Original: 2185

CHRISTINE C. QUINN
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THE COUNCIL
OF
THE CITY OF NEW YORK

COMMITTEES
CIVIL SERVICE & LABOR
CONTRACTS
HEALTH
WOMEN'S ISSUES
YOUTH SERVICES

May 23, 2001

Robert Zimmerman
Secretary
Pennsylvania Department of Health
P.O. Box 90
Health and Welfare Building
Harrisburg, Pennsylvania 17108

Dear Secretary Zimmerman:

As current and former legislators in New York State, we have grave concerns about the proposed HIV Names Reporting policy pending in Pennsylvania. Similar legislation passed in New York State in 1997 – some of us supported it, some of us did not. Names Reporting/Partner Notification was introduced in New York State in 1998 with the ostensible goal of slowing the spread of HIV by allowing individuals to protect themselves from infected partners. The debate over the legislation took place in the wake of national horror about NuShawn Williams, the HIV-positive man who had apparently willfully infected 13 unwitting sex partners. Legislators were – and are – understandably concerned about the unchecked spread of HIV.

Regardless of our original positions, we are now firmly convinced that Names Reporting has been a counterproductive approach to the issue. Not only has Names Reporting had no measurable impact on the anonymous transmission of HIV, it has discouraged people in the highest risk categories from even being tested – leaving HIV infections to progress to the point of illness, and failing to prevent transmission of the virus. Simply stated, we have found that Names Reporting is too fraught with social implications to be medically useful and has serious and negative repercussions in the fight against AIDS.

Although the AIDS epidemic is over twenty years old, discrimination against HIV-infected individuals has barely lessened. And as the epidemic has progressed, the stigma of HIV has been compounded by the association of HIV-infection with intravenous drug use, sex work, incarceration and poverty. People living with HIV – as well as people suspected of being at high risk for HIV – experience regular, life-disrupting discrimination at the hands of healthcare workers, family members, employers and providers of public accommodation. **The AIDS epidemic is a social problem as much as a medical one, and our solutions to it must be measured by their social effectiveness.**

Because being identified as HIV-positive – to others or even to oneself – has such intensive social consequences, it is urgent that we actively *remove*, not create, barriers to testing. This is important as new infection rates soar among low-income communities, people of color, immigrants and other hard-to-reach populations.

The New York State Department of Health continues to offer anonymous testing from a handful of locations around the state, and although these testing sites are still bound by Partner Notification requirements which provide additional disincentives to testing, they are much more successful in recruiting at-risk individuals for testing than locations which can only offer "confidential" services. However, since Names Reporting is also required throughout the course of treatment, we find that many of our constituents, once tested HIV-positive, defer treatment indefinitely.

In our capacities as policy-makers and providers of direct services to our constituents, we have found that Names Reporting creates an enormous social barrier to both testing and treatment of people at risk for HIV. As you know, solutions to the medical problem of AIDS are stymied at every turn by social problems. Names Reporting has compounded these problems in New York State. Frankly, we cannot force people to come in for testing or even treatment, and they *will* not come in when they feel compromised.

We urge you instead to consider implementing the Unique Identifier (UI) system, assigning an anonymous number-code to each case for the purpose of tracking infections. This system, currently in place in ten states, addresses both the medical need to track the epidemic and the social need to create an environment where at-risk individuals can cooperate with medical efforts.

Please feel free to contact any of us for further information or discussion of our experiences with Names Reporting. We wish you the best of luck in Pennsylvania's battle against AIDS.

Sincerely,

Christine C. Quinn
New York City Councilmember

Stephen DiBrienza /cc
Stephen DiBrienza
Chair, New York City Council
General Welfare Committee

Deborah Glick /c.c.
Deborah Glick
Chair, New York State Assembly
Social Services Committee

Tom Duane /cc
Thomas K. Duane
New York State Senator

Catherine M. Abate /cc
Catherine M. Abate
Former New York State Senator &
President/CEO, Community Healthcare Network

cc: Joel Hirsh, Director of Epidemiology
Pennsylvania State Legislators

AIDS Law Project of Pennsylvania

a non-profit,
public interest
law firm

Original: 2185

MAY 31 AM 9:18
REVIEW COMMISSION

ActionAIDS
FRIENDS FOR LIFE

HIV Reporting in the Commonwealth of Pennsylvania
AIDS Service Providers Position Paper

Representing over 50 AIDS service providers in Pennsylvania, we urge the Commonwealth to not adopt names reporting of people with HIV. The collection of the names of people with HIV is opposed by the organizations directly serving people with HIV in Pennsylvania. Yet, the State's Department of Health recently recommended that the Commonwealth adopt this approach.

Instead, we and AIDS advocates throughout the state propose that HIV be reported through "unique identifiers"— a coding system that protects the privacy of each person by not linking HIV status to individuals. Unique identifiers are simple alpha-numeric codes based on a person's initials, Social Security number, and birth date.

We completely agree that tracking HIV is of the utmost importance in managing the health needs of the state and its residents. HIV tracking will allow us to better allocate limited resources, target and evaluate prevention efforts, educate the public about the epidemic, and project future trends.

We disagree, however, on the approach. Studies have demonstrated that names reporting does deter people from getting testing and care.

A 1990 study reported in the medical journal *AIDS* found that more than 60% of individuals tested anonymously would not have been tested if their names had been reported to public health officials. Other data -- including a 1996 study reported in *AIDS,* a study presented at the *XI International Conference on AIDS* and a 1994 study reported in the *American Journal of Public Health* -- showed that individuals are more likely to voluntarily test for HIV, if the testing is anonymous, because they believe that they can control the dissemination of their test results. A 1996 study reported in the *Journal of the American Medical Association* (*JAMA*), found that persons who tested in *JAMA,* names reporting would deter HIV testing by African-Americans and Latinos.

The State Health Department has relied upon the experiences of other states, particularly neighboring states, for its positions. This reliance, however, is misplaced.

In 1997, New York state adopted names reporting. In 2001, however, New York's City Council sent a letter to the Pennsylvania Health Department expressing "grave concerns" about the Commonwealth's proposed HIV names-reporting policy. "Regardless of our original positions," the letter said, "we are now firmly convinced that names reporting has been a counterproductive approach to the issue." Now calling for code-reporting, the Council stated that "names reporting is too fraught with social implications to be medically useful and has serious and negative repercussions in the fight against AIDS."

The State of New Jersey argues that it has not experienced a significant decrease in the number of people being tested since it adopted names reporting. This argument is flawed because it is not based on people who are HIV positive and, therefore, in need of care. Instead, the argument is based on everyone who seeks testing, regardless of their HIV status. People testing positive, however, represent only 1-2% of people being tested. Even a significant reduction in their numbers would not be measurable within the total number of people tested. Therefore, those most needing to get into care could be dropping out and yet not be noticed.

Current estimates are that 30% of people with HIV do not know it. This is an enormous public health crisis in the United States, as hundreds of thousands of people with HIV are not in care. We must do everything we can to get these people into care, not put up barriers

People get into care by being able to trust providers in their communities, not by being reported. If the Commonwealth takes away our ability to keep our clients' confidentiality, it will strip us of our ability to gain their trust.

For additional information, please contact:

Ronda B. Goldfein	**AIDS Law Project of Pennsylvania (215) 587-9377**
Kevin Conare	**ActionAIDS (215) 981-0088**

Pennsylvania AIDS Service Organizations Supporting Use of Unique Identifiers to Track HIV

ACLU (American Civil Liberties Union of Pennsylvania)
ActionAIDS
ActUP Philadelphia
AIDS Fund of Philadelphia
AIDS Law Project of Pennsylvania
ASIAC (AIDS Services in Asian Communities)
BEBASHI (Blacks Educating Blacks About Sexual Health Issues)
Black United Fund of Pennsylvania
Calcutta House
Children's Hospital of Philadelphia Special Immunology Programs
CHOICE
Circle of Care
Congreso de Lationos Unidos
Critical Path AIDS Project
Direct Action Interest Group of AMSA
GALAEI (Gay and Lesbian Latino/a AIDS Education Initiative)
Giovanni's Room
Liberty City Democratic Club
MANNA (Metropolitan AIDS Nutritional Neighborhood Alliance)
National Congress for Puerto Rican Rights - Philadelphia Chapter
ODAAT (One Day At A Time)
OutFront Philadelphia
PCASO (Pennsylvania Coalition of AIDS Service Organizations)
PCHA (Philadelphia Community Health Alternatives)
Pennsylvania Lesbian and Gay Task Force
Philadelphia FIGHT
POPEC (Pride of Philadelphia Election Committee)
Positive Effect Outreach Ministry
Project H.O.M.E.
Project TEACH
Reboot Philadelphia
SafeGuards Gay Men's Health Project
SALGA Philadelphia (South Asian Lesbian and Gay Association)
Southwest Community Services
SPARC
Spiral Q Puppet Theater
St. Christopher's Hospital for Children's Family Program
St. Mary's Episcopal Church
St. Mary's Family Respite Center
Washington West Project
Westminster Allies
Womens Way
Youth Health Empowerment Project

2002 MAY 31 AM 9:18
REGULATORY
REVIEW COMMISSION

AIDS Law Project of Pennsylvania

PHONE: (215) 587-9377 FAX: (215) 587-9902
1211 Chestnut Street, Suite 600 • Philadelphia, PA 19107

FAX COVER SHEET

TO: PA Health and Human Services Committee

DATE: 5/30/02

FAX #: (various)

 # OF PAGES: (Including this sheet) 4

FROM: Ronda Goldfein / AIDS service providers in Pennsylvania

MESSAGE:
Please see position paper on HIV Names Reporting

ORIGINAL WILL FOLLOW BY: ☐ U.S. MAIL ☐ CERTIFIED MAIL ☐ OVERNIGHT MAIL

Original: 2185

June 13, 2002

FROM: Arthur H. McTighe, MD

TO: The Independent Regulatory Review Commission

RE: HIV names reporting proposed by Department of Health

Ladies and gentlemen:

Thank you for the opportunity to present my views to you on the final regulations proposed by the Department of Health regarding HIV names reporting and anonymous testing. These proposed regulations are fundamentally flawed and must be rejected.

I am a physician in practice in Lewisburg and in Sunbury, Pennsylvania. I graduated from the University of Pittsburgh Medical School in 1969, interned at Presbyterian-University Hospital in Pittsburgh, and completed my residency in laboratory medicine at Yale New Haven Hospital in New Haven. I served in the US Public Health Service for about 5 years, and was in practice at the Maryland General Hospital in Baltimore for 12 years before coming back to Pennsylvania 11 years ago.

I am the Director of Clinical Laboratories at both the Sunbury Community Hospital and the Evangelical Community Hospital. I am the Chairman of the Infection Control Committee at Evangelical Hospital and the immediate past Chairman of the Infection Control Committee at the Sunbury Hospital. At Evangelical Hospital I also hold the position of Vice President for Medical Affairs. I have more than 30 years experience in laboratory medicine and medical microbiology. In addition, I am board certified in pathology and in medical microbiology and am a member of the faculty of the Penn State University Medical School in Hershey.

I have been involved in AIDS diagnosis for the past 21 years and have managed HIV antibody testing laboratories for the 15 years that HIV testing has been available. I have personally counseled many persons requesting HIV testing in both Baltimore and Central Pennsylvania. So, I have extensive direct and personal experience with the issues with which the proposed regulations deal.

We have had several people with AIDS in Lewisburg and Sunbury. For every one of these people with AIDS there are at least three or four other HIV-infected people. So, HIV/AIDS is not a problem from which Lewisburg and Sunbury are isolated.

Although many citizens of these communities are relatively enlightened and tolerant, it is clear to me that people with AIDS in rural Pennsylvania are subject to the same types of discrimination that are reported all over the country. They have lost their jobs and homes and have become isolated and shunned. Instead of compassion, they have been shown contempt and have been made the object of cruel jokes. It is this treatment that those who wonder if they might be HIV-infected particularly fear. They ask me to send their blood for testing under bogus names or invented ID numbers that only they and I can recognize.

For me to tell these people that I will have a legal obligation to report them to the government, **by name**, will simply dry-up testing. No one is served by such a policy. Not the HIV-infected patient who for optimal treatment should be diagnosed early, nor the sex partners of a person who does not know that he or she is already infected. To require reporting of HIV infection **by name** will actually help further spread HIV infection. For this reason such a policy is literally dead wrong.

If there is a need to have more accurate epidemiological information regarding the incidence of HIV infection, then adopt a system of unique identifiers for reporting, as has been done in Maryland, Illinois, California, and several other states.

It is also absolutely necessary to preserve the ability for me to test patients for HIV in a completely anonymous fashion, in the event that the patient will not otherwise consent to be tested. **This cannot be limited to only selected Health Department sites,** because of the fear patients have that they will be discovered or recognized by health department staff.

The final regulations offered by the Department of Health state that there can be anonymous HIV testing in state-designated sites which are financially supported by funding from the Department of Health, presumably either official Department of Health Centers or other facilities under contract to the Department of Health.

Patients requesting anonymous testing will view such facilities as suspect, because these facilities either are or are financially dependent on the government.

In comments on the regulations, the Department of Health states that there may be 130 testing sites in the Commonwealth. But this number is not stated in the regulation itself, only in the non-binding comments to questions. Even so, where will these centers be located? Will they be convenient to persons in rural areas? Will patients trust that there will be absolute anonymity and confidentiality in such facilities?

I appreciate your consideration and trust that you will reject these misguided regulations. The HIV names reporting and the inadequate anonymous testing, which the regulations mandate, will spread HIV infection, not contain it.

Thank you.

Original: 2185

Andrew Park, Esq.
521 S. 9^{th} St., #3F
Philadelphia, PA 19147
May 29, 2002

<u>VIA FAX 717 783-2664</u>

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Philadelphia, PA 17101

Dear Mr. Nyce:

I am a 38 year old HIV negative man living in Philadelphia. I get tested for HIV every 6 months. I do it at my doctors office, and it is usually accompanied by some discussion about my health in general. These discussions do not take place when I visit the doctor for an unscheduled visit for a seasonal cold or some other such emergency illness. On my last visit for an HIV test, we determined that I needed to pay more attention to my blood pressure. My father had his first heart attach when he was 38 and died of heart disease 15 years later. I altered my diet and began to monitor my blood pressure. This visit may have saved me from a medical emergency or death.

The reason that I go to the doctor, however, is for the HIV test. I consider that an urgent and important reason to go to the doctor. Without that reason, I can not honestly say that I would go absent having a flu or some such other reason that one goes to the doctor.

If my name is going to be reported to a state agency, then I will not go to my doctor to get tested. I will also probably loose out on having those non-emergency conversations with my doctor about my health in general.

I urge you to reject any measure that would require names reporting for people who test positive for HIV.

Sincerely,

Andrew Park

Andrew Park, Esq.

MAY 31 AM 11:25
REVIEW COMMISSION

Original; 2185

Pennsylvania Department of Health
IIRC Hearings on Names Reporting
June 12, 2002

Testimony of Kevin R. Conare
Executive Director, ActionAIDS

Hello. My name is Kevin Conare. I am a person living with AIDS and I am the director of ActionAIDS, the largest AIDS service organization in Pennsylvania. Each year we serve over 3,300 people living with HIV throughout Philadelphia. Our clients reflect the epidemic in the city both demographically and geographically. Before working in AIDS services, I was a hospital administrator specializing in planning and finance in California and New York.

I talk to you today, therefore, from several perspectives. First, as a public health professional. Second, as an AIDS service provider. And third, as a person living with AIDS.

The first hat I want to wear is the public health planning one. I do so because the dialogue about names reporting versus unique identifiers is often framed as if AIDS activists and public health professionals are on different sides of the fence. This is erroneous. Those of us who oppose names reporting know well the complexities of disease tracking and disease control. We fully understand and support HIV tracking in the state and the country.

One thing I have noticed in discussions about HIV reporting, is that supporters of names reporting makes analogies to other diseases that are misleading. HIV disease is a communicable disease, that is hard to get, that has a slow progression of symptoms, and that is not curable, but requires years of complicated drug regimens to manage. It cannot be compared to STD'S which can often be controlled through one time or very time-limited interventions. It cannot be compared to TB, which is air borne and can also be controlled through 3-6 month interventions.

The only plausible argument for names reporting is cost. And I will let others discuss the ways code reporting can be made efficient. Instead, I tell you that the cost of names reporting will out way the benefits. Here, I put on my AIDS service hat.

It's true, most people who seek testing and services will not be deterred by names reporting. But, the people most at risk and with the least resources will. We know this from experience and our offices reflect that. If you walk into our office in Center City, you will see a big banner that says ActionAIDS. If you walk into our West Philadelphia office, you will see a sign that says "West Office." If you walk into our North office on the "Bloque de Oro" - the Golden Block at 5th and Lehigh - you will see a sign that says "El Programa de Familia - Family Program."

It took years to get clients to feel comfortable coming to a space in their own communities. We were able to do this by respecting their need for confidentiality. Even today, we have many clients who live under the same roof with relatives that do not know their HIV status. This is true too of our clients in shelters, on the streets, and in abusive relationships. But today, 78% of our clients are on the new complicated drug regimens, even though most are living near the poverty level. People get into care by being able to trust providers in their communities, not by being reported. If you take away our ability to keep our clients' confidentiality, you will strip us of our ability to gain their trust. Please do not do this.

Even for myself, with all my years in healthcare, this proved to be true. I would not get tested by our family doctors. We are East Indian and I was not ready for my community to know that I was gay and that I had HIV. I certainly would not have gotten tested in hospitals, where I knew the word would get out. I only got tested because it was anonymous. It took me a year to get into care. Today I am very open about my status. I am grateful that I was able to get to that point on my terms and when I wanted. Names reporting would have only made it take longer and I would have waited until I was sick.

Original: 2185

IRRC PUBLIC MEETING 6/13/02

THOUGHTS OF BARRY BUSCH:840 Upland Ave., Upland, Pa. 19015

SUBJECT: DOH FINAL REGULATION 10-166 HIV REPORTING SYSTEM

Gentleman in the interest of the protection of Pennsylvanian residents from the HIV virus and for the successful identification and treatment of those testing HIV positive as well as the fostering of HIV testing itself ,it is most important that this state adopt an HIV reporting system that does not deter we citizens from getting voluntarily tested and enables the collection of the most accurate information possible so that this states HIV reporting system assimilates data that will insure that the dollars we have to spend on prevention and care are properly targeted.

The only entity that will benefit from Final Regulation 10-166 as submitted by the Department of Health if approved by you will be the HIV virus itself. It's spreading throughout the Commonwealth will not be detered. Final Regulation 10-166 will promote the spread of HIV.

Alot of the negative effects of this shortsighted regulation you have already heard.

Today, I bring you a personal story. My story. I was never tested for HIV and was unaware of my infection until I became deathly sick in 1998. So sick , everyone , my doctors, my family, my friends expected me to die. In fact my doctor says that He has never heard of someone with my degree of AIDS living. But for some reason I did. I can't help wonder if some force of nature, creation gave me life for the sole purpose of sharing this story with you .

During one of my few episodes of consciousness during a five month hospital stay, which by the way as I had no insurance ,as do most of those living in the most at risk environs, was paid for from the coffers of the state of Pennsylvania (and believe me I am most appreciative of the state footing the medical bills) . Anyway during my hospital stay, one day I had a HIV caseworker come to me offering me knowledge and support but also delving into my private life. Asking me personal questions about my lifestlye , So as to determine how I was infected , who I infected,when,where and how.

Well , I consider myself one of the most honest people in the world. I actually contain a bit of guilt now in my being for what I did. It was not the right thing to do. But knowing my answers where going into a state file with my name on it , a file that would last forever, long after I'm gone , I succumbed to the most basic of human instints. I lied.

I was asked about my sex habits, my drug use, my relationships ,my private lifestyle. And the caseworker was right in asking me these questions. For the county I live in was doing all it could , in fact it still is doing all it can to stop the spread of the HIV virus.

It was my obligation to answer honestly,truthfully. Did I? No. I ,one of the most honest people in the world, lied.

Every question asked ,my mind went through a thought process that accertained how much of myself I was willing to devuldge. Self preservation being the most forceful inbreed motivation we as humans have ,won out . Won out over the truth. I took the societal excepted responses. 'Oh , I had to catch it from heterosexual sex. I guess one of the girls I've experienced must of had it.'

What a bunch of bunk. There is no doubt in my mind that I became infected due to a lifestyle in my past that included shooting up, introvenieus drug use As well as what I call cocoa-whoring, having sex with anybody I could find ,who had money , so I could get high. If this was your lifestyle and reason you became HIV infected , would you answer the questions that need to be asked in order for our state to develope an accurate plan to combat the spread of HIV, honestly, knowing your answers where going into a state file with your NAME on it.

If a truthful answer in any way might throw a shadow on your existance , would you answer honestly. Truthfully. If you say yes , you are lying to yourself. I lie, you'ld lie. We will all lie. Self preservation. You can't overcome it.

It is shortsighted and foolhardy to institute an HIV reporting system for whatever reasoning DOH claims, that is geared to collecting inaccurate data. And that is exactly what will be collected with a Names-Based HIV Reporting System. The object of a HIV reporting system is to collect data so that DOH can determine where to target the limited funds it will have to fight AIDS ,where it will do the most good. Final Regulation 10-166, by it's very nature will be the direct cause of the mis-targeting of funds. PURPOSELY WASTEFUL OF TAXPAYERS MONEY.

Our limited dollars must be targeted with a precision that pinpoints where dollars need to be spend to control the HIV virus. This regulation will do the opposite. Any plan crafted from inaccurate data is doomed to be an inaccurate plan. We Pennsylvanians have been fighting DOH over this for years now. Not because we're just stubborn, although I think DOH is but because we on the streerts, in the field are not like DOH honcho's looking at this from an ivory tower. We see and live it in the trenchs. And most of all we, I feel our state is under an obligation to do all it can to stop the spread of HIV to those Pennsyvanians not yet infected.

The HIV virus's spread will be the only entity to benefit from this regulations approval by you.

To touch breifly on annonymous testing. Sure there's 130 sited for people to be directed to to get annonymous testing. But are you so nieve to believe that if a caseworker tells someone ' well I can't give you an annonymous test. You'll have to go to such and such a location. Here call one of these few people. Their the only ones who can test you annonymously.' Do you really think that person if going to follow through. I hope you know more about peoples habits than that.

In fact, the state of Delaware adopted almost an identical system to the one DOH wants to implement now. And guess what? So few people went to get an annonymous test that the annonymous testing was deemed useless. Funding was withdrawn. No one gets tested annonymously in Delaware now.

Nice to have annonymous testing sites. But there is no site like on site. With this regulation annonymous tested will be next to nil. zilch. non-existant..

The House Health Committee in unison has commented against this regulation as has the Democratic side of the Senate Health Committees. It is our hope that you do not allow the minority comment of the Senate Republican Health Committee members to prevail.
I urge you gentleman , in the hope of those Pennsylvanians who unlike myself are HIV free to disapprove Final Regulation 10-166.

Barry Busch
840 Upland Ave. 6/13/02
Upland, Pa. 19015
610-876-6750

Original: 2185

City of Bethlehem
INDUSTRY • EDUCATION • RELIGION • MUSIC • RECREATION
AN EQUAL OPPORTUNITY EMPLOYER

BUREAU OF HEALTH
Phone: 610-865-7083
Fax: 610-865-7326
TDD: 610-865-7084

June 10, 2002

Joel H. Hersh, M.Ed., M.P.A.
Director, Bureau of Epidemiology
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, Pennsylvania 17120

Dear Mr. Hersh:

On behalf of the Bethlehem Health Bureau and the Bethlehem Board of Health, please accept this letter of support for the Pennsylvania Department of Health regarding proposed amendments to **Pennsylvania Title 28. Health and Safety, Chapter 27. Communicable and Noncommunicable Diseases.** Specifically, these amendments call for the collection and reporting of HIV, CD4 T-Lymphocyte counts less than 200 and perinatal exposure of newborns to HIV by name.

The Bethlehem Health Bureau is very much supportive of these proposed regulations because from a public health perspective, timely and comprehensive information would provide the State with the opportunity to more accurately identify the prevalence of HIV/AIDS throughout the Commonwealth. Confidential information gathered during collection and reporting of HIV by name is invaluable if public health agencies hope to develop, initiate, and evaluate efficient community-based interventions, which target HIV-infected persons and partners at-risk. And more importantly, confidential reporting by name will give those who are infected with HIV a better opportunity to access wanted medical and social services, if they so choose.

The Bethlehem Health Bureau totally supports the proposed amendments recommended by the Pennsylvania Department of Health for the reason that the current seriousness of HIV/AIDS in Pennsylvania cannot be taken too lightly. In as much, reliable and timely HIV incidence data becomes essential for early detection and treatment of the disease and to ensure that health care and support services are obtainable in all statewide communities and for all populations at risk.

Please let me know if there is any other way in which the Bethlehem Health Bureau can support this indispensable public health measure.

Sincerely,

James Bertsch, RN, MPH
Bethlehem Health Bureau Director

Original: 2185

COUNTY OF BUCKS

DEPARTMENT OF HEALTH

Health Building, Neshaminy Manor Center, Doylestown, PA 18901 - 215 - 345 - 3318

FIELD OFFICES

Bucks County Government Services Center, 7321 New Falls Road, Levittown, PA 19055 -215- 949 - 5805
Bucks County Government Services Center 515 West End Blvd., Quakertown, PA 18951 -215- 536- 6500

County Commissioners
MICHAEL G. FITZPATRICK, ESQ, Chairman
CHARLES H. MARTIN
SANDRA A. MILLER

Director
LEWIS D. POLK, M.D., M.P.H.

2002 JUN 11 AM 8:59

June 10, 2002

Joel H. Hersch, Director
Bureau of Epidemiology
PA Department of Health
P.O. Box 90
Harrisburg, PA 17108

Dear Mr. Hirsch:

I am writing to indicate the support of the Bucks County Health Department to the amendments to PA Code, Chapter 27, "Reporting of AIDS, HIV Test Results, CD4T – Lymphocyte Counts and Perinatal Exposure of Newborns to HIV" as published in the PA Bulletin, Vol. 31, No. 16.

Requiring name–based reporting for HIV infections will enhance our agencies' ability to provide in-depth case management services to those infected and to their at-risk partners. Services essential to their well being as well as the community at large. A task that was almost impossible to do due to the limitation of information available.

Very truly yours

Gordian V. Ehrlacher
Public Health Administrator

Cc: File

THE COUNTY OF CHESTER

COMMISSIONERS:
Karen L. Martynick, Chairman
Colin A. Hanna
Andrew E. Dinniman

CHESTER COUNTY HEALTH DEPARTMENT
Chester County Govt. Services Center
601 Westtown Road, Suite 290
P.O. Box 2747
West Chester, PA 19380-0990
610-344-6225 FAX: 610-344-6727

JOHN P. MAHER, M.D., M.P.H.
County Health Director

Original: 2185

June 10, 2002

Mr. Joel H. Hersh, Director
Bureau of Epidemiology
PA Department of Health
P. O. Box 90
Harrisburg, PA 17108

RE: Written Testimony re
HIV Reporting

Dear Mr. Hersh:

Enclosed please find the Chester County Health Department's written testimony in support of the proposed new regulations (28 PA Code Ch 27) which would require "Reporting of AIDS, HIV Test Results, CD4T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV.

Should you have any questions, please feel free to contact me at the above address/number.

Yours truly,

John P. Maher, M.D., M.P.H.
County Health Director

JPM/jsj

p:\phs\ltrHersh.doc

2002 JUN 11 AM 8:59
REVIEW COMMISSION

"Protecting You and Your Environment"

Original: 2185

THE COUNTY OF CHESTER

COMMISSIONERS:
Karen L. Martynick, Chairman
Colin A. Hanna
Andrew E. Dinniman

CHESTER COUNTY HEALTH DEPARTMENT
Chester County Govt. Services Center
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JOHN P. MAHER, M.D., M.P.H.
County Health Director

June 10, 2002

WRITTEN TESTIMONY RE HIV REPORTING

By John P. Maher, M.D., M.P.H.

My name is Dr. John Maher. I have been a physician for 42 years, involved in public health and community medicine for 36 years, and the Director of the Chester County Health Department for 24 years. I have taught in three different medical schools and at the state university graduate level for almost 20 years.

What follows here is an update of the testimony we submitted in April, 1999, and again in May of 2001, supporting the proposal to make HIV-positivity a reportable condition, by name.

The Chester County Health Department (CCHD) is one of the ten County/Municipal Health Departments existing under the Commonwealth's Local Health Administration Law (Act 315-1951), which provides the front-line public health services to over 40% of the state's population. As such, we have a real, legitimate and ongoing interest in how the issues of the surveillance, monitoring, reporting, and epidemiological follow-up of communicable diseases are dealt with.

The CCHD got involved in HIV/AIDS-related issues very early on. In the early 1980s we alerted area physicians to the newly described clusters of unusual diseases being reported in the medical literature among MSM risk groups on the west coast.

This Department was the prime mover in the establishment of the Chester County HIV/AIDS Consortium.

Through regular columns in the County Medical Society's monthly journal, as well as in periodic CCHD Newsletters to all local health care providers, we have kept everyone up-to-date as the HIV/AIDS epidemic progressed.

We were actively involved in the Ryan White programs, HERR, CTPN, and TPAC here in southeast PA. We worked to create the Early Intervention program and clinic service here, and then to keep it here.

We provided lectures to discuss HIV/AIDS at innumerable meetings of diverse community businesses and professional groups and agencies, disseminated information about Act 148, and required every new CCHD employee to read and sign off on a statement of HIV confidentiality, underscoring that a breach of same constitutes grounds for summary dismissal.

"Protecting You and Your Environment"

Our HIV/AIDS records are strictly confidential—even I, as County Health Director, do not have access to them without specific cause and need to know. They are kept in a separate, dedicated secure computer system, in a locked room, in an office suite that is also locked when not in use.

All of this is by way of preamble to the fact that the Chester County Health Department, with the advice and consent of the Chester County Board of Health, supports the reporting by name and not by "unique identifier," of HIV infection.

In the early days (1980s) of the HIV/AIDS epidemic this Department recognized the uniqueness of the situation including the socio-economic-political reasons for reporting only AIDS, and not HIV. In addition, in those days, many people thought that only AIDS was the epidemic, and that not everyone with HIV was destined to develop AIDS or become a public health problem. Further, from the Department's point of view, we had at the time little, if anything, to offer such patients—other than general information, testing, and counseling about the risks of unprotected sex. At the same time, of course, much of our limited local resources were tied up in dealing with the Rabies epizootic in this region.

Now, however, things are very different.

- We are all now aware that the epidemic is HIV, not AIDS yet we have no way for public health agencies to determine the actual incidence or prevalence of HIV infection in our communities.
- We have nearly 20 years of experience with HIV/AIDS and have had no breaches of confidentiality. Those that did occur elsewhere were due to individual rather than system failures.
- Many social and legal protections have been put in place to protect the civil liberties of HIV+ patients.
- Universal precautions have reduced occupational exposure to bloodborne pathogens.
- We now have sensitive tools for monitoring HIV replication in infected persons (CD4+ T cell counts, and plasma HIV RNA levels);
- Highly active anti-retroviral therapy (HAART) has become the standard of care for the treatment of HIV infection.
- New antiviral drugs, continue to be developed, and when used early and in combination are very (though not perfectly) effective.
- Chemoprophylaxis regimens against many of the AIDS-defining opportunistic illnesses have been developed, and when used early in the course of HIV infection result in significant reductions of AIDS morbidity and mortality.
- New vaccines are in the testing stages of pharmaceutical research.
- HIV/AIDS case fatality rates have dropped and this is now becoming a chronic disease.

Countering all these positive trends are the facts that:

(a) while HIV/AIDS is now a chronic disease, it is still an infectious/transmissible disease;
(b) younger groups of MSM still have riskier behaviors and higher rates of transmission;
(c) the epidemiology continues to change, and growing numbers of injecting drug users, women, minorities and sexual partners of high risk individuals are involved;

(d) HIV can still be transmitted vertically from pregnant women to newborn babies;
(e) HIV+ patients can still present with problematic TB, MAC, STDs and other OIs that might have been preventable or at least less problematic had they been identified, referred, diagnosed and treated earlier.
(f) Early and accurate identification of HIV+ individuals will provide health officials with objective data to link patients with appropriate medical and social services, as well as help in the evaluation of program effectiveness.

At this point in time, then, it is appropriate to keep reminding everyone that the "epidemic" is not AIDS but rather HIV. Modern medicine now has a lot to offer infected and/or at-risk patients. It is time then, to treat this disease for what it is:--a preventable, and now treatable, (if not curable), communicable disease which continues to constitute a public health threat.

Anonymous testing, unique identifiers, and other such catering to fear, prejudice and futility, are no longer necessary or helpful. In fact, they are counter-productive and wasteful of scarce resources.

Exposed individuals need to be tested and counseled. Infected individuals need to be treated and/or "prophylaxed." The spread of this deadly disease has been slowed. Now it is time to apply time-tested public health and epidemiological measures to halt it! This can only be done if we know who is infected and can set the wheels in motion for early intervention, referral and treament, and to identify and follow-up with contacts.

It is my understanding that Pennsylvania is one of only twelve states and territories that do not require HIV reporting and one of only 16 which do not require that reporting by name. That in itself is embarrassing. Not to act to correct that deficiency would be a public health scandal!

Thank you for the opportunity to present these comments.

JPM/jsj

[Glossary:

HIV: Human Immunodeficiency Virus
AIDS: Acquired Immune Deficiency Syndrome
MSM: Men who have sex with men
TB: Tuberculosis
MAC: Mycobacterium-Avium Complex
STDs: Sexually Transmitted Diseases
OIs: Opportunistic Infections]

Original: 2185

ERIE COUNTY
DEPARTMENT OF HEALTH

Rick Schenker
County Executive

Joseph Trzybinski
Director

BOARD OF HEALTH
Howard A. Nadworny, MD. Chair
William W. Cabell, D.C.
Richard A. Orloski, D.O.
Anthony M. Ruffo, D.O.
Shelly J. Yacobozzi R.N.

JUN 11 AM 8:59
REVIEW COMMISSION

June 10, 2002

Joel H. Hersch, Director
Bureau of Epidemiology
PA Department of Health
P.O. Box 90
Harrisburg, Pennsylvania 17108

Dear Mr. Hersch:

I am writing to indicate my support to the amendment to 28 PA Code, Chapter 27, "Reporting of AIDS, HIV Test Results, CD4T – Lymphocyte Counts and Perinatal Exposure of Newborns to HIV" as published in the PA Bulletin, Vol. 31, No. 16.

Hopefully, Pennsylvania will finally join the majority of states that require name-based reporting for HIV infections. Reporting HIV testing results will give us the information we need to determine the extent of disease in Erie County. We could only guess before. Our job is to prevent the spread of diseases in the community. Reporting results by name will allow us to provide case management services for those that are infected with the virus and their at-risk partners. We will finally have the information we need to do our job.

I also commend you for providing assistance to local health departments for the implementation of the new requirements.

Sincerely,

Joseph Trzybinski
Director

JT/sk

Original: 2185

The City of York
Pennsylvania
1 Marketway West, 3rd Floor York, PA 17401
www.yorkcity.org

John S. Brenner, Mayor

York City Bureau of Health
Phone: 717-849-2252
Fax: 717-852-9397

June 10, 2002

Mr. Joel H. Hersh, Director
Bureau of Epidemiology
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108

Dear Mr. Hersh:

The York City Bureau of Health continues to support strongly the effort to make HIV reporting by name in Pennsylvania. This is the correct reporting method to adopt for several reasons. First, name reporting of AIDS is already being done and this expansion makes HIV infection no different than AIDS and other sexually transmitted and communicable diseases. After a little over twenty years, it is time and many would argue past time to stop treating HIV infection any differently.

Second, name reporting will allow local public health professionals to contact HIV infected persons in a confidential manner. They can then provide information concerning HIV infection, how to minimize its damage and how to prevent transmission to others, as well as referral to medical care and to community resources for additional assistance.

Third, name reporting will improve the accuracy of data in that duplication of reporting will essentially be eliminated. As individuals move from city to city or jurisdiction to jurisdiction, their name will remain constant even if they move across the country.

All in all, name reporting will result in accurate data that will enable public health planners and educators at the local and state levels to address future responses to this tragic and widespread epidemic. In addition, local public health professionals will better serve individuals with HIV infection and their medical care will be enhanced through case management activities that would not be possible without name reporting.

Sincerely yours,

David L. Hawk MD

David L. Hawk, M.D., M.P.H.
Deputy Director of Community Development – Health Bureau
City of York, Pennsylvania

DEPARTMENT OF HEALTH
...in pursuit of good health

BUREAU OF COMMUNITY HEALTH SYSTEMS
Telephone: (717) 787-4366
DIVISION OF SCHOOL HEALTH
Telephone: (717) 787-2390
FAX: (717) 783-4790

FAX TRANSMISSION

DATE: 6/11/02

TIME: 8:40 AM

TO: Robert Nyce, Executive Director IRRC

FROM: Jeff Blystone

2002 JUN 11 AM 8:56

___ **URGENT** ___ **Please Review/Comment** ___ **FYI**

MESSAGE:

Attached are letters of support received for the proposed Amendments to chapter 27

TOTAL PAGES, INCLUDING COVER SHEET: 9

Original: 2185

County of Montgomery
COMMISSIONERS
Michael D. Marino, ESQ.
Chairman
James R. Matthews Ruth S. Damsker
HUMAN SERVICES DIRECTOR
Joseph Roynan
610-292-2031
jroynan@mail.montcopa.org

P.O. Box 311
Norristown, Pennsylvania
19404-0311
TDD: 610-631-1211
www.montcopa.org

June 11, 2002

Independent Regulatory Review Committee

Dear Committee;

On behalf of the County of Montgomery, I am writing to indicate our county governments support of the addition of HIV to the reportable disease category. Additionally supported is the requirement of the names of persons infected to be recorded and maintained confidentially. This requirement will assist with the monitoring of treatment compliance, and treatment effectiveness.

An illness of this severity needs close monitoring to prevent its progression and to assist in the prevention of the exposure of uninfected persons.

Sincerely,

Joseph Roynan

Joseph Roynan
Human Services Director
Montgomery County

Cc: County Commissioners, Chief Operating Officer, Solicitor, and Director of Health

cc:

2002 JUN 11 AM 10:13
REVIEW COMMISSION

Original: 2185

2002 JUN 11 AM 10: 13

REVIEW COMMISSION

CITY OF
ALLENTOWN
PENNSYLVANIA
18102
BUREAU OF HEALTH

MAILING ADDRESS
435 Hamilton Street
Allentown PA 18101-1699

OFFICES

Alliance Hall
245 North Sixth Street
Allentown PA 18102-4128

PHONE: (610) 437-7760

FAX: (610) 437-8799

June 11, 2002

Helen K. Burns, PhD
Deputy Secretary for Health
Planning and Assessment
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108

Dear Dr. Burns:

It has come to our attention that the Commonwealth of Pennsylvania will soon announce that HIV infection will become a reportable condition by patient name. The Allentown Bureau of Health and its Board strongly support this action for the following reasons:

1. It is the mission of the public health system to not only count the number of infections but also to prevent the further spread of disease in a community. Name reporting is essential to be able to conduct contact interviews and notify others who may have been exposed.

2. Name reporting will allow public health staff to interview patients to assess their need for a variety of services - competent medical care, dental care, financial assistance, housing, pharmaceutical assistance, support groups, drug and alcohol treatment, etc. HIV positive patients can me offered free tuberculosis skin testing and free treatment if found to have TB infection. Immunizations can also be made available for free or at minimal cost.

3. All states including Pennsylvania require the name reporting of AIDS cases after HIV infection has met the AIDS case definition. In addition, most states currently require name reporting of HIV infection using the same methods as surveillance for AIDS.

4. Public health departments in Pennsylvania have a proven track record in protecting people's privacy in relation to other sexually transmitted diseases, and have additional safeguards in place as it pertains to HIV/AIDS.

In summary, the Allentown Bureau of Health foresees that name reporting for HIV infections will result in improved access to effective care and treatment programs for HIV positive persons, resulting in better and longer health. It will also reduce the likelihood of additional infection through early partner notification and education about how to prevent the spread of HIV infection to others.

Sincerely,

Barbara E. Stader

Barbara E. Stader, RN, MSN
Director of Health

DBS:pss ([illegible])

DEPARTMENT OF HEALTH
...in pursuit of good health

BUREAU OF COMMUNITY HEALTH SYSTEMS
Telephone: (717) 787-4366
DIVISION OF SCHOOL HEALTH
Telephone: (717) 787-2390
FAX: (717) 783-4790

FAX TRANSMISSION

2002 JUN 11 AM 10: 13

DATE: 6/11/02

TIME: 10:05 AM

TO: Robert NYCE, Executive Director, IRRC

FROM: Jeff Blystone

___ **URGENT** ___ **Please Review/Comment** ___ **FYI**

MESSAGE:

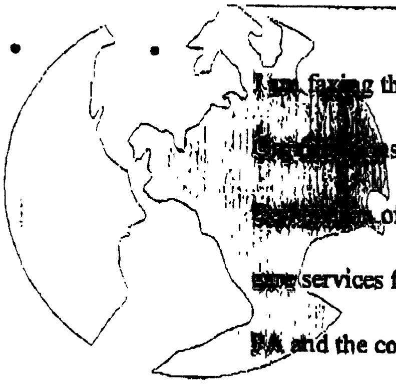
TOTAL PAGES, INCLUDING COVER SHEET: 4

Original: 2185

Keystone Rural Health Center
820 Fifth Ave.
Chambersburg, PA 17201

To:	Mary Lou Harris	**Fax:**	717-783-2664
From:	Jenny Englerth	**Date:**	06/10/2002
Re:	HIV Reporting Regulation	**Pages:**	2

☐ **Urgent** x **For Review** ☐ **Please Comment** ☐ **Please Reply** ☐ **Please Recycle**



I am faxing this in follow up the meeting held with IRRC staff and PA Coalition of AIDS Service Organizations representatives. Bruce Flannery had asked that I send directly to you an explanation of the current system used to create unique identifiers for individuals receiving HIV care services funded through the Ryan White Care Act. This software system is used throughout PA and the country to report services provided by funded organizations.

Thank you again for taking the time to meet with us on this important issue.

Appendix C-Unique Record Number (URN)

The Unique Record Number (URN) is a unique code assigned to each client based on portions of the individual's first and last name, date of birth, and gender. The URN is used to distinguish one client from all others and is essential for merging and unduplicating client records across providers.

The URN is created from the following:

- First and third letters of the first name
- First and third letters of the last name
- Two-digit Month, Day, and Year of birth
- Code for Gender (1=Male; 2=Female; 3=Transgender; 9=Unknown)
- If a field is missing, or say the first or last name is only two letters long, then the number 9 is inserted for that field

The letter and numbers above form the 11 digit un-encrypted unique record number. For example, the URN for a client named Jane M. Doe, female, born on March 15, 1965 would be: JNDE0315652.

After this number is created, it is encrypted, or scrambled, using a complex algorithm. The resulting nine-digit code does not resemble the original information in any way. It is virtually IMPOSSIBLE to retrace the information in the URN or retrace any personal information about the clients. Decoding a URN is not feasible; too much of the original information is removed during the encryption process to be able to work backwards to the original 11-digit information.

For the client level demonstration sites (who have special data reporting requirements), only the encrypted URN is submitted to HRSA. As a further safeguard, HRSA strips each record of the encrypted URN and replaces it with a sequential number that is used to uniquely identify each client. NO identifying information is sent to the Health Resources and Services Administration (HRSA).

Original: 2185

PENNSYLVANIA COALITION OF
PCASO
AIDS SERVICE ORGANIZATIONS

2002 JUN 11 AM 8:59
REVIEW COMMISSION

June 10, 2002

Mr. John R. McGinley, Jr., Chair
Independent Regulatory Review Commission
333 Market Street
Harrisburg, PA 17101

via fax 717 783-2664, hard copy to follow

Re: Final Rulemaking, HIV Reporting, 10-166

Dear Mr. McGinley:

On behalf of the Pennsylvania Coalition of AIDS Service Organizations (PCASO), I am writing to amend our comments submitted on June 6, 2002 to the Independent Regulatory Review Commission (IRRC) via fax.

In earlier comments, as well in discussions with members of IRRC staff "team" reviewing this proposed regulation, we have raised concerns about the scope of individuals required to report HIV to the Commonwealth in the proposed regulation. Here, our conversations and comments have focused upon the requirement that non-medical personnel, be required to report a condition they cannot diagnose.

Upon a close read of the proposed regulation over this past weekend however, we believe that beyond our initial concern, there is an inconsistency and duplicative language in the proposed regulation, resulting in great confusion on this very subject.

The Department is proposing adding four elements (AIDS, CD4 test results, HIV and perinatal exposure) to existing Section 27.21, which states quite clearly (in existing language) that "only physicians and hospitals are required to report . . ." (section 27.21a(a)(5). The Department further proposes language at 27.32a(b)(1) which is extremely confusing and seems to refute standing language at 27.21a(a)(5). Here, the proposed language indicates that "a physician, hospital, person providing HIV services or person in charge of an entity providing HIV services, who makes a diagnosis of AIDS or who receives HIV or CD4 T-lymphocyte test results or provides HIV or CD4 T-lymphocyte test results to patients, shall report the following . . ."

We are concerned that the very limited scope of reporters at section 27.21a(a)(5) is inconsistent with language added at section 27.32a(b)(1) and leave the reader unable to determine who is required to report.

As previously discussed with your staff, we are firm in our belief that only individuals professionally qualified to make a diagnosis should be required to make a report. Otherwise, they are simply reporting elements of a diagnosis (lab results, e.g.) without the complete diagnostic picture--which can only be determined by a physician upon evaluation of a patient. To illustrate by use of a parallel, it is like reporting a case of diabetes based solely on the presence of elevated blood glucose levels. Diabetes, like HIV and all other diseases, can only be diagnosed upon thorough evaluation by a licensed medical professional.

I thank you in advance for your consideration and look forward to your review of this proposal.

Sincerely,

Bruce W. Flannery
Executive Director

PENNSYLVANIA COALITION OF
PCASO
AIDS SERVICE ORGANIZATIONS

Facsimile Cover Sheet

To: Mary Lou Harris

Fax Number: ________________

No. of Pages 3 **(including cover)**

From: **Bruce Flannery, Executive Director**
Telephone: (610) 518 0886
Fax: (610) 518 0885

Re: Further Comments

Mary Lou:

Discovered a potential problem w/ regs. as drafted over the weekend - Thought I'd bring to your attention in writing.

Thanks

Bruce

The information contained in this fax is confidential and intended solely for the individual to whom it is addressed.

Please call (610) 518 0886 should you have any problems receiving this transmission

624 WEST LINCOLN HIGHWAY EXTON, PA 19341 (610) 518-0886 FAX (610) 518-0885

HAP

THE HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA

2002 JUN 10 PM 3:59
REVIEW COMMISSION

Original: 2185

June 10, 2002

Robert E. Nyce
Executive Director
Independent Regulatory Review Commission
14th Floor, Harristown 2
333 Market Street
Harrisburg, PA 17101

RE: Title 28, Code Chapter 27, Reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV

Dear Mr. Nyce:

The Hospital & Healthsystem Association of Pennsylvania (HAP), on behalf of its approximately 250 member hospitals and health systems, commends the Pennsylvania Department of Health for developing reporting requirements that will permit the commonwealth to more accurately track the prevalence of HIV disease and AIDS. Knowledge of HIV disease should enhance the department's ability to develop, implement, and evaluate public health interventions for HIV-infected persons and other at-risk persons; increase opportunities to provide case management services; and link infected persons to community medical, social, and support services to prevent or slow the progression of HIV infection to life-threatening AIDS.

HAP supports the department's proposed regulations to establish confidential name-based reporting for HIV infection. Confidential name-based reporting is consistent with the requirements established for other disease reporting in Pennsylvania and the recommendations established by the United States Center for Disease Prevention and Control (CDC) for HIV reporting. Upon enactment of these regulations, Pennsylvania would join the vast majority of other states that currently require confidential name-based HIV disease reporting. HAP believes that confidential name-based reporting will allow for the most accurate tracking of HIV disease prevalence and promote increased opportunities for disease intervention. Confidential name-based reporting also needs to be implemented in order for Pennsylvania to qualify for the highest levels of HIV grant funding through the Ryan White Care Act.

At the same time, HAP supports the continued use of anonymous testing at state-designated anonymous testing sites. It is important that such sites remain available to allow individuals who are at-risk for HIV or infected with HIV and who might otherwise refuse to be tested to confidentially an alternative site for testing and treatment.

4750 Lindle Road
P.O. Box 8600
Harrisburg, PA 17105-8600
717.564.9200 Phone
717.561.5334 Fax
haponline.org

Robert E. Nyce
June 10, 2002
Page 2

HAP requests that the Independent Regulatory Review Commission approve the regulations given the information that the department has already deliberated and weighed in balance of the confidential name-based reporting methodology.

Sincerely,

Paula A. Bussard

PAULA A. BUSSARD
Senior Vice President, Policy and Regulatory Services

PAB/zf

HAP

THE HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA
4750 Lindle Road
PO Box 8600
Harrisburg, PA 17105-8600
(717) 561-5344 Phone
(717) 561-5334 Fax
pbussard@haponline.org

FAX TRANSMISSION

3 page(s), including cover sheet

TO:	Robert E. Nyce
FAX:	(717) 783-2664
FROM:	Paula A. Bussard
DATE:	June 10, 2002
SUBJECT:	HAP Comments - Reporting Requirements for HIV Disease and AIDS

MESSAGE:

Women's Institute For Family Health

1632 N. Diamond Street, Philadelphia, PA 19132 Phone (215) 763-3680 Fax (215) 763-4016

Original: 2185

June 10, 2002

EMBARGOED MATERIAL

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market St. 14th floor
Harrisburg, PA

Dear Mr. Nyce:

I am writing to express my strong opposition to HIV reporting by name in Pennsylvania.

HIV reporting by name will discourage everyone, including those at greatest risk along with people from every socio-economic strata, regardless of race/ethnicity, gender or sexual identity from seeking testing, counseling and medical care appropriate to their needs. The Commonwealth of Pennsylvania has been successful in implementing HIV/AIDS services through unique identifiers that safeguard and respect the human rights of consumers of HIV/AIDS services. This right, should not, under any circumstances be compromised or taken away.

Women's Institute for Family Health is a non-profit health, education and advocacy organization whose mission is to provide diverse and culturally relevant services to improve and maintain the health of women and families. Through our many programs we serve more than eight hundred client families per year, many of whom are at high risk and/or living with HIV/AIDS. The proposed regulation of HIV reporting by name will pose long term and dire consequences to many of the people we represent. It is therefore imperative that approval of this regulation be denied.

Sincerely Yours,

Laura Roache

Laura Roache, M.Ed.
Executive Director

cc: Honorable State Senator, Shirley M. Kitchen
Honorable State Representative, Jewell Williams

PPhA
PENNSYLVANIA PUBLIC HEALTH ASSOCIATION

Original: 2185

EMBARGOED MATERIAL

2002 JUN 11 PM 1:19

June 10, 2002

Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street - 14th Floor
Harrisburg, PA 17101

Dear Mr. Nyce:

I am writing on behalf of the Pennsylvania Public Health Association in support of the Pennsylvania Department of Health's regulatory proposal to make HIV infection confidentially reportable by name.

Name-based HIV reporting, now in place in thirty-four states, has shown itself to be an essential tool in the fight against HIV/AIDS. Name reporting allows for more accurate tracking of the HIV/AIDS epidemic, earlier case finding and linkages to prevention and care, and more effective allocation of scarce resources than non-name-based reporting systems.

Confidentiality has not been an issue in the experience of the thirty-four states using a name-based system. Pennsylvania currently has over fifty diseases and conditions, including other sexually transmitted diseases, required to be reported in a confidential name-based format. The same method should be used for reporting HIV infection. While concern regarding confidentiality may be understandable, general and HIV-specific confidentiality laws and regulations prohibit disclosure of any person's HIV status or other HIV-related information to government or private agencies, police, employers, or insurance companies. Also, there is no evidence nationally that name-based reporting leads to decreased testing; under the proposed state plan, anonymous testing sites will continue to be available for those who prefer that option.

Sincerely,

Robert Gage
President

TEMPLE UNIVERSITY
A Commonwealth University

Office of the Vice Provost
for Research

1601 N. Broad Street - Suite 406 USB - (083-45)
Philadelphia, Pennsylvania 19122-6099
Phone (215) 204-6938 • Fax (215) 204-7486
http://www.research.temple.edu

Human Subjects (Main Campus) (215) 204-7460
Office of Technology Transfer (215) 204-5732
Sponsored Projects Administration (215) 204-8691

Fax

To: Robert Nyce
From: Robert Gage - PPHM
Fax: 717-783-2664
Pages: 2, incl. cover
Phone:
Date: 6/11/02
Re: HIV Reporting

☒ Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

● **Comments:**

Allegheny County Health Department

Original: 2185

DIRECTOR
Bruce W. Dixon, M.D.

EMBARGOED MATERIAL

3333 Forbes Avenue
Pittsburgh, Pennsylvania 15213
Phone: (412) 578-8008
Fax: (412) 578-8325

June 10, 2002

Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108

Gentlemen:

I am writing in support of the Regulations for Reporting of HIV by Name in the Commonwealth of Pennsylvania, which is presently, I understand, undergoing regulatory review. As you know, the Allegheny County Health Department Board of Health made HIV reportable either by name or unique identifier approximately one year ago; since that time we have had over 700 case reports which were previously unknown to the Department. While many of these have been reported using a unique identifier, I feel very strongly that name reporting is far more prudent. The intent of reporting is not only to get an accurate count of the number of HIV-infected people in our region and ultimately, in Pennsylvania. This will help in grant applications for funding. But more importantly, it will ensure that people receive ongoing care, so critical in populations where health care is at a minimum.

One of the provisions of our Regulation is that we will survey the reporting physician or facility at three-month intervals to ensure that the person is still in care and if not, to try to make arrangement to get them back to the care giver. Obviously, trying to do this by unique identifier is impossible and we feel that this puts the burden back on the reporting physician who does not have either the skills or time to go out and locate patients who have dropped out of care. We also have some evidence that people who are newly-found to be HIV infected will get re-tested to ensure that the results are not spurious; this tends to inflate the numbers somewhat. Although technically, unique identifiers should eliminate this possibility, occasionally transposition of one or another of the digits in making unique identifiers result in over-reporting. I hasten to add that we have had no breaches in confidentiality in any of our reporting.

Lastly, although we have two sites which perform anonymous HIV testing in Allegheny County, we have not seen any increase in people seeking testing through those sources which would indicate to me that, generally, there is acceptance of reporting in our County. I feel that this would be reasonably well accepted in the Commonwealth as a whole.

It is long past time for the Health Department to treat HIV as any other reportable infectious disease; I encourage you to proceed as rapidly as possible to ensure that adequate reporting comes about in the Commonwealth.

Sincerely,

Bruce W. Dixon, M.D.
Director

BWD:bap

ALLEGHENY COUNTY HEALTH DEPARTMENT

3333 Forbes Avenue, Pittsburgh, PA 15213, (412) 578-8008, FAX (412) 578-8325

DIRECTOR, Bruce W. Dixon, M.D.

DATE: 6-11-02 **TIME:** 10:53

TO: Robert Nyce, Exec. Director

Agency: IRRC

Address:

FAX Number: 717-783-2664

FROM: Dr. Bruce Dixon, Director

ALLEGHENY COUNTY HEALTH DEPARTMENT

Address:

FAX Number: (412) 578-8325

Memo:

Total number of pages (including this sheet) 3

If you do not receive all pages, please notify Barbara as soon as possible at (412) 578-8008

The Circle of Care

ORIGINAL: 2185

260 South Broad Street
Suite 1000
Philadelphia, PA 19102-5076
215.985.2657
Fax: 215.732.1252

June 7, 2002

-7 PM 1:13

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101
(FAX 717 783-2664)

Dear Mr. Nyce:

I am writing to you to express grave concern over the proposed HIV name reporting system for Pennsylvania. While having a system for reporting HIV is extremely important for public health, implementing a name-based system, instead of a coded unique.identifier system, has a significant potential for undermining the intended public health objectives.

The Circle of Care is a network of 16 health care and social service organizations that have served over 1,200 HIV affected women, children, youth and families since 1989. Our focus on family-centered care, and HIV prevention, including perinatal prevention, has provided us with a perspective on how to effectively reach and engage individuals and communities in care.

Evidence from other states and service systems that have used names for reporting HIV, as well as our experience leads us to the conclusion that requiring names reporting will put up an immediate barrier for many who need HIV testing and who should be in care. Unfortunately HIV is still stigmatized and many individuals fear their name will be released, and that they will face discrimination. Regardless of the likelihood of these legal violations occurring, it is a persistent fear in many communities. This will serve as a significant barrier, and result in people not knowing they are HIV positive, and not getting into care until they are sick and present with symptoms.

I urge you and the other members of the IRRC to reject any plans for a HIV names-based reporting system, and ask that you direct the Pennsylvania Department of Public Health to develop a proposal for implementing a reporting system that uses unique identifiers. Women, children, youth and families in Pennsylvania who are at high risk of HIV will needlessly be faced with a barrier to care if HIV name-based reporting is allowed to proceed.

Sincerely,

Nurit Shein,
President of the Board

Alicia Beatty
Director

Original: 2185

IRRC

From: Arthur H. McTighe [amctighe@evanhospital.com]
Sent: Friday, June 07, 2002 6:16 PM
To: IRRC
Subject: disagree DOH proposal RE: mandatory reporting by name for HIV +

June 7, 2002

Mr. Robert E. Nyce

Executive Director

Independent Regulatory Review Commission

333 Market Street, 14th Floor
Harrisburg, Pennsylvania 17101
FAX: (717) 783-2664

RE: HIV names reporting proposed by Department of Health

Dear Mr. Nyce:

I disagree completely with the proposal by the Pennsylvania Department of Health to require mandatory reporting by name of those citizens who test positive for HIV antibodies. I believe that such a policy would be counterproductive and, in fact, would be literally dead wrong.

I am a physician and pathologist in practice in Lewisburg and in Sunbury, two semi-rural communities about an hour north of Harrisburg. I am the Director of Clinical Laboratories at both the Sunbury Community Hospital and the Evangelical Community Hospital. I am the Chairman of the Infection Control Committee at Evangelical Hospital and the immediate past Chairman of the Infection Control Committee at the Sunbury Hospital. At Evangelical Hospital I also hold the position of Vice President for Medical Affairs. I have more than 30 years experience in laboratory medicine and medical microbiology. In addition, I am board certified in pathology and in medical microbiology and am a member of the faculty of the Penn State University Medical School in Hershey.

We have had several people with AIDS in Lewisburg and Sunbury. For every one of these people with AIDS there are at least three or four other HIV-infected people. So, HIV/AIDS is not a problem from which Lewisburg and Sunbury are isolated.

Although many citizens of these communities are relatively enlightened and broad-minded, it is clear to me that people with AIDS here are subject to the same types of discrimination that are reported all over the country. They have lost their jobs and homes and have become isolated and shunned. Instead of compassion, they have been shown contempt and have been made the object of cruel jokes. It is this treatment that those who wonder if they might be HIV-infected particularly fear. They ask me to send their blood for testing under bogus names or invented ID numbers that only they and I can recognize.

For me to tell these people that I will have a legal obligation to report them to the government, **by name**, will simply dry-up testing. No one is served by such a policy. Not the HIV-infected patient who for optimal treatment should be diagnosed early, nor the sex partners of a person who does not know that he or she is already infected. To require reporting of HIV infection **by name** will actually help further spread HIV infection. It is for this reason that such a policy is literally dead wrong.

But if there is a need to have more accurate epidemiological information regarding the incidence of HIV infection, then adopt a system of unique identifiers for reporting, as has been done in Maryland, Illinois, California, and several other states.

It is also absolutely necessary to preserve the ability for me to test patients for HIV in a completely anonymous fashion, in the event that the patient will not otherwise consent to be tested. This cannot be limited to only selected Health Department sites.

I appreciate your consideration and trust that you will reject mandatory reporting of HIV infection status by name.

Sincerely,

Arthur H. McTighe, M.D.

Vice President for Medical Affairs and

Director of Laboratories at Evangelical Hospital

June 7, 2002

Mr. Robert E. Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, Pennsylvania 17101
FAX: (717) 783-2664

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Vice President for Medical Affairs
Director of Laboratories

Original: 2185

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Philadelphia Community Health Alternatives

Executive Director
Nurit Shein

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YEARS OF
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SERVICE

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Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Re: Opposition to Names Reporting for HIV Surveillance

Dear Mr. Hersh:

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By implementing reporting using unique identifiers instead of names, the Health Department can easily accomplish several essential goals at once: 1) the protection of people living with HIV, 2) effective tracking of the epidemic, and 3) increased funding from federal sources for prevention and treatment.

This is the time to demonstrate your leadership and vision. I urge you to do so. Thank you.

Sincerely,

Nurit Shein
Executive Director

June 2002

1201 Chestnut Street, Philadelphia, PA 19107 ■ 215-563-0652 ■ Fax: 215-563-0662 ■ www.pcha1.org
AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

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Sincerely,

Noelle E Sewell

PCHA Staff

June 2002

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Virginia Austin
PCHA Staff

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Sincerely,

Ray Brown

PCHA Staff

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Sincerely,

Ned J. Hammer
PCHA Staff

June 2002

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Nurit Shein

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Sincerely,

Deborah Washington
PCHA Staff

June 2002

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Sincerely,

Vivian Cooperman

PCHA Staff

June 2002

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Minerva Caro

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Steven M. Ach

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REVIEW COMMISSION

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Re: Opposition to Names Reporting for HIV Surveillance

Dear Mr. Hersh:

I am writing to oppose reporting the names of people with HIV to the Commonwealth as proposed by the Pennsylvania Department of Public Health.

I agree that the tracking of HIV is essential. Using names, however, will deter the most vulnerable and at-risk people from seeking testing and seeking care. I support, instead, the development of a non name-based HIV surveillance system to achieve the public health goals of HIV surveillance in Pennsylvania.

You should be aware that 95% of people testifying in public hearings you held around the state opposed names reporting. PCHA operates the largest HIV testing clinic in the city of Philadelphia, testing over 3000 individuals annually. All surveys conducted at our sites confirm that the practice of names reporting frightens people and deters them from getting tested and treated.

By implementing reporting using unique identifiers instead of names, the Health Department can easily accomplish several essential goals at once: 1) the protection of people living with HIV, 2) effective tracking of the epidemic, and 3) increased funding from federal sources for prevention and treatment.

This is the time to demonstrate your leadership and vision. I urge you to do so. Thank you.

Sincerely,

Erin Resnick

PCHA Staff
Sexual Health Clinic Coordinator

June 2002

1201 Chestnut Street, Philadelphia, PA 19107 ■ 215-563-0652 ■ Fax: 215-563-0662 ■ www.pcha1.org
AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

PCHA
Philadelphia Community Health Alternatives

2002 JUN -7 AM 11:15
REVIEW COMMISSION

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Executive Director
Nurit Shein

Re: Opposition to Names Reporting for HIV Surveillance

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Sincerely,

Melissa E. Sorey

PCHA Staff

June 2002

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AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original; 2185

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Philadelphia Community Health Alternatives

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Sincerely,

Sophear M. Fleet
PCHA Staff

June 2002

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AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

PCHA
Philadelphia Community Health Alternatives

Executive Director
Nurit Shein

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20
YEARS OF
DEDICATED
SERVICE

2002 JUN -7 AM 11:15
REVIEW COMMISSION

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

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Sincerely,

Anna Chappelle

PCHA Staff

June 2002

1201 Chestnut Street, Philadelphia, PA 19107 ■ 215-563-0652 ■ Fax: 215-563-0662 ■ www.pcha1.org
AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

EVANGELICAL
COMMUNITY HOSPITAL

Healthcare...
Above and Beyond

One Hospital Drive
Lewisburg, PA 17837

570.522.2000
FAX: 570.522.2745

www.evanhospital.com

June 7, 2002

2002 JUN 10 AM 7:21
REVIEW COMMISSION

Mr. Robert E. Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, Pennsylvania 17101
FAX: (717) 783-2664

RE: HIV names reporting proposed by Department of Health

Dear Mr. Nyce:

I disagree completely with the proposal by the Pennsylvania Department of Health to require mandatory reporting by name of those citizens who test positive for HIV antibodies. I believe that such a policy would be counterproductive and, in fact, would be literally dead wrong.

I am a physician and pathologist in practice in Lewisburg and in Sunbury, two semi-rural communities about an hour north of Harrisburg. I am the Director of Clinical Laboratories at both the Sunbury Community Hospital and the Evangelical Community Hospital. I am the Chairman of the Infection Control Committee at Evangelical Hospital and the immediate past Chairman of the Infection Control Committee at the Sunbury Hospital. At Evangelical Hospital I also hold the position of Vice President for Medical Affairs. I have more than 30 years experience in laboratory medicine and medical microbiology. In addition, I am board certified in pathology and in medical microbiology and am a member of the faculty of the Penn State University Medical School in Hershey.

We have had several people with AIDS in Lewisburg and Sunbury. For every one of these people with AIDS there are at least three or four other HIV-infected people. So, HIV/AIDS is not a problem from which Lewisburg and Sunbury are isolated.

Although many citizens of these communities are relatively enlightened and broad-minded, it is clear to me that people with AIDS here are subject to the same types of discrimination that are reported all over the country. They have lost their jobs and homes and have become isolated and shunned. Instead of compassion, they have been shown contempt and have been made the object of cruel jokes. It is this treatment that those who wonder if they might be HIV-infected particularly fear. They ask me to send their blood for testing under bogus names or invented ID numbers that only they and I can recognize.

For me to tell these people that I will have a legal obligation to report them to the government, **by name**, will simply dry-up testing. No one is served by such a policy. Not the HIV-infected patient who for optimal treatment should be diagnosed early, nor the sex partners of a person who does not know that he or she is already infected. To require reporting of HIV infection **by name** will actually help further spread HIV infection. It is for this reason that such a policy is literally dead wrong.

But if there is a need to have more accurate epidemiological information regarding the incidence of HIV infection, then adopt a system of unique identifiers for reporting, as has been done in Maryland, Illinois, California, and several other states.

It is also absolutely necessary to preserve the ability for me to test patients for HIV in a completely anonymous fashion, in the event that the patient will not otherwise consent to be tested. This cannot be limited to only selected Health Department sites.

I appreciate your consideration and trust that you will reject mandatory reporting of HIV infection status by name.

Sincerely,

Arthur H. McTighe, M.D.,
Vice President for Medical Affairs
Director of Laboratories

ORIGINAL: 2185

FAMILY
PLANNING
COUNCIL

Promoting Reproductive Health in Southeastern Pennsylvania

2002 JUN -7 PM 1:03
REVIEW COMMISSION

June 7, 2002

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101
(FAX 717 783-2664)

Dear Mr. Nyce:

I am writing to you to express grave concern over the proposed HIV name reporting system for Pennsylvania. While having a system for reporting HIV is extremely important for public health, implementing a name-based system, instead of a coded unique identifier system, has a significant potential for undermining the intended public health objectives.

The Family Planning Council is a network of providers with 85 clinic locations in 5 counties in Southeastern Pennsylvania. FPC providers see 123,000 women, men, and adolescents patients and provide over 10,000 HIV test per year. Our focus on integrating HIV prevention in family planning clinics has provided us with a perspective on how to effectively reach and engage individuals from many diverse communities in care.

Evidence from other states and service systems that have used names for reporting HIV, as well as our experience leads us to the conclusion that requiring names reporting will put up an immediate barrier for many who need HIV testing and who should be in care. Unfortunately, HIV is still stigmatized and many individuals fear their name will be released, and that they will face discrimination. Regardless of the likelihood of these legal violations occurring, it is a persistent fear in many communities. This will serve as a significant barrier, and result in people not knowing they are HIV positive, and not getting into care until they are sick and present with symptoms.

I urge you and the other members of the IRRC to reject any plans for a HIV names-based reporting system, and ask that you direct the Pennsylvania Department of Public Health to develop a proposal for implementing a reporting system that uses unique identifiers. Furthermore, I urge that the planned HIV reporting system also include a provision for laboratory and provider reporting to the Philadelphia Department of Public Health along with the Pennsylvania Department of Health, to insure accuracy of data collection methods.

Sincerely,

Dorothy Mann
Dorothy Mann,
Executive Director

SUITE 1000 • 260 SOUTH BROAD STREET • PHILADELPHIA, PA 19102-5076 • (215) 985-2600 • FAX (215) 732-1252
WWW.FAMILYPLANNING.ORG

Original: 2185

EMBARGOED MATERIAL

SAFE GUARDS

THE SAFEGUARDS PROJECT

A NEW DIRECTION ○ A HEALTHY FUTURE

June 7, 2002

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101
(FAX 717-783-2664)

Dear Mr. Nyce:

I am writing to you to express grave concern over the proposed HIV name reporting system for Pennsylvania. While having a system for reporting HIV is extremely important for public health, implementing a name based-system, instead of a coded unique identifier system, has a significant potential for undermining the public health objectives.

The Safeguards Project is a non-profit organization that promotes the health of men who have sex with men in Philadelphia. Our network's program promote behavior change, enhance community health awareness, encourage institutions to create healthier environments and advocate for social change that will foster positive health outcomes. We also provide foundation for our community health interventions and public advocacy work.

Evidence from other states and services systems that have used names for reporting HIV, as well as our experience leads us to the conclusion that requiring names reporting will put up an immediate barrier for many who need HIV testing and who should be in care. Unfortunately, HIV is still stigmatized and many individuals fear their name will be released, and that they will face discrimination. Regardless of the likelihood of these legal violations occurring, it is a persistent fear in many communities. This will serve as a significant barrier, and result in people not knowing they are HIV positive, and not getting into care until they are sick and present with symptoms.

I urge you and the other members of the IRRC to reject any plans for a HIV name-based reporting system, and ask that you direct the Pennsylvania Department of Public Health to develop a proposal for implementing a reporting system that uses unique identifiers. Women, children, youth and families in Pennsylvania who are at high risk of HIV will needlessly be faced with a barrier to care if HIV name-based reporting is allowed to proceed.

Sincerely,

Andrew Bills,
Executive Director

Original: 2185

Robert Nyce
Executive Director, 14th flr,
Harristown 2
Harrisburg, PA 17101

Regarding; 28 PA. CODE CH. 27, Reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV, 31 Pa.B. 2126,

Dear Mr. Nyce:

In regards to the Department's proposed regulations that would require **names reporting** of individuals who have tested positive to HIV, I would like to express my strong opposition to such measure. Alternative legislation has been proposed that suggests using a unique identifier instead of individual names. This system would more effectively balance the needs of the Center for Disease Control to have accurate epidemiological information with the privacy rights of the individual.

Several studies have shown that reporting of names will dissuade people from being tested. It is of utmost importance that as many at-risk people as possible are tested. Someone unaware of his/her HIV status may be more likely to infect others. In addition, early treatment has been effective at saving lives and reducing long-term health care costs.

It is no doubt important for the CDC to have as accurate information as possible in regards to infection rates. As 'names reporting' is likely to have a chilling effect on so-called confidential testing, infection rates will be underreported. It is quite possible that a system using a unique identifier has perhaps a greater rate of error (e.g. duplicate reporting) than a names reporting system. However, more people will be tested if they need not worry about the state being given their name. An infected person getting treatment is more important than the CDC being able to account for each one.

It also seems likely that such a system will be more expensive to administer, given that a 'names reporting' system is already in place (e.g. AIDS reporting). However, treatment of cases that were not tested due to names reporting will be more costly. We Pennsylvanians enjoy our privacy. We did not like the kids in school taking names on the blackboard, and we do not want our government doing it. A breach of this privacy and confidentiality should not occur merely to save a little money on creating a new reporting system for communicable diseases.

A few months before I got married in 1990, I was tested for HIV at an anonymous state operated site (I was lucky). Had there not been available an anonymous testing site, I would never have been tested. I understand that the plan is to keep the anonymous sites, but you should not underestimate the fear at-risk people have of public disclosure. The names reporting system will cost lives, public confidence, and treatment money.

Sincerely,

Thomas P. Duffin

2002 JUN -7 AM 8:45
REVIEW COMMISSION

Original: 2185

PCHA
Philadelphia Community Health Alternatives

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

2002 JUN -6 PM 2:30
REVIEW COMMISSION

Re: Opposition to Names Reporting for HIV Surveillance

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I agree that the tracking of HIV is essential. Using names, however, will deter the most vulnerable and at-risk people from seeking testing and seeking care. I support, instead, the development of a non name-based HIV surveillance system to achieve the public health goals of HIV surveillance in Pennsylvania.

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This is the time to demonstrate your leadership and vision. I urge you to do so. Thank you.

Sincerely,

Ray Brown

PCHA Staff

June 2002

1201 Chestnut Street, Philadelphia, PA 19107 ■ 215-563-0652 ■ Fax: 215-563-0662 ■ www.pcha1.org
AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

PCHA
Philadelphia Community Health Alternatives

Mr. Robert Nyce
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Independent Regulatory Review Commission
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Sincerely,

Virginia Austin
PCHA Staff

June 2002

1201 Chestnut Street, Philadelphia, PA 19107 ■ 215-563-0652 ■ Fax: 215-563-0662 ■ www.pcha1.org
AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

PCHA
Philadelphia Community Health Alternatives

2002 JUN -6 PM 2:30
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Executive Director
Nurit Shein

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Sincerely,

Noelle E Sewell

PCHA Staff

June 2002

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AIDS Task Force of Phila. ■ An Affiliate of United Way Southeastern Pennsylvania Donor #02304

Original: 2185

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2002 JUN -6 PM 2:30
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Sincerely,

PCHA Staff

June 2002

Original: 2185

PENNSYLVANIA COALITION OF
PCASO
AIDS SERVICE ORGANIZATIONS

June 6, 2002

Mr. John R. McGinley, Jr., Chair
Independent Regulatory Review Commission
333 Market Street
Harrisburg, PA 17101

via fax 717 783-2664, hard copy to follow, USPS Express Mail

Re: Final Rulemaking, HIV Reporting, 10-166

Dear Mr. McGinley:

On behalf of the Pennsylvania Coalition of AIDS Service Organizations (PCASO), our Board of Directors, members organizations,and consumers of their services, I am writing to express our concern with the final form proposed draft regulations on HIV reporting currently before the Independent Regulatory Review Commission (IRRC).

Though there are myriad issues of detail raised in our initial correspondence with the Department and IRRC that have not been addressed in this final iteration of these regulations, our major concerns lie with two elements of the regulation; the intent of the Department to collect names and much additional identifying information for those testing positive for HIV; and the intent of the Department to conduct "public health interventions" with individuals who have tested positive for HIV, but are not known to be in active care.

Since the beginning of dialogue with the Department of Health many years ago, we have opposed reporting the names of people with HIV to the Commonwealth for the reason that there was, and remains, significant evidence pointing to a potential deterrent effect for individuals to seek HIV testing, diagnosis and subsequent care. Here, the peer reviewed publications to date are evenly split as to the potential for deterring individuals from testing. Accordingly, we strongly believe it is a mandate to the Commonwealth to err on the side of caution and develop a non name-based HIV surveillance system to achieve the public health goals of comprehensive HIV surveillance in Pennsylvania, modeled on those used successfully in other states.

Though it can be argued that this deterrent effect may ultimately be limited to relatively small numbers of people, they are, in many cases, individuals who are at the greatest risk of HIV infection given patterns of transmission of recent years--those engaging in injecting drug use (and by association, their sexual partners and children), the undocumented, and those others fearing "government" reprisal, e.g., young mothers, fearful, however irrationally, of losing their children.

Any surveillance tool with the potential to deter those who we most seek to diagnose, treat, and educate about potential for further transmission to others is ineffective, and not in the interests of the public health. At a time when other state have been successful in implementing systems of HIV reporting utilizing "unique identifiers," offering all the data collection abilities without the negative consequences, it seems the logical choice.

Similarly, in the Department's statement of intent to provide "public health interventions" to those known to have tested positive for HIV but are not known to have entered care, it is assumed that the presence of a Department of Health employee on someone's doorstep will result in their entering a lifetime commitment to the remarkably expensive, often grueling pharmacological regimens currently prescribed for HIV infection, and their associated side effects. In this assumption, the Department fails to understand the complexity of the lives of individuals most likely to test positive for HIV.

Today, well in excess of 50% of those currently being diagnosed with HIV are living in poverty with significant mental health problems, active addiction, and often, no means of accessing or paying for healthcare, either privately or through publically supported programs. To assume that a "housecall" will cure these ails is incomprehensible. Further, to fail to address issues of mental health and addiction in advance of HIV is often to invite failure; HIV is not the most pressing health issue in many circumstances, and an individual must make an informed and timely decision to enter into care when they are ready to actively participate in it.

This proposed methodology, as described only in the preamble of the draft regulation and most recently in the Department's "questions and comments," appears to be borrowed from established "shoe leather epidemiology" protocols for addressing outbreaks of syphilis, gonorrhea or tuberculosis--conditions readily treated with a short course of antibiotics. To take a disease with as complex an impact on the body and an equally complex treatment regimen as HIV, and try to "fix" it with an intervention designed for far more simple infections is, at best, facile, and fails to recognize the Department's limited resources and capacity of personnel.

The Department would be better off limiting its efforts towards gleaning the best data possible at this time, while supporting interventions at the community level.

In closing, it should be noted that a number of neighboring states have made the decision to adopt a system of HIV reporting based on names. Despite the appearance of these transitions as having been successful, there have been a number of problems, particularly around issues of privacy and associated deterrents. FYI, I attach a letter from the members of the New York State General Assembly and Council of the City of New York, to the PA Secretary of Health cautioning the Department on this proposed regulation.

I look forward to seeing you and your colleagues deliberate on this critical issue.

Sincerely,

Bruce W. Flannery
Executive Director

/attachment

Original: 2185

June 5th, 2002

Dear Mr. Nyce,

Thank you for faxing the materials on names reporting. Please do let me know the vote of the June 13th meeting.

Very Sincerely

Tim Cwiek

Timothy Cwiek
Phila. Gay News
Phone (215) 625-8501 x. 208
Fax (215) 925-6437

Original: 2185

2002 JUN -4 PM 2:54
REVIEW COMMISSION

Germantown Settlement/WISDOM
Computer Center and Library
#16 East Wister Street
Philadelphia, Pa.19144-2318
(215) 991-6550

To: Mr. Robert Nyce – fax# - 1-717-783-2664
Independent Regulatory Review Commission

Re: Action Alert : Pa. Names Reporting

Pennsylvania has been gearing up to start statewide reporting of HIV cases. Currently only AIDS and not HIV is a reportable condition in the Commonwealth. Mandatory HIV names reporting would be a public disaster and unnecessarily dangerous.

The undersigned petitioners are against Pennsylvania name reporting;

1 Treva Dantzler
2 Kelly Davis
3
4
5 Alvesta Graves
6
7 Karen
8 Porter Campbell
9
10
11
12
13 Allen Scott

To: Mr. Robert Nyce – fax# - 1-717-783-2664 (#2)
Independent Regulatory Review Commission

14 Jacephine Plummer
15 Tone White
16 Linda Smith
17 Jonny Jones
18 Michael Porterfield
19 Robert Sanders
20 Donzell Coleman
21 Regina Goldman
22 Bobby Burks
23 Frederick Goady Early
24 Emma Taylor
25 Samuel Jynes
26 CHarles Carson
27 Harry Faison
28 Jackson Browne
29 Leon Jackson
30 Kayla Frances

Original: 2185

NORTH CENTRAL PHILADELPHIA HEALTH COALITION
"ADVOCATES FOR MINORITY HEALTH ISSUES"

Coordinators
Denise Pride
Project Development Manager

Tyrone Smith
HIV/AIDS Consultant

Members
BEBASHI (Blacks Educating Blacks
About Sexual Health Issues)
Calcutta House
Circle of Care
City Wide Youth Agency
Gaudenzia House
HOPE *Clinic*
Hunting Park Health Center
Maternity Care Coalition
Minute By Minute
One Day At A Time
SILOAM
STOP (Sobriety Through Out-Patients)
Stop And Surrender
The Right Foundation
Women's Christian Alliance
Women's Initiative for Family Health
YOACAP (Youth Outreach Adolescent
Community Awareness Program)

Coalition Email:
NCPHCoalition@aol.com

"Protecting Our Future"

2002 JUN -7 PM 1:49
REVIEW COMMISSION

June 6, 2002

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

RE: HIV Names Reporting

Dear Mr. Nyce:

On behalf of the *North Central Philadelphia Health Coalition*, we are contacting you to express our strong opposition to the proposed names reporting of HIV and CD4 count.

Although we understand the intent is to gather more accurate information regarding the complete picture of HIV/AIDS infections, we also understand how much of a deterrent it will be to people coming forward to get testing.

Collectively, we have many years of experience in counseling, testing and outreach. We are confronted with the challenge of convincing people to get tested and treated everyday. And we witness the response to "anonymous" testing versus "confidential" HIV testing. Individuals are known to have given false information in an effort to hide their true identity during *confidential* testing or refuse to be tested at all. Testing is one of our most effective weapons against the spread of this disease. We need to find more creative ways to encourage testing, not discourage testing…as *names reporting* will certainly do.

The *North Central Philadelphia Health Coalition* urges you to abandon the idea of a name-based reporting system. We do, however, encourage you to consider using a code-based system by developing a unique-identifier for tracking purposes as other states have already successfully accomplished.

Sincerely,

Denise Pride
Denise Pride
267-918-8942
Project Development Manager

Tyrone Smith
Tyrone Smith
215-851-1876
HIV/AIDS Capacity Building Consultant

c/o Greater Philadelphia Urban Affairs Coalition
1207 Chestnut Street, Suite 217
Philadelphia, PA 19107-4102

c/o North Philadelphia Chamber of Commerce
800 West Montgomery Avenue
Philadelphia, PA 19122

Radio Address By Mayor John Street

HIV Reporting: Use of Names is Unnecessary (www.phila.gov/radio/addresses)

5/26/01

Good morning. This is Mayor John Street. More than 6,200 of our neighbors -- more than 6,200 Philadelphians -- have died of AIDS. More than 7,000 Philadelphians are currently living with AIDS. We must end this epidemic. And early detection of those who are HIV-positive is essential to this cause.

There is nothing more critical to the prevention of AIDS than ensuring that those who are at risk seek immediate HIV testing. There is nothing more critical to reducing the mortality rate from AIDS than ensuring that individuals at risk seek immediate HIV testing. It is therefore imperative to avoid policies that would compromise early detection by making citizens reluctant to be tested for the HIV virus.

Recently, the Commonwealth of Pennsylvania proposed a new public health initiative. The State wants to include names in reporting persons infected with HIV.

There is no question that the state has a legitimate interest in collecting statistical and demographic information on people living with HIV. And there is no doubt that aggressive and comprehensive information-gathering is the foundation of enlightened public health initiatives that address the AIDS crisis. The use of names, however, is unnecessary. In fact, the inclusion of names hinders efforts to obtain reliable data and may even produce distorted data. In order to protect their privacy, people omit or delay HIV testing. An under-count of existing HIV cases is the inevitable result.

The State's policy, if enacted, would be a deterrent. When names are introduced, fewer people choose to be tested. Fewer people are treated. The predictable consequence is an increase in the incidence of both HIV and AIDS. The use of names in HIV reporting is counter-productive.

There is an alternative to name-based reporting. Our city has used it for years -- and used it effectively. Code-based reporting is a system in which a computer-generated set of symbols identifies individuals and protects their privacy. This set of symbols conveys demographic information, thereby making it possible to target appropriate public health services to individuals in those neighborhoods most affected by AIDS and HIV. Each year, our AIDS Activities Coordinating Office arranges 30,000 HIV tests at 40 sites across the city. The process is strictly confidential, and it's been highly successful.

Enlightened public health policy must encourage all our citizens to do everything possible to keep themselves healthy. Judged by this measure, name-based HIV reporting falls short of the mark. We can do better, and I'm confident we will.

It is my hope that in the coming months, we will be able to engage in some serious dialogue with the state government on the topic of HIV reporting. I believe we can work together to craft a mutually agreeable policy, a policy that promotes accurate data collection while also protecting the privacy rights of all of our citizens.

From City Hall, this is Mayor John Street. Please let me hear from you at www.phila.gov. Enjoy your long weekend. Go Sixers. And don't forget to drink your water.

For the recorded version of Mayor Street's address visit KYW Newsradio's website, www.kyw1060.com

FAMILY
HEALTH
COUNCIL
of Central Pennsylvania, Inc.

Cindy Groff
President and CEO

Original: 2185

RECEIVED
2002 JUN -5 AM 8:56
INDEPENDENT REGULATORY
REVIEW COMMISSION

Suite 200, 3461 Market Street
Camp Hill, Pennsylvania 17011-4441

717/761-7380 • Fax: 717/763-4779
http://www.fhccp.org

Joint Commission Accredited

June 4, 2002

Robert Nyce, Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Dear Mr. Nyce:

The Family Health Council of Central Pennsylvania, Inc., appreciates the opportunity to submit comments regarding the Pennsylvania Department of Health's final rulemaking regarding reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV.

The comments are enclosed. Thank you for your consideration.

Sincerely,

Cindy Stewart

Cindy Stewart
President and CEO

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COMMENTS OF

THE FAMILY HEALTH COUNCIL OF CENTRAL PENNSYLVANIA, INC.

REGARDING

THE PENNSYLVANIA DEPARTMENT OF HEALTH
FINAL RULEMAKING
REPORTING OF AIDS, HIV TEST RESULTS, CD4 T-LYMPHOCYTE COUNTS AND PERINATAL EXPOSURE OF NEWBORNS TO HIV

JUNE 4, 2002

The Family Health Council of Central Pennsylvania, Inc., (FHCCP) welcomes the opportunity to comment on the Department of Health's re-draft of regulations regarding reporting of HIV test results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV. And we note that a number of the concerns we registered when the draft regulations were initially issued remain.

FHCCP is an HIV/AIDS contractor with the Department of Health and the fiscal agent for the AIDS Planning Coalition of South Central Pennsylvania. FHCCP also holds an HIV/AIDS related contract with the Philadelphia Department of Health. In addition, FHCCP holds multiple federal and state contracts, including family planning, the Supplemental Nutrition Program for Woman, Infants and Children (WIC), the HealthyWoman Project and chlamydia.

FHCCP supports the reporting of individuals who test positive for HIV, believing that it is imperative to have data on the prevalence of HIV/AIDS in order to track the disease, address unmet needs, target prevention efforts, and assure continued federal funding.

However, FHCCP would like to register concern regarding the Department's intent to require name reporting of HIV-infected individuals. While we are aware of and commend the Department's sterling record on protecting confidentiality, we remain concerned about any increased potential for a breech of confidentiality and the resultant discrimination that HIV-infected individuals might face.

One significant concern is how this regulation will affect previously tested persons already in care and assure the confidentiality of their medical records. We would ask that the Department clarify how follow-up of HIV-infected persons will occur under a system of names-based reporting, and how confidentiality will be protected and/or improved. Partner notification further complicates confidentiality protection. How will this be handled?

We are encouraged by the Department's intent to ensure anonymous testing in order to encourage individuals to be tested who might otherwise refuse testing. However, we believe that for this to be effective the Department will need to actively promote the availability of anonymous testing so that those who are concerned about having their names reported may be aware of this option.

In addition, we are concerned that there be adequate test sites so that access to anonymous testing will not be an issue. We believe a minimum of one per county, and more in areas in which there is a significant high-risk population, is advised. We would ask that the Department clarify its plans with regard to publicizing anonymous testing and ensuring adequate sites.

FHCCP also requests clarification from the Department about its plans to require reporting of perinatal exposure of a newborn to HIV. Will all newborns be tested? Will the mothers be tested as well? When? Is it the intent of the Department to implement mandatory testing of pregnant women and/or newborns? How will confidentiality be ensured throughout any follow-up process? The lack of clarity in this section raises many questions and concerns and we seek clarification from the Department regarding its intent.

We thank the Department for its consideration of these concerns and look forward to a response.

BEBASHI

Original: 2185

2002 JUN -6 PM 12:49
REVIEW COMMISSION

June 4, 2002

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

Dear Mr. Nyce:

The purpose of this letter is to express our opposition to Names-Based HIV reporting in the Commonwealth of Pennsylvania. While we recognize the need for HIV reporting, in order to maintain a true picture of the AIDS/HIV epidemic, we believe that Names-Reporting may create several undesirable consequences that will have a disproportionate impact on those most at risk: low income minorities.

BEBASHI has been on the front lines of the war against AIDS since 1985. Last year, our prevention programs in schools, shelters, churches and drug treatment programs; our anonymous HIV and STD testing programs; our counseling programs for women, adolescents and substance abusers; our case management programs helping people living with HIV to obtain medical care, housing and cash assistance and; our support groups and emergency food cupboard reached over 14,000 people.

There are several reasons for our opposition to Names-Reporting:

- There is a reliable and effective alternative to names reporting: Unique-Identifier reporting;
- Names-Reporting will not increase medical or geographic information for planning purposes. Rather, it is merely a system for labeling the information;
- Unique-Identifier reporting has been shown to generate higher and more honest risk data than names reporting;
- At least ten (10) other states have adopted the Unique-Identifier system;
- A Unique-Identifier system meets the CDC (Centers for Disease Control) criteria for effective reporting; CDC risk data was reported in only 59% of the case reports using a Names-Reporting system. Conversely, Illinois and Maryland, two states that use a Unique-Identifier system, reported risk information in 74% and 77% of their cases respectively;
- Over 90% of the people who testified in the Commonwealth's public hearings spoke against Name- Reporting;
- The Integrated Planning Council of the Department of Health recommended a Unique-Identifier system.
- And, the most important reason for our opposition to Names-Reporting is that surveys that have been conducted of individuals seeking or considering HIV testing have demonstrated that Names Reporting may be a deterrent to people getting tested.

Using **names** to label HIV cases defeats the purpose of maintaining better HIV statistics if fewer people get tested. Fewer people getting tested for HIV will translate to higher medical costs as people may only seek treatment when they are already ill.

It is estimated that as many as one third of the people who are infected with HIV, may not know it. As a provider of HIV testing as well as services that link low income HIV+ people into medical care, it has been difficult to convince people of the need for HIV testing. One of our most potent weapons is the availability of anonymous testing. Anything that limits access to people for anonymous testing or sends a message to them that their confidentiality may be compromised, real or imagined may discourage the people who are most at risk from being tested. Moreover, they may continue to infect others with HIV if they do not know that they are infected.

1217 Spring Garden Street • 1st Floor • Philadelphia, PA 19123 • 215-769-3561 • Fax: 215-769-3860
www.bebashi.org

BEBASHI

We need to develop new, creative ways to encourage people, especially low income minorities who may be more cynical of the government and/or medical system, to get tested-not discourage them.

I urge you to say **NO to Names-Based HIV reporting** and encourage the adoption of a unique identifier system that has proven to be more effective. Thank you in advance for your consideration.

Sincerely,

Gary J. Bell
Executive Director

BEBASHI

FAX

DATE: June 6, 2002

TO: Robert Nyce **FAX:** 717-783-2664

BEBASHI
1217 Spring Garden St. 1st Floor
Philadelphia, PA 19123
(215) 769-3561 * FAX: (215) 769-3860

FROM: Gary J. Bell

RE:

☐URGENT ☐FOR REVIEW ☐ PLEASE COMMENT/REPLY ☐ FYI Only

- **Comments:**

Mailed under separate cover.

Disclosure Statement

This statement has been disclosed to you from records Protected by federal confidentiality rules 42CFR part 2. The federal rules prohibit you from making and further disclosures of this information unless permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42CFR part 2. A general authorization for the release of medical or other inform is NOT sufficient for this purpose. The federal rules restrict any use of this information to criminally investigate or prosecute any patient.

FAMILY HEALTH COUNCIL
of Central Pennsylvania, Inc.

Cindy Groff
President and CEO

Suite 200, 3461 Market Street
Camp Hill, Pennsylvania 17011-4441

717/761-7380 • Fax: 717/763-4779
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2002 JUN -4 AM 9:24
INDEPENDENT REGULATORY
REVIEW COMMISSION

Original: 2185

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Independent Regulatory Review Commission
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Sincerely,

Cindy Stewart

Cindy Stewart
President and CEO

Improving the Health of Women & Families

FAMILY
HEALTH
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of Central Pennsylvania, Inc.

Cindy Groff
President and CEO

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Camp Hill, Pennsylvania 17011-4441

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REGARDING

THE PENNSYLVANIA DEPARTMENT OF HEALTH
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FAMILY
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of Central Pennsylvania, Inc.

Suite 200, 3461 Market Street, Camp Hill PA 17011-4441

FAX

PHONE: 717-761-7380
FAX: 717-763-4779

Date: 6·4·02

pages including this one.

Phone:
FAX:
TO: Robt. Nyce

FROM: Olivia Surkop

REMARKS:

Comments

Hard copy to follow

Original: 2185

BEBASHI

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2002 JUN 11 AM 9:18

INDEPENDENT REGULATORY
REVIEW COMMISSION

June 4, 2002

Mr. Robert Nyce
Executive Director
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

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Sincerely,

Gary J. Bell
Executive Director

EP. LeANNA M. WASHINGTON, CHAIRWOMAN
ROOM 128 SOUTH OFFICE BUILDING
HARRISBURG, PENNSYLVANIA 17120-2020
PHONE: (717) 772-6956
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DANA SHAW
REGIONAL EXECUTIVE DIRECTOR

THE PENNSYLVANIA LEGISLATIVE BLACK CAUCUS

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VICE CHAIRMAN

SEN. SHIRLEY KITCHEN
SECRETARY

REP. JEWELL WILLIAMS
TREASURER

Pennsylvania General Assembly
COMMONWEALTH OF PENNSYLVANIA
HARRISBURG

Pennsylvania Legislative Black Caucus

2001 – 2002

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February 6, 2001

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Oliver, Frank L. District 195 Philadelphia County	34, East Wing Seat #200 (717)787-3480 Daisy Latham (717)773-0684 – fax	2839 West Girard Ave. Philadelphia, PA 19130 (215)684-3738 – office Michelle Brownlee (215)235-4629
Preston, Joseph, Jr. District 24 Allegheny County	332A, South Office Bldg. Seat #151 (717)783-1017 Tawna Bauer (717)787-7520 –fax	6203 Penn Avenue Pittsburgh, PA 15206 (412)361-3692 – office Saundra Roberts (412)665-5501 – fax
Robinson, William Russell District 19 Allegheny County	320, South Office Bldg. Seat #9 (717)787-9460 Gail Gingrich (717)772-9997 – fax	2203 ½ Wylie Avenue Pittsburgh, PA 15219 (412)471-7760 – office Shirley Lawson (412)471-8056 – fax
Roebuck, James R., Jr. District 188 Philadelphia County	210, South Office Bldg. Seat #203 (717)783-1000 Sonia Terech (717)783-1665 – fax	4800 Baltimore Avenue Philadelphia, PA 19143 (215)724-2227 – office Curtis Jones (215)724-2230 – fax
Thomas, Curtis W. District 181 Philadelphia County	326, South Office Bldg. Seat #146 (717)787-9471 Jeannie White-Porter (717)787-7297 – fax	1348 West Girard Avenue Philadelphia, PA 19123 (215)232-1210 – office Barbara Peek (215)232-1203 – fax

Washington, LeAnna M. District 200 Philadelphia County	126, South Office Bldg. Seat #150 (717)772-6955 Cynthia Bellamy (717)783-8724 – fax	1555-D Wadsworth Avenue Philadelphia, PA 19150 (215)242-0472 – office Jamal Weaver (215)753-4538 – fax
Waters, Ronald G. District 191 Philadelphia/Delaware Counties	103, South Office Bldg. Seat #185 (717)772-9850 April James (717)787-7597 – fax	6027 Ludlow Street, Unit A Philadelphia, PA 19139 (215)748-6712 – office (215)748-1687 – fax
Williams, Anthony District 8 Philadelphia County	366, Main Capitol Bldg. Seat # 18 717)787-5970 Linda Sanders (717)772-0574 – fax	5008 Baltimore Avenue Samuel J. Patterson Mercy Wellness Ctr, 2nd Floor Philadelphia, Pa 19143 (215)748-6811 – office Lana Watkins (215)644-0660 – fax
Williams, Jewell District 197 Philadelphia County	104, South Office Bldg. Seat # 148 (717)772-2004 Tajuanna Wallace (717)787-7597 – fax	2224 N. Broad Street Philadelphia, PA 19132 (215)763-2559 – office (215)763-2561 - fax
Youngblood, Rosita C. District 198 Philadelphia County	121A, East Wing Seat #165 (717)787-7727 Rose Kepp (717)705-2087 – fax	5736 Greene Street Philadelphia, PA 19144 (215)849-6426 – office Rodnie Jamison (215)849-5476 – fax

Introduced by Councilman Angel L. Ortiz
Resolution No. 010405
Original: 2185

..Title

Urging the City of Philadelphia and the State of Pennsylvania to support and utilize a non name-based surveillance systems of HIV reporting and, if needed, for the City of Philadelphia to not comply with a proposed name based HIV reporting system.

..Body

WHEREAS, Non name-based surveillance systems, such as unique identifier reporting, support our public health goals by providing data which can help us allocate limited resources while supporting efforts to target and evaluate prevention programs, project the direction of the epidemic, while assuring anonymity and not deterring people from seeking HIV testing and care; and

WHEREAS, The state administration has proposed mandatory state wide name based reporting for HIV positive individuals and in the absence of guaranteed access to health care and strong privacy protections, the negative aspects of name reporting outweigh the potential benefits of this approach; and

WHEREAS, HIV name reporting has been shown to be a deterrent to individuals seeking HIV testing and treatment, and the implementation of HIV name reporting is not currently accompanied by guaranteed access to care and treatment; and

WHEREAS, Philadelphia's refusal to comply with the names based HIV reporting will apply pressure upon the State to rethink their HIV surveillance proposal and develop a plan consistent with the pronounced needs of its citizens; and

WHEREAS, Throughout Pennsylvania, citizens who submit to HIV testing should be entitled to anonymity. The consequences of a consumer's HIV status becoming public should be a concern to all citizens of Philadelphia. Rural, Suburban and Urban Pennsylvanians could all face physical and emotional harm if their status became publicly known; and

WHEREAS, It is paramount that concerned citizens have access to HIV testing without any unnecessary impediments or delays. Early detection of HIV leads to more effective prevention strategies and treatment possibilities. Studies have shown that mandatory HIV names reporting would result in fewer individuals being tested, including a 1995 Los Angeles study which found that 86.1% of respondents would not have sought an HIV test if they knew their names were going to be reported to a governmental agency. Names based surveillance will force many consumers to delay HIV testing and/or disregard HIV testing further endangering their health; and

WHEREAS, Other than Pennsylvania's Act 148 (35 P.S. §7601 et. seq. concerning the confidentiality of HIV-related information), no strong Federal or state privacy law governing health information currently exists; and

WHEREAS, Recent court decisions suggest limited or no discrimination protections for asymptomatic HIV positive individuals under the American with Disabilities Act (ADA); now therefore

RESOLVED, THAT THE COUNCIL OF THE CITY OF PHILADELPHIA, Supports the development of a non name-based HIV surveillance system to achieve the public health goals of HIV surveillance and urges the City of Philadelphia to not comply with a proposed name based HIV reporting system.

FURTHER RESOLVED, That the City of Philadelphia calls on the Federal Government and Commonwealth to provide the resources necessary to support Philadelphia's non name-based surveillance systems. That the City of Philadelphia calls on the Bush and Ridge Administrations, the United States Congress and the Pennsylvania State Legislature, to enact and enforce strong confidentiality laws to protect the privacy of all health-related information.
..End

Adopted May 24, 2001

FAX

Office of Councilman Angel L. Ortiz
City Hall, Room 590
Philadelphia, PA 19107

Date June 4, 2002

Number of pages including cover sheet ___

To:

Robert Nyce
Independent Regulatory
Review Commission

Phone
Fax Phone
CC:

From:

Philadelphia Councilman
Angel ortiz

Phone **215.686.3420**
Fax Phone **215.686.1930**

RLMARKS:

☒ Urgent ☐ For your review ☐ Reply ASAP ☐ Please comment

Please consider Philadelphia City Council's Unanimously passed Resolution against 'names reporting.'

Original: 2185

Mr. Robert Nyce, Executive Director,
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

(FAX 717 783-2664).

Dear Mr Nyce,

As a concerned citizen of the State of Pennsylvania, I am opposed to Names reporting because it will discourage people at greatest risk from seeking testing and counseling and getting into care.

Please consider my opinion when voting on this issue on June 13th.

Sincerely,

Jerry O'Neill