

Original: 2185

48th DISTRICT
JAY COSTA, JR.
SENATE BOX 203043
HARRISBURG, PA 17120-2043
PHONE: (717) 767-7663
FAX: (717) 788-5976

1201 ARDMORE BLVD., SUITE 402
PITTSBURGH, PA 15221
PHONE: (412) 241-6990
FAX: (412) 260-0340

2808 BROWNVILLE ROAD
PITTSBURGH, PA 15210
PHONE: (412) 488-6111
FAX: (412) 488-6102

214 EAST EIGHTH AVENUE
HOMESTEAD, PA 15120-1892
PHONE: (412) 868-7886
FAX: (412) 868-7833



Senate of Pennsylvania

June 19, 2001

Robert J. Nyce, Executive Director
Independent Regulatory Review Commission
14th Floor, Harristown2
333 Market Street
Harrisburg, PA 17101

Dear Mr. Nyce:

I am contacting you regarding the Department of Health's Proposed Regulation #10-166 (#2185) titled "Reporting of AIDS HIV Test Results, CD4 T-Lymphocyte Counts and Perinatal Exposure of newborns to HIV." In particular, I would like to address the issue of Names Reporting versus the use of Unique Identifiers.

AIDS and the transmission of HIV remain one of the most serious and grave diseases known to mankind. I am pleased that the Pennsylvania Department of Health is pursuing an active role in educating the Commonwealth and proposing regulations further providing for the health and well-being to those who are directly (or indirectly) affected by the disease. However, there is one area of the Department's proposal, which in my view could have serious repercussions on the extended welfare of the citizens in this Commonwealth - Names Reporting over implementing a Unique Identifier system.

Although the disease was first discovered more than two decades ago, the complications associated with AIDS/HIV have resulted in the general public stigmatizing the disease and those who have contracted it. Because social status has a direct correlation to the number of people who actually receive testing, it is important that this factor be taken into consideration when determining the best solution to gather health statistics.

While reviewing correspondence from patients and medical facilities, along with discussions with various AIDS advocates, the main concern was that anonymous testing was favored over confidential testing for various reasons. If Pennsylvania adopts Names Reporting, there was a consensus of concern and evidence supporting those concerns, that a large number of people would either delay or defer being tested for HIV through fear of being identified and stigmatized. The fact that HIV has become such a stigmatized disease, any report linking a name

COMMITTEES
JUDICIARY, DEMOCRATIC CHAIRMAN
BANKING AND INSURANCE
PUBLIC HEALTH AND WELFARE
TRANSPORTATION

SENATE DEMOCRATIC POLICY COMMITTEE
PENNSYLVANIA COUNCIL ON THE ARTS
PUBLIC EMPLOYEE RETIREMENT COMMISSION
PENNSYLVANIA COMMISSION ON SENTENCING
LEGISLATIVE BUDGET AND FINANCE
PENNSYLVANIA COMMUNITY DEVELOPMENT BANK
OPERATIONS COMMITTEE

RECEIVED
SENATE COMMITTEE ON
PUBLIC HEALTH AND WELFARE
JUN 19 2001

PAGE 2 - Senator Jay Costa, Jr. (Proposed Regulation #10-166 #2185)

to an HIV test would, in many cases, prove to be unfavorable to those being tested. By implementing a Unique Identifier system, it will permit medical facilities to track this epidemic while establishing an anonymous social environment for any person opting to be tested. Establishing statewide names reporting appears to be an unnecessary and perhaps punitive social barrier that may actually be a counterproductive approach to the task at hand. This could delay treatment and leave thousands of people who may be in the highest risk category undetected.

It has been a general concern that the Pennsylvania Department of Health has not provided enough concrete reasons why mandating names-based HIV case reporting would be more sufficient than implementing a Unique Identifier system. Should the Department move forward in mandating Names-Based testing, measures to strengthen statewide privacy protections for public health data must be examined immediately.

I would urge that it is the best interest of the citizens of this Commonwealth that the Pennsylvania Department of Health seriously re-consider the recommended regulations to report the names of people with HIV. Your attention and re-evaluation of the Names Reporting approach to detecting HIV is greatly appreciated. Should you have any questions, please do not hesitate to contact my office.

Sincerely,



Jay Costa, Jr.
43rd Senatorial District

JC/jal