Congress of the United States
House of Representatives
Washington, D.C. 20515

February 5, 2004

The Honorable Tommy G. Thompson
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Mr. Secretary:

We are writing to ask you to ensure that the new initiative to increase HIV testing that is being sponsored by the Centers for Disease Control and Prevention (CDC) will not leave thousands of Americans with a diagnosis of HIV infection but without access to life-saving medications and medical care.

There is a gap between CDC's public health efforts and the President's budget for the Ryan White CARE Act. On one hand, CDC is promoting HIV testing in the hopes of diagnosing Americans who are currently unaware they are infected. This campaign will create new demand for HIV treatments and medical care. On the other hand, the President's fiscal year 2005 budget asks for insufficient HIV/AIDS funding including less than one-sixth of the increase needed to ensure that all HIV-positive Americans have access to essential therapies.

This scenario is unacceptable. While CDC's testing initiative may be important to slowing the spread of HIV, it should be matched by efforts to help those diagnosed with HIV to live longer, more productive lives. We urge you to intervene to assure that the President's budget adequately funds the Ryan White CARE Act, including AIDS drug assistance.

CDC's new initiative, called "Advancing HIV Prevention," was launched in early 2003. The premise is simple: because Americans who do not know they are infected are believed to be more likely to pass HIV to others, improving the diagnosis of HIV has the potential to slow the course of the epidemic.[1]

To promote early detection, CDC is pursuing a wide and ambitious agenda. CDC is funding community-based organizations to test for HIV in non-medical settings such as correctional facilities and is leading a national campaign to encourage health care providers to offer routine HIV testing.[2] The agency has already purchased and distributed 250,000 rapid HIV

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[1]Centers for Disease Control and Prevention, *Advancing HIV Prevention: The Science behind the New Initiative* (2003) (online at http://www.cdc.gov/hiv/partners/ahp_science.htm).

[2]Centers for Disease Control and Prevention, *supra* note 1.

tests and has broadcast via satellite a series of educational programs to thousands of health care providers.[3] The agency's goal is to reduce the number of Americans who are unaware of being infected to less than 5% of all those who are infected.[4]

One important — but unaddressed — outcome of this initiative will be a marked increase in the demand for HIV treatment as new diagnoses are made. The CDC hopes to "ensure that every person with HIV infection has the opportunity to get tested, has access to state of the art medical care, and ongoing prevention services."[5] However, while the CDC plan will increase testing and diagnosis, the Administration has not made a corresponding commitment of resources to assure access to medication and primary medical care, under the Ryan White CARE Act, for those diagnosed through this initiative.

Congress passed the Ryan White CARE Act in 1990 to assure access to HIV/AIDS care for all Americans. Title I provides funds to areas hit the hardest by the HIV/AIDS epidemic for outpatient care and case management. Title II funds grants to states to improve the quality, availability, and delivery of health care for HIV-infected individuals. Title III funds nonprofit groups to provide primary care, early intervention, and capacity-building and planning services. Title IV provides funds to meet the special needs of women, infants, and children living with HIV.

While the CDC initiative will increase demand for all Ryan White CARE Act services, the impact will most clearly be seen in those programs funded by Title II, which includes the AIDS Drug Assistance Program (ADAP). Originally created by Congress in 1987 to help states purchase AZT for uninsured Americans with AIDS,[6] ADAP was moved to the Ryan White CARE Act in 1990 to provide for a range of HIV/AIDS treatments. More than a decade later, ADAP still serves as a key safety net across the country. In June 2002, ADAP served more than 80,000 Americans with 257,000 prescriptions.[7]

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[3]Centers for Disease Control and Prevention, *AHP Initiative Quick Facts* (Jan. 12, 2004) (online at http://www.cdc.gov/hiv/partners/QuickFacts.htm).

[4]Centers for Disease Control and Prevention, *HIV Strategic Plan through 2005* (2001) (online at http://www.cdc.gov/hiv/partners/psp.htm).

[5]Centers for Disease Control and Prevention, *Letter on the Initiative to CDC Colleauges* (Apr. 21, 2003) (online at http://www.cdc.gov/hiv/partners/ahp_colleague.htm).

[6]Henry J. Kaiser Family Foundation, *AIDS Drug Assistance Programs* (Apr. 2002).

[7]National Alliance of State and Territorial AIDS Directors, Kaiser Family Foundation, and AIDS Treatment Data Network, *National ADAP Monitoring Project Annual Report* (Apr. 2003).

Unfortunately, ADAP suffers from substantial underfunding and state-to-state variation in the drugs covered. Despite federal spending of $714.3 million in fiscal year 2003, there are about 800 people waiting to be enrolled in drug assistance programs and 15 states with waiting lists or other cost-containment strategies that impact access.[8]

In 2003, the National Alliance of State and Territorial AIDS Directors (NASTAD) estimated that an increase of $280 million was needed in the fiscal year 2004 budget to provide for those waiting to receive ADAP services and to cover all effective treatments.[9] This estimate did not include the additional costs of drugs for new patients diagnosed because of the CDC initiative. After NASTAD's ADAP Crisis Task Force negotiated $65 million in discounts and rebates from pharmaceutical companies, and Congress increased ADAP funding by $34.5 million in fiscal year 2004, a gap of $180.5 million still remains.

Using conservative assumptions, it can be estimated that an additional $45.3 million will be needed in fiscal year 2005 to fund ADAP just to care for those diagnosed as a result of the CDC initiative.[10] This figure is very likely an underestimate.[11]

The President, however, has proposed just a $35 million increase in ADAP funding for fiscal year 2005.[12] This increase does not come close to matching the $180.5 million ADAP

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[8]National Alliance of State and Territorial AIDS Directors, *ADAP Watch* (Jan. 22, 2004) (online at www.nastad.org).

[9]The $280 million estimate included projected growth in ADAP enrollment absent the CDC initiative, unmet need within the program, costs to treat HCV, costs of the new drug therapies, and ending the waiting list. National Alliance of State and Territorial AIDS Directors, *AIDS Drug Assistance Program (ADAP) FY2004 Projected Need* (2003) (citing a figure of $280 million prior to discount of $65 million obtained from pharmaceutical companies); E-mail communication from NASTAD to Government Reform Committee minority staff (Jan. 23, 2004) (citing $65 million discount obtained from pharmaceutical companies).

[10] This calculation is explained in an addendum to this letter.

[11]There are several reasons why this figure is very likely an underestimate. First, the CDC initiative may be more successful than anticipated. If CDC gets all the way to its goal over four years, the costs will double. Second, because the CDC initiative is targeting patients who may not have usual sources of medical care, the percentage requiring the services of the AIDS Drug Assistance program may be considerably higher than 18%. If half of those diagnosed need drug assistance, the treatment costs will nearly double. Third, the estimate is based on average current costs, which may reflect underfunding of the program in some states.

[12]The President's FY2005 proposal of $784 million is $45 million more than his FY2004 proposal of $739 million, which was $10 million less than what Congress provided for ADAP in FY2004. Department of Health and Human Services, *President Proposes Increase in Minority*

shortfall estimated by NASTAD, and it does not match the estimated $45.3 million projected ADAP need for funds due to the CDC initiative. It provides less than one-sixth of the total $225.8 million increase needed for ADAP next year. The President's budget also fails to increase other elements of Ryan White CARE Act funding adequately.

By failing to provide necessary funds for HIV/AIDS care, the Administration is risking the success of the CDC's HIV testing initiative. Patients and providers may be less likely to test if lifesaving medications cannot be obtained. Communities may be reluctant to partner with CDC to encourage widespread testing while many of their citizens are languishing on ADAP waiting lists.

We understand that the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment recently asked HHS to model the impact of the CDC initiative on demand for ADAP services. Analysis of this gap by HHS is critically important. However, there is already ample evidence to justify a major increase in the President's fiscal year 2005 budget.

We urge you to reverse this retreat from critical, life-saving HIV care. At a time when this Administration is pursuing a major commitment to AIDS overseas, it is wrong to overlook the epidemic's sufferers at home. We look forward to receiving your response to this letter.

Sincerely,

Nancy Pelosi
Democratic Leader

Steny H. Hoyer
Democratic Whip

Henry A. Waxman
Ranking Minority Member
Committee on Government Reform

Barney Frank
Member of Congress

Sherrod Brown
Ranking Minority Member
Subcommittee on Health
Committee on Energy and Commerce

Donna M. Christensen
Chair
Health Brain Trust
Congressional Black Caucus

AIDS Funding (Jan. 16, 2004); *Bush to Seek More for AIDS Programs*, Washington Post (Jan. 15, 2004).

Barbara Lee
Chair
Task Force on Global HIV/AIDS
Congressional Black Caucus

Tammy Baldwin
Member of Congress

Enclosure

Addendum: Estimating the Center for Disease Control and Prevention's Testing Initiative's Impact on the AIDS Drug Assistance Program

The cost to ADAP of the CDC initiative can be estimated by:

Number of Patients Diagnosed As a Result of CDC Initiative	X	% of Those Diagnosed Who Will Need Drug Assistance	X	Average Federal Cost of Drug Assistance

A conservative estimate of the number of people who will be diagnosed with HIV next year because of the CDC program is 23,750. This is based on the CDC's goal of reducing the number of Americans who are unaware of being infected to less than 5% of all of those infected, or approximately 40,000 people. There are now estimated to be 230,000 Americans who have undiagnosed HIV infection. Meeting this goal will require relatively stable trends in new infection and routine diagnosis plus 190,000 extra diagnoses over time. The CDC's goal was set in 2001 for achievement in 2005. Now that the implementation of the Advancing HIV Prevention initiative has begun, a conservative estimate would anticipate that CDC could get halfway to its goal with an additional four years past its 2005 target. This would require an extra 23,750 diagnoses per year. Centers for Disease Control and Prevention, *HIV Strategic Plan through 2005* (2001) (online at http://www.cdc.gov/hiv/partners/psp.htm) (sets goal of less than 5% of those with HIV unaware of infection). Centers for Disease Control and Prevention, *CDC's New HIV Initiative* (2003) (online at http://www.cdc.gov/hiv/partners/question.htm) (estimates approximately 230,000 Americans with undiagnosed HIV infection).

A reasonable estimate of the percentage of those identified by the CDC initiative who will need drug assistance through ADAP is 18%. This is the proportion of all HIV-positive Americans in medical care who receive medications through ADAP. National Alliance of State and Territorial AIDS Directors, Kaiser Family Foundation, and AIDS Treatment Data Network, *National ADAP Monitoring Project Annual Report* (Apr. 2003) (citing 80,035 clients receiving medications in June 2002); *Many in US with HIV Don't Know It or Seek Care*, New York Times (Feb. 26, 2002) (citing CDC report that 447,000 Americans have HIV and are in care).

The average cost per additional person in ADAP can be estimated conservatively by current spending, because many states' formularies are restrictive. Based on data from June 2002, the average annual cost of drug assistance per person is $10,601. National Alliance of State and Territorial AIDS Directors, Kaiser Family Foundation, and AIDS Treatment Data Network, *National ADAP Monitoring Project Annual Report* (Apr. 2003) (citing June 2002 expenditures of $70,705,142 for 80,035 clients).

These estimates lead to the conclusion, using the equation above, that costs for ADAP attributable to the CDC initiative can be conservatively estimated at 23,750 patients diagnosed X 18% who need drug assistance X $10,601 per person = $45.3 million.