

BABETTE JOSEPHS, MEMBER

REPLY TO:

HOUSE BOX 202020
HARRISBURG, PENNSYLVANIA 17120-2020
PHONE: (717) 787-8529
FAX: (717) 787-0861
E-MAIL: bjoeph@pahouse.net

1528 WALNUT STREET, SUITE 1901
PHILADELPHIA, PENNSYLVANIA 19102
PHONE: (215) 893-1515
FAX: (215) 560-5610
WEB SITE: babette.org

SE PHILADELPHIA JOINT LEGISLATIVE OFFICE
951 E. PASSYUNK AVENUE
PHILADELPHIA, PENNSYLVANIA 19147
PHONE: (215) 463-4500
FAX: (215) 463-2415



House of Representatives
COMMONWEALTH OF PENNSYLVANIA
HARRISBURG

COMMITTEES

DEMOCRATIC CHAIR,
STATE GOVERNMENT COMMITTEE

PHILADELPHIA DELEGATION
DEMOCRATIC POLICY COMMITTEE
CONVENER

THE WOMEN OF THE PA GENERAL
ASSEMBLY
CAMPAIGN FINANCE REFORM CAUCUS
COMMON SENSE FIREARMS SAFETY CAUCUS
SUBSTANCE ABUSE CAUCUS

Original: 2185

June 10, 2002

John McGinley, Jr., Chair
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101
VIA FAX: (717) 783-2664

2002 JUN 10 PM 4:01
INDEPENDENT REGULATORY REVIEW COMMISSION

RE: HIV Name Reporting, Reg.#10-166

Dear Mr. McGinley:

I am writing to express my opposition to reporting HIV test results by name. I am not a member of the House Health and Human Services Committee, but still I am displeased that the Department of Health has ignored bi-partisan comments made in June of 2001 which strongly recommended that the Department not report by name.

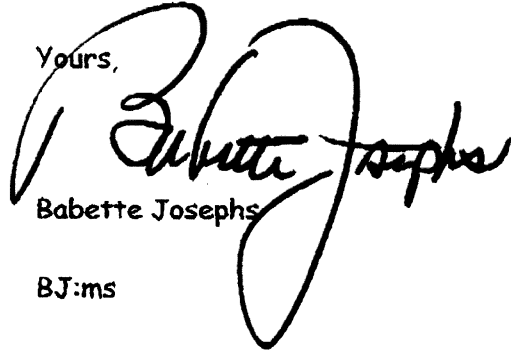
The Health and Welfare Committee was not the only body of experts ignored by the Department. At hearings held by the Department itself, I testified against the proposed names reporting policy. The overwhelming majority of witnesses agreed with my position. Nevertheless, the Department paid no attention to people with AIDS or HIV/AIDS experts and advocates and continued to insist on its regulation. I trust that IRRC will be more responsive.

At a time where HIV infection rates are at an all-time high, it is imperative that the state establish a system which encourages the maximum number of people who believe they are at risk to be tested and that the personal life style information of those individuals be as accurate as possible. We know that the only way to fight HIV/AIDS is to encourage individuals to avoid risky behavior. HIV and AIDS are still highly stigmatized diseases, and the groups most affected by these epidemics are the least likely to trust government. Names reporting will discourage people from stepping forward, so they cannot be advised how to avoid risk. The Department's intent or actual confidentiality procedures are not relevant if the perception is otherwise.

June, 2002
HIV Name Reporting
page two

As I testified to the Department, I support a unique identifier system - a coding system that protects individual privacy, does not deter testing, and still collects relevant data to allow us to accurately track this epidemic.

Yours,

A handwritten signature in black ink, appearing to read "Babette Josephs". The signature is written in a cursive style with large, sweeping loops, particularly in the "B" and "J".

Babette Josephs

BJ:ms

Original: 2185

BABETTE JOSEPHS, MEMBER

REPLY TO:

- HOUSE BOX 202020
HARRISBURG, PENNSYLVANIA 17120-2020
PHONE: (717) 787-8529
FAX: (717) 787-0861
E-MAIL: bjosephs@pahouse.net
- 1528 WALNUT STREET, SUITE 1901
PHILADELPHIA, PENNSYLVANIA 19102
PHONE: (215) 893-1515
FAX: (215) 560-5816
WEB SITE: babette.org
- SE PHILADELPHIA JOINT LEGISLATIVE OFFICE
951 E. PASSYUNK AVENUE
PHILADELPHIA, PENNSYLVANIA 19147
PHONE: (215) 463-4500
FAX: (215) 463-2415



House of Representatives
COMMONWEALTH OF PENNSYLVANIA
HARRISBURG

COMMITTEES

APPROPRIATIONS,
DEMOCRATIC CHAIR, SUBCOMMITTEE
ON HEALTH AND HUMAN SERVICES
CHILDREN AND YOUTH SERVICES
HEALTH AND HUMAN SERVICES
JUDICIARY

VICE CO-CHAIR,
PHILADELPHIA DELEGATION
DEMOCRATIC POLICY COMMITTEE
CONVENER,
THE WOMEN OF THE PA GENERAL
ASSEMBLY
CAMPAIGN FINANCE REFORM CAUCUS
COMMON SENSE FIREARMS SAFETY CAUCUS
SUBSTANCE ABUSE CAUCUS

June 7, 2001

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

Re: DOH REG. IRRG #10-166 HIV Reporting by Name

Dear Mr. Hersh:

I support a unique identifier system for tracking HIV cases in Pennsylvania.

Using this system rather than actual names will not adversely affect the amount of federal money received by Pennsylvania. We only risk losing funding if we do not report HIV data at all. Names reporting is clearly counter productive, because the real funding jeopardy we face is that the commonwealth will report fewer HIV cases and thus lose monies under the new federal grant formula.

It is absolutely imperative that the state set up a system which encourages the maximum number of people who believe they are at risk to be tested and that the personal life style information of those individuals be as accurate as possible. Since HIV and AIDS are highly stigmatized diseases and since the groups most affected by these epidemics are the least likely to trust government, names reporting will discourage people from stepping forward regardless of the Department's intent or actual confidentiality procedures. The question is of perception. Individuals who fear losing privacy will not be tested. Individuals who are asked to detail their private lives will be less than frank if that sensitive information is to be put on the same paper as their real names.

As Dr. McTighe, a physician and laboratory medical director in practice in Central Pennsylvania wrote, "... [P]eople with AIDS here are subject to the same types of discrimination that are reported all over the country. They have lost their jobs and homes and have become isolated and shunned... For me to tell these people I will have a legal obligation to report them to the government, **by name**, will simply dry-up testing... To require reporting HIV infection **by name** will actually help further spread HIV infection." Dr. McTighe's experience is confirmed by many studies documenting the deterrent effect of name-based reporting of HIV test results.

RECEIVED
2001 JUN 11 AM 9:02
REVIEW COMMISSION
ANTHONY

June, 2001
page two
Unique Identifier

Recommendation: Amend the regulation making HIV data reportable using a non-name based system.

There are a limited number of anonymous testing is available. The regulation seems to further limit availability by requiring that anonymous testing be conducted only at a "State-designated anonymous testing site". The regulation does not define "State-designated", or whether sites currently providing anonymous testing are "State-designated."

Recommendation: Increase opportunities for anonymous testing by including a commitment to increased statewide access in the regulation.

Recommendation: Include commitment to meeting CDC data security/confidentiality standards in the regulation.

Yours,

A handwritten signature in black ink that reads "Babette Josephs". The signature is written in a cursive style with a large, looping initial "B".

Babette Josephs

BJ:ms

cc: Bruce Flannery, PICASO
Kevin Conare, Action AIDS
Ronda Goldfein, AIDS Law Project of Pennsylvania
John R. McGinley, IRRC