

VOICE OF T•II CANN

ADAP Crisis Worsens

“Emergency Supplemental ADAP Appropriation” Fails in Senate

In the first days of June, AIDS activists around the country mounted a determined attempt to find a “Champion” Senator willing to offer an amendment in the Senate to the “Emergency Defense Appropriation” bill. Attempts to save the ADAPs from current and future cut backs and restrictions were spurred by Senators Frist (R-TN), Helms (R-NC), Durbin (D-IL), and Specter (R-PA) to offer amendments calling for as much as \$700 million in additional funds for global HIV/AIDS programs including funds for the Global Fund for AIDS, Tuberculosis, and Malaria. As many readers may know, the Durbin/Specter amendment was defeated on a vote, and the White House heavily lobbied Senator Frist (Senator Helms was recovering from surgery and not present) to back off from his \$500 million for Global AIDS. A scaled back version similar to the \$200 million passed on this bill in the House did survive.

Most AIDS advocates are extremely supportive of major and rapid assistance for global HIV/AIDS programs. With millions of lives at stake and millions needing anti-retroviral therapy anyone familiar with the role of ADAP in the U.S. for access to medications is usually immediately sympathetic to U.S. leadership for similar access to HIV-positive people anywhere on the globe.

However, it's equally true that access to drugs remains an American domestic crisis. Anyone who thinks access to HIV medica-

tions is not a “homeland security” issue has never had to face the prospect of not being able to get HIV treatments, when they are needed. The logic of “fixing” both domestic ADAP with an \$82 million “emergency” supplemental and “jumpstarting” global AIDS – at the same time – seems obvious. However, it was not to be, due to political constraints and political budget differences between Democrats and Republicans and between the White House and Congress. Now the “grassroots” and AIDS advocates across the U.S. must make it a political priority – in an election year.

The efforts by “grassroots” HIV/AIDS activists, on short notice, to generate support, however, were very impressive. Specific active approaches from the grassroots (coordinated with many members of the ADAP Working Group in Washington, DC) were made with Senators Smith (R-OR), Murray (D-WA), Schumer (D-NY), Clinton (D-NY), Graham (D-FL), and Nelson (D-FL). California Senators were also lobbied. North Carolina also mounted an intense drive with Senator Edwards (D-NC) on ADAP. All these states have known significant ADAP problems and in all these states there are informed AIDS advocates concerned about the ADAP problems and cutbacks that they know are coming. North Carolina has 505 HIV-positive people on their ADAP waiting list as of early June.

Members of ATAC (AIDS Treatment Advocacy Coalition – see

www.ATAC.org), FLAAC (Florida AIDS Action – see www.floridaaids-action.org), ACT UP, Health Gap, GMHC (Gay Men’s Health Crisis), Project Inform, T•II CANN, other national AIDS organizations, and numerous local ASO’s were involved in extensive call and fax drives even with the short time frame we had for political action.

Every single Senate office contacted in this effort was supportive, and all were willing to speak in support – if someone else would take the lead. Each was constrained from taking a leadership role by conflicts with party leadership, by conflicting committee responsibilities, and by the political agreements already in place between Appropriations committee

Continued on page 5

UPDATE . . .

...on the Unending Struggle for a Medicare Drug Benefit

HHS Secretary Tommy Thompson claims there’ll be a bill enacted by November and House GOP leaders plan to bring up their bill (bitterly opposed by Democrats) on the House floor. Meanwhile, Democrats on the Senate Finance Committee are crafting THEIR competing and quite different bill. But most knowledgeable Washington analysts expect no bi-partisan agreement—and thus no action—this year. ■

Oregon Senator Urges Passage of the Early Treatment to HIV Act

Recently, at the 2002 National ADAP Educational Forum in Washington, DC, Senator Gordon Smith (R-Oregon) urged the House and Senate to pass a bill giving states the option of extending Medicaid benefits to the predisabled with HIV disease, saying the measure is necessary to “bring much needed treatments” to people with HIV and AIDS. He also called on the AIDS community to put more pressure on Congress in order to secure passage of the legislation.

“We know that by treating individuals with HIV early, we can not only improve their quality of life but we can reduce the possibility of transmitting HIV to others,” said the senator, a member of the Senate Budget Committee. “We may even save money on these treatments in the long run.”

Smith is the only Republican Senate sponsor of a bill that would give states the option of extending a prescribed set of Medicaid benefits to the predisabled with HIV who, if disabled, would qualify for

Medicaid. The bill, known as the Early Treatment to HIV Act (ETHA), could solve one of the most vexing access-to-treatment dilemmas for people with HIV and AIDS. Under existing rules, many people with HIV and AIDS are unable to access Medicaid until they become sick and disabled even though early access to highly active antiretroviral therapy (HAART) would slow disease progression in many patients, improving and extending lives in the process. So far, ETHA has only five sponsors in the Senate, including Smith who urged program participants at the National ADAP Conference to “corner your senators and ask them to co-sponsor this very important legislation.”

“If we do not get [the Senate’s] help, an awful lot of HIV-positive Americans will simply go without,” said Smith, the Senate’s Deputy Whip who co-chairs the Senate Task Force on Medicare and Prescription Drugs.

Smith, who describes himself as a maverick Republican willing to cross party lines in the interests of his constituents, said he has “worked tirelessly to try and find ways of providing a safety net so that no American goes without health care.”

“Help me to help you in your cause as you interface with members of Congress,” urged Smith, who was elected to the Senate for the first time in 1996 and is running for re-election this year. “Get them to join on with (ETHA).”

Domestic Terrorism

Smith told the audience that “you are here at a busy time in terms of war and peace, a time when we are trying to provide for the safety of the American people and also to turn our nation – as best as we are able to with the tools of government – back to a time of prosperity.”

Smith described HIV/AIDS as a “domestic form of terrorism,” telling the audience that “I cannot

think of anything more terrorizing than to be told that someone has HIV/AIDS.”

“Although HIV/AIDS affects rich and poor alike, our health care system is not very egalitarian,” he said. “More than 40 million Americans have no insurance whatsoever and millions more cannot afford insurance.”

For many others, insurance covers only the “most basic of needs,” noted Smith. Before the advent of the AIDS Drug Assistance Programs (ADAPs), many Americans with HIV/AIDS had two choices; they could forgo treatment and wait until they became sick enough to qualify for Medicaid or they could pay for the drugs out of pocket until they exhausted their resources and qualified for Medicaid through the program’s spend down provisions, Smith said.

“In my mind, those are not choices that any of our citizens should be confronted with,” he said.

Smith said the drug assistance programs have “given thousands of low income Americans a chance to benefit from the same breakthrough drugs that wealthy HIV-positive Americans may now take for granted.”

“Some of these drugs reduce HIV/AIDS mortality rates by as much as 70 percent,” noted the Senator. “In my own state of Oregon, about 2,000 people are currently living with HIV/AIDS and about 2,700 have died of this dreadful disease over the years.”

In Oregon, the ADAP provides medication assistance to more than 1,100 Oregonians annually. “These are 1,100 Oregonians who would not have received high quality treatment just a few short years ago,” Smith said. “These are thousands of lives which have been made better because the ADAP program exists.”

Smith told the audience “we have

Continued on page 3

THE VOICE OF T•II CANN

Volume 6 Number 2
Published Bi-monthly
Annual Subscriptions: \$25.00

The Voice Editorial Board:

William Arnold Thomas P. McCormack
Gary Rose Mabrey Whigham

If you have anything of interest to share with the Title II community, please fax it to (202) 588-8868. Visit T•II CANN’s website at www.tiicann.org.

© Ryan White CARE Act Title II Community AIDS National Network (T•II CANN), 2002

The Voice newsletter and other activities of T•II CANN, including The National ADAP Educational Forum annual and regional meetings, have been supported by generous, unrestricted grants from Bristol-Myers Squibb, Hoffmann-La Roche, Inc., Merck & Co., Ortho Biotech Immunology, Glaxo Smith Kline, Boehringer Ingelheim, Virologic, Virco, and Gilead Sciences. General activities of T•II CANN are supported by unrestricted education grants from Glaxo Smith Kline, Pfizer, Abbott Laboratories, Pharmacia, Gilead Sciences, Visible Genetics, Schering Plough, and donations from foundations and private citizens and the gift of thousands of unpaid volunteer hours from staff, board members, and supporters.

Continued from page 2

to build upon those successes. To begin with, we must increase funding for ADAP," he said. "It is essential that this program remains capable of supporting not only the lives it has extended but those lives it has not yet reached."

Smith reminded the audience that ADAPs "need \$82 million more in the emergency supplemental appropriations bill and an increase of \$80 million in the regular Health and Human Services appropriations bill."

He said support for ADAPs and other AIDS-related programs "should not be a partisan issue."

"AIDS does not care if you are a Republican or Democrat or an American or anything else," Smith said. ■

In Brief . . .

Editor's Note: Due to limited space in *The Voice*, the T•II CANN Editorial Committee is often faced with the daunting task of deciding which important information to include in each issue. Since this information is often important to our readers, T•II CANN has created the "In Brief" column to provide this information in a summary format and direct you to the source.

- A working group called the "Women at Barcelona," made up of scientists, activists, service providers, women living with HIV, and others whose focus is women/HIV/AIDS has been formed to work on a Women's Satellite Meeting and other women's events at the International AIDS Conference at Barcelona in July of 2002. For more information, visit their website at www.womenatbarcelona.net.
- Title II federal funding history can be found on the HRSA's website, www.hrsa.gov. ■

In It For the Long Haul

By: Jeff Graham, *Executive Director, AIDS Survival Project*

About the Author: Jeff Graham is the Executive Director of AIDS Survival Project, an Atlanta-based agency providing advocacy and educational programs. He also serves as the co-facilitator of the Georgia ADAP Task Force, an advocacy program of the AIDS Survival Project.

World AIDS Day, December 1, protestors gather outside the state capitol to bring attention to the budget crisis that threatens the ability of the state health department to provide essential medications used to fight HIV. For months, community advocates had been urging the leadership of the health department and the Governor's office to work to find a solution to this problem before the money ran out and services were compromised. The negotiations had yet to produce a firm commitment to increase the budget for this program. Any additional funding would have to come from state revenues, as federal funding levels had failed to keep up with the growing demand for services. The state was facing a tight budget of its own, and funding for AIDS was considered controversial by both the Governor and the legislature.

The day after the spirited protest, the Governor's office announced that they would be releasing funds through an emergency appropriation to keep the program solvent until the legislature could tackle the problem during its regular session at the start of the year. The crisis had been averted, but for how long?

This story is not unique to Georgia; it's a story that has been repeated in many states around the country. What is interesting about this story is that it is not referencing events from the past year, but from a protest that occurred in 1992. The program the activists and advocates were fighting for was called the AZT Indigent Trust Fund, Georgia's precursor to what is now known throughout the nation as the AIDS Drug Assistance Program (ADAP). The lesson to be learned from the story is less about the power of protest (although that, too, is a valid lesson), and more about the importance of perseverance.

We won the battle for an emergency appropriation of \$150,000 from the Governor. We were successful in getting the state legislature to begin to fund this program directly

to the tune of nearly \$300,000. We had raised public awareness of the challenges that HIV-positive people have in accessing medications. Unfortunately, back in 1992, we had made a serious error in judgment that would hamper our efforts in years to come. We thought that by winning these battles, our work was done.

In 1996, we were faced again with a crisis in funding for medications. Protease inhibitors had hit the market, and combination therapy had become the recognized standard of care. Georgia's share of the federal funding for ADAP had grown to tens of millions of dollars. However, state funding for AIDS-related medications had stayed right at the levels we had fought so hard for four years earlier. We had not been building our support in either the Governor's office or the halls of the state legislature. In 1992, \$150,000 was enough to keep the program running. In 1996, we would need at least \$2.5 million, and the waiting list was growing so rapidly that it was nearly impossible to predict what the total costs would be at the end of the next complete state

Continued on page 6

Bush Administration Supports Medicaid Expansion for the Predisabled with HIV/AIDS

The Bush Administration supports the concept of extending Medicaid benefits to the predisabled with HIV disease, a move that would allow some people with HIV and AIDS to access Medicaid without having to qualify for the program by becoming sick and disabled, said the Director of the Administration's Office of National AIDS Policy.

"We want to engage the maximum number of individuals at the earliest possible point in their infection in the health care system," commented Scott Evertz, head of the White House Office of National AIDS Policy, who spoke during the Presidential Advisory Council meeting on HIV/AIDS (PACHA) in Washington, DC in March. In many cases, people with HIV disease cannot qualify for Medicaid until they become sick and disabled even though earlier access to Medicaid-covered drugs would significantly slow disease progression in vast numbers of patients. Evertz assailed the current system as making "absolutely no sense" and said the administration would work to "reform" it.

The Bush Administration, he

explained, supports the "overall intent" of legislation now pending in Congress that would give states the option of extending a prescribed set of Medicaid benefits to the predisabled with HIV disease. The legislation, known as the Early Treatment to HIV Act (ETHA), H.R. 2063 and SB 987, has 145 co-sponsors in the House but only three are Republicans. In the Senate, only one of the bill's six sponsors is a Republican. Nevertheless, the administration "supports concepts" in the legislation but "would like to see a lot more Republicans on board," Evertz told *The Voice* during an interview at the PACHA meeting.

"I can see us either supporting (ETHA) or a facsimile thereof," he said. Evertz said he did not know whether President Bush would sign ETHA if it passes Congress.

"I don't think we have come down on whether we support or don't support [ETHA]," he said. Evertz also said the administration would look at expanding Medicaid eligibility through regulatory means if Congress is unable to pass legislation expanding Medicaid benefits to the predisabled with HIV disease.

"If, for some reason, we end up with legislative hurdles that we can't get over, approving state waivers would be the quickest way to go," said Evertz, who was appointed Director of the National AIDS Policy Office in April 2001. "Getting folks who test HIV-positive onto Medicaid is the overall principle that we are supporting."

(Editor's Note: Section 204 of the 1999 Ticket-to-Work and Work Incentives Improvements Act already offers states Medicaid matching funds to cover designated groups of working, predisabled persons, including those with HIV. But only Mississippi and the District of Columbia have elected this coverage so far, leaving over \$100 million in special federal funding unclaimed.)

National ADAP Conference

Evertz delivered remarks at the opening dinner for the 2002 National ADAP Educational Forum in Washington, D.C., telling an audience of about 200 ADAP directors, Ryan White Title II administrators, pharmaceutical representatives, and others that "ADAP is an issue that makes perfect sense."

Continued on page 6

VA Prescription Co-Payments Rise

The VA prescription co-payments for non-service-connected illnesses rose from \$2 per prescription to \$7 each on February 7. Waivers of accrued past due drug co-payment debts will only be forgiven if requested in writing from the hospital's fiscal chief—and only then for those with incomes under the basic VA Pension level of \$796.33 a month for a family of one. In addition, those with incomes under \$24,304 a year can have accumulated co-pay debt waived once their charges mount to \$480 yearly.

This rise in price will make prescriptions from the VA slightly harder to access as an alternative

to ADAPs, although they'd still be well worthwhile on cost-effectiveness grounds.

Since people living with HIV/AIDS are typically on so many prescriptions, a \$7 co-pay will surely mean some burden, except for those whose income falls under the \$796.33 monthly total exemption level, or under the \$24,304 income/\$480 co-pay cap level.

However, where ADAPs may not in the past have bothered to assist needy or near-needy vets (however defined) with co-pays when they were only \$2 a prescription, at \$7, ADAPs may now have to assist in payment of these co-pays.

Even with the last three years' worth of significant VA budget increases, fast-rising VA medical costs forced this co-payment increase.

A worse alternative had been pushed by the Office of Management and Budget (OMB)—denying all care to "Category 7" veterans (non-service-connected ones with incomes over \$24,304 a year). Fortunately, Secretary Principi went all the way to President Bush and secured an agreement to somehow find enough money elsewhere in the federal budget to prevent such a draconian cutback. ■

Continued from page 1

leadership. So while there were no-defense related “pork” items in the bill, ADAP was, unfortunately, in the political consensus of the moment, neither “pork” enough nor “emergency” enough.

ADAP is however a genuine emergency and we have asked for and gotten an “Emergency ADAP Supplemental” before (in 1996 at the request of President Clinton – with both Democrat and Republican Congressional support). Now the “grassroots” AIDS community has to tell their political leaders that an ADAP crisis IS an issue for their state and their city. That Americans without access to AIDS treatments is a medical and public health disaster and something that political leaders need to address in the FY '03 Budget Appropriations process, that will last the rest of this year right up to national and local elections this November.

We desperately now need an additional \$162 million in FY '03 and without it no ADAP will be immune to the possibility of eligibility changes, drug coverage changes, waiting lists – or worse. Many states will have severe and noticeable problems by year-end, but if we do get the \$162 million in additional funding in the FY '03 budget Secretary Thompson does have authority to release that funding “early” (that is before 1 April 2003) when an “emergency” exists. It’s an ADAP emergency now and it will be a lot more so by fall.

Meet with your Congress Members & Senators in their home states and district offices during the Congressional August recess – only you can carry the message effectively. It’s an additional \$162 million for ADAP, adequate Ryan White CARE Act funding increases for all Titles.

Time to loosen up your dialing fingers and fax boards as the word on ADAP and AIDS needs HAS to come from constituents, “grassroots,” and VOTERS in this election year. This time we MUST prove that AIDS advocacy and activism is NOT asleep – or our communities will suffer the lack of HIV treatment consequences. ■

The National Alliance of State and Territorial AIDS Directors (NAS-TAD) has put together a list of ADAPs in trouble. In addition, a number of jurisdictions with currently fiscally stable ADAPs (e.g., Florida and New York) report the potential need to implement ADAP restrictions based on current funding levels and projected trends in program utilization. A lot of these shortfalls were announced at the start of the program-funding year, which suggests many more states will be making similar choices as the year progresses.

ADAPs with waiting lists, client expenditure caps, and/or drug access restrictions:

Alabama	
Guam	
Idaho	
Indiana	will close to new enrollment starting July 1
Kentucky	waiting list of 2
Maine	over 85 on waiting list and ARV restrictions
Mississippi	will likely not make it to the end of the FY without instituting some restrictions
Montana	waiting list started June 2002
New York	will likely not make it to the end of the FY without instituting some restrictions and will be adding no new drugs to the formulary
North Carolina	over 500 on waiting list
Oregon	
South Dakota	
Texas	ARV restrictions
Wyoming	

Companies Announce ADAP Price Freeze

At the Presidential Advisory Council (PACHA) on HIV/AIDS meeting in March, Pfizer CEO and PACHA member Hank McKinnel announced that Pfizer and its subsidiary Agouron would freeze prices on their drugs sold to AIDS Drug Assistance Programs (ADAPs) for two years. His announcement was made in response to AIDS community requests for the nation’s HIV drug producers to exercise restraint as ADAPs were experiencing mounting funding crises due to substantially inadequate federal funding for the years 2001/2002. The freeze would apply to Pfizer/Agouron’s Viracept (nelfinavir) and Rescriptor (delavirdine).

Abbot Laboratories also recently announced a two year price freeze.

Bristol-Myers Squibb, marketers of Videx, Zerit, and Sustiva, also announced a one year price freeze and Hoffmann-LaRoche, Inc. is expected to make a similar announcement shortly. While it is hoped that GlaxoSmithKline, Gilead Sciences, Ortho-Biotech, and Boehringer-Ingelheim will make similar concessions, no announcements have been made as of press time.

“It is the community’s position that since they work with the companies in coalition to fund ADAP which purchases these companies’ products, the companies must do their part to keep the programs stable by foregoing price increases that could make the situation worse,” commented ADAP Working Group Chair Bill Arnold. ■

Continued from page 3

fiscal year, some eighteen months away. The Governor's office was very explicit, that this time they would not be supportive of our efforts to increase the state contribution for ADAP. It was apparent that this time, a quick solution was a near impossibility.

By the end of 1997, we had developed our first ADAP working group. We had begun to build bridges between medical providers and social service agencies, as both became aware of the new role that medications would play in their ability to serve those living with HIV. The community advocates and pharmaceutical industry representatives were overcoming their mistrust of each other. The bureaucrats had begun to realize that communication with this working group was essential, even if it was awkward at times. It took several years of effort, but by the end of the 2000 legislative session, the Georgia ADAP waiting list had been eliminated, again.

This time, however, many of us had learned the lesson of perseverance. We had seen the long-range budget projections, and knew that the federal increases had begun to taper off. We were celebrating this victory, but we were not pulling back on our work. By May of

2001, need had again surpassed available resources - and the ADAP waiting list was back. However, this time, the Georgia advocates were already at work. The Georgia ADAP Task Force now meets several times a year to develop budget projections and legislative strategies. We work to ensure that there are individuals at as many public hearings as possible to talk about the program, and that both providers and consumers of services are well represented at these forums. We also talk about ADAP to other interested advocates such as those who represent the concerns of people of color, the poor, the homeless, women, children, and families. Our work on ADAP funding does not end.

The 2002 legislative session proved the importance of the creation of ongoing advocacy structures. Five years of coalition building had begun to pay off. ADAP was listed as a priority program at both the department and executive level. The legislature was well versed in the important role that this program plays in the continuum of care for those living with HIV. Appropriators took more time to review the materials in our briefing books. In one of the tightest budget years in recent memory, Georgia's ADAP was spared mandatory budget cuts, and saw a signifi-

cant increase in state level funding. Once again, the waiting list had been eliminated, but this time there was no question that our work was far from over. ■

Continued from page 4

"It makes absolute fiscal sense and it makes sense from a compassion standpoint," he said. "Please know that you have an ally, even if it doesn't always appear that we are responding as quickly as we should."

Evertz vowed to "fight for everything from prevention through comprehensive care and treatment and research." As AIDS czar, he promised to work especially hard on "preventing new HIV infections."

"As long as I am in office, I will talk about strategic, prevention intervention based on sound medical science," he said. "We will not allow the politics of the left or the right direct our prevention efforts. I will continue to make sure that does not happen." ■

Visit T•II CANN's website at
www.tiicann.org.



Ryan White CARE Act Title II
Community AIDS National Network
1775 T Street, NW
Washington D.C. 20009-7124

Non-Profit Org.
U.S. Postage
PAID
Merrifield, VA
Permit No. 1947