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CAEAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

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April 16, 1998

Mr. Todd Summers
Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Todd:

Thank you so much for taking the time out of your busy schedule last week to meet with me on such short notice. It was very good to see you again. Clearly, we have our work cut out for us; but when it comes to HIV/AIDS, that's business as usual. the CAEAR Coalition is committed to doing it's part, and I'm sure you are, too.

I am enclosing our talking points, which ask for $570 million in FY '99 for Title I and $113 million for Title III of the Ryan White CARE Act. I also have included our draft of appropriations language for your information. If I can provide you with any additional information, please do not hesitate to contact me.

Again, Todd, thanks for all you do on behalf of people living with or affected by HIV/AIDS. I look forward to working with you more closely in the days and weeks ahead. Take care of yourself and your blessings.

Yours in the struggle,

Phill Wilson
Interim Executive Director

PW/tt

Enclosures

CAeAR
CITIES ADVOCATING EMERGENCY AIDS RELIEF

$570 MILLION NEEDED IN FY 99 FOR CARE ACT TITLE I

Hope, not hoax – new treatments require new resources.

- The CAEAR Coalition is requesting a minimum of $570 million in FY 99 funding for TITLE I of the Ryan White CARE Act. **This would be an increase of $105 million over FY 98.** The promise of new treatments, such as protease inhibitors, is inextricably linked to the primary health care and support services funded under TITLE I.

- The 51 metropolitan areas eligible in FY 99 to receive emergency assistance under TITLE I provide care to at least 74% of all reported cases of AIDS in the United States. The infrastructure of care services created under TITLE I continues to be a critical component of AIDS care in America.

- According to the Centers for Disease Control and Prevention, AIDS prevalence will continue to increase. This fact underscores an increasing need for medical and other services for people living with AIDS. As the number of AIDS deaths has begun to decrease, the number of people living with AIDS has grown. Twenty percent of TITLE I clients annually are new cases.

Expanded services are required by new federal HIV Treatment Guidelines -- 59% of TITLE I services provide primary health care.

- A decade and a half of research has brought significant breakthroughs in the treatment of HIV. These breakthroughs have led the U.S. Public Health Service to recommend, as the proposed standard for medical care, viral load testing and use of combination therapies, including protease inhibitors.

- The new standards of care require that TITLE I areas ensure access to medical care, the new anti-HIV drugs and the support services that enable successful adherence.

- The first step in accessing the new combination therapies is a physician's visit, followed by diagnostic tests, including the viral load test, and then for many, a prescription – all services provided with TITLE I dollars. Funding for drugs without funding for the mechanisms which make those drugs available is an ineffective policy and a cruel hoax for those who stake their lives on the hope of these new AIDS treatments.

- Currently, the lowest estimated cost for measuring a person's viral load is $100 per test, and quarterly monitoring is recommended. Test costs, in some locales, are as high as $250 per test. The Health Resources and Services Administration (HRSA) estimates there are 350,000 TITLE I clients and that at least 30% of these clients are expected to use TITLE I funding to pay for viral load testing. **To provide quarterly viral load testing for these TITLE I clients requires a minimum FY 99 increase of $42 million.**

- The new treatments are often complicated and have the potential for severe side effects. A person who fails to take these medications as prescribed runs the risk of developing resistant viral strains. Close monitoring by a physician, provided with TITLE I funding, is required.

- TITLE I services are predominantly used by symptomatic people with AIDS who require significantly more – and more complex – medical visits. The number of primary care exam slots for HIV care also increases as people with HIV live longer. A goal of TITLE I communities is to expand access to care and treatment at an earlier stage of disease -- an unachievable standard for most communities with current resources.

- The provision of medical health care services accounts for the expenditure of 59% of Title I funds. This includes not only physicians visits, but tens of millions of dollars for the direct purchase of medicines, and millions more transferred from TITLE I to TITLE II AIDS Drug Assistance Programs (ADAPs). In FY 97, 10% of TITLE I funds, or $41,059,269, was transferred to ADAP -- based on local priorities.

- The need for services that are traditionally not considered primary medical care, such as nutrition and case management services, has also grown with the use of the new combination therapies. The reason is simple: many of these services are critical to a person's ability to adhere to an effective drug regimen. **The CAEAR Coalition requests a very conservative increase of $11 million to address the expansion in services, other than viral load testing.**

Epicenter EMAs struggle to respond to flood of new patients seeking medical care.

- **New Clients.** HRSA estimates that 20% of TITLE I clients every year are new clients. TITLE I communities across the country have documented client increases ranging from 13% to as high as 74%. **A minimum FY 99 increase of 10% in TITLE I funds, or $46 million is required to provide for these new TITLE I clients.**

New TITLE I Areas in FY 99 – existing areas continue to lose funding.

- **In FY 99, two new areas become eligible for TITLE I.** Both Norfolk, Virginia, and Las Vegas, Nevada, have become eligible for TITLE I emergency assistance in FY 99, increasing the total number of TITLE I communities from 49 to 51. **To reflect that growth in TITLE I areas, the CAEAR Coalition is requesting a minimum increase in FY 99 funding of $6 million.**

- **In FY 98, fifteen TITLE I areas lost funding as compared to the previous year.** Despite modest increases in CARE Act funding overall, some, though not always the same, TITLE I communities have lost funding three of the last four fiscal years in comparison with their previous year funding. Clearly funding for TITLE I of the CARE Act has fallen behind the need to provide increased resources to each and every TITLE I community.

For further information, contact the CAEAR Coalition,
1413 K Street, NW, Suite 700, Washington, D.C. 20005, 202.789.3565, fax 202.789.4277; *or*
The Sheridan Group, 1808 Swann Street, NW, Washington, D.C., 20009, 202.462.7288, fax 202.786.1964

Draft Appropriations Report Language

The Committee has provided $570 million in funding for Title I and $113 million in funding for Title III of the CARE Act. These funding levels are critically important to assuring access to, and successful utilization of, the new anti-HIV drugs and combination therapies.

Title I expands this fiscal year to another two metropolitan areas, providing resources to the 51 U.S. communities where over 74% of all Americans with AIDS have been diagnosed. The CARE Act mandates local control of Title I funds which are allocated to the medical health services and the supportive services that enable individuals to adhere to complex combination therapy that include protease inhibitors. Without adequate funding to these communities hardest hit by the AIDS epidemic, access to the physicians' visits and medical tests required to prescribe the new drugs will remain impossible.

Title III provides HIV-specific funding to 183 community health providers located in urban, suburban and rural parts of the United States,. These directly funded programs allow for early diagnosis and ongoing primary medical care, including the new combination therapies, for 83,000 people infected with HIV. This in turn has reduced hospitalizations by 75%. In addition, Title III funded clinics, with 25% of its clients women of child-bearing age, are uniquely situated to provide the successful AZT intervention that reduces HIV transmission from mothers to infants from 25.5% to 8.3%.

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