

PRESIDENTIAL

ADVISORY

COUNCIL ON

HIV/AIDS

April 7, 1999

The Honorable William Jefferson Clinton
The White House
Washington, D.C.

Dear Mr. President:

As your Advisory Council on HIV/AIDS, we bring to your attention our concern with two sentences in the Omnibus Appropriations Bill of 1998 which have a potentially tremendous negative impact on publicly funded HIV/AIDS research. These two sentences would allow individuals (and corporations) to use the Freedom of Information Act (FOIA) to gain access to researchers' raw data whenever the research is funded by a federal grant.

The language provides: "That the Director of the Office of Management and Budget amend... Section -.36 of OMB Circular A-1 10 to require Federal awarding agencies to ensure that all data produced under an award will be made available to the public through the procedures established under the Freedom of Information Act." A second sentence allows a "reasonable user fee" to be charged for the release of data. While the intent of this legislation in making information about this research available is laudable, the outcome could have detrimental effects.

On January 6, Representative George Brown (D-CA), ranking Democrat on the House Science Committee, introduced H.R. 88 to repeal this provision, pointing out that the language as stands would require "the premature release of research results." Congressman Brown says his legislation would " protect researchers from harassment."

The Omnibus Appropriations language could have potentially serious and detrimental effects on all government sponsored research - including HIV/AIDS, by allowing:

- Early release of research data, which does not reflect the real and final truth;
- Mis-use of in accurate, partially completed research data;
- Potential for loss of subject confidentiality; and
- Potential loss of valuable time and effort on the part of researchers, who must devote energy to complying with this law, as opposed to performing the research for which funds were granted.

We urge you to support H.R. 88, and to support a similar repeal bill in the Senate.

Sincerely,

(Original signed by RSH on 4/7/99)

R. Scott Hitt, M.D.
Chair

cc: The Honorable George Brown
Sandra L. Thurman, Office of National AIDS Policy
Daniel Mendelson, Office of Management and Budget

