors of the legislation that is in Sacramento now—SB 945—to change the system to a name-based system for HIV.

**MK:** **So you like the bill that Senator Nell Soto put forward, in other words?**

**WE:** Yes, correct.

**MK:** **What about the concerns that we have been hearing here about the people who have HIV may be unwilling to go forward if their names are going to be included—that it is going to be more of a frightening tactic with people like that, prohibiting them perhaps from reporting?**

**WE:** Yeah, I think that is a very important point—the idea about, in particular—the point about testing and people being afraid to get tested, they fear that their name is going to be reported. I think that is a very compelling point. I think we also have a lot of evidence and studies that say that that is just not really going to happen. And, hopefully, working with folks in San Francisco and in San Diego and all over the state, we talk to folks and work with our community-based organizations and really do some education around that—so that people know that that is not what this system was designed for, and they don't need to be afraid.

**MK:** **Again, if you would like to join us, you can do so toll-free at 866-733-6786, or by e-mail, [Forum@KQED.org](mailto:Forum@KQED.org). We welcome your calls here. Fred Dillon, you said earlier that you are resigned probably to this going forward. Do you still have concerns about Senate Bill 945?**

**FD:** Again, we do have these concerns about the deterrence of testing. And, there have been several folks that have mentioned studies that show in states with name reporting, there hasn't been a big decline in testing . . . and that is probably true, in general. But again, we talked to our stakeholders, we talked to our clients, we talked to people in San Francisco, and just, generally, in the community, people who are at risk and asked them: "Would you get tested if you knew your name was going to be reported?" And, a large number say "no", so that worries us. So, what can we do to do everything possible to promote testing, and make this as safe a system as possible, so people feel comfortable moving forward? I think that is what we need to explore, and really make sure whatever bill we move forward in California does the best job of making people feel safe—feel their data is safe.

**MK:** Michael Montgomery, I would like to hear what you have to say on that.

**MM:** I just want to note that we still have alternative sites—alternative test sites—which provide anonymous testing throughout the State of California, and that option is not going to be eliminated. It is in statute, so people will always have the choice to go get tested at an anonymous test site, and anonymous test sites do not report into the system.

**FD:** I would just say to that, too: our concern about that is people could get tested anonymously and then when they go in for treatment, they would know they would be reported at that point. And, our concern is that some people might choose not to seek treatment. And, again, we want to promote, as much as possible, we want to get people into the care system—not only find out that they are HIV-infected, but to also get them into treatment, so they can reduce their viral load and what not. So, that is very important to us as well.

**WE:** I want to mention that, right now, if someone were to get tested and were diagnosed with AIDS, that would be exactly what would happen. We have been reporting AIDS by name for over 20 years, and the system is confidential, and we haven't seen that same effect. So people will go into treatment, because they need treatment and their names—what happens to that name is we know where to put resources, that is it.

**FD:** Yeah, Whitney, I appreciate that, and that is true. What I would say to that is AIDS is in the later stage of the disease—usually when people are quite sick and go and seek treatment because of that and get reported at that point. HIV—as you know, people can be HIV-infected for up to ten years and not have any knowledge of it—so we want to do everything possible to get those people tested and get them into the system, because we know for a fact—as Michael Krasny talked about early in the program—about 25 to 30% of people don't know they are infected. So, we want to do everything we can to get people to get tested and get into the system.

**MK:** Let's bring Debbie into the program here. Hi, Debbie.

**Caller #6:** Hi. I just wanted to call to comment on the woman that had called in a few minutes ago. I found her comments to be very offensive, because she seemed to equate people with HIV and AIDS to sexual predators and people that write bad checks—which are people that are breaking

the law knowingly. I found the fact that she seemed to think she wasn't responsible for her own safety to be very naïve and offensive. So, I just wanted to make that comment.

**MK:** I thank you for the comment. She did say she was certainly sympathetic, and realized that AIDS comes about from all different reasons, but felt that there are people who would keep their own infection confidential. What were you going to say, Fred Dillon?

**FD:** Well, I was going to say in Maryland, for example—similar to what the woman who called in—he had called for—the Comptroller there—had called for putting all the people that had been reported with HIV on a list on the Internet, so people could check and see if their partners had HIV. That, to us, is one of the things that worries us most about moving to a name-based system—is making sure nothing would happen to those lists where the information could get out there to the public.

**MK:** Well, let's look at what some of our listeners have said by e-mail. This is from a listener from Leslie who writes, "Why does the government need to know the names of those receiving medication anyway? Do they think that there is fraud going on?" Reality is, Michael Montgomery, it is not so much that the government wants to know these names—I mean it is healthcare reasons.

**MM:** No, it is, in fact, the name does not get reported to the federal government. But, the federal government, CDC, wants the states to use the name-based system so that we can assure that we are not counting people more than once, and that we are not counting people in more than one state, and that we are getting an accurate picture of the population that we are serving. So, it is really a question of reliability and accuracy. It is just simply a fact that a code prevents us from carrying on certain basic surveillance activity.

**MK:** Another question from a listener named Greg. And, this is to you, Fred Dillon. He says, "I believe we require the reporting of most sexually transmitted diseases to public health authorities, so that they can follow-up with potential context for treatment. Why should HIV/AIDS be different? What makes HIV/AIDS different from syphilis? Why is the stigma worse for HIV/AIDS than syphilis?"

**FD:** Well, syphilis is a very treatable condition. That is a one-shot deal—one shot of Penicillin. It is a very different disease, so the stigma associated with that has been very different than HIV. So, we have felt that HIV needed to be treated differently than some of the other sexually transmitted diseases over time.

**MK:** Whitney Engeran, let me get you on this. I mean, were you in favor of the system before the \$50 million came into the picture, the present system, that is?

**WE:** Well, yes. The short answer is "yes" because we had data. (Then) we had epidemiologists in front of the Commission monthly talking to us about the system, and how it was broken and how many thousands of cases we were behind in counting. When we looked at how much need there was out there, and we saw that we needed to know where to put the resources, and we were

behind, and we knew we never were going to be able to catch up, we said: “This isn’t going to work.” In terms of the cases that we are behind, we are 13,000 cases behind in LA County in reporting. So, in fact, we believe we are underreporting the number of cases there are that we could possibly be getting even more resources for.

**MK:** Is there, Michael Montgomery, a distinction to be made perhaps in reporting accuracy and getting data between say metropolitan urban areas, on the one hand, and more rural areas?

**MM:** That is an interesting question. I think some of the states that are small states that have code-based reporting systems like say Delaware or Hawaii have a much smaller issue to deal with, and have less problems with duplication than the states the size of California. So, with a code—even a fairly sophisticated code like we have—we can come up with duplicate codes, because of the really large population we are dealing with. So, I think just on that level it creates problems.

**MK:** You were reassuring listeners before about the security of the system, and the fact there hasn’t been a breach since 1987 in security. The kind of nightmare story that we hear about this Florida health worker who sent out 6,500 names of those with AIDS and HIV—names that inadvertently went to 800 coworkers. You are saying something like that could not happen here?

**MM:** It could not happen, because none of the computers that have HIV and AIDS registry data on them are attached to the Internet. They can’t go out beyond a very closed system in a locked room.

**MK:** Fred Dillon, go ahead.

**FD:** Just to talk a little bit about the rural versus metropolitan area, too: I would just say there have been concerns—particularly people in very rural areas—when their name gets reported to the government, given how small some of these communities can be, that folks they know may see that in the public health department. So, there have been concerns that have been expressed in very rural areas about that, the nature of that, and what it could mean for folks. Again, that is another reason why we have felt a unique identifier was the best approach.

**MK:** And, on that same point, Whitney Engeran?

**WE:** Well, I think that there are laws that prevent it. I mean look at the case in Florida. If the person who released that information had e-mailed that had been found to have done it on purpose or maliciously, I mean, he was going to go to jail. Public health officials sign documents that say they will not do this, they can be fired, people will go to jail. So, whether you are in a rural or an urban area, if public health officials violate the trust of the public—which is, and this data is confidential—they can go to jail.

**MM:** And, can I point out too . . .

**MK:** (This is) Michael Montgomery (speaking).

**MM:** . . . that in the cases where we have code-based reporting, the reasons these backlogs in San Francisco and Los Angeles are so large is because they have to go—public health workers have to go—to doctor’s offices and clinics to verify a code or to complete a code. And, when they get there and the logs that tie a name to a code are not being maintained by that office, those public health workers have to go into medical records to determine whether the reported code is valid or whether it is a duplicate. And, so what you really have is, in essence you have, public health workers are still going in and looking at names and looking at medical records. So, I just don’t see that there is a real difference in terms of what county health departments are exposed to.

**MK:** Do you think, Michael Montgomery—it seems to be the handwriting on the wall—that we are going to be going to names in California—that that is going to cut down on the backlog considerably?

**MM:** I think the counties still have a big challenge, because they are going to have to go back and convert all the code-reported cases to name-based cases. But, I think that the county health departments that have really been concerned about the labor involved in doing the code-based system are unanimous in saying that the name-based system would be much simpler, much more quick to fulfill. We are going to have a huge challenge in front of us, because it is going to take several years to have a name-based system that is operating long enough and accurately enough that CDC is going to begin accepting our data.

**MK:** Fred Dillon, go ahead.

**FD:** My hope, therefore, is that what California can maybe unify around, to a degree, is—as the Ryan White CARE Act Reauthorization moves forward—there is this timeframe at which HIV data will start to be incorporated into the formula, and clearly it is going to take California some time to get that data in place in the way it needs to be. So, I am hoping we can push that timeframe up from 2007 to more like 2008 or 2009 before that data starts to get incorporated into these formulas.

**MK:** It seems pretty likely that this bill will pass now, then . . .

**FD:** I think some version of a name-reporting bill is . . .

**MK:** . . . with revisions of it, or is the ACLU going to continue to be in opposition? What is their opposition all about?

**FD:** I think they have basic privacy concerns about names being reported to the government on a host of issues. But, in particular, I think they also have these concerns about the deterrence of testing and what that means for the population.

**MK:** Do you see this going forward, Michael Montgomery, without much of a hitch? I certainly got the sense from you that there is no time for delay.

**MM:** Well, certainly the administration is very interested in seeing a bill moving forward as rapidly as possible. It is . . .

**MK:** **You mean the California Administration of Arnold Schwarzenegger, or the federal administration?**

**MM:** The (California) Department of Health Services is aware of the situation, and very concerned that we have the legislation that we need to be able to assure that California has received its fair share of federal funding.

**MK:** **What kind of timeline are we looking at then, do you think?**

**MM:** I am sorry, in terms of a bill or . . .?

**MK:** **A bill, yeah.**

**MM:** Well, I am not a legislator, but I would hope that it is something to be pulled out of the current session and moved forward.

**MK:** **And, those would be your hopes too, Whitney Engeran?**

**WE:** Absolutely, and we very much need to work with all of our friends in Northern California and Southern California all over to come up with a consensus.

**MK:** **At this point, San Francisco seems to be, at least according to one of our callers, the odd people out on this, Fred Dillon.**

**FD:** Well, again, as I said, there are a range of folks throughout the state that have concerns about this. So, I think people are going to have to come together and come up with what is the best bill possible, and hopefully we can get it done this year. I think the legislature comes back into session, it only has about a month of time to get something like this done.

**MK:** **How close are you going to be working with legislators?**

**FD:** We will be working very closely, especially with State Assemblymember (*sic*) Sheila Kuehl (and) State Assemblywoman Carole Migden, on these issues to try to work out what kind of bill could we move forward if we were going to have a name-reporting bill.

**MK:** **And, likewise with the Department of Health Services, Michael Montgomery?**

**MM:** Pardon?

**MK:** **Likewise with you guys, in terms of working closely with legislators?**

**MM:** We will certainly be in communication with them, and work with them on finding language that will satisfy their concerns.

**MK:** Whitney Engeran?

**WE:** Yeah, LA County is one of the sponsors of the bill, so we are working really closely with legislators.

**MK:** The bill being 945?

**WE:** Yes, SB 945.

**MK:** Well, it is not apt to die in Committee again, then?

**WE:** I hope not.

**FD:** It is possible though that another bill could be introduced. There has been talk, I think, among the LGBT Caucus that they would maybe carry a bill themselves. So, there may end up being a different author. It is hard to know at this point.

**MK:** This again would be a bill that would require healthcare providers and labs to report cases of HIV infection to local health officers using patients' names. That is what this whole controversy has been about, and that is what the \$50 million apparently seems to be dependent upon. I want to thank those who joined us for the hour: Michael Montgomery, who is Chief of the California State Office of AIDS with the Department of Health Services—who is with us this hour from Sacramento. Thank you, Michael.

**MM:** Thank you for having me.

**MK:** Also, I want to thank Fred Dillon—who is here in studio—Deputy Director of Public Policy and Communications for the San Francisco AIDS Foundation. Thank you, Fred.

**FD:** Thank you very much.

**MK:** We also had, in the second half of the hour, LA County Commission on (HIV) AIDS Public Policy (*sic*)—(we) had Whitney Engeran. Thank you, Whitney.

**WE:** You bet, thank you.

**MK:** And, we also thank Michael Weinstein—who was with us earlier—President of the AIDS Healthcare Foundation in Los Angeles. And, also thanks to State Senator Carol Migden, who represents California's Third Senate District—which includes parts of San Francisco, Marin and Sonoma Counties. I want to tell you what is coming up on the second hour of Forum this morning: we are getting into what is decidedly a lighter topic. We are going to talk with a couple of entertainers. We will be joined by Margaret Gomez—who has a one-

woman show of monologue here in San Francisco at the Magic Theater—all about her life with her parents in show business. And, we are going to split the hour—also going to talk in the hour coming up with Colombian Singer Andrea Achevetti—who has put out a new album, kind of a solo album. We will talk about Colombian music and hear some of her music. Should be a lot of fun. I hope you will join is for that. Forum's producers are Robin (*inaudible*), Mark Brydell. Working with us in production this week, as well: Steve Rodman is our Engineer, and our Executive Producer is Raoul Ramirez. For all of us at KQED, thanks to all of you. I am Michael Krasny.

*-End-*