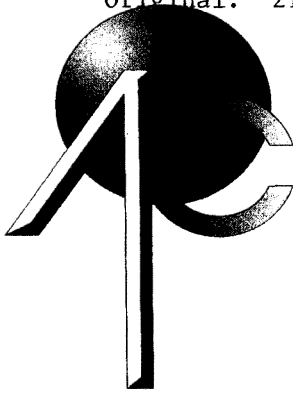


Original: 2185



RECEIVED
BUREAU OF EPIDEMIOLOGY
01 MAY 21 11:11:55

May 17, 2001

PHILADELPHIA AIDS CONSORTIUM
2001 MAY 31 AM 9:27

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

Dear Mr. Hersh:

The Philadelphia AIDS Consortium welcomes the opportunity to submit comments on the Department of Health's proposed regulations regarding reporting of HIV/AIDS.


Enclosed, please find an official position as passed unanimously by the Consortium's Board of Directors at its February 20th meeting of 2001.

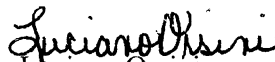
The Consortium has historically opposed any and all names reporting of HIV/AIDS cases due to multiple factors and concerns including but not limited to: 1) integrity and confidentiality of data; and, 2) societal and economic stigma and prejudice uniquely associated with this virus.

However, due to technological advances in securing client specific DBases and initial shifts in public awareness of this disease, the Board of Directors updated its position on names reporting to reflect current trends and needs.

While the Consortium applauds the Department's initiative to make HIV/AIDS reporting accurate and up to date, we strongly believe that a Unique Identifier Reporting system best accomplishes this objective with no ill effects, systemically or statistically. Additionally, we believe that a modified Unique Identifier Reporting system is the *only* known method that prevents barriers to clients accessing and receiving care.

Thank you for the opportunity to share our concerns with you as stated in the attached position. If we can be of any further help or assistance in your assessment of the proposed regulations, please call me directly at 215.985.6200; ext. 306.

Sincerely,

Larry Hochendoner
Executive Director


Luciano Orsini
Board President

cc: Board Membership; Senior Staff

PHILADELPHIA AIDS CONSORTIUM
260 South Broad Street • Suite 1320 • Philadelphia, PA 19102
Phone: 215•985•6200 Fax: 215•985•6212



DEPARTMENT OF HEALTH
BUREAU OF AIDS
01 MAY 21 10:11:55

The Philadelphia AIDS Consortium
Official Position Paper
As Adopted By the Board of Directors February 20, 2001

NAME BASED HIV REPORTING IN PENNSYLVANIA

The Philadelphia AIDS Consortium is the Commonwealth of Pennsylvania's HIV Services Planning Coalition and fiscal agent for the five counties of southeastern Pennsylvania. In its role as Planning Coalition, the AIDS Consortium's consumer driven board of directors is responsible for ensuring that infected and affected members of the community are represented in all fiscal and planning activities, and as a result the Consortium has become one of the only places in the region where a Consumer's voice can truly be heard. **The Philadelphia AIDS Consortium's primary goal is to represent the needs and protect the interests of persons infected and affected by HIV and AIDS in southeastern Pennsylvania.**

Furthering this goal, the Philadelphia AIDS Consortium is in support of a client specific reporting system for HIV/AIDS consumers. This practice, already adopted by many states in the nation, is one that will enable the Commonwealth to better serve those participants diagnosed with HIV and to better predict where resources are most needed.

The Philadelphia AIDS Consortium supports names reporting as an application of a client specific identifier system in those phases of our long established continuum of care where it is most appropriate and effective.

Specifically, TPAC supports names reporting in the secondary and tertiary levels of client care to expedite and standardize client specific reporting. However, in primary levels of care; i.e., testing, counseling and prevention, TPAC strongly urges that a unique identifier system be used. Instituting a continuum of reporting that mirrors the continuum of care, is a win win proposition for both the client and public health management systems.

By using unique identifiers we protect clients at their most vulnerable time of testing, eliminating multiple barriers to effective diagnosis and counseling. By using names reporting we strengthen our public health systems delivery of medical services.

As a client specific reporting system in the initial phase of HIV/AIDS continuum of care, unique identifiers provides the best, most precise data available, ensuring credible elements for planning thereby capturing maximum funding resources.

As a client specific reporting system in delivering direct medical and respite care in the HIV/AIDS continuum of care, names reporting allows medical professionals to treat HIV/AIDS clients in the same manner as clients treated for all other communicable diseases, providing the same standard and quality of care afforded all consumers of health care.

PHILADELPHIA AIDS CONSORTIUM
260 South Broad Street • Suite 1320 • Philadelphia, PA 19102
Phone: 215•985•6200 Fax: 215•985•6212

Original: 2185

PA Academy of Family Physicians Fax Cover Sheet

Pennsylvania Academy of Family Physicians
2704 Commerce Drive, Suite A, Harrisburg, PA 17110-9365
Phone: (717) 564-5365 or 1-800-648-5623 - FAX: (717) 564-4235

Tar Wars:

PA Family Physicians Strike Back

The Academy and Foundation are working together to educate Pennsylvania's youth about the health risks of tobacco use. We challenge each Academy member to take one-hour of one day to visit a local 4th - 5th grade class during the 2000-2001 school year to make a **TAR WARS** presentation.

Call 1-800-TAR-WARS to obtain the Tar Wars curriculum packet.

TO: Joel H. Hersh
Director, Bureau of Epidemiology

FAX #: 717-772-6975

FROM: Andrew Sandusky, Legislative Specialist

DATE: May 17, 2001

RE: Comments on proposed HIV reporting regulations.

MESSAGE:

Mr. Hersh:

Please find attached a letter detailing the Academy's position on the proposed regulations on HIV reporting. Additionally, please be advised that a hard copy has been mailed today.

Should you have any questions or concerns, please do not hesitate to contact me.

Sincerely,
Andrew

RECEIVED
MAY 17 2001
MAY 17 2001
MAY 17 2001

Transmitting **3** pages including this one.



Pennsylvania Academy of
FAMILY PHYSICIANS

President
Kevin P. Shaffer, MD
Eric

May 17, 2001

President-Elect
Mark D. Burd, MD
Danville

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

Vice-President
Paul D. Williams, DO
Harrisburg

Treasurer
Ronald J. Buckley, MD
Allentown

Immediate Past President
Christine M. Stabler, MD
Lancaster

Executive Vice President
John S. Jordan

Dear Mr. Hersh:

I am writing on behalf of the over 4,700 members of the Academy of Family Physicians in support of the proposed regulations to require confidential name-based reporting for HIV positive cases, abnormal CD4 counts and prenatal exposure.

In formulating this position of support, the Academy investigated several significant elements of the proposed regulations with the overarching question being, "How will this regulation benefit our patients?" The Academy looked to the CDC and its guidelines as enumerated in MMWR 1999;48 (No. RR13) "Guidelines for HIV case surveillance, including monitoring for HIV infection and AIDS," as the standard in requiring "name-based" reporting as opposed to a unique identifier method. The Academy believes that the Department will use every mechanism available to ensure confidentiality of reporting the conditions as described in the regulations, as it has done successfully thus far in the reporting of AIDS patients.

The Academy also based its support on the inclusion of §27.32a - Confidential and Anonymous Testing, as written in the proposed regulations. Allowing for anonymous testing in state-designated anonymous testing sites was a concern of many Academy members and we are happy to see that the Department has recognized this crucial element.

Finally, Academy members are confident that the Department will use named-based reporting as a mechanism to provide it and local health departments with enhanced opportunities to provide case management services to our patients. The Academy is further confident that named-based requirements will be used with the goal of getting patients more services and tracking those services as a quality of care issue, without fear of breach of confidentiality.

Thank you for giving the Academy an opportunity to address the Department on this significant public health policy. We look forward to working with you as this proposal

RECEIVED
MAY 17 2001
12:49 PM
PA ACADEMY AND FOUNDATION

moves through the regulatory process. Should you have any questions or concerns on the Academy's position, please do not hesitate to contact me at 814-833-5653.

Sincerely,



Kevin P. Shaffer, MD
President

cc: **Robert S. Zimmerman, Jr., Secretary of the Department of Health**
Academy Board of Directors
Academy Public Policy Commission
Wanda D. Filer, M.D., Chair, Public Policy Commission
John S. Jordan, CAE, Executive Vice President
Charles I. Artz, Esq., Academy General Counsel
Andrew Sandusky – Academy Legislative Specialist



Original: 2185

Pennsylvania Academy of
FAMILY PHYSICIANS

RECEIVED
2001 MAY 23 AM 9:04

STATE DEPARTMENT OF HEALTH
REVIEW COMMISSION



President
Kevin P. Shaffer, MD
Erie

May 17, 2001

President-Elect
Mark D. Burd, MD
Danville

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

Vice-President
Paul D. Williams, DO
Harrisburg

Treasurer
Ronald J. Buckley, MD
Allentown

Dear Mr. Hersh:

Immediate Past President
Christine M. Stabler, MD
Lancaster

I am writing on behalf of the over 4,700 members of the Academy of Family Physicians in support of the proposed regulations to require confidential name-based reporting for HIV positive cases, abnormal CD4 counts and prenatal exposure.

Executive Vice President
John S. Jordan

In formulating this position of support, the Academy investigated several significant elements of the proposed regulations with the overarching question being, "How will this regulation benefit our patients?" The Academy looked to the CDC and its guidelines as enumerated in MMWR 1999;48 (No. RR13) "Guidelines for HIV case surveillance, including monitoring for HIV infection and AIDS," as the standard in requiring "name-based" reporting as opposed to a unique identifier method. The Academy believes that the Department will use every mechanism available to ensure confidentiality of reporting the conditions as described in the regulations, as it has done successfully thus far in the reporting of AIDS patients.

The Academy also based its support on the inclusion of §27.32a - Confidential and Anonymous Testing, as written in the proposed regulations. Allowing for anonymous testing in state-designated anonymous testing sites was a concern of many Academy members and we are happy to see that the Department has recognized this crucial element.

Finally, Academy members are confident that the Department will use named-based reporting as a mechanism to provide it and local health departments with enhanced opportunities to provide case management services to our patients. The Academy is further confident that named-based requirements will be used with the goal of getting patients more services and tracking those services as a quality of care issue, without fear of breach of confidentiality.

Thank you for giving the Academy an opportunity to address the Department on this significant public health policy. We look forward to working with you as this proposal

moves through the regulatory process. Should you have any questions or concerns on the Academy's position, please do not hesitate to contact me at 814-833-5653.

Sincerely,

A handwritten signature in black ink that reads "Kevin P. Shaffer MD". The signature is written in a cursive style with a small "MD" at the end.

Kevin P. Shaffer, MD
President

cc: Robert S. Zimmerman, Jr., Secretary of the Department of Health
Academy Board of Directors
Academy Public Policy Commission
Wanda D. Filer, M.D., Chair, Public Policy Commission
John S. Jordan, CAE, Executive Vice President
Charles I. Artz, Esq., Academy General Counsel
Andrew Sandusky – Academy Legislative Specialist



Consumer Advisory Board
of the
Southwestern PA AIDS Planning Coalition

RECEIVED
2001 MAY 31 AM 9:23
REVIEW COMMISSION

May 17, 2001

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

Re: HIV Reporting

Dear Mr. Hersh:

On behalf of the Consumer Advisory Board of the Southwestern Pennsylvania AIDS Planning Coalition, We are writing to express our grave concern with the proposed draft regulations on HIV reporting currently under consideration and out for public comment.

We oppose reporting the names of people with HIV to the Commonwealth. As you are aware, based on the overwhelming message delivered in the public hearings conducted statewide by the department on this subject, and in the academic publications available to date, there is significant evidence that HIV reporting by name can and will deter individuals from seeking an HIV test. This is particularly true of those individuals who are perhaps at the greatest risk of infection. We support the development of a non name-based HIV surveillance system to achieve the public health goals of HIV surveillance in Pennsylvania.

Regarding testing, while we favor the department's intent to continue the availability of anonymous testing, we feel that opportunities for anonymous testing should be increased throughout the state. Though the Department has stated that more than 100 such testing sites are now available, we believe this number includes sites offering confidential testing, which cannot be confused with anonymous. Indeed, in the Counties of Philadelphia and Allegheny, where nearly 80% of the reported AIDS cases are concentrated, there are approximately 10 genuine anonymous testing providers currently available. The proposed regulations seem to potentially limit the availability of anonymous testing by requiring that anonymous

**Allegheny
Armstrong
Beaver
Butler
Cambria
Fayette
Greene
Indiana
Somerset
Washington
Westmoreland**

**Fifth Floor
907 West Street
Pittsburgh, PA
15221
412-242-2441
1-888-379-3755
fax 412-247-1640
email cab@trfn.cipgh.org
http://trfn.cipgh.org/cab/**

OFFICE OF THE ATTORNEY GENERAL
STATE OF PENNSYLVANIA

01 MAY 22 AM 8:15

testing be conducted only at a "State-designated anonymous testing site." Through the publicly funded anonymous testing options to ensure that individuals are not deterred from seeking HIV testing, and that true anonymous tests are available and accessible to all Pennsylvanians.

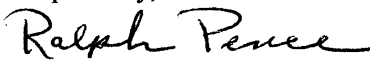
On the subject of reporting risk factors, the regulations as drafted ask only for "probable mode of transmission," a subjective assessment. Here, providers must be provided with the most current categories of transmission risk as delineated by the CDC and should be instructed to use only those categories. Requiring subjective risk factors to be reported allows for judgments to be made about an individual. Identifying specific nationally aggregated risk factors is far more accurate, reasonable, and appropriate and will provide standardized data that can be compared CDC reporting.

On the subject of reporting by the many entities referenced in the regulations, we remind you that only physicians can make a diagnosis of HIV. The results of a laboratory test, independent of a physician's judgment, is not a diagnosis of HIV nor should it constitute grounds for a public health intervention. Neither laboratories nor "entities providing HIV services" should be required to report information about an individual's HIV status or other markers, as they cannot clinically interpret that information. Only a clinician can and should make a diagnosis or moderate clinical progress. It is unrealistic and inappropriate to require these entities to abide by these regulations.

In closing, we are further concerned about the area of regulations lacking specificity. Here, clear language must be provided around the security of many required electronic transmission of HIV and related data. Additionally, and "public health interventions" as described in the regulatory narrative must be accompanied by regulatory language describing these activities. Involving community-based organizations in these interventions and designing these interventions using best practice models. Further, they should only be implemented as the "court of last resort" and not as the first step as the regulations suggest.

Our thanks for your consideration; we look forward to seeing significant revisions of the regulations in the near future.

Respectfully,



Ralph Pence
Co-chair
Consumer Advisory Board
Southwestern Pennsylvania AIDS Planning Coalition



Matt Ometz
Co-chair

cc: Senator Vincent Hughes
Representative Dennis M. O'Brian
Representative Frank L. Oliver
Senator Harold F Mowery

Original: 2185

COMMITTEE OF CONCERNED CITIZENS

REC
BUREAU OF

P.O. Box 32389
PHILADELPHIA, PA 19146-0889

Phone (215) 336-8415
Fax (215) 336-1557
Email comconcit@hotmail.com

01 MAY 2

01 MAY 29 AM 10:02

May 17, 2001

Dr. Walter Tsou, Commissioner
Philadelphia Department of Public Health
1101 Market Street, Suite 840
Philadelphia, PA 19107

PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH
COMMUNICATIONS SECTION
MAY 17 11 05 AM '01

Dear Commissioner:

We are writing to express concern about the Pennsylvania Health Department's plan to require that the names of people living with HIV infection be reported to the state. Although the Pennsylvania Health Department says that name reporting does not discourage people from access to HIV testing and care, research shows that it does.

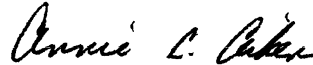
Name reporting of HIV will only undermine the hard work being done by your department and community-based organizations in the Delaware Valley to encourage people to access HIV testing and care.

We urge you to tell the Pennsylvania Health Department that Philadelphia cannot comply with HIV name reporting requirements. Mayor Street supported this position in his 1992 campaign when he wrote that name-based HIV reporting, "Could deter people from getting tested and seeking care."

Please tell the State Health Department that Philadelphia is only willing to cooperate with HIV reporting by Unique Identifier (letter/number codes that take the place of names). The ten states and territories that chose to use Unique Identifiers have proven that states can measure the spread of HIV accurately and do effective service planning without risking the privacy of their residents.

We need you and Mayor Street to protect the health of Philadelphians. We are looking to you to stand up for the right of all Philadelphians to ensure that HIV testing will not be compromised by name-based reporting.

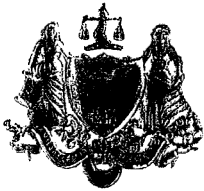
Sincerely,



ANNIE L. AIKEN
Financial Coordinator
Committee of Concerned Citizens

James E. Helman
JAMES E. HELMAN
Administrative Coordinator &
Editor, Citizens Voice

Charles Reeves
CHARLES REEVES
Community Development Coordinator
Committee of Concerned Citizens



Original: 2185

CITY OF PHILADELPHIA

DEPARTMENT OF PUBLIC HEALTH
1101 Market Street, 8th Floor
Philadelphia, PA 19107

WALTER H. TSOU, MD, MPH
Health Commissioner

May 17, 2001

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

Dear Mr. Hersh:

I am writing to comment on the proposed amendments to 28 PA. CODE CH. 27 concerning HIV reporting, as published in the April 21, 2001 issue of the *PA Bulletin* (Vol. 31, No. 16).

Our comments/recommended changes are as follows:

- The State may want to consider the issue of non-compliance with reporting rules, that is establishing a penalty for non-compliance, as the Allegheny Health Department has chosen to do in their regulations.
- There will be a major financial and human resources impact on high morbidity areas such as Philadelphia related to the State's proposed "dual" reporting of laboratory data, and the State makes no mention of how it would intend to financially support such "dual" reporting. Specifically, in section 27.22, pg17, laboratories are to report findings of positive HIV tests and CD4 results to the State, and in our case also to the City, with the set of data items described in (i) through (xi). The health care providers are then responsible for filing a report on the positives with the local Health Department. The report from providers is required whether or not the individual was previously reported as AIDS and/or HIV. This required report includes variables in addition to that required for laboratory submission. The additional items are described on page 20, section 27.32,b items (10), (11) and (14). The State must either require such reporting be done for only *new, previously unreported* cases, or must financially support the increased reporting requirements.

RECEIVED
2001 MAY 31 AM 9:16
PHILADELPHIA DEPARTMENT OF HEALTH
HEALTH COMMISSIONER

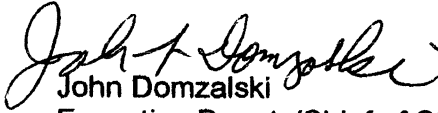
- *Recommended language change:* 27.22 (c) (2) reports of HIV and CD4 T-lymphocyte test results. Laboratories shall report electronically to the Department's Bureau of Epidemiology. The report shall include the following information unless the person or entity submitting the specimen for testing is located within Philadelphia. Laboratories reporting HIV and CD4 T-lymphocyte test results for persons or entities located within Philadelphia will exclude item (i) when reporting to the State Bureau of Epidemiology and include item (i) when reporting results to Philadelphia.
- *Recommended language change:* 27.32 (a) [Physicians and hospitals shall report cases of AIDS promptly to the Department of Health, Division of Acute Infectious Disease Epidemiology, PO Box 90, Harrisburg, Pennsylvania, or to the local health department in the cities of Allentown, Bucks, Chester, Erie and Philadelphia and in the cities of Allentown, Bethlehem and York when the individual who is the subject of the report is a resident, or is diagnosed within, the county or city.
- *Recommended language change:* 27.32 (d) An LMRO receiving reports of diagnosed AIDS, positive HIV test results, reportable CD4 T-lymphocyte results, and perinatal exposures to HIV shall forward completed case reports containing the information included in subsection (b) electronically to the Department's Bureau of Epidemiology. Philadelphia county will substitute an identifier other than name and without individual's street address as described in subsection (b) 1 for reports of positive HIV test results.
- *Recommended language change:* 27.32a. Confidential and anonymous testing.
 - Anonymous testing for HIV, except for blinded HIV testing authorized under section 5(f) of the Confidentiality of HIV-related Information Act (35P.S. 760(f)), may only be provided at State-designated anonymous testing sites. Anonymous testing is testing provided to an individual without collecting the individual's name. All other HIV testing shall be conducted confidentially with the name of the tested individual collected, and the name of the individual reported when the result of the test is reportable. Persons or entities reporting as required in this section shall offer all HIV and AIDS related services confidentially and may not provide anonymous testing, or consider any test or its results to be anonymous. Anonymous testing for HIV in Philadelphia will be provided at those sites designated by the local health authority. Anonymous testing in Philadelphia is testing provided to an individual without collecting the name or any other information that could be used to identify an individual (street address, or algorithms

based all or in part on the individual's name, social security number, date of birth). Confidential HIV testing in Philadelphia will require that the name of the individual tested be collected and reported to the local health authority upon receipt of reportable test results. Case reports on reportable HIV results obtained from all but anonymous test sites will be reported to the State's Bureau of Epidemiology substituting a Unique identifier for the name of the individual for whom a reportable HIV test result was obtained.

- TO BE ADDED TO THE END OF THE STATE'S VERBAGE REGARDING REPORTING ANONYMOUS TEST RESULTS: Philadelphia will report anonymous HIV test results without identifiers, utilizing the case identifier number to differentiate case reports.
- *Recommended language change:* 27.32d Record audits. Our recommendation is to remove the time limitation which only allows us to request audits back to January 1, 2000. There is no particular reason to limit by time frame our ability to request prior information about HIV infections.

Thank you for the opportunity to comment on these important regulations.

Sincerely,


John Domzalski
Executive Deputy/Chief of Staff

- c: John F Street, Mayor, City of Philadelphia
Estelle B. Richman, Managing Director of Social Services
Walter Tsou, MD, MPH, Health Commissioner
Joseph C. Cronauer, Co-Director, AACO



RECEIVED
01 MAY 24 AM 10:46

RECEIVED
MAY 21 10 55 AM '01
COMMUNICATIONS SECTION

May 17, 2001

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

RE: Proposed Changes in HIV Reporting

Dear Mr. Hersh:

Thank you for providing us an opportunity to respond to the proposed changes in the HIV/AIDS reporting laws for the Commonwealth of Pennsylvania as published in the Pennsylvania Bulletin, April 21 2001, Vol.31, No.16. In order to better understand the epidemiology of HIV and provide assistance in prevention and treatment of this pathogen, we support the need to track changes in the incidence of HIV infection as opposed to AIDS alone. However, we are concerned that the proposed changes as written may create unintended problems, which we will delineate below.

The proposed changes require physicians and laboratories to report all patients with absolute CD4 counts < 200 as well as those with a CD4 %<14. While we are sure that the aim of this proposed change is to use a surrogate marker for individuals who are likely to be HIV infected, we are concerned that this test lacks the specificity to accomplish this goal. Extremely low CD4 counts are seen in a variety of clinical scenarios completely unrelated to HIV infection. T and B cell enumeration studies are a routine part of our evaluation of children who may have a congenital immune deficiency. Thus very low T cells (including low CD4 cell) are seen in a variety of congenital entities (e.g. DiGeorge's syndrome). Patients with lymphopenia unrelated to HIV may also have very low CD4 counts. Enumeration of CD4 cells is often a part of the work-up for this condition. In addition, organ transplant recipients often have low CD4 cell counts as a result of immune suppression or viral infections unrelated to HIV. In fact, some centers monitor CD4 and CD 8 counts during anti-lymphocyte antibody therapy for rejection to assure themselves that their therapy has achieved an adequate biologic effect. Thus, they will often continue to treat until they document a low CD4 count. These represent a number of scenarios where physicians and laboratories would be required to report patients to the Health Department in the context of "HIVreporting" where in fact data may already exist that the patients don't have HIV infection at all (e.g. in our transplant recipients). In fact, at the Children's Hospital of Pittsburgh these scenarios will be a more common explanation for a low CD4 count than HIV infection. Reporting of these patients will lead to undue paperwork requirements on the laboratories, physicians and public health officials. Finally, if the report leads to an investigation requiring the health department to contact the families, it may cause undue stress.

A second issue of concern is the potential duplicity of reporting associated with requirements that both the laboratory report patients with positive HIV RNA viral loads, HIV DNA assays, HIV western blots as well as the patients with low CD4 counts. In our center, HIV DNA tests are performed by one laboratory, HIV RNA viral loads by another and T cell enumerations by a third. Does the state have a plan to deal with the likelihood that a single name will be reported multiple times. Also, if our patient has serial specimens sent, would they have to be reported by the lab each time the test was positive? Even if laboratories maintain records on who they had already reported, if a patient changes insurance providers, they may now need to have their specimens sent to yet another laboratory who will need to report the patient. The duplicity of reporting and the increased challenges this will bring to maintaining confidentiality need to be considered if not addressed.

A third concern is around the issue of patient confidentiality. Given the reporting requirements, laboratories may now be required to maintain and transmit patient information which can create increased opportunities for breaches of confidentiality. While we recognize that the ability to carry out such functions is an integral part of performing the laboratory services, the additional "paper trails" being created by the newly mandated information sheets, etc., will challenge the ability to protect our patient's rights. Further, the mere existence of special information sheets attached to certain specimens may draw attention to the specimen (and the attached name), thus potentially violating patient confidentiality.

A final issue to be addressed is the ongoing importance of having anonymous testing available. Currently, in Allegheny County the AIDS Taskforce and Planned Parenthood of Western Pennsylvania offer confidential and anonymous testing. Appropriate counseling is provided in both scenarios. The availability of anonymous testing is critical for some individuals who otherwise would not come for any testing. In addition to the test itself, individuals benefit from being counseled about HIV and HIV risk reduction strategies.

In summary, we have raised the above concerns (particularly the issues associated with mandated reporting of very low CD4 count results) in response to the proposed changes in the HIV reporting law. We want to again emphasize that we support the need to track incidence of HIV infection and not just incidence of AIDS. However, attention must be paid to the potential implications of these changes with special reference to the issue we have addressed. Thank-you very much for considering our concerns.

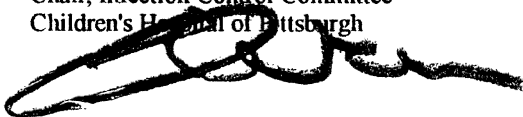
Sincerely,



Michael Green, MD, MPH
Associate Professor of Pediatrics and Surgery
University of Pittsburgh School of Medicine
Chair, Infection Control Committee
Children's Hospital of Pittsburgh



Marian Michaels, MD, MPH
Associate Professor of Pediatrics and Surgery
University of Pittsburgh School of Medicine
Director, Pediatric HIV Program
Children's Hospital of Pittsburgh



Eugene Weiner, MD
Professor of Surgery
University of Pittsburgh School of Medicine
Medical Director
Children's Hospital of Pittsburgh



Original: 2185

THE HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA

RECEIVED

2001 MAY 18 AM 9:18

REGULATORY
REVIEW COMMISSION

May 16, 2001

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

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. Hersh:

The Hospital & Healthsystem Association of Pennsylvania (HAP), on behalf of its approximately 250 member hospitals and health systems, welcomes the opportunity to comment on the proposed regulations dealing with the reporting of Acquired Immune Deficiency Syndrome (AIDS), Human Immunodeficiency Virus (HIV) test results, CD4 T-lymphocyte counts, and perinatal exposure of newborns to HIV. HAP commends the Department 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 34 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 be tested and subsequently access treatment. This component is critical.

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

However, HAP would like to bring the following concerns and/or recommendations with regard to the proposed regulations to the Department of Health's attention:

Subchapter A. General Provisions

- It appears that the Department of Health's definition of a local morbidity reporting office includes a municipal health department, county health department, or one of the six district headquarters of the Department of Health located throughout the commonwealth. It also appears that the Department will no longer require that physicians or hospitals report the presence of infection or disease to the local morbidity office in which the patient resides, but rather to a local morbidity office in which the disease or infection is diagnosed. HAP commends the Department of Health for making this change to facilitate ease of reporting on the part of physicians and hospitals. HAP recommends that the Department of Health make a similar change to its other disease reporting requirements and clearly indicate that physicians or hospitals that have a choice of a municipal office, county office, or district office can choose to report to any one of those sites.
- The Department of Health proposes adding CD4 T-lymphocyte test results to its reporting requirements when CD4 T-lymphocyte counts are less than 200 cell/uL or less than 14 percent of total lymphocytes. The Department has indicated that these reports will allow the Department to identify those individuals who are infected with HIV but who have not specifically been tested for HIV. These are individuals who may not appear ill but can spread HIV through consensual acts, including unprotected intercourse or intravenous needle sharing. Therefore, the Department of Health is looking at a proactive public health measure that may identify potentially infected persons to reduce or limit the spread of disease and to provide counseling, testing, and treatment to the infected individual as early as possible to minimize the progression to AIDS.

However, the Department of Health also recognizes that a number of individuals with cancer could also have a low CD4 T-lymphocyte count as an indication of a suppressed immune system for reasons totally unrelated to HIV. The Department has indicated that it would consider all the elements of a report before contacting the provider to determine whether the provider has considered an HIV test for the individual. This reporting requirement could be extremely burdensome to oncologists and physicians caring for cancer patients, and it is unclear what the Department of Health will do with the information it receives related to cancer patients. The Department of Health should clarify how it will manage the information received on cancer patients, including whether that information will be referred to the Cancer Registry in the Division of Statistical Registries in the Bureau of Health Statistics and Research.

- The Department of Health has indicated that it will use the CDC case definition for AIDS. HAP recommends including the case definition in its regulations rather than just referring to the definition.

Subchapter B. Reporting of Diseases

- The Department of Health has indicated that it will require laboratories, physicians, hospitals, case management organizations, drug and alcohol abuse treatment facilities, mobile vans, and small clinics to adhere to the reporting requirements through the use of a software program that would allow for electronic reporting to the local morbidity reporting office. The Department needs to ensure that laboratories and providers can submit reports even if some of the required information cannot be obtained. Additionally, the Department needs to develop and communicate a plan regarding how it intends to provide the software and training to laboratories, physicians, hospitals and other providers named in the regulations. Finally, the Department needs to recognize that all of the listed providers of health care services may not be equipped to submit reports electronically, and therefore the Department must develop a mechanism that will allow for the submission of those reports confidentially by these entities.
- The Department of Health has indicated that providers, hospitals, and other persons or entities that diagnose AIDS or receive HIV and CD4 T-lymphocyte test results must maintain the data required on the Department's HIV/AIDS report in the patient's file. The Department needs to clarify what exactly it means by patient's file and whether that information can be maintained electronically or must be in hard copy. It is unclear whether the information can be maintained in the hospital's infection control practitioner's disease report files or must be in the patient's medical record. It is also unclear whether that information must be maintained in hard copy or whether the information can be maintained in a secure electronic file.
- The Department has included two new subsections in the regulations, which allows the Department to conduct record audits of physicians, hospitals, and other persons or entities providing HIV services, who make the diagnosis of AIDS, or who receive or provide HIV test results. The Department has indicated in its preamble and regulations that these audits would extend back to January 1, 2000, to allow the Department to complete HIV and CD4 T-lymphocyte case reports, thereby enabling the Department to track disease trends, complete case investigations, and obtain information needed to complete applications for CDC and United States Health and Human Services funding grants. The Department has indicated that such audits must be completed in order to demonstrate that HIV case data is sufficiently accurate and reliable to use in the grant formula. If not, Pennsylvania may only be able to use AIDS case data, which would result in a significant decrease in HIV/AIDS funding in the commonwealth.

Although HAP appreciates the implications of having inaccurate HIV data, the need for retrospective record audits is a result of the Department's inability to develop and implement HIV infection reporting requirements in a timely manner. Therefore, to minimize the expense and burden on physicians, hospitals and other affected

Joel H. Hersh
May 16, 2001
Page 4

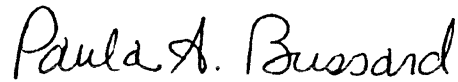
providers, HAP recommends that the Department work collaboratively with physicians and hospitals to develop the most effective and least disruptive means to collect the needed information.

The Department has also proposed regulations that will allow the Department to conduct case investigations to determine whether underreporting is occurring, to investigate reporting delays, and to investigate other reporting problems. The Department will review patient records of physicians, hospitals and other persons and entities to ensure conformance with AIDS, HIV, and CD4 T-lymphocyte test reporting requirements. Again, HAP recommends that the Department work collaboratively with providers to develop guidelines that would be used and followed when conducting compliance audits with respect to disease reporting.

Again, HAP appreciates the opportunity to comment on the Department of Health's proposed regulations addressing the reporting of AIDS cases and HIV test results. HAP believes that its suggestions and recommendations will improve or clarify the proposed regulations. HAP looks forward to working with the Department of Health in areas of infection control and epidemiology to benefit community health and protect the public from harmful diseases or infections. In particular, HAP looks forward to working with the Department in the development of the lookback strategy and development of compliance guidelines that will guide future record reviews.

If you have any questions about the issues or suggestions outlined in this letter, feel free to contact Lynn Gurski Leighton, Director, Clinical Services, HAP at 717-561-5308 or by email at lgleighton@haponline.org.

Sincerely,



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

PAB/mg

cc: John McGinley, Jr., Chairperson, Independent Regulatory Review Commission
Harold F. Mowery, Jr., Chair, Senate Public Health and Welfare Committee
Vincent J. Hughes, Minority Chair, Senate Public Health and Welfare Committee
Dennis M. O'Brien, Chair, House Health and Human Services Committee
Frank L. Oliver, Minority Chair, House Health and Human Services Committee
Lori McLaughlin, Esq., Chief Counsel, Department of Health
Howard A. Burde, Esq., Deputy General Counsel, Office of General Counsel
Helen K. Burns, Deputy Secretary for Health Planning and Assessment, Department of Health

Original; 2185



Cindy Groff
President and CEO

RECEIVED
2001 MAY 24 AM 8:56
FACILITY
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

May 16, 2001

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

Dear Mr. Hersh:

The Family Health Council of Central Pennsylvania, Inc., appreciates the opportunity to submit comments regarding the Pennsylvania Department of Health's proposed 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 Groff
President and CEO

Improving the Health of Women & Families

COMMENTS OF
THE FAMILY HEALTH COUNCIL OF CENTRAL PENNSYLVANIA, INC.

REGARDING

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

MAY 16, 2001

The Family Health Council of Central Pennsylvania, Inc., (FHCCP) welcomes the opportunity to comment on the Department of Health's proposed regulations regarding reporting of HIV test results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV.

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 HIV/AIDS related contracts with the U.S. Department of Housing and Urban Development and the Philadelphia Department of Health. In addition, FHCCP holds multiple federal and state contracts, including family planning, WIC, the HealthyWoman Project and chlamydia.

FHCCP commends the Department for moving in this direction and 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 breach 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 also 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 become 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.



Original 2185

THE HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA

May 16, 2001

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

RECEIVED
2001 MAY 29 AM 10:29
HEALTH COMMISSION
10

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. Hersh:

The Hospital & Healthsystem Association of Pennsylvania (HAP), on behalf of its approximately 250 member hospitals and health systems, welcomes the opportunity to comment on the proposed regulations dealing with the reporting of Acquired Immune Deficiency Syndrome (AIDS), Human Immunodeficiency Virus (HIV) test results, CD4 T-lymphocyte counts, and perinatal exposure of newborns to HIV. HAP commends the Department 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 34 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 be tested and subsequently access treatment. This component is critical.

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

However, HAP would like to bring the following concerns and/or recommendations with regard to the proposed regulations to the Department of Health's attention:

Subchapter A. General Provisions

- It appears that the Department of Health's definition of a local morbidity reporting office includes a municipal health department, county health department, or one of the six district headquarters of the Department of Health located throughout the commonwealth. It also appears that the Department will no longer require that physicians or hospitals report the presence of infection or disease to the local morbidity office in which the patient resides, but rather to a local morbidity office in which the disease or infection is diagnosed. HAP commends the Department of Health for making this change to facilitate ease of reporting on the part of physicians and hospitals. HAP recommends that the Department of Health make a similar change to its other disease reporting requirements and clearly indicate that physicians or hospitals that have a choice of a municipal office, county office, or district office can choose to report to any one of those sites.
- The Department of Health proposes adding CD4 T-lymphocyte test results to its reporting requirements when CD4 T-lymphocyte counts are less than 200 cell/uL or less than 14 percent of total lymphocytes. The Department has indicated that these reports will allow the Department to identify those individuals who are infected with HIV but who have not specifically been tested for HIV. These are individuals who may not appear ill but can spread HIV through consensual acts, including unprotected intercourse or intravenous needle sharing. Therefore, the Department of Health is looking at a proactive public health measure that may identify potentially infected persons to reduce or limit the spread of disease and to provide counseling, testing, and treatment to the infected individual as early as possible to minimize the progression to AIDS.

However, the Department of Health also recognizes that a number of individuals with cancer could also have a low CD4 T-lymphocyte count as an indication of a suppressed immune system for reasons totally unrelated to HIV. The Department has indicated that it would consider all the elements of a report before contacting the provider to determine whether the provider has considered an HIV test for the individual. This reporting requirement could be extremely burdensome to oncologists and physicians caring for cancer patients, and it is unclear what the Department of Health will do with the information it receives related to cancer patients. The Department of Health should clarify how it will manage the information received on cancer patients, including whether that information will be referred to the Cancer Registry in the Division of Statistical Registries in the Bureau of Health Statistics and Research.

- The Department of Health has indicated that it will use the CDC case definition for AIDS. HAP recommends including the case definition in its regulations rather than just referring to the definition.

Subchapter B. Reporting of Diseases

- The Department of Health has indicated that it will require laboratories, physicians, hospitals, case management organizations, drug and alcohol abuse treatment facilities, mobile vans, and small clinics to adhere to the reporting requirements through the use of a software program that would allow for electronic reporting to the local morbidity reporting office. The Department needs to ensure that laboratories and providers can submit reports even if some of the required information cannot be obtained. Additionally, the Department needs to develop and communicate a plan regarding how it intends to provide the software and training to laboratories, physicians, hospitals and other providers named in the regulations. Finally, the Department needs to recognize that all of the listed providers of health care services may not be equipped to submit reports electronically, and therefore the Department must develop a mechanism that will allow for the submission of those reports confidentially by these entities.
- The Department of Health has indicated that providers, hospitals, and other persons or entities that diagnose AIDS or receive HIV and CD4 T-lymphocyte test results must maintain the data required on the Department's HIV/AIDS report in the patient's file. The Department needs to clarify what exactly it means by patient's file and whether that information can be maintained electronically or must be in hard copy. It is unclear whether the information can be maintained in the hospital's infection control practitioner's disease report files or must be in the patient's medical record. It is also unclear whether that information must be maintained in hard copy or whether the information can be maintained in a secure electronic file.
- The Department has included two new subsections in the regulations, which allows the Department to conduct record audits of physicians, hospitals, and other persons or entities providing HIV services, who make the diagnosis of AIDS, or who receive or provide HIV test results. The Department has indicated in its preamble and regulations that these audits would extend back to January 1, 2000, to allow the Department to complete HIV and CD4 T-lymphocyte case reports, thereby enabling the Department to track disease trends, complete case investigations, and obtain information needed to complete applications for CDC and United States Health and Human Services funding grants. The Department has indicated that such audits must be completed in order to demonstrate that HIV case data is sufficiently accurate and reliable to use in the grant formula. If not, Pennsylvania may only be able to use AIDS case data, which would result in a significant decrease in HIV/AIDS funding in the commonwealth.

Although HAP appreciates the implications of having inaccurate HIV data, the need for retrospective record audits is a result of the Department's inability to develop and implement HIV infection reporting requirements in a timely manner. Therefore, to minimize the expense and burden on physicians, hospitals and other affected

Joel H. Hersh
May 16, 2001
Page 4

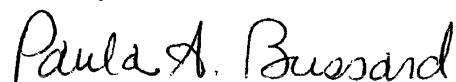
providers, HAP recommends that the Department work collaboratively with physicians and hospitals to develop the most effective and least disruptive means to collect the needed information.

The Department has also proposed regulations that will allow the Department to conduct case investigations to determine whether underreporting is occurring, to investigate reporting delays, and to investigate other reporting problems. The Department will review patient records of physicians, hospitals and other persons and entities to ensure conformance with AIDS, HIV, and CD4 T-lymphocyte test reporting requirements. Again, HAP recommends that the Department work collaboratively with providers to develop guidelines that would be used and followed when conducting compliance audits with respect to disease reporting.

Again, HAP appreciates the opportunity to comment on the Department of Health's proposed regulations addressing the reporting of AIDS cases and HIV test results. HAP believes that its suggestions and recommendations will improve or clarify the proposed regulations. HAP looks forward to working with the Department of Health in areas of infection control and epidemiology to benefit community health and protect the public from harmful diseases or infections. In particular, HAP looks forward to working with the Department in the development of the lookback strategy and development of compliance guidelines that will guide future record reviews.

If you have any questions about the issues or suggestions outlined in this letter, feel free to contact Lynn Gurski Leighton, Director, Clinical Services, HAP at 717-561-5308 or by email at lgleighton@haponline.org.

Sincerely,



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

PAB/mg

cc: John McGinley, Jr., Chairperson, Independent Regulatory Review Commission
Harold F. Mowery, Jr., Chair, Senate Public Health and Welfare Committee
Vincent J. Hughes, Minority Chair, Senate Public Health and Welfare Committee
Dennis M. O'Brien, Chair, House Health and Human Services Committee
Frank L. Oliver, Minority Chair, House Health and Human Services Committee
Lori McLaughlin, Esq., Chief Counsel, Department of Health
Howard A. Burde, Esq., Deputy General Counsel, Office of General Counsel
Helen K. Burns, Deputy Secretary for Health Planning and Assessment, Department of Health

Original: 2185

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

RECEIVED
BUREAU OF EPIDEMIOLOGY
2001 MAY 31 AM 9:26
01 MAY 22 AM 9:16
COMMUNICATIONS
REVIEW/COMMISSION

May 16, 2001

Dear Mr. Hersh,

I am writing to you as someone who has worked in HIV prevention, testing, counseling and reporting for close to 20 years. From my early years in HIV prevention and testing, to later years working in HIV epidemiology (in Delaware) to my present work as a nurse in HIV research, I have worked with hundreds of people at high risk for HIV infection, as well as people living with "the virus".

I am also a Presbyterian minister, and in that latter capacity I have counseled many who have passed through denial to acceptance as they face an early death, and the knowledge that they must reveal their diagnosis to loved ones and family, co-workers, landlords, employers, as well as those they may have infected.

It is clear to me that it is indeed very important clinically and psychologically to know ones own HIV status. That knowledge can be the inspiration for recovery from years of substance use. That knowledge can be the beginning of taking responsibility for one's actions in the family and in the community. Such knowledge definitely changes one's life. But such knowledge is not benign : it can also be the beginning of suicidal thoughts, increased substance use, and even deliberate criminal acts. So how do we as people who care about the health and welfare of our communities handle HIV reporting?

I believe that we do all we can to encourage everyone to get testing. Indeed, we make getting tested as easy and attractive as possible. With professional, intelligent counseling, people will notify their past sexual and/ or needle sharing partners. Such notification is essential to stop the spread of this epidemic, or at least slow down the speeding train of infection.

How will names reporting make HIV testing more attractive to those most at risk? Having to reveal one's identity is sure to be a major deterrant to those who most need to be tested : people who are involved in illegal activities (like IV drug use), people who are unfaithful in their marriages, people whose jobs and/or housing would be lost if their HIV status was known.

We definitely need to know the extent of HIV infection in our state of Pennsylvania. Accurate numbers will help us more realistically address the epidemic: to formulate effective, relevant prevention strategies, and to adequately fund and resource the complicated and numerous social service and medical needs of those already living with HIV.

Other states have instituted sophisticated and effective epidemiological practices with unique identifiers. I support such reporting practices. I hope you will consider the effectiveness of unique identifier reporting rather than reporting by name.

In the end, perhaps the important public health question is "who do we want to attract into testing?" I would answer "those who are the most disenfranchised in our communities. We need to reach them, gain their trust and get them invested in protecting others. Folks will not come for testing if they have the slightest inclination that their HIV status could one day become public knowledge.

Sincerely,



Rev. Deborah Gausmann, RN
6836 Meade Street
Pittsburgh, Pa. 15208

Bankes, Julie

From: Hersh, Joel
Sent: Wednesday, May 16, 2001 8:21 AM
To: 'Karen Brown'
Cc: Bankes, Julie
Subject: RE: HIV reporting in Pennsylvania

RECEIVED
2001 MAY 22 AM 9:43
REVIEW COMMISSION

Karen: Physicians and labs will be required to report. I understand your issue. I will officially designate your concern as a response to the proposed regulations and include it as part of the public record. We will answer the question when we move towards final regulations. Thanks, Joel

Julie: Record as an official response and generate appropriate letters to IRRC, etc. Thanks, Joel

-----Original Message-----

From: Karen Brown [mailto:kbrown@core.org]
Sent: Wednesday, May 09, 2001 8:47 AM
To: 'Hersh, Joel'
Subject: RE: HIV reporting in Pennsylvania

CORE is an organ procurement organization whose territory includes the Western half of Pennsylvania over to Chambersburg, all of West Virginia and a small county in New York. Blood is drawn on each donor and screened by CORE's laboratory for a number of serologies which include but are not limited to: Hepatitis B and C, HTLV I-II Antibody, HIV I-II Antibody and HIV Antigen. We perform serologies on potential organ donors prior to making arrangements to recover the organs in the operating room. We perform serologies on tissue/cornea donors after the tissue has been recovered due to time constraints for recovering the tissue/corneas. Currently, if we obtain an HIV positive screening test on a potential organ donor, we abort the donor case. If we obtain a positive Hepatitis, HTLV or HIV serology on a tissue/cornea donor we do not release the tissue/corneas for transplant.

Currently I am obligated to report any positive HIV tests to West Virginia or New York state if we run serologies on a donor who was a resident of that state. Each of the two states has a form that I utilize to report the positive HIV. I will need a small supply of forms that Pennsylvania will utilize to report any positive HIV findings. Also, will I be obligated to send out the sample for Western Blot confirmation testing prior to reporting a positive HIV screening test to PA? New York and West Virginia have a block on their form where you check off if the test result you are reporting is an HIV EIA test or an HIV Western Blot confirmation test. Confirmation tests are not required as part of the reporting process.

Does Pennsylvania plan to require any laboratory or physician to report all positive HIV EIA screening tests independent of the Western Blot confirmation? Due to a limited volume of blood sample I may or may not have sufficient specimen to send out for Western Blot analysis. Due to the donor being deceased I am unable to procure another blood sample.

-----Original Message-----

From: Hersh, Joel [mailto:jhersh@state.pa.us]
Sent: Tuesday, May 08, 2001 17:08
To: 'Karen Brown'
Subject: RE: HIV reporting in Pennsylvania

Karen: We have published draft regulations that would require HIV reporting beginning January 2002. The draft is out for public comment at this time. The reporting will be required of physicians, labs, HIV testing sites etc. I'm not sure I

understand your e-mail regarding cadavers. If you could explain a bit more on what you do, how you come in contact with a cadaver, etc, maybe I can be more helpful. Thanks, Joel

Joel H. Hersh
Director,
Bureau of Epidemiology
Pennsylvania Department of Health
Ph:717-783-4677; Fax:717-772-6972
E-Mail: jhersh@state.pa.us

-----Original Message-----

From: Karen Brown [mailto:kbrown@core.org]
Sent: Tuesday, May 08, 2001 4:51 PM
To: 'Hersh, Joel'
Subject: RE: HIV reporting in Pennsylvania

I read in the local newspaper that the reporting of HIV is to go into effect June 1 of this year. Can you tell me more about it? I only run on cadaver blood for donation do I still need to report the HIV screen if positive? Do you have special forms for reporting?

Thanks.

-----Original Message-----

From: Hersh, Joel [mailto:jhersh@state.pa.us]
Sent: Monday, November 20, 2000 07:59
To: 'Karen Brown'
Subject: RE: HIV reporting in Pennsylvania

Karen: We are not prepared at this time to discuss the type of HIV reporting that we will implement for physicians, hospitals, and labs. This includes screening tests. Sorry, but you'll have to wait until we go public, but thanks for the question. Joel

Joel H. Hersh
Director,
Bureau of Epidemiology
Pennsylvania Department of Health
717-783-4677
E-Mail: JHersh@State.PA.US

-----Original Message-----

From: Karen Brown [mailto:kbrown@core.org]
Sent: Friday, November 17, 2000 10:27 AM
To: 'webmaster@health.state.pa.us'
Subject: HIV reporting in Pennsylvania

Will HIV reporting in Pennsylvania include results for initial EIA screening tests for HIV?

Karen A Brown, BA, MT(ASCP)
Director of Regulatory Affairs & Laboratory Services
Center For Organ Recovery & Education (CORE)
1-800-366-6777

Original: 2185

Bankes, Julie

From: Karen Brown [kbrown@core.org]
Sent: Wednesday, May 16, 2001 11:28 AM
To: 'Bankes, Julie'
Subject: RE: HIV Comment

RECEIVED
2001 MAY 22 AM 9:43
COPY
REVIEW COMMISSION
Ⓢ

Karen A. Brown, BA, MT (ASCP)
204 Sigma Drive
RIDC Park
Pittsburgh, PA 15238

-----Original Message-----
From: Bankes, Julie [mailto:jbanks@state.pa.us]
Sent: Wednesday, May 16, 2001 10:17
To: 'kbrown@core.org'
Subject: HIV Comment

Good morning Karen. I am Joel Hersh's secretary. I am generating a response letter to you. What is your mailing address please?

Original: 2185

May 15, 2001

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

RECEIVED
2001 MAY 23 AM 9:04
PENNSYLVANIA
REVENUE COMMISSION

RE: Opposition to Names Reporting for HIV Surveillance

Dear Joel Hersh:

As a concerned citizen, I oppose reporting the names of people with HIV to the Commonwealth as proposed in the draft regulations published in the PA Bulletin dated 4/20/01.

I agree that the tracking of HIV is essential. Using names, however, will deter the most vulnerable and at-risk individuals from seeking testing and care. Instead, I support 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. That is because, even with anonymous test sites, 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 for your time and consideration.

Sincerely,

Rebecca E. Bernstein

Rebecca E. Bernstein
328 Spruce Street, #2
Philadelphia, PA 19106

- c: Senator Vincent Hughes
Senator Harold F. Mowery, Jr.
Representative Dennis M. O'Brien
Representative Frank L. Oliver

Original: 2185



01 MAY 29 11:10:02
✓

RECEIVED
MAY 29 2001 11:10:02
COMMUNICATIONS SECTION

James F. Young
Executive Director

2565 Germantown Ave
Philadelphia, PA 19133

Phone
215.226.0351
Fax
215.226.1486

May 14, 2001

Dr. Walter Tsou
Health Commissioner
Philadelphia Department of Public Health
1101 Market St. - Suite 480
Philadelphia, PA 19107

Dear Commissioner Tsou:


I am writing to express concern about the Pennsylvania Health Department's plan to require that the names of people living with HIV infection be reported to the State. *Although the Pennsylvania Health Department says that name reporting does not discourage people from access to HIV testing and care, research shows that it does!*

Name reporting of HIV will only undermine the hard work being done by your department and community-based organizations in the Delaware Valley to encourage people to access HIV testing and care.

I urge you to tell the Pennsylvania Health Department that Philadelphia cannot comply with HIV name reporting requirements. Mayor Street supported this position in his 1992 campaign when he wrote that name-based HIV reporting, "could deter people from getting tested and seeking care."

Please tell the State Health Department that Philadelphia is only willing to cooperate with HIV reporting by Unique Identifier (letter/number codes that take the place of names). The ten states and territories that chose to use Unique Identifiers have proven that states can measure the spread of HIV accurately and do effective service planning without risking the privacy of their residents.

We need you and Mayor Street to protect the health of Philadelphians. We are looking to you to stand up for the right of all Philadelphians to ensure that HIV testing will not be compromised by name-based reporting!

Sincerely,

Constance Pointer, Project Coordinator
Neighborhood Action Bureau, Inc.
2565 Germantown Avenue
(215) 226-0351
JIM3930@aol.com

6439 Jackson St.
Pittsburgh, PA 15206-2233

May 15, 2001

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

Director Hersh,

I am writing to comment on the proposed amendments to Chapter 27 of Title 28 of the Pennsylvania Code. I support HIV reporting. It is long overdue in the Commonwealth. I believe that instituting statewide HIV reporting makes logical sense and will help to ensure that Pennsylvania receives appropriate HIV/AIDS related funding.

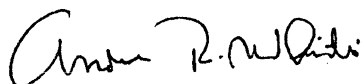
However, I do take exception to the proposed use of an individual's name as the identifier to be used for HIV reporting. I realize that your proposed changes account for privacy and confidentiality. I would challenge though, that the perceived fear of the person's name being mishandled could be problematic. Individuals may not go to be tested if they know that their names would be used as an identifier for HIV reporting. If these individuals did not get tested because of a lack of confidence in the system, then both they and the public at large would suffer.

I support the use of a unique identifier system for HIV reporting. The Allegheny County Health Department is scheduled to start using a unique identifier system on June 1. Allegheny County's approach of leaving the choice of method of HIV status reporting up to the individual being tested by name, unique identifier, or anonymously is a better approach.

I am asking that you seriously consider changing the proposed amendment to Chapter 27 to allow for HIV reporting by name, unique identifier, or anonymously instead of name only.

Thank you for your time and consideration in this matter.

Sincerely,



Andrew R. Whitis

2001 MAY 29 4:10:29
REVIEW COMMISSION
0

Original: 2185

May 15, 2001

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

Dear Director Hersh,

We have recently learned of a proposal that the Department of Health be allowed to gather the names of those who test positive for HIV.

We are strongly against such a regulation. Besides considerations of privacy, there is the frightening possibility that individuals will avoid HIV testing for fear that their names will be made known. Such reluctance can only increase the spread of HIV.

The names would go to the Department of Health, but who can say with any certainty where they might go from there? Should these names escape the Department files, jobs might be lost, insurance denied, and other forms of discrimination might follow.

For the purposes of health statistics, the identification of HIV carriers should be limited to a code system only.

Sincerely yours,



Karl and Isabelle Patten
232 S. 3rd St.
Lewisburg, PA 17837

cc: The Honorable Harold F. Mowery
The Honorable Dennis M. O'Brien
The Honorable Vincent J. Hughes
The Honorable Frank L. Oliver

RECEIVED
MAY 15 2001
DEPARTMENT OF HEALTH
HARRISBURG, PA



Planned Parenthood® of Central Pennsylvania, Inc.

RECEIVED

2001 MAY 22 AM 9:38

REVIEW COMMISSION



May 14, 2001

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

Dear Mr. Hersh:

On behalf of Planned Parenthood of Central Pennsylvania and the AIDS Community Resource Center, I am writing to express my grave concern with the proposed draft regulations on HIV reporting currently under consideration and out for public comment.

While I realize how valuable HIV reporting will be for Pennsylvania and AIDS Service Organizations, I oppose reporting the names of people with HIV to the Commonwealth. As you are aware, based on the overwhelming message delivered in the public hearings conducted statewide by the department on this subject, and in the academic publications available to date, there is significant evidence that HIV reporting by name can and will deter individuals from seeking HIV testing. This is particularly true of those individuals who are perhaps at the greatest risk of infection. At PPCP/ACRP, we support the development of a non name-based HIV surveillance system to achieve the public health goals of Pennsylvania.

Thank you for attempting to develop thoughtful regulations which take into consideration all of the complex systems which will be influenced by the language of such a document. I look forward to seeing revisions of the regulations in the near future.

Sincerely,

Dee Stremmel,
Director of Education

York
728 South Beaver St.
York, PA 17403
845-9683
Fax 717-843-6979

Hanover
Center Square
Hanover, PA 17331
637-6544
Fax 717-637-0831

Red Lion
2997 Cape Horn Rd.
Red Lion, PA 17356
244-1412
Fax 717-246-3318

Gettysburg
963 Biglerville Road
Gettysburg, PA 17325
334-9275
Fax 717-334-8906

Original: 2185

May 14, 2001

Mr. Joel Hersh
Director
Bureau of Epidemiology
Commonwealth of Pennsylvania
Department of Health
P.O. Box 90
Harrisburg, PA 17108
Re: Opposition to Names Reporting for HIV Surveillance

RECEIVED

2001 MAY 22 AM 9:42

REVIEW COMMISSION



Dear Mr. Hersh:

As an HIV service care provider, friend to many consumers of HIV services and as a member of ACT UP Philadelphia, I oppose reporting the names of people with HIV to the Commonwealth as proposed in the draft regulations published in the PA Bulletin dated 4/20/01.

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. That is because, even with anonymous test sites, the practice of name-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,

Amanda L. Latshaw
2037 Spring Garden Street
Philadelphia, PA. 19130

Original: 2185

→ Joel Heush
(051500005)

James L. Dean, MD, FACP
532 Telner Street
Philadelphia, PA 19118
Email: Jdean532@aol.com

Board Certified - Infectious Diseases
Board Certified - Internal Medicine
Telephone: 215-242-3261
Fax: 215-242-4832

Member, American Academy of HIV Medicine
Member, Infectious Diseases Society of America
Member, Medical Staff, The Graduate Hospital
Member, Board of Directors, The AIDS Law Project of PA

May 14, 2001

The Honorable Robert S. Zimmerman
Secretary of Health
Health and Welfare Building #802
Harrisburg, PA 17120

RE: HIV Reporting

Dear Mr. Zimmerman:

I am writing to you as a Board Certified Infectious Diseases Physician who has been providing care to people living with HIV since 1989. I can tell you from my experience that names reporting of HIV will discourage people from being tested for HIV. No other disease in the history of medicine crosses medical, legal, political and socioeconomic lines in the manner in which HIV does.

It is the fear of discrimination, discrimination that still exists in the year 2001, that will discourage testing and treatment of HIV should names be kept on a list. Many of my patients fear that employers and insurance companies can have access to such a list. This is just one example. However, a fear of discrimination exists on many levels. I can describe numerous real life scenarios in which my patients have experienced discrimination. I can tell you that their fear is REAL, not imagined. Should so many people not seek diagnosis and treatment because of names reporting, the epidemic will become worse.

I strongly urge you to support a Unique Identifier Number method of collecting the demographic information that is requested to accurately describe the populations affected by HIV. The Unique Identifier Number has worked in other jurisdictions and CAN work in Pennsylvania.

I would be happy to discuss this issue in person at your request.

Sincerely,

James, L. Dean, MD, FACP

2001 MAY 29 AM 10:30
RECEIVED
OFFICE OF THE SECRETARY OF HEALTH
HARRISBURG, PA

Page 2.
Robert S. Zimmerman
RE: HIV Reporting

Cc:

The Honorable Vincent Hughes
Minority Chair
Public Health and Welfare Committee
543 Main Capitol
Senate Box 203007
Harrisburg, PA 17120-2020

Hon. Frank L. Oliver
Minority Chair
Health and Human Services Committee
34 East Wing
Harrisburg, PA 17120-2020

Hon. Dennis M. O'Brien
Chairman
Health and Human Services Committee
PA House of Representatives
100 Main Capitol
Harrisburg, PA 17120-2020

Hon. Harold F. Mowery, Jr.
Chairman Public Health and Welfare Committee
PA Senate
169 Main Capitol
Harrisburg, PA 17120-3031

Kevin R. Conare
Executive Director
ActionAIDS
1216 Arch Street
6th Floor
Philadelphia, PA 19107

Original: 2185

→ Joel Heush
(051500005)

James L. Dean, MD, FACP
532 Telner Street
Philadelphia, PA 19118
Email: Jdean532@aol.com

Board Certified - Infectious Diseases
Board Certified - Internal Medicine
Telephone: 215-242-3261
Fax: 215-242-4832

Member, American Academy of HIV Medicine
Member, Infectious Diseases Society of America
Member, Medical Staff, The Graduate Hospital
Member, Board of Directors, The AIDS Law Project of PA

May 14, 2001

The Honorable Robert S. Zimmerman
Secretary of Health
Health and Welfare Building #802
Harrisburg, PA 17120

RE: HIV Reporting

Dear Mr. Zimmerman:

I am writing to you as a Board Certified Infectious Diseases Physician who has been providing care to people living with HIV since 1989. I can tell you from my experience that names reporting of HIV will discourage people from being tested for HIV. No other disease in the history of medicine crosses medical, legal, political and socioeconomic lines in the manner in which HIV does.

It is the fear of discrimination, discrimination that still exists in the year 2001, that will discourage testing and treatment of HIV should names be kept on a list. Many of my patients fear that employers and insurance companies can have access to such a list. This is just one example. However, a fear of discrimination exists on many levels. I can describe numerous real life scenarios in which my patients have experienced discrimination. I can tell you that their fear is REAL, not imagined. Should so many people not seek diagnosis and treatment because of names reporting, the epidemic will become worse.

I strongly urge you to support a Unique Identifier Number method of collecting the demographic information that is requested to accurately describe the populations affected by HIV. The Unique Identifier Number has worked in other jurisdictions and CAN work in Pennsylvania.

I would be happy to discuss this issue in person at your request.

Sincerely,

James L. Dean, MD

James, L. Dean, MD, FACP

2001 MAY 29 AM 10:30
RECEIVED COMMUNICATIONS
DEPARTMENT

Page 2.
Robert S. Zimmerman
RE: HIV Reporting

Cc:

The Honorable Vincent Hughes
Minority Chair
Public Health and Welfare Committee
543 Main Capitol
Senate Box 203007
Harrisburg, PA 17120-2020

Hon. Frank L. Oliver
Minority Chair
Health and Human Services Committee
34 East Wing
Harrisburg, PA 17120-2020

Hon. Dennis M. O'Brien
Chairman
Health and Human Services Committee
PA House of Representatives
100 Main Capitol
Harrisburg, PA 17120-2020

Hon. Harold F. Mowery, Jr.
Chairman Public Health and Welfare Committee
PA Senate
169 Main Capitol
Harrisburg, PA 17120-3031

Kevin R. Conare
Executive Director
ActionAIDS
1216 Arch Street
6th Floor
Philadelphia, PA 19107

ActionAIDS
FRIENDS FOR LIFE

Kevin R. Conare
Executive Director

BOARD OF DIRECTORS

Pedro J. Rivcra, Esq.
President

Sara Velazquez, Esq.
Vice-President

Linda Newkirk-
Davenport
Treasurer

Barrington James
Brooks
Secretary

Gregg David Alleyne,
M.D.

William Cody Anderson

David S. Blum, Esq.

Marc-Antoney Carr

Lorraine Dennis

Peter R. Eobbi
Buddy Representative

Loreto Aldama Farinas,
Esq.

Amy Finkelstein, M.D.
Chair, Programs

Jeanette Scott Gillison

Dale L. Grundy
Chair, Public Affairs

Karl Krumholz, A/A
Chair, Development

Wil Maxton, DTR, CPT

Susan Pauls

Patricia Bogin Wisch,
Ed.D.
Chair, Nominations

1216 Arch St., 6th Floor
Philadelphia, PA 19107
P 215.981.0088
F 215.864.6930

3901 Market St., Box 1934
Philadelphia, PA 19104
P 215.387.6055
F 215.387.7989

2718 North 5th St.
Philadelphia, PA 19133
P 215.291.9700
F 215.291.0626

www.actionaids.org

May 14, 2001

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

01 MAY 22 AM 10:16

Re: Opposition to Names Reporting for HIV Surveillance

Dear Mr. Hersh:

On behalf of the board, staff, volunteers and clients of ActionAIDS, the largest AIDS service organization in the Commonwealth, I write to oppose reporting the names of people with HIV to the Commonwealth as proposed in the draft regulations published in the PA Bulletin dated 4/20/01.

We 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. We 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. That is because, even with anonymous test sites, the practice of name 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/we urge you to do so. Thank you.

Sincerely,


Kevin R Conare
Executive Director

cc: Senator Vincent Hughes
Representative Dennis M. O'Brien
Representative Frank L. Oliver
Senator Harold F. Mowery

RECEIVED
MAY 14 2001 11 09:25
PHILADELPHIA



ACLU of Pennsylvania
125 South 9th Street, P.O. Box 1161
Philadelphia, PA 19105-1161
(215) 592-1513
fax: (215) 592-1343
aclulegis@aol.com

RECEIVED
2001 MAY 22 AM 9:42

REVIEW COMMISSION

James D. Crawford
President

Larry Frankel
Executive Director

May 14, 2001

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

RE: PROPOSED RULEMAKING ON REPORTING OF CERTAIN HIV TEST RESULTS

Dear Mr. Hersh:

The American Civil Liberties Union strongly opposes the reporting of HIV test results by names. We firmly believe that the public health and the privacy interests of all Pennsylvanians will be better served by reporting HIV test results by a non-name based system.

There is a significant body of data that documents the deterrent effect of a name-based system for reporting HIV test results. The existing evidence demonstrates that name-based reporting is a counterproductive public health measure because it causes many at risk individuals to avoid HIV testing. One study found that more than 60% of individuals tested anonymously would not have undergone testing if their names would have been reported to public health officials. Susan M. Kegeles, et al., *Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It Under Other Circumstances*, 4 AIDS 585 (1990). Other studies have found that individuals are much more likely to voluntarily test for HIV, if the testing is anonymous, because those individuals believe that they can actually control the dissemination of their test results. See, Kathleen Irwin, et al., *The Acceptability of Voluntary HIV Antibody Testing In the United States: A Decade of Lessons Learned*, AIDS, vol. 10, no. 14, 1707 (1996); Geoffrey Reed et al., *The Impact of Mandatory Name Reporting on HIV Testing and Treatment*, Poster Presentation for the XI International Conference on AIDS (July 1996); Douglas Hirano, et al., *Anonymous HIV Testing: The Impact of Availability on Demand in Arizona*, 84 AM. J. PUB. HEALTH 2008 (1994).

There is also data that suggests that a name-based system for reporting HIV test results will have a particularly adverse impact in minority communities. In 1989, one

Joel H. Hersh
May 14, 2001
Page 2

researcher found that name reporting would deter HIV testing by African-Americans and Latinos. E. Fordyce, et al., *Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested*, 262 JAMA 349 (1989). While this study is more than ten years old, we know of no study that has refuted its core findings with regard to minority populations.

We are also concerned that requiring that test results be reported by name will cause at risk individuals to delay testing. A study reported in JAMA on October 28, 1996, found that persons tested anonymously sought testing and medical care much earlier than persons tested confidentially. The delay in seeking testing and medical care that may result from reliance on a name-based reporting system raises significant doubts about assertions that name reporting will advance the public health.

Because so much data suggest that using a name-based reporting system will deter and delay testing for HIV, the ACLU of Pennsylvania recommends that the proposed regulations be amended to call for a non-name based system for reporting HIV test results. Such systems are being used in Illinois, Maryland, Massachusetts, Puerto Rico, Rhode Island and Vermont. California, the District of Columbia, Hawaii and Kentucky are developing such systems. If those states can protect the privacy interests of their citizens, then Pennsylvania can, and should, as well.

The proposed regulations implicitly acknowledge the ability of the Department to pursue its surveillance program without requiring that names be used to report test results. Section 27.32a states that anonymous testing can be provided at State-designated sites and that results from those sites will be reported with an anonymous code. Thus the Department clearly understands how to operate a non-name based reporting system.

While we support the continued use of anonymous test sites, we are extremely troubled by the fact that the regulations are absolutely silent as to how many such sites there will be. Nor is there any indication of any commitment to maintain a sufficient number of anonymous test sites in the future. Nor is there any indication that such sites will be accessible to everybody in the Commonwealth regardless of where they live. The ACLU recommends that the regulations be amended to include not only specific language as to the number of anonymous test sites that will be designated by the state but also specific commitments to continue designating anonymous test sites that are accessible in every county of Pennsylvania.

Joel H. Hersh
May 14, 2001
Page 3

The ACLU also thinks that the regulations should require that testers who do not provide anonymous tests be required to counsel those who are tested as to the risks to personal privacy associated with non-anonymous testing and to provide a referral to an anonymous test site if the client wishes to be tested anonymously.

Finally, the ACLU objects to two sections of the "Regulatory Analysis Form." Item 14 calls for a description of who will be adversely affected by the regulation. The Department seems to believe that no one will be adversely affected and minimizes the concerns of persons with HIV or at risk for HIV. As stated earlier, we believe that there is abundant data that suggests the concerns of persons with HIV or at risk for HIV are real and substantial. The consequences of avoiding testing or delaying testing are significant and pose major problems for individuals and the public health.

Item 23 asks for a description of alternative regulatory schemes that were considered. The Department states that no alternative regulatory schemes were considered. Apparently, the Department is conceding that it did not properly consider any non-name based reporting system. Since quite a few other states are using such systems, it only seems appropriate and reasonable to expect the Department to engage in a more thorough analysis of those systems than the Department indicates it has undertaken. We believe that such an analysis would lead the Department into proposing a non-name based system for reporting HIV cases.

Very truly yours,



Larry Frankel
Executive Director

Cc: Members of Senate Public Health and Welfare Committee
Members of House Health and Human Services Committee

Original: 2185



COUNTY OF ERIE

2001 MAY 23 AM 9:05

Judith M. Lynch
County Executive

Joseph Trzybinski
Director

REVIEW DIVISION



Department of Health

606 West Second Street
Erie, Pennsylvania 16507
814 / 451-6700
Fax: 814 / 451-6767

ERIE COUNTY BOARD OF HEALTH

Howard A. Nadworny, MD, Chair
Cheryl L. Kinem
Mark J. Levine, MD
Gwendolyn M. White, CTIW
Stanley J. Zagorski

May 11, 2001

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


Dear Mr. Hersh:

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 disease in the community. Reporting results by name will allow us to provide case management services for those that are infected with the virus and then 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/sfa

Original: 2185

Edward K. Hanlon
1268 Country Club Drive
Springfield, PA 191064

RECEIVED

2001 MAY 22 AM 9:42

PHILADELPHIA COUNTY
REVIEW COMMISSION



May 12, 2001

Joel Hersh, Director
Bureau of Epidemiology
Commonwealth of Pennsylvania
P. O. Box 90
Harrisburg, PA 17108

**RE: Opposition to Names Reporting
For HIV surveillance**

Dear Mr. Hersh:

As a concerned citizen, I oppose reporting the names of people with HIV to the Commonwealth as proposed in the draft regulations published in PA Bulletin dated 4/20/01.

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 goals of HIV surveillance in Pennsylvania.

You should be aware that 95% of people testifying in public hearings you held around the state oppose names reporting. That is because, even with anonymous test sites, the practice of name-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 protections 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.

Sincerely,

Edward K. Hanlon

Original: 2185

Bankes, Julie

From: Hersh, Joel
Sent: Friday, May 11, 2001 12:21 PM
To: 'Lynn Gurski-Leighton'
Cc: Bankes, Julie
Subject: RE: Proposed HIV reporting

Lynn: I am in Atlanta and will not be back until 5/18. The public comment process is now open and I will officially consider the issues/questions below as official ones coming from The Hospital and Health System Association of Pennsylvania. You will receive by regular letter an acknowledgement. The responses to your issues will be officially made when we publish the preamble to the final regulations. If you have additional questions/issues/comments you may make them in this form or in writing within the thirty day public comment period. Thanks, Joel

Joel H. Hersh
 Director, Bureau of Epidemiology
 Pennsylvania Department of Health
 Ph:717-783-4677;Fax:717-772-6975
 e-mail: JHersh@state.pa.us

-----Original Message-----

From: Lynn Gurski-Leighton [mailto:LGLEIGHTON@Haponline.org]
Sent: Friday, May 11, 2001 10:06 AM
To: jhersh@state.pa.us
Subject: Proposed HIV reporting regulations

Joel,

Here are some of my questions and concerns related to the proposed regulations. Can you either try to answer them in writing or give me a call sometime later today after 1:30 pm or Monday after 10:30 am? I will not be in the office most of next week so I am under the gun to get the letter written before I leave on Tuesday to get it over to your office.

These are the issues identified-

1. What happens with information on low CD4-Tlymphocyte counts where the patient is a diagnosed cancer patient and is not really a candidate for HIV testing? My guess is that many physicians, particularly oncologists, will think that this requirement will be burdensome for them.
2. Potential problem for hospital on perinatal exposure to HIV since the hospital will have to rely heavily on physician documentation which is not always really good. And may delay reporting if the diagnosis is not picked up until medical records codes the chart.
3. Should spell out the CDC definition for AIDS in the regulations
4. Sounds like a provider can report to a city health department, state health center or district office. Is this an accurate read?
5. Information on mode of transmission or treatment may be difficult for hospital to complete on the report form. Will the software require that entries be made into each field in order to send the report?
6. Indicate in the proposal that the provider will need to keep a copy of the report on file. Does this mean on file in the infection control practitioner office where the filed case reports or kept or is the intention that this information be in the medical record? What is the intention here and it will be a problem if the expectation be that it is in the medical record.
7. See that the department wants to move forward with audits of cases prior to the actual implementation of the regulations to try to get a better grasp on the incidence of HIV. However, how do you intend to conduct such an audit? DOH should really talk to providers about the best way to accomplish this without aggravating the facilities. On the inpatient side, it may or may not show up in the principal or secondary diagnosis codes. I have no idea how you might get it from outpatient records. And, it looks like you plan to conduct future audits. What would these look like?
8. Software and training - how do you plan to roll that out and involve providers and laboratories?

Thanks,

Lynn

Lynn Gurski-Leighton
 Director, Clinical Services, HAP
lgleighton@haponline.org
 717-561-5308 - phone
 717-561-5334 - fax

5/11/2001

Effective January 2, 2001, The Hospital and Healthsystem Association's (HAP's) website address has changed to <http://haponline.org>. Please update your email list and bookmark for HAP's website.

P.O. Box 8600
Harrisburg, PA 17105-8600

5/11/2001

May 11, 2001

Dr. Walter Tsou
Health Commissioner
Philadelphia Department of Public Health
1101 Market Street, Suite 840
Philadelphia, PA 19107

Dear Commissioner Tsou,

I am writing to express concern about the Pennsylvania Health Department's plan to require that the names of people living with HIV infection be reported to the State. *Although the Pennsylvania Health Department says that name reporting does not discourage people from access to HIV testing and care, research shows that it does!*

Name reporting of HIV will only undermine the hard work being done by your department and community-based organizations in the Delaware Valley to encourage people to access HIV testing and care.

I urge you to tell the Pennsylvania Health Department that Philadelphia cannot comply with HIV name reporting requirements. Mayor Street supported this position in his 1992 campaign when he wrote that name-based HIV reporting, "could deter people from getting tested and seeking care."

Please tell the State Health Department that Philadelphia is only willing to cooperate with HIV reporting by Unique Identifier (letter/number codes that take the place of names). The ten states and territories that chose to use Unique Identifiers have proven that states can measure the spread of HIV accurately and do effective service planning without risking the privacy of their residents.

We need you and Mayor Street to protect the health of Philadelphians. We are looking to you to stand up for the right of all Philadelphians to ensure that HIV testing will not be compromised by name-based reporting!

Sincerely,



Alisha Sieminski
916 South 48th Street
Philadelphia, PA 19143
(215)727-3015

RECEIVED
MAY 11 2001
PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH

JEWISH HEALTHCARE FOUNDATION



May 10, 2001

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

Centre City Tower
650 Smithfield Street
Suite 2330
Pittsburgh, PA 15222
(412) 594-2550
FAX (412) 232-6240
E-Mail: info@jhf.org

Dear Mr. Hersh:

As the administrator of federal Ryan White Title II CARE Act funds, Housing Opportunities for Persons with AIDS (HOPWA) funds and Commonwealth of Pennsylvania 106 funds for HIV/AIDS care, housing and prevention services for the Southwestern AIDS Planning Region and as a concerned Pennsylvania taxpayer, I am well aware of the need for accurate information regarding HIV infection in the Commonwealth. I have closely followed both the Center for Disease Control's development of its reporting regulations and guidelines and the developments related to Ryan White formula funding in the recent re-authorization of the CARE Act. In addition, I hear daily from individuals with HIV disease and those at risk for HIV infection. It is on their behalf and with my own awareness and knowledge of the issues, that I feel I must comment on the Department of Health's proposed regulations for *Reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV* as published in the Pennsylvania State Bulletin on April 21, 2001.

First, and most emphatically, let me re-state my opposition to requiring names reporting of HIV. Almost all individuals with HIV and providers of services to people living with HIV in the Commonwealth oppose this method of collecting HIV information since it may deter people from getting tested. This was overwhelmingly evident from the comments provided to the Department of Health during statewide public hearings on the issue in 1999. As I said in my testimony before you on March 8, 1999, "... We know that certain individuals and communities will not go for testing if they believe that their name will be recorded. If we truly care about testing as a means of getting people into care, why would we add one more thing, even a perceived barrier, to what individuals face when deciding to go in for testing. ... [W]hy would we even hazard adding to a person's fear and reluctance to be tested when we know that early detection and treatment affords the best chance of survival? Aren't there already enough reasons not to be tested?"

HIV reporting by unique identifier in Pennsylvania can meet all of the requirements and guidelines issued by the federal funding agencies. Unique identifiers will protect individuals and it will protect the Department of Health from any potential legislative or judicial demands. No system of reporting HIV guarantees that it will link people to care. And since we know that we already don't have the resources to care for as many people as need it, I'm not sure that this is a realistic goal of any reporting system. However, a well thought-out

unique identifier system of reporting HIV infections – a system based on available resources, community acceptance and confidentiality protections – can be tied into and carried through to care services.

That said, let me also address the proposed regulations themselves. The wording of many of the items causes great concern. I recommend the Department review and revise them to be more accurate and appropriate.

- The definition of *Perinatal exposure of a newborn to HIV* (Subchapter A. General Provisions. § 27.1) contains wording that would allow for, in fact seems to require, a judgment to be made on whether or not the fetus has been “subject[ed] to risk of HIV infection”. I do not believe that it is the Department of Health’s intention that a laboratory or clinician, or the Department itself, make such a judgment on an individual. The intention may be to only test newborns born to a mother known to have HIV but the language is so loose that it appears to allow testing of any/all newborns when HIV in the mother is suspected -not documented. The wording of this definition must be changed so as to remove this possibility.
- Regarding the requirement of reporting laboratory results (Subchapter B. Reporting of Diseases. General. §27.22 (b)): A lab report of a CD 4 count is not a diagnosis of HIV/AIDS. Only a clinician with a full understanding of a patient’s medical history can and should make a diagnosis. This proposed regulation seems to be allowing labs and the Department to make a diagnosis. In addition, the decision on when to start treatment should be made by doctor and patient; for DOH to follow-up based on a lab report is to undermine that relationship and is an inappropriate approach to care. Both of these objections may be a violation of the Corporate Doctrine of Medicine. The Jewish Healthcare Foundation’s contract with the Department of Health prohibits us from violating this Doctrine; I assume such a prohibition is applicable statewide.
- The regulation that would require labs to report positive HIV test results within five days (§ 27.22 (d)5) raises the possibility that the Department could know about and respond to a positive HIV test result before the individual who tested positive has been informed of the test results. It realistically may take a physician or testing site more than five days to reach a patient – especially if 2 or 3 of the 5 days are holidays or weekends. I can not think of anything more intrusive, disrespectful and frightening than to be contacted by a Department of Health staff person informing me that I am HIV+ and asking if I want him/her to contact my sexual partner(s) to encourage them to get tested for HIV and all of this happening before I have had a chance to speak with my doctor. The proposed regulations allow this scenario to take place. I respectfully suggest that these be appropriately revised so that such a situation cannot occur.
- The inclusion of an “entity providing HIV services” among the list of those required to report (§ 27.32 (a)) could lead to the Department requiring pharmacies, Drug & Alcohol treatment providers, Mental Health Centers, AIDS Service Organizations, and homeless shelters or housing providers to report HIV cases. Again, when dealing with diagnostic situations, those reporting should be clinicians. It is unfair and inappropriate to require other health and human services entities to abide by these regulations.

- The requirement to include the “probable mode of transmission” among the items to be reported (§ 27.32 (a) 10) is vague and will result in many, and I am sure interesting, items of information that will not be able to be categorized into any useful information. Reporting entities should be provided with the most current categories of risk as delineated by the CDC and should be instructed to use only those categories. Further, “probable mode of transmission” again allows for judgments to be made about an individual by persons not necessarily qualified to make such personal judgments. Identifying risk factors is far more accurate, reasonable, appropriate and will provide standardized data that can be compared nationally.
- The language of requiring reporting entities to include in their reports “Other information the Department determines to be relevant” (§27.32 (a) 14) is just too broadly worded to be acceptable. Relevant to what? How will the Department determine what information it wants/deems relevant? This must be revised or deleted.
- Anonymous testing (§27.32a) is a hugely important component. There are a limited number of sites where such testing is currently available in the Commonwealth – only one in Allegheny County. The opportunities for anonymous testing should be increased and yet the proposed regulations seem to further limit the availability by requiring that anonymous testing be conducted only at a “State-designated anonymous testing site”. The regulations contain no information as to what determines a testing site to be “State-designated.” How will an individual know where to go for anonymous testing? What will the Department do to ensure that all Pennsylvanians have access to anonymous testing should they so choose? Will the sites that are currently providing anonymous testing become “State-designated”? I urge the Department to extensively reconsider the regulations regarding anonymous testing. The Commonwealth of Pennsylvania should continue to provide publicly funded anonymous testing options to ensure that individuals are not deterred from seeking HIV testing.
- Record audits going back to January 1, 2000 (§ 27.32d (a)), when the requirement to report HIV is not effective until 2002, not only contradicts the regulations themselves, it probably violates patient/client confidentiality. Releases signed by persons with HIV at that time did not include releasing HIV status information to the Department of Health. Release of information in those files and who may access that information requires the informed consent of the consumer until such time as these regulations are in effect.

Lastly, I would like to comment on a couple of items discussed in the narrative that accompanies the proposed regulations.

- The Department puts forth that one of the rationales for names reporting is to ensure that HIV infected individuals receive treatment. Yet there is nothing in the regulations regarding how this will be accomplished. No methods are laid out, no funds are allocated. The focus of both the proposed regulations and the narrative appears to be on tracking down the partners of those who test positive. Surely, the rationale loses its impact and persuasiveness when not upheld by the actual practice.

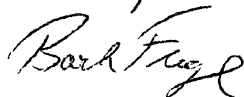
Joel Hersh
May 10, 2001
Page 4

- The narrative implies that the Commonwealth will lose federal funding unless it reports HIV cases by name. This is misleading and inaccurate. A Unique Identifier system will NOT impact the amount of funding received by the Commonwealth from HRSA and CDC. Pennsylvania will only risk federal funding if it does not report HIV data at all. The method used is irrelevant.
- The narrative states that newly hired staff would carry out case management activities and includes counseling, testing and partner notification as part of these activities. These are not case management activities as defined by HRSA for Ryan White services, the Department of Health Division of HIV/AIDS or the Department of Public Welfare for its Targeted Case Management services. In addition, there is nothing in the regulations that establishes the appropriate qualifications required for these staff to provide case management.

As per their recent meeting with Deputy Secretaries Helen Burns and Gary Gurian, the Pennsylvania Coalition of AIDS Service Organizations (PCASO) will be submitting revised language specific to many of the concerns I have raised here. I will support any changes and improvements recommended by PCASO. However, if I can be of any assistance in making revisions, please do not hesitate to call.

Thank you for the opportunity to comment on the proposed regulations for HIV reporting and for the attention I am sure will be paid to all of the public's comments.

Sincerely,



Barb Feige
HIV/AIDS Program Coordinator

Cc: Honorable Dennis O'Brien, Chair, Health & Human Services Committee, PA House of Representatives
Honorable Harold Lowery, Chair, Public Health & Welfare Committee, PA Senate

6810 Finch Place
Philadelphia, PA 19142-2525

09 May 2001

Dr. Walter Tsou
Health Commissioner
Philadelphia Department of Public Health
1101 Market Street, Suite 840
Philadelphia, PA 19107

RECEIVED
MAY 09 2001 9:29
PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH
HEALTH COMMISSIONER

Dear Commissioner Tsou,

I am writing to express concern about the Pennsylvania Health Department's plan to require that the names of people living with HIV infection be reported to the State. *Although the Pennsylvania Health Department says that name reporting does not discourage people from access to HIV testing and care, research shows that it does!*

Name reporting of HIV will only undermine the hard work being done by your department and community-based organizations in the Delaware Valley to encourage people to access HIV testing and care.

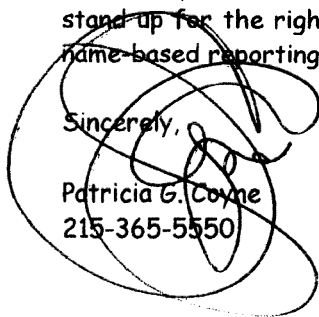
I urge you to tell the Pennsylvania Health Department that Philadelphia cannot comply with HIV name reporting requirements. Mayor Street supported this position in his 1992 campaign when he wrote that name-based HIV reporting, "could deter people from getting tested and seeking care."

Please tell the State Health Department that Philadelphia is only willing to cooperate with HIV reporting by Unique Identifier (letter/number codes that take the place of names). The ten states and territories that chose to use Unique Identifiers have proven that states can measure the spread of HIV accurately and do effective service planning without risking the privacy of their residents.

We need you and Mayor Street to protect the health of Philadelphians. We are looking to you to stand up for the right of all Philadelphians to ensure that HIV testing will not be compromised by name-based reporting!

Sincerely,

Patricia G. Coyne
215-365-5550





THE COUNTY OF CHESTER



COMMISSIONERS:
Colin A. Hanna, Chairman
Karen L. Martynick
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

Original: 2185

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

May 9, 2001

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

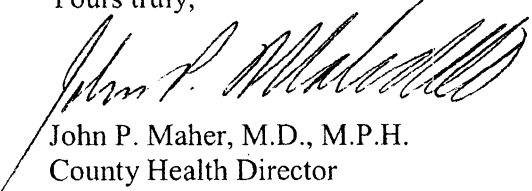
RE: Written Testimony re
HIV Reporting

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



THE COUNTY OF CHESTER



COMMISSIONERS:

Colin A. Hanna, Chairman
Karen L. Martynick
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

5/8/01

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 41 years, involved in public health and community medicine for 35 years, and the Director of the Chester County Health Department for 23 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, 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 treatment, 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

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

May 9, 2001

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. ^{Joel}~~Hersh~~:

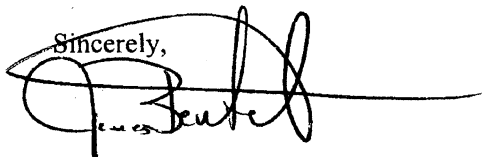
On behalf of the Bethlehem Health Bureau and the Bethlehem Board of Health, please accept this letter of support for the Pennsylvania Department of Health regarding proposed amendments to **Pennsylvania Title 28. Health and Safety, Chapter 27. Communicable and Noncommunicable Diseases**. Specifically, 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



10 EAST CHURCH STREET, BETHLEHEM, PENNSYLVANIA 18018



Pennsylvania MEDICAL SOCIETY®

May 7, 2001

CAROL E. ROSE, MD
President

HOWARD A. RICHTER, MD
President Elect

EDWARD H. DENCH JR., MD
Vice President

MICHAEL J. PRENDERGAST, MD
Chair

JITENDRA M. DESAI, MD
Secretary

ROGER F. MECUM
Executive Vice President

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

Dear Mr. Hersh:

The Pennsylvania Medical Society strongly supports the amendments to 28 PA. CODE CH. 27: *Reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV* as published in the *Pennsylvania Bulletin*, Vol. 31, No. 16, April 21, 2001. The Medical Society is particularly supportive of the Department of Health's proposal for the reporting of HIV infection by name as is done for other sexually transmitted diseases.

The Pennsylvania Medical Society has, for many years, been concerned that attempts to control the spread of HIV are entangled in politics to the point that political considerations dominate over good public health practice. These amendments will do much to correct that problem. They will allow epidemiologists to finally understand the extent and spread of infection in Pennsylvania. This will have great value in targeting efforts and resources to those at risk. Equally as important, reporting of infection by name will allow for critical public health practices such as contact tracing, confirmation of treatment and assurance of services to infected individuals. It is, therefore, critical that reports identify the infected individual.

We are fully cognizant of concerns about confidentiality. Physicians are very dedicated to protecting any medical information about their patients. We are especially concerned about any breach in confidentiality that stigmatizes a person infected with HIV. However, we do not believe that reporting HIV infection by name will compromise confidentiality because appropriate safeguards exist to prevent it. Reporting for other sexually transmitted diseases occurring in Pennsylvania, including AIDS, is currently done by name. We are not aware of any breach of confidentiality caused by such reporting to the Department of Health. National studies have also shown that states with name reporting have not experienced confidentiality problems.

The Pennsylvania Medical Society applauds the Pennsylvania Department of Health and its dedicated staff whose members worked so diligently to champion the cause of putting the health of Pennsylvania's citizens ahead of politics by proposing these amendments. We offer our strongest support and are willing to assist in any way possible.

Sincerely,

Carol E. Rose, MD
President

777 East Park Drive

P.O. Box 8820

Harrisburg, PA 17105-8820

Tel: 717-558-7750

Fax: 717-558-7840

E-Mail: stat@pamedsoc.org

www.pamedsoc.org

RECEIVED
2001 MAY 14 AM 10:27
PENNSYLVANIA
REVIEW COMMISSION

**Cc: Robert Zimmerman
Robert Muscalus, DO
Hon. Harold F. Mowery, Jr.
Hon. Dennis M. O'Brien
John R. McGinley, Jr.**



Pennsylvania MEDICAL SOCIETY®

RECEIVED
2001 MAY 10 PM 2:04

LABORATORY
REVIEW COMMISSION

May 7, 2001



CAROL E. ROSE, MD
President

HOWARD A. RICHTER, MD
President Elect

EDWARD H. DENCH JR., MD
Vice President

MICHAEL J. PRENDERGAST, MD
Chair

JITENDRA M. DESAI, MD
Secretary

ROGER F. MEGUM
Executive Vice President

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

Dear Mr. Hersh:

The Pennsylvania Medical Society strongly supports the amendments to 28 PA. CODE CH. 27: *Reporting of AIDS, HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV* as published in the *Pennsylvania Bulletin*, Vol. 31, No. 16, April 21, 2001. The Medical Society is particularly supportive of the Department of Health's proposal for the reporting of HIV infection by name as is done for other sexually transmitted diseases.

The Pennsylvania Medical Society has, for many years, been concerned that attempts to control the spread of HIV are entangled in politics to the point that political considerations dominate over good public health practice. These amendments will do much to correct that problem. They will allow epidemiologists to finally understand the extent and spread of infection in Pennsylvania. This will have great value in targeting efforts and resources to those at risk. Equally as important, reporting of infection by name will allow for critical public health practices such as contact tracing, confirmation of treatment and assurance of services to infected individuals. It is, therefore, critical that reports identify the infected individual.

We are fully cognizant of concerns about confidentiality. Physicians are very dedicated to protecting any medical information about their patients. We are especially concerned about any breach in confidentiality that stigmatizes a person infected with HIV. However, we do not believe that reporting HIV infection by name will compromise confidentiality because appropriate safeguards exist to prevent it. Reporting for other sexually transmitted diseases occurring in Pennsylvania, including AIDS, is currently done by name. We are not aware of any breach of confidentiality caused by such reporting to the Department of Health. National studies have also shown that states with name reporting have not experienced confidentiality problems.

The Pennsylvania Medical Society applauds the Pennsylvania Department of Health and its dedicated staff whose members worked so diligently to champion the cause of putting the health of Pennsylvania's citizens ahead of politics by proposing these amendments. We offer our strongest support and are willing to assist in any way possible.

Sincerely,

Carol E. Rose, MD
President

777 East Park Drive

P.O. Box 8820

Harrisburg, PA 17105-8820

Tel. 717-558-7750

Fax: 717-558-7840

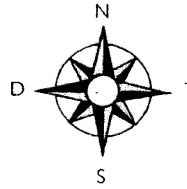
E-Mail: stat@pamedsoc.org

www.pamedsoc.org

Cc: Robert Zimmerman
Robert Muscalus, DO
Hon. Harold F. Mowery, Jr.
Hon. Dennis M. O'Brien
John R. McGinley, Jr.

Original: 2185

NEW DIRECTIONS Treatment Services



(051000001)
→ Legal
cc Gurian
May 07, 2001

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

To: Yvette

Dear Secretary Zimmerman,

This correspondence is for the purpose of commenting on the proposed rule-making which would amend 28 PA Code CH. 27 to require reporting of HIV and CD4 test results. By way of why I've chosen to comment, I might note that I have been involved in providing HIV testing on a large scale since the test was first licensed in 1985. This was first as director of one of the ten local health departments state-funded under the Local Health Administration Law and currently as director of a non-profit agency providing fixed site and outreach testing in Reading and in the Lehigh Valley.

I support the name reporting of HIV and CD4 data as described in the Department's proposal in many of the situations in which these tests would be done. This is true particularly given what has become the routine nature of testing for HIV status while providing other health care services. In general, most people receiving such services would not decline testing simply because they were told that positive tests were reportable. I commend the Department for taking this step given the amount of controversy doing so was sure to generate.

An important exception should, however, be made in regard to street outreach and other "grassroots" prevention activities focusing on persons often wary of the government, i.e., persons who may be in violation of laws dealing with immigration, prostitution, drug use, and so on. These are the people we most need to test from the public health perspective and they are also those most likely to balk at testing if name reportability is enacted. I do not believe that anonymous testing via one of the local or state health department programs as provided for in the proposal adequately addresses this issue. Such agencies are not only quite obviously part of the government but, more importantly, they generally do not provide the kind of bilingual, "street wise" outreach workers that nonprofit agencies utilize. Certainly in the cities in which New Directions operates (i.e., primarily Allentown and Reading) there is very little public sector activity specifically targeting this population on the street, in bars, and in other such places.

In view of the above, I recommend that all targeted, publicly funded testing where those involved have received appropriate state training be done utilizing unique identification numbers rather than names.

Thank you for your consideration of these comments.

Sincerely,


Glen J. Cooper
Executive Director

xc G. Gurian

1810 Steelstone Rd., Suite 101
Allentown, PA 18109
(610) 264-5900 phone
(610) 264-5907 fax



RECEIVED
2001 MAY 22 AM 9:43
PA DEPARTMENT OF HEALTH
HEALTH COMMISSION

20-22 N. 6th Ave.
Reading, PA 19611
(610) 478-0646 - phone
(610) 478-1671 - fax



Original: 2185

OFFICERS

Robin Wilcox, MPA - President
Institute for Healthy Communities

Robert Gage, MSPH - President Elect
Montgomery County Health Dept.

David Hawk, MD, MPH - Immediate Past
President
York City Bureau of Health

Sally Fabian, RN, MSN - Secretary
BCHIP, Inc

Wanda Vierthaler, MPH, CHES- Treasurer
Pennsylvania Health Department

Richard J. Cohen, PhD, FACHE
Philadelphia Health Management Corp.

BOARD MEMBERS

Gerald M. Barron, MPH
Allegheny County Health Department

Rickie Braver, MPH
Jefferson Health System

Sharon Colaizzi, RN, BSN
Magee Women's Hospital

Jonathan Crossette, MPH
Children's Hospital of Philadelphia

Virginia M. Dato MD, MPH
University of Pittsburgh

Lisa Davis, MHA
Pennsylvania State University
Dept of Health Policy and Admin

Cliff Dearthoff
The Foundation of the PA Medical Society

Alice J. Hausman PhD, MPH
Temple University Dept of Health Studies

May 1, 2001

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

Dear Mr. Hersh:

The Pennsylvania Public Health Association, supports proposed amendments to 28 PA. Code CH.27 published in the PA Bulletin, Doc. No. 01-680. Specifically, the **Association supports protecting the public's health through reporting of HIV infection by name** in the same manner as other sexually transmitted diseases are reported. This will serve two purposes. First, Pennsylvania will have a more accurate idea of the number of HIV infections in our communities. Second, Pennsylvania will be in a better position to prevent future infections. Without such measures, the Commonwealth could find itself in the position of numerous countries where a substantial proportion of the population is HIV infected and where the deaths of young productive members of society and/or their need for expensive medication is so great that it is threatening the economic and social health of the entire country.

The more accurate assessment of the HIV problem afforded by these amendments will permit improved medical service delivery and evaluation to currently infected individuals. At this time we do not know how many individuals are currently infected with HIV nor how many are not being provided with life lengthening treatment. Each individual with HIV will require, in the best current scenario, years of expensive medications with many side effects or, in the worse case scenario, treatment for numerous opportunistic infections followed by an early death. Reporting of names will permit direct assistance to both the infected individual and exposed contacts.

These amendments also emphasize that the Department of Health is available to assist individual clinicians in counseling, testing, referral and partner notification of currently infected individuals, where consistent with Act 148. Partner notification (also known as contact tracing) is important for the prevention of both disease and morbidity and has been demonstrated with other sexually transmitted diseases to decrease the incidence and morbidity of infections. The fact that there is no cure or vaccine for HIV infections

RECEIVED
MAY 10 11 2001
DEPARTMENT OF HEALTH
HARRISBURG, PA

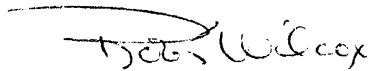
Joel H. Hersh
May 1, 2001
Page 2

01 MAY -4 PM 4:40

makes contact tracing more, not less important. Individual clinicians rarely have the time or training to provide this important public health service with the sensitivity and support required. Contact tracing provides contacts with early treatment (if infected) and knowledge necessary to prevent future infections (their own if not infected, others if already infected). Treatment of pregnant women has the added benefit of prevention of infection in the newborn.

Effective public health requires a delicate balance of individual rights and public good. Here the public good far outweighs any perceived risk of loss of confidentiality. The Pennsylvania Public Health Association also supports the funding needed to make this system work appropriately. Consider that HIV medications can cost \$10,000 per year per individual. The savings from prevention are clear without even factoring in the decrease in disease, suffering and death of Pennsylvanians.

Sincerely yours,



Robin Wilcox

Original: 2185

BUREAU OF HEALTH
245 North 6th Street
Allentown, PA 18102-4128



BUREAU OF EPIDEMIOLOGY
01 MAY -8 AM 10:45

Alliance Hall
(610) 437-7702
FAX (610) 437-8799

City of Allentown

May 4, 2001

Joel H. Hersh, M.P.A.
Director
Bureau of Epidemiology
P.O. Box 90
Harrisburg, PA 17108

Dear Mr. Hersh:

I am writing to comment on the proposed rulemaking for the reporting of AIDS, HIV test results, CD4 T-lymphocyte counts and perinatal exposure of newborns to HIV which appeared in the April 21, 2001 edition of the Pennsylvania Bulletin. As I stated two years ago during public testimony, the Allentown Health Bureau and its Board strongly support the proposal to make the aforementioned conditions reportable by name for the following reasons:

1. 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 be 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.
2. 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. Staff can assist these contacts in getting counseling and testing services.
3. 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.

RECEIVED
2001 MAY 11 AM 8:53
REVIEW COMMISSION

Letter to Joel H. Hersh
May 4, 2001
Page 2

RECEIVED
BUREAU OF EPIDEMIOLOGY
01 MAY -8 AM 10:45

All of these activities can be accomplished earlier when HIV positivity is detected and name reporting is made - rather than waiting until AIDS is reported years later. The end result will be twofold:

- 1) Improved access to effective care and treatment programs for HIV positive persons, resulting in better and longer health.
- 2) A reduction in additional infections through early partner notification and education about how to prevent the spread of HIV infection to others.

Sincerely,



Barbara E. Stader, R.N., M.S.N.
Director of Health

n:\pudliner\stader\hersh letter

Original: 2185

Department of Anesthesiology
Geisinger Medical Center
Danville, PA 17822-2025

APR 30 11:17
April 30, 2001

~~01 APR 30 11:17~~

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

Re: HIV infection reportable by name

Dear Mr. Hersh:

I am writing in support of the Department of Health proposed regulation to make HIV infection reportable by name. Certainly, confidentiality is of extreme importance in issues such as this. However, public health concerns must be addressed and confidentiality can still be maintained with an appropriate reporting system.

Sincerely,



Joseph J. Stemm, MD
Associate, Department of Anesthesiology

RECEIVED
2001 MAY -3 AM 10:03
REVIEW COMMISSION

Original: 2185

The City of
YORK
PENNSYLVANIA

Mayor Charles H. Robertson

RECEIVED
2001 MAY -7 AM 8:32
PENNSYLVANIA
YORK

**DIVISION OF
COMMUNITY AFFAIRS**

Director's Office
849-2292

April 30, 2001

Health
849-2252

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

Housing Services
849-2264

Planning & Zoning
849-2307

Permits/Licensing
849-2256

Dear Mr. Hersh:

**DIVISION OF
PUBLIC SERVICES**

Director's Office
849-2245

I am pleased to see in the Pennsylvania Bulletin that the Department of Health is proposing to amend Chapter 27 to allow for reporting of AIDS, HIV infection, CD4 T-Lymphocyte Counts and Perinatal Exposure of Newborns to HIV, and more importantly making the **reporting by name**. This is the correct decision 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 twenty years, it is time and many would argue past time to stop treating HIV infection any differently.

Building/Electrical Maintenance
845-9351

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.

Environmental Services
849-2245

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.

Highway Maintenance
849-2320

Recreation & Parks
854-1587

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
David L. Hawk, M.D., M.P.H., Director
York City Bureau of Health

First Capital Of The United States

1 Marketway West • 3rd Floor • York, Pennsylvania 17401-1231 • FAX (717) 849-2329

4/23/01

Mr Walter Trow

RECEIVED

01 MAY 18 AM 11:20 01 MAY 18 AM 9:21

As a Health Worker in Philadelphia
 would like to encourage you Not Starting
NAME-BASED HIV Reporting! Having
 Worked in this field for 10 Years + I know
 people would be afraid to be TESTED
 (over) →

and would be afraid to get Care &
Education while getting Care which

would only aid in spreading the Virus!

I personally know that once many
 people are diagnosed and receive Care and
Education they STOP participating in

activities that can spread the Virus!

Sorry for the informal Note! Wanted to Mail ASAP!
 NOTE

01 APR 2001 11:3:55
 DEPARTMENT OF HEALTH



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

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

Director

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

April 25, 2001

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

Dear Joel:

The Pennsylvania Bulletin of April 21, 2001 includes proposed regulations on Reporting of AIDS, HIV Test Results, etc. Name reporting would be required. Comments were to be sent to you.

As you know from past conversations on this matter, I (as well as many others) have for years wanted HIV positive test results to be reportable.

The obtaining of information on the numbers and characteristics of those who become infected with HIV would permit much better and more current planning and provision of services. This would be in contrast to the present situation of having to wait ten or more years until an infection with HIV progresses to AIDS (when it becomes reportable).

There now seems to be broad-spread support for making HIV infection reportable. However, I realize that some favor a system of reporting by "unique identifier" instead of name reporting. I favor reporting by name because I believe that those required to report will be more likely actually to report and to report accurately. It may prove not possible to have (at this time) reporting by name. In that case, information provided by reporting by "unique identifier" would be better than the current situation (in which no data is available at all until an individual with HIV infection reaches the stage when AIDS can be diagnosed).

The matter of confidentiality in a system of name reporting should not be a problem. Currently, all reportable diseases (including AIDS itself) are reportable by name, and confidentiality has been well protected historically. For those who might still be deterred from being tested for HIV by concerns about confidentiality, designated anonymous testing sites will still be available.

Sincerely,

Lewis D. Polk, M.D., M.P.H.

RECEIVED
APR 27 2001
DEPARTMENT OF HEALTH
BUREAU OF EPIDEMIOLOGY