# ADAP

**Working Group**

**An AIDS Drug Assistance Program Advocacy Coalition**

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Abbott Laboratories
Agouron Pharmaceuticals, Inc.
AIDS Action Council
AIDS Alliance for Children, Youth & Families
AIDS Foundation of Chicago
AIDS Healthcare Foundation
AIDS Project Los Angeles
AIDS Treatment Data Network
American Academy of HIV Medicine
Boehringer Ingelheim
Bristol-Myers Squibb
Broward Log Cabin Club of Florida
Cities Advocating Emergency AIDS Relief Coalition
Florida AIDS Action
Gilead Sciences
Glaxo Smith Kline
Hoffmann-La Roche
LA Gay & Lesbian Center
Merck & Co.
Mother's Voices
National AIDS Treatment Advocacy Project
National Association of People With AIDS
Positive Opportunities
Project Inform
San Francisco AIDS Foundation
Schering-Plough Corporation
The National Native American AIDS Prevention Center
Title II Community AIDS National Network
Triangle Pharmaceuticals
Visible Genetics, Inc.

2/02

**Chair**
**William E. Arnold**


13 February 2002

## PRESS RELEASE – MEDIA ADVISORY

**THE ADAP WORKING GROUP**
Contact: Bill Arnold (202) 588-1775

IMMEDIATE RELEASE

### ADAP National forecasting model indicates immediate need for "Emergency Supplemental Appropriation" of $82 Million for United States access to HIV/AIDS treatments.

**The ADAP Working Group today released it's annual pharmacoeconomic model forecasting a need for an increase of $162 million to cover FY 2002 shortfalls and FY 2003 funding under Title II of the Ryan White CARE $82 Million of this amount is needed almost immediately as an "emergency supplemental appropriation" to reverse State ADAP access and use *reduction plans, remove HIV+ Patients from waiting lists in several States and insure that* the 587 HIV+ patients who are expected to apply to ADAPs each month in the coming 14 months – will actually receive medical treatment.**

"We knew that uninsured and underinsured, low income HIV+ Americans would be in trouble as a result of shortfalls in ADAP funding in the FY '01 and FY '02 budgets. We have been expecting waiting lists and inability to treat patients. We didn't expect to see quite this many stranded patients so quickly. When you forecast carefully - as we do - the numbers say we need these additional funds to provide treatment for 15,135 new patients – for a full 12 months of treatment, if needed - who are unable to access private or public insurance coverage adequate to meet their health care needs. That's beyond the 80,000 patients now being treated each month via ADAP. Recent telephone survey data shows that several hundred of these untreated patients are lined up already – waiting – and the FY '02 inadequate funding won't even be released until April 1st, 2002. This is not acceptable in America. Emergency funds for these folks are needed tomorrow not in 2003" said Bill Arnold, long time Chair of the ADAP Working Group a Washington based advocacy coalition.

The ADAP Working Group has been making its economic forecasts early each year since 1996 with great accuracy. The goals of adequate funding to enable all HIV+ Americans to access the very impressive life-saving new anti-retroviral treatments developed since. The goals of making treatments available to all who need them have been broadly supported by political leadership in both the Democrat and Republican parties for many years. We believe that Congress and the Administration MUST continue to insure that HIV+ Americans – ALL OF THEM – continue to have access to the medical benefits available due to the advances in science, research and drug development in the treatment of HIV disease.

Over 80,000 HIV+ Americans are accessing treatment via ADAPs right now and if 15,000 more need treatments and care – then ADAP must deliver it. We simply can not say to those who now discover that they need HIV treatment that they must get sicker and sit on a bureaucratic "waiting list" somewhere in the United States of America while we possess health treatment benefits which they need - today.

For copies of the forecast or other information contact us... (202) 588 –1775

Talking points...

- ADAPs have been under funded for the past two fiscal years and continue to be unable to meet the needs of all those eligible. A number of state ADAPs-including Alabama, Arkansas, Georgia, Texas, Kentucky, North Carolina, South Dakota and West Virginia -currently have access restrictions limiting enrollment in the program or cutting back on the availability of critical HIV treatments. These restrictions are in place to maintain the fiscal viability of the programs in the face of continuing increases in the number of clients seeking services and soaring program expenditures on pharmaceutical treatments. The programs simply do not have the resources to serve all eligible clients.

- Current data clearly indicate that both the number of clients seeking ADAP services and program drug expenditures will continue to increase, as they have for the last six years. Flat funding of HIV care programs-ADAPs in particular-will result in more states being forced to curtail ADAP services and to deny low income, uninsured individuals access to life saving HIV treatments. ADAPs have an been extremely successful-and cost effective-means of helping to dramatically reduce the number of AIDS deaths over the past several years; now is not the time for the federal government to decrease or abandon its commitment these critical, life saving programs.

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1/02

**Chair**
**William E. Arnold**


6 February 2002

**Introduction to the ADAP Budget Projection Model, Fiscal Year 2003**

The ADAP Working Group is a unique ad hoc coalition of HIV/AIDS community-based organizations, biotechnology, pharmacy and pharmaceutical research companies. Our mission is to ensure adequate access to HIV/AIDS-related therapies through the AIDS Drug Assistance Program (ADAP), funded under Title II of the Ryan White CARE Act.

The ADAP Working Group believes that the enclosed budget projection provides an accurate representation of the cost of providing a basic standard of HIV/AIDS care to those on ADAP in Fiscal Year 2003, which runs April 1, 2003 - March 31, 2004. It also addresses the funding crisis in the CURRENT FY '02 program year.

The cost of treating a person with AIDS on Medicaid can be upwards of $40,000 a year*. In fiscal 2003, adequate HIV disease treatment (including HAART and related HIV conditions) per person on ADAP will average a little more than $12,000 for the year. Without adequate ADAP funding, uninsured and underinsured people with HIV will have to wait until they are sick and disabled in order to qualify for Medicaid and receive the full HIV/AIDS treatment that could have prevented their illness progression to "full blown" AIDS. This is clearly unsound health care policy.

The impact of multi-drug anti-HIV therapy has been well publicized over the past few years. The many incremental gains in the prevention and treatment of opportunistic infections have also made a significant contribution to extending and improving the lives of people with AIDS. The stunning drop in US deaths from AIDS since 1995 is a testament to these facts. The adoption of the US Public Health Service guidelines on the use of antiretroviral therapy has further improved the standard of care for people with HIV and AIDS.

The ADAP Working Group believes that it is ethically unacceptable to deny access to available treatments to HIV+ Americans. Nor can we afford to deny optimum HIV and AIDS treatment to all those that could benefit from it. The ADAP population is particularly vulnerable, often depending on a fractured system of care and on other vital Ryan White services. They should not have to decline into complete physical disability to receive the HIV/AIDS treatments they need.

The following summarizes the ADAP Budget Projections:

**FY 2002**

| | |
|---|---|
| Projected ADAP budget need for **FY 2002**: | $1,050,767,246. |
| Base budget (from FY 2001): | $ 885,945,624. |
| Projected Increase in Need **FY 2002** | $ 164,821,622. |
| Expected State Share Increase (20% of Need) | $ 32,964,324.** |
| Federal Increase Approved for **FY 2002** | $ 50,000,000. |
| Current projected **FY 2002** shortfall: | **($ 81,857,298.)** |

To address the **FY 2001** Shortfall we project the need for an **"EMERGENCY SUPPLEMENTAL APPROPRIATION"** of: +$81,857,298

**FY 2003**

| | |
|---|---|
| Projected ADAP budget need for **FY 2003**: | $1,171,094,860. |
| Projected base budget for **FY 2003**: | $ 968,909,948. |
| Current projected ADAP shortfall for **FY 2003** | **($ 202,184,912.)** |

To address the FY 2003 increased demand we project needs as follows:

| | |
|---|---|
| **Federal Share (80%***):** | **+$161,747,929.** |
| State Share (20%***): | +$ 40,436,982.** |

*Source: Connors, Medicaid Working Group (data from Community Medical Alliance, Santa Barbara, CA, 1993). The inflation-adjusted annual cost of treating advanced AIDS, based on this data, would be $53,056.
**The Model assumes a 20% State match of the annual increase in need ($32,964,324 in FY2002, and $40,436,982 in FY03). The actual amounts may vary, dependent upon State legislative ADAP budget actions during calendar 2002 and 2003.
***This percentage is derived from referencing Congressional Report Language. The historical ADAP budget data shows funding ratios of 74% Federal funds and 26% State funds. The current projection avoids artificially inflating the Federal share by projecting a 20% state match of the total increase in need for each year (see footnote **, above). However, we recognize in reality economic recession related State Budget deficits may affect actual funding outcomes and totals.

**Projection Methods**

A computer model, developed by respected pharmacoeconomists, was used to estimate the cost of providing the standard of care to these utilizing ADAP clients on a month-by-month basis out to March 31, 2004. The same model has been utilized by the ADAP Working Group to project ADAP need for the past six years.

The model uses real world information about the immune system status of ADAP clients to project the need for preventive and acute treatment with outpatient drugs. The expected incidence of illness is based on an analysis of data from the Multicenter AIDS Cohort Study (MACS) by Bacellar et al (Journal of Infectious Disease 1994;170). The same model has predicted individual state ADAP expenditures within 5% of the actual totals. A total of 22 states have utilized this model for fiscal projection purposes.

The model makes assumptions about antiretroviral therapy as described in the new NIH/PHS Guidelines. In addition to their basis in the new NIH/PHS Guidelines, these projections mirror current trends in State ADAPs.

The model cannot anticipate the changes and refinements in the standard of care that may occur within the timeframe of this projection. The ADAP Working Group will update the projection model whenever new and validated information that impacts the model becomes available.

The enclosed slides provide more details on the methodology and the results.

William E. Arnold
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The following slides illustrate the methods used, the results projected (in additional detail) and provide additional information.

This entire document is available electronically – contact us for electronic copies or web site locations.

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