

Assist T•II CANN With Ryan White Care Act Reauthorization

T•II CANN will be working on behalf of both service-providers funded under Title II and people living with HIV/AIDS who are dependent on Title II funded programs. To be as responsive as possible to the needs and concerns of our community, we need the following:

1. We want to keep you informed! If you are not yet on our fax-board or e-mail lists, please send us your information so that you will be able to receive important information and alerts as Reauthorization of the CARE Act proceeds.
2. We need your input! If you are a Title II funded service provider or a PLWHIV who depends on ADAP or other Title II funded services, and you are interested in serving on our Reauthorization Advisory Committee, please contact us by e-mailing or faxing your name, address, phone number, fax number, and e-mail address to grose@T2cann.org or weaids@aol.com; fax: 202/588-8868.
3. The T•II CANN Board is always interested in new board members. If you are a provider, or consumer, of Title II funded services and are interested in serving on our Board of Directors over the next three years (which will include Ryan White Reauthorization in Congress) contact Bill Arnold or Gary Rose at T•II CANN (202) 588-1775. The Board meets in person twice a year and more often by conference call. Board members are reimbursed for T•II CANN related expenses.

Thanks for your help!

The Ryan White Care Act Title II Community AIDS National Network, Inc. (T•II CANN) is a non-profit organization focused on CARE Act issues. We are dedicated to initiating and supporting activities that develop and that ensure access to care for all people infected or affected by HIV. For more information on membership and its benefits, please fax contact information to T•II CANN at (202) 588-8868. ■

ADAP Federal Resources in FY 2000

Again in 1999, Republican leadership has appropriated more funding for the Ryan White CARE Act and the ADAP "earmarked" funds under Title II of the CARE Act than the President asked for in his initial budget request. Perhaps we can all genuinely say that funds for AIDS care and treatment are no longer a partisan issue. Certainly we are very, very grateful for the support from The White House and from Congressional leadership in the Senate and House on both sides of the aisle.

The "unfilled ADAP need" is significant enough that last minute advocacy efforts to increase the \$57 million in additional funding agreed to by all parties in early November seemed justified to T•II CANN so we actively lobbied with members of the Republican leadership in the House and with particular members of both parties in the Senate and in the House for an additional \$10 million for ADAP at the last minute. We were successful and the ADAP increase for FY 2000 will now be \$67 million (not \$57 million). In the final bill we expect the new funding level for Title II to be \$296 million which is an increase of \$19 million and the new Federal ADAP level to be a much needed \$528 million. As usual, Congresswoman Nancy Pelosi (D-CA) was again vigilant and aggressive in pursuit of funding for all AIDS/HIV needs, but specific help from John Porter (R-IL), Dave Obey (D-WI), Richard Burr (R-NC), and Maurice Hinchey (D-NY) also played key roles in final decisions. A simple "thank you" does not seem adequate.

The ADAP Working Group (an advocacy coalition of AIDS organizations and pharmaceutical manufacturers) in Washington had calculated, and asked for, an increase of \$90.2 million based on economic modeling "ADAP need" forecast.

The increase in core Title II funding is a most welcome change and a departure from previous "flat funding" of state AIDS efforts despite obvious need. The demand for access to new treatments through ADAPs is going to continue to be driven by the success of "new" HIV+

patients who start HAART (Highly Active Anti-retroviral Therapy) and the extended lives of those already on treatment. This all will continue in the context of no available, affordable, or only inadequate health insurance, for millions of Americans. So the ADAPs' "lifeline" function looks to be with us for a long, long time.

The \$67 million ADAP increase (while very helpful and much appreciated) of course is not the requested \$90.2 million which is needed to ensure access to ADAPs. This shortfall will exacerbate problems of access to drugs in many states and especially in those states who do not provide adequate state funds to enhance the federal funding. On September 17, some states anticipated having problems with their FY '99 funding levels (after a very significant \$167 million increase in federal funds to a total of \$461 million in 1999).

Whether insufficient resources leads to outright rationing, lotteries, capping enrollment, starting waiting lists, limiting the expenditure per patient, restricting who can access protease inhibitors, or actual program closings - with patients frantically running to drug company patient assistance programs to avoid therapy interruptions, we don't yet know. However, it's always a personal nightmare for HIV+ people directly affected - and for their families, friends, and service/care providers.

If your state does not provide at least 20% in state funds to supplement federal ADAP dollars, many would consider your state to not be doing it's "fair share." The chart in this issue of *The Voice* identifies most recent known state ADAP contributions. If your state advocacy communities are not working on your governor and state legislature - then "grass roots" work remains to be done. The use of Medicaid expansion projects and high risk insurance pools and other programs providing access to medications can also help. At the grass roots level, AIDS advocates and their allies need to look at all available

Continued on page 4

Fourth Annual ADAP Educational Forum Convened In Washington

Part Two Of A Two Part Series

Contributed By: James C. Arvantes, Associate Consultant at Martin Medical Services in Washington, D.C. and editor of *Positive Populations*.

Note from the Editor: Part one of this article was featured in the July/August issue of The Voice. For a copy, contact the T•II CANN offices.

Federal Funds Must "Follow the Epidemic," Declares Congressional Delegate

The federal government needs to do a better job of providing AIDS resources for minority and marginalized communities, population groups hit hardest by the AIDS epidemic, said Donna Marie Christian-Christensen, M.D., a nonvoting congressional delegate representing the U.S. Virgin Islands

in Congress and a member of the Congressional Black Caucus (CBC).

African-Americans comprise 12 percent of the U.S. population but account for 43 percent of the nation's AIDS cases, according to the Centers for Disease Control and Prevention (CDC). Similarly, Hispanics make up 11 percent of the U.S. population but comprise 20 percent of the country's AIDS cases. Overall, racial and ethnic minorities account for more than 54 percent of the total AIDS cases reported since 1981.

"Our concern, like yours, is to make sure that dollars go to the communities who need them most and to the communities and community based organizations who are best positioned and effective at reaching those who have been marginalized or ignored up until now," said Christian-Christensen.

Federal funds, she said, "must follow the epidemic," something that has not happened in the past even though AIDS remains the leading cause of death for African-American males between the ages of 25 to 44 and the second leading cause of death for African-American women in the same age group. Moreover, three of the seven persons who contract HIV in this country every day are African-Americans while one in 50 African-American men and 1 in 60 African American women are infected with HIV.

These numbers are "staggering and can no longer be addressed in a business as usual manner," Christian-Christensen said. Last year, the CBC asked the federal government to declare a state of emergency in response to the disproportionately high rates of HIV/AIDS cases among minorities, a request that resulted in the allocation of \$156 million in federal funds for the HIV prevention and treatment needs of minority communities.

The money, while welcome, can "never fully address the needs of communities of color," Christian-Christensen conceded. It is "at best, only a beginning," she said.

Most of the \$156 million at the time had not been allocated, though \$30



Donna Marie Christian-Christensen, M.D. describes health care as the "new civil rights battlefield."

million went out at the end of 1998, said Christian-Christensen.

"The process of getting the dollars into our communities has been much slower than we anticipated and slower than we would have liked," she explained.

Christian-Christensen provided a breakdown of the allocation levels, explaining that the CDC and the Substance Abuse and Mental Health Administration received the biggest percentages of the \$156 million, netting \$68.3 and \$39.2 million respectively, followed by the Health Resources and Services Administration with \$27.1 million. The Office of Minority Health received \$2.2 million.

Minority-based CBOs Lack Staff, Expertise

Many of the community based organizations (CBOs) applying for the money through a competitive grants process lack the infrastructure or the grant writing experience needed to obtain the funds even though these CBOs are in the best position to reach minorities, indicated Christian-Christensen. As she explained, "the CBOs who have always gotten the grants are going to continue to get them."

"Some of the [CBOs] don't have the necessary staff," Christian-Christensen said. "They have someone who runs the organization but they don't have a good financial officer."

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If you have anything of interest to share with the Title II community, please send it to:

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Visit T•II CANN's website at www.t2cann.org.
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Continued on page 6

A Quick, Non-Controversial Way To Stretch ADAP Budget

By Thomas P. McCormack, Technical Advisor on Disability, Insurance, and "Back to Work" Issues to T•II CANN

State AIDS Drug Assistance

Programs (ADAPs) face fiercely escalating costs because of the large numbers of "pre-disabled," early intervention HIV patients who are without adequate private sector insurance. When funds run short, responses include seeking additional (or first time) state supplemental appropriations; instituting waiting lists for new applicants or the more expensive new pharmaceutical products; lowering ADAP income and/or asset eligibility levels; and calling, without much specificity, for "expansion" of Medicaid.

Many Disabled Are "Too Rich" For Medicaid (And Its Drug Coverage)

But many state ADAPs already spend large amounts of money on patients who are already disabled, but whose incomes from Social Security Disability Insurance (SSDI) and other sources exceeds their state Medicaid income level. In some states, ADAP income levels are so high that virtually all HIV patients, except those with the most generous private disability income benefits, can qualify.

This is far from true for Medicaid, though Medicaid income levels are set at the \$500 monthly Supplemental Security Income (SSI) level in most states. Less than half the states have higher SSI levels, but the additions are usually small, except for \$676 in California and \$587 in New York; see www.ssa.gov/statistics/ores_home.html for other states' higher-than-normal SSI levels.

All this matters because the average SSDI benefit is about \$790, far above Medicaid levels. What this means, in a program sense, is that most SSDI patients' drug costs currently have to be paid by ADAP, not by Medicaid.

States Can Raise Medicaid Level To 100 Percent of Poverty For Aged and Disabled

Raising the Medicaid income levels for those who are disabled and on SSDI, therefore, can mean shifting their pharmacy costs from the limited, hard-pressed ADAP budget to the more open ended Medicaid budget.

Yet while we can dream of "waivers" to bring Medicaid to those who are "only" HIV-positive, there's an easier, well-worn path already available under current law to have Medicaid take up more of the slack. This is the option, available to states under federal Medicaid law since 1988, to give Medicaid to aged and disabled persons with countable incomes below 100 percent of the poverty level. The poverty level is updated each year to take account of the costs of living, and includes upward adjustments.

This level is even above California's generous Medicaid level; far higher than those of New York and other states which supplement SSI; and, most of all, nearly \$200 monthly above Medicaid levels in the majority of states.

If the typical state exercised its already-available Medicaid option to cover aged and disabled persons at 100 percent of poverty, it would mean that ADAP could shift the pharmacy costs it presently bears for all those with SSDI and other income between \$500 and \$687 to Medicaid. Funds freed up by the cost shift to Medicaid could allow for a more comprehensive pharmacy package; the elimination of waiting lists; the raising of income levels; or wider coverage of the "pre-disabled" uninsured population, whatever the state's most pressing needs might be.

State ADAP and general pharmacy assistance officials interested in estimating savings from this Medicaid eligibility change can do so if their patient-by-patient data includes accurate information on the exact income amounts, and sources, in order to determine the number of patients (and their costs) with SSDI

and other income above the state's current SSI/Medicaid level but below \$687. These would be those whose costs will shift to Medicaid. See contact information at the end of the article for details on figuring eligibility under the 100 percent of poverty option.

Advocating For 100 Percent of Poverty Medicaid Level For Aged and Disabled

An important feature of states "100 percent of poverty coverage of the aged and disabled" Medicaid option is that both aged and disabled coverage must be elected together under the same eligibility standard. Hence, the disabled will enjoy the same rules as are available for the aged over 65. This is important because the disabled, according to Social Security figures, only amount to 12 percent of the number of the aged over 65.

The great majority of beneficiaries of a state Medicaid expansion will therefore be the elderly, not the disabled. For purposes of public relations in mounting an expansion campaign, this is vital. The elderly in need of Medicaid drug coverage are a much, much easier sell to state legislators than are needy disabled persons, particularly those with HIV!

Framing a proposed expansion of Medicaid to the aged and disabled at 100 percent of poverty has other advantages, too. The national debate on adding pharmacy coverage to Medicare pits the Democratic universal coverage plan against a GOP alternative aimed only at the "neediest" Medicare beneficiaries. (Representative Bill Thomas (R-CA), in his Medicare Commission proposal, suggests giving Medicaid drug coverage to those with SSDI and other income under 135 percent of poverty, for example.)

100 Percent of Poverty Medicaid Level = Big Savings To Thirteen "Drug Aid" States

In Maine, Massachusetts, Vermont, Connecticut, Rhode Island, New York, New Jersey, Pennsylvania, Maryland, Illinois, Michigan, Minnesota, and Wyoming there's an even better argument for this Medicaid expansion. These states currently cover, at 100 percent state cost, prescriptions for elderly (and, often, disabled) persons with income above the Medicaid level but below state-set pharmacy assistance

Continued on page 7

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Continued from page 1
mechanisms. ADAP is a huge help and a partial answer to access to HIV health care/treatment problems, but it will never be a 100 percent successful or 100 percent dependable even with the dramatic increases in support.

If 17 states were predicting ADAP resource shortfalls in the FY '99

(which ends March 31, 2000) then the "missing" \$23.2 million in the next FY 2000 federal funding must be expected to increase the pressures and the problems for those ADAPs. Many are already struggling in an era of continued demand for access to treatments which are successful - and by their very success are creating healthier people needing access to treatments longer.

The work continues, the results keep getting better, and there are many more living with HIV and AIDS to help out. The "grass roots" work and the "grass roots" of AIDS advocacy has plenty of work left to do and lots more living reasons to keep doing it. ■

**Projected FY 2000 Ryan White Title II State ADAP Grant Allocations:
A Comparison of the ADAP Working Group's Budget Request,
President's Budget, and Final Budget Agreement**

State	FY 1999 ADAP Allocation	ADAP Working Group's FY 2000 Budget Request (+\$90.2 million)	President's FY 2000 Budget Request (+\$35 million)	FY 2000 Final Budget Agreement (+\$67 million)
Alabama	\$3,980,350	\$4,843,796	\$4,358,713	\$4,639,920
Alaska	\$323,832	\$380,598	\$342,483	\$364,579
Arizona	\$4,057,555	\$5,467,662	\$4,920,103	\$5,237,528
Arkansas	\$1,807,885	\$2,195,305	\$1,975,456	\$2,102,904
California	\$65,268,301	\$77,312,392	\$69,569,932	\$74,058,314
Colorado	\$3,787,337	\$4,567,175	\$4,109,795	\$4,374,943
Connecticut	\$7,793,422	\$9,077,457	\$8,168,394	\$8,695,387
Delaware	\$1,672,776	\$2,028,548	\$1,825,399	\$1,943,166
District of Columbia	\$7,690,482	\$9,083,343	\$8,173,690	\$8,701,025
Florida	\$48,506,224	\$59,320,310	\$53,379,670	\$56,823,519
Georgia	\$13,815,417	\$16,924,838	\$15,229,897	\$16,212,472
Hawaii	\$1,323,209	\$1,598,904	\$1,438,781	\$1,531,606
Idaho	\$317,399	\$374,712	\$337,187	\$358,941
Illinois	\$14,548,865	\$17,113,175	\$15,399,374	\$16,392,882
Indiana	\$3,907,434	\$4,600,527	\$4,139,806	\$4,406,891
Iowa	\$791,352	\$939,724	\$845,615	\$900,171
Kansas	\$1,426,149	\$1,702,882	\$1,532,346	\$1,631,207
Kentucky	\$2,223,935	\$2,756,392	\$2,480,353	\$2,640,376
Louisiana	\$8,061,495	\$9,683,667	\$8,713,895	\$9,276,082
Maine	\$529,713	\$619,943	\$557,859	\$593,850
Maryland	\$14,175,707	\$17,272,084	\$15,542,369	\$16,545,103
Massachusetts	\$8,413,207	\$10,794,072	\$9,713,098	\$10,339,749
Michigan	\$6,710,407	\$8,114,191	\$7,301,595	\$7,772,665
Minnesota	\$2,022,344	\$2,475,849	\$2,227,904	\$2,371,640
Mississippi	\$2,725,768	\$3,497,970	\$3,147,665	\$3,350,740
Missouri	\$5,125,558	\$6,205,316	\$5,583,884	\$5,944,134
Montana	\$227,326	\$255,040	\$229,499	\$244,305
Nebraska	\$658,388	\$802,395	\$722,039	\$768,622
Nevada	\$3,079,624	\$3,513,665	\$3,161,788	\$3,365,774
New Hampshire	\$555,448	\$637,600	\$573,747	\$610,763
New Jersey	\$25,276,079	\$29,176,560	\$26,354,670	\$27,948,519
New Mexico	\$1,351,089	\$1,581,247	\$1,422,893	\$1,514,692
New York	\$85,950,679	\$100,040,367	\$90,021,811	\$95,829,670
North Carolina	\$6,371,562	\$7,857,190	\$7,070,330	\$7,526,481
North Dakota	\$75,060	\$86,321	\$77,677	\$82,688
Ohio	\$6,914,142	\$8,082,802	\$7,273,349	\$7,742,597
Oklahoma	\$2,129,573	\$2,522,933	\$2,270,273	\$2,416,743
Oregon	\$2,790,105	\$3,256,663	\$2,930,524	\$3,119,590
Pennsylvania	\$15,042,119	\$18,360,908	\$16,522,153	\$17,588,098
Puerto Rico	\$15,505,350	\$18,164,724	\$16,345,615	\$17,400,171
Rhode Island	\$1,284,606	\$1,516,506	\$1,364,636	\$1,452,677
South Carolina	\$5,966,236	\$7,804,220	\$7,022,665	\$7,475,740
South Dakota	\$105,085	\$137,329	\$123,576	\$131,549
Tennessee	\$6,357,173	\$6,754,633	\$6,078,189	\$6,470,330
Texas	\$32,998,730	\$39,876,464	\$35,883,030	\$38,198,064
Utah	\$1,136,630	\$1,428,223	\$1,285,194	\$1,368,109
Vermont	\$238,049	\$270,735	\$243,622	\$259,339
Virginia	\$8,252,363	\$9,987,753	\$8,987,528	\$9,567,369
Washington	\$5,400,065	\$6,246,515	\$5,620,957	\$5,983,599
West Virginia	\$797,786	\$882,830	\$794,419	\$845,672
Wisconsin	\$2,082,392	\$2,499,391	\$2,249,089	\$2,394,191
Wyoming	\$96,506	\$109,863	\$98,861	\$105,239
Guam	\$10,723	\$3,924	\$3,531	\$3,759
Virgin Islands	\$340,989	\$392,369	435,375	\$375,854
Total	\$461,000,000	\$551,200,000	\$496,000,000	\$528,000,000

FY 2000 estimated federal appropriations are based on estimated living AIDS cases by state from July 1, 1989 - June 30, 1999. Final award amounts subject to change.



**T•II CANN
Congressional
Recognition Dinner**

Although interrupted by an uninvited guest, Hurricane Floyd, who breezed through Washington during the day, spirits were undampened at the first ever T•II CANN Congressional Recognition Dinner which was held in the U.S. Capitol building in September. TII•CANN Board members, Congressional staff, and other invited guests from the HIV/AIDS community had the opportunity to honor the contributions of Congressman John Porter, the Chair of the House Appropriations subcommittee on Labor, Health and Human Services, and Senator Harry Reid, the Senate Democratic Whip.

Both Congressman Porter and Senator Reid spoke of how they have been touched by persons living with HIV/AIDS, of the friends they have lost to this disease, and to their continuing commitment to fighting HIV/AIDS. With Congressman Porter's recent announcement that he would be retiring from Congress at the end of 2000, honoring him this year was especially important. We look forward to continuing to work with them both over the coming year.

Joining us in presenting awards to Congressman Porter and Senator Reid were Congressional Dinner sponsors Hoffmann-La Roche and Merck. Hosting tables were Bristol-Myers Squibb and Glaxo Wellcome Inc. We thank everyone for their generosity in helping to make this year's dinner a success. T•II CANN hopes to make this an annual event and looks forward to seeing everyone next year!

Photos above
Clockwise: Glaxo Wellcome table; Congressman Porter; William E. Arnold, Vice Chair & CEO of TII•CANN; Herbert Perry, LPA/EA, Chair & CFO of TII•CANN, Senator Reid, William E. Arnold, and Nancy Carlton of Merck.

ADAP Congressional Briefing

Contributed By: James C. Arvantes, Associate Consultant at Martin Medical Services in Washington, D.C. and editor of *Positive Populations*.

This year's ADAP congressional briefing served as another illustration of the critical role AIDS drug assistance programs play in providing medication assistance to uninsured and underinsured people with HIV disease. The briefing highlighted the following developments:

◆ ADAPs will incur a total funding shortfall of \$13 million in the current fiscal year based on the projected growth rate of ADAP services (about 800 new patients a month.)

◆ In fiscal year 2000, ADAPs will need an increase of \$90.2 million in federal funds to provide access to necessary therapies for eligible patients.

◆ ADAPs will need an increase of \$22.5 million in state funding and other sources to meet patient needs during this same period.

The increasing pressure on state ADAPs to provide access was a central focus of the event. Twenty-six states had limited ADAP services or faced budget shortages before the end of fiscal year 1998. Seventeen states either maintained waiting lists for ADAP or access to protease inhibitors provided by ADAP in the 1998 fiscal year.

Dr. Richard Moore, Director of the Program in Pharmacoepidemiology and Pharmacoeconomics; Associate Professor, Department of Medicine, at The Johns Hopkins University; and doctor at the Johns Hopkins HIV clinic in Baltimore, told the audience that "ADAP is a key part of our ability to treat patients. The majority of patients in our practice depend very much on this program," he said.

Winnie Pressley, a mother of three, grandmother of two, and a recent ADAP client living in Washington, D.C., put a human face on the ADAP, saying simply that the program "saved my life. There was a time when I thought I was going to die from this dreadful disease," she said.

Pressley started taking the combination therapies a few years ago, enabling her to "turn my life around," she said. "Instead of getting sicker and sicker, I am now getting better and better," Pressley explained.

Late last year, Pressley was able to find a job. But as a member of the

work force, Pressley lost her Medicaid benefits, leaving her without insurance until ADAP stepped in and "caught me between the gaps," she noted.

"If ADAP had not been there to save my life, I don't know where I would be today," Pressley commented.

The following are selected highlights from the program.

Dr. Richard Moore Sees 'Optimistic' Outcomes For Patients on Combination Therapies

The majority of patients taking combination therapies still have not developed resistance to the medications, a strong indication that a high percentage will remain relatively healthy for the foreseeable future if they continue on the regimens, said Dr. Moore. "Quite frankly, we don't know what the greater life span is at the moment," Moore acknowledged. "But the best data we have, suggests at least three years to the life span." And those are three "high quality years," he said.

Moore called the three-year estimate "incredibly conservative," since the data suggests that the combination regimens - a protease inhibitor with two or more Antiretrovirals - could add many years to a patient's life. The data on the combination therapies, he said, are "generally optimistic," even though a certain percentage have developed resistance to the therapies.

Moore, responding to a question from the audience, took issue with a March 1999 *Esquire Magazine* article that said most people on the combination regimens are doomed to develop resistance and fail on the therapies. Moore disputed the findings in that article, saying he was "quite optimistic" about the long-term effectiveness of the combination therapies.

"What we have now are five protease inhibitor drugs, six nucleoside transcriptase inhibitors, and three non-nucleoside reverse transcriptase inhibitors," he said.

At the same time, there are drugs in the pipeline that will give patients more treatment options in the near future.

Combination Therapies Reduce Illness, Prolong Life, and Save Money

Moore described the combination therapies as "incredibly important

and powerful in reducing the burden of illness and prolonging life." During the first half of 1997, for example, AIDS related deaths dropped by 44 percent nationally compared to the same time a year earlier, a direct result of protease inhibitors and combination therapies.

"One of the things I study is new medical technologies," Moore said. "I cannot find an example of any medical technology that has come out in the last 30 years that has been so dramatically effective in reducing the burden of illness and improving survival, not a one - in the short term and projected into the long term."

The combination regimens lead to dramatic declines in in-patient hospitalizations, emergency room visits, and the incidence of opportunistic infections.

"Yes, we are spending more money on pharmaceuticals but money is being saved directly on medical care and somewhat indirectly, and very importantly, on other societal kinds of costs over the long term," he said.

Moore predicted that "these therapies are going to turn out to be some of the most cost-effective technologies from an economic standpoint."

Florida Congressman Decries Efforts to 'Short Change' HIV and AIDS Initiatives

Republican Congressman Mark Foley of Florida, a member of the influential House Ways and Means Committee, urged fellow lawmakers to reject disease-specific funding comparisons that are intended to increase federal spending for certain afflictions at the expense of HIV and AIDS programs.

"Without question, I have noticed an increase in rhetoric from other agencies and groups who have come to my offices and suggested somehow that AIDS is getting too much money - that they have somehow been short changed because (their disease) is not as politically popular," said Foley. Foley reminded the audience that "we are in the battle against disease together, whether it is Alzheimer's, lupus, breast cancer, or prostate cancer."

"You name the diseases - we are in this fight together to increase funding at the National Institutes of Health (NIH) to increase research dollars and to increase treatment dollars," said

Continued on page 8

Continued from page 2

The CBC plans to monitor who receives the grants and will “ask some CBOs to come in and tell us what the problems are in getting the grants,” she said.

Christian-Christensen described health care as the “new civil rights battlefield.” “We of all backgrounds, colors, religions, sexual preferences and economic status came together in an earlier time and brought about justice, fairness, and equality to America,” she said. “We can do it again.”

Outreach Expert Explains How To Reach Out To Hispanic Populations

Outreach efforts that target Hispanic populations must be well-planned, culturally appropriate, and based on a thorough understanding of the intended community in order to succeed, said Esperanza Martinez, Program Coordinator for the Hispanic AIDS Awareness Program in Miami, Florida.

Martinez refers to outreach efforts as “targeted marketing campaigns” that can take months, even years, to fully and successfully implement. “First of all, you need to know your community - who they are, where they are, how they obtain their information, and their educational levels,” she explained.

It is important, she said, to partner with minority organizations that already have a relationship with the targeted community. “Participate in their meetings and make yourself known within those organizations,” urged Martinez.

It’s also a good idea to talk with community leaders, asking them for advice and suggestions on how to best reach the intended audience, incorporating at least some of their ideas into outreach initiatives.

“We need to develop materials that are culturally sensitive and language specific,” Martinez explained. “Often enough, I find the material that has been translated from English to Spanish is at an 8th or 9th grade level and is extremely technical. Sometimes, I can’t even understand it.”

Organizations should also recruit community members to review materials in order to ensure that the information is appropriate and written in an understandable manner, she pointed out. In many instances, organizations will rely on

Spanish speaking employees to review outreach materials, a method that is flawed since it does not include input from the intended community.

“I developed a brochure that used words that were very familiar to me as a Colombian but that other Spanish speaking people did not understand,” Martinez explained.

“Take materials to the folks you intend to distribute it to and ask them if they understand it,” she added.

Martinez encouraged organizations to hire and train bilingual and bicultural staff, even contracting with interpreter services, if necessary.

Understanding, Overcoming Cultural Barriers

Martinez was quick to point out that there are variations, even wide cultural differences between Hispanic groups.

“If an organization is trying to reach a predominately Mexican community in Arizona, the outreach efforts would be much different than those for a predominately Puerto Rican community in New York,” she explained.

Organizations cannot simply devise one “Hispanic approach” and expect that strategy to work for all Hispanic groups, she said. There are, however, some commonalities within the Hispanic community at large that can be used to break down barriers. Hispanics, for instance, tend to obtain information from the radio, making radio advertising an effective means of reaching them. They also rely on pharmacists for medical information, often to the exclusion of medical doctors, making pharmacists a natural ally when trying to convey information to Hispanic populations.

There are other commonalities within the Hispanic culture as well - cultural values that tend to predominate and which should be taken into consideration when developing outreach strategies. Hispanics, for example, are often very religious, believing that events and circumstances are outside of their own control, falling under the purview of God.

“Unfortunately, Latinos tend to look at AIDS as a punishment from God,” Martinez said. “They look at people who are becoming infected and

believe that it happens to homosexuals or to people who practice behaviors that are not moral.”

Hispanics also categorize diseases, labeling some as acceptable and others as non-acceptable. Diabetes, heart disease, osteoporosis, cervical cancer represent “acceptable diseases” in the Hispanic culture; Alzheimer’s, mental illness, substance abuse, and HIV/AIDS are examples of non-acceptable diseases.

Moreover, Hispanics tend to be present oriented, focusing on today and ignoring tomorrow. This is especially true for recent immigrants who are concerned about deportation issues and are living in the United States on a day to day basis.

Finally, there is the issue of saving face, accepting and often perpetuating double standards in order to avoid embarrassment while refusing to share information.

“Admitting that someone in our family has HIV or AIDS is admitting that the person is a bad person - that there is someone bad within our family,” Martinez explained, explaining the mind set of many Hispanics. “Many of them will not share that information.”

James C. Arvantes may be contacted at Martin Medical Services, Inc., (202) 518-7768. ■

The 1999 AIDS Drug Assistance Program National Educational Forum was sponsored by the following pharmaceutical companies:

- Bristol-Myers Squibb Company
- Hoffmann-LaRoche Inc.
- Merck & Co, U.S. Human Health Division
- Agouron Pharmaceuticals, Inc.
- Roxane Laboratories
- DuPont Pharmaceuticals Company.

This year’s meeting was facilitated by The Title II Community AIDS National Network (T•II CANN) and PAREXEL International.

Continued from page 3

income levels. These general pharmacy assistance income levels, while above Medicaid's, are usually not quite as generous as ADAP levels.

Were these states to raise their Medicaid levels to 100 percent of poverty, they could claim at least 50 percent federal Medicaid matching funds for the pharmacy costs which they currently bear at 100 percent state-only expense. The savings to the state treasuries would be substantial. Relieving current state-only pharmacy assistance costs is one of the reasons that Rhode Island's Medicaid director recently asked the legislature to approve the 100 percent of poverty Medicaid option.

States Already Pay Most Medical Costs of Aged and Disabled Under 100 Percent of Poverty, Meaning Limited Additional Costs for Taking Expansion Option

There are three more reasons why electing the 100 percent of poverty Medicaid option makes good sense. The option will bring Medicaid drug coverage not just to disabled AIDS patients and elderly persons below that income level, but also to those with other disabilities who are just as likely to have above-average, but unaffordable, prescription needs. In addition, the raised Medicaid level brings the rest of the Medicaid services package to aged and disabled persons. Medicaid would pay deductibles and copayments that

Medicare doesn't (e.g., \$768 per hospital admission, 20 percent of doctor bills) and care which Medicare doesn't cover at all but which Medicaid can (e.g., dental care, eyeglasses, podiatrists, and hearing aids in many states).

Lastly, federal Qualified Medicare Beneficiary (QMB) law already requires state Medicaid programs to pay almost all remaining non-drug medical costs of the aged and disabled under 100 percent of poverty that aren't met by Medicare. So almost all additional state costs from taking the option would be pharmacy expenses and few, if any, other medical costs. The current QMB law, in other words, already makes states go most of the way toward full medical coverage of the aged and disabled anyway. One, small step more will mean little to state budgets, but much to those who need drugs. ■

Contact the editor of *The Voice* at PotoInc@aol.com or by fax at (973) 579-3622 for the following:

- 1 List of states with state-funded pharmacy assistance for aged.
- 2 List of states which already offer 100 percent of poverty Medicaid to aged and disabled, 1999.
- 3 Detailed eligibility rules for 100 percent of poverty Medicaid coverage of aged and disabled.

COMMUNITY ANNOUNCEMENTS



Lisa Hudgens, a prominent Mississippi AIDS activist, ADAP Working Group participant, and new Board member of T•II CANN was wed to Mario Rossilli on August 7. Mario is best known for his reporting for *The Clarion-Ledger*, Jackson, Mississippi of the Mississippi ADAP

collapse crisis of late 1997 and '98 when 600 people suddenly found themselves without access to AIDS Drugs. His reportage got him nominated for the Pulitzer Prize, and awarded the 1998 Robert F. Kennedy Journalism Award. He also received the annual T•II CANN AIDS

Awareness Award of 1998. Lisa and Mario are both personal friends of many of us. Congratulations!

Just discovered by a T•II CANN board member: an apparently currently-maintained website, with interactive features, for industry Patient Assistance Programs (PAPs). Where available, program income levels and downloadable application forms are provided, as is information about any other eligibility criteria or limitations. There is a "new developments" appendix at the site as well.

There are two addresses for accessing the site: www.volunteersinhealthcare.org and <http://rxassist.org>.

BOARD PROFILES

T•II CANN welcomes three new members to its Board of Directors, Rich Fortenberry, a volunteer at T•II CANN; Lisa Rossilli, formerly of Project Connect AIDS Service Organization; and Howard Moses, formerly the Deputy Assistant Secretary of the U.S. Department of Education. T•II CANN is excited to be able to draw upon the knowledge and experience that each of these individuals bring to the board.

Rich Fortenberry came to T•II CANN in April, 1999. He provides community-based organization development and technical assistance and helps with care and treatment advocacy. Prior to coming to T•II CANN, Rich was the principal founder and first president of the Heartland CARES foundation in Kentucky. Rich has served on various task forces including the HRSA Title III Objective Review Committee, HRSA/NRHA Nat'l Task Force on Rural HIV & AIDS, and the Kentucky Legislative Research Commission.

Lisa Rossilli brings a variety of experience to the T•II CANN board. Until July 1998, Lisa was the Assistant Director of the Project Connect AIDS Service Organization in Jackson, Mississippi. Prior to her work with Project Connect, Lisa was the Health Program Coordinator at the Mississippi Children's Home Society and Family Service Association. She recruited, hired, trained, and supervised young adults for the peer-to-peer education program; conducted presentations; and developed health educational curriculum.

Howard Moses served as the Deputy Assistant Secretary in the Office of Special Education and Rehabilitative Services at the U.S. Department of Education. Howard brings to T•II CANN a wealth of government experience. Howard received a Hammer Award from the Vice President's National Partnership for Reinventing Government for his efforts in making technology accessible to federal employees and customers of the Department with disabilities.

Continued from page 5

Foley, who was first elected to Congress in 1994.

It would be a mistake, he said, to “start subdividing ourselves into disease categories and to climb on each other’s back to achieve financial success in our program.”

“We will find the resources,” Foley assured the audience. “We are increasing NIH funding and we are doing all we can for other diseases.” The federal government spends billions annually on defense, putting billions into single projects like the B-2 bomber, he noted. “We have all kinds of money to slosh around here and help other nations out in times of crisis - the international monetary fund and all these other venues,” Foley commented.

“We ought to stand up to the responsibility and get access to drugs and therapies for all people, not just those on insurance, not just those covered by Medicaid or Medicare but every American who can not find their way to access the monies necessary for drug treatment,” he said.

Meeting the Needs of the State ADAP

Foley describes the Florida ADAP as a “good success story,” a demonstration of how the federal government has met the needs of the state.

“A year and a half ago, we had more than 2,000 people on a waiting list to get into the ADAP,” he explained. “Thanks to gradual increases in federal funding — \$12 million for 1998, \$19 million for 1999 - there is no longer a waiting list.”

The Florida ADAP now serves more than 2,000 patients. But many people with HIV disease who would qualify as ADAP patients remain undiagnosed, meaning the drug assistance program could experience a surge in enrollment if these people learn of their HIV status.

“There are some populations that are hard to reach who are under-utilizing the resources that are available,” Foley commented.

In Florida, for example, the state has growing numbers of elderly people - individuals over the age of 65 — who are just learning they are HIV-positive. Foley describes them as a “unique category of people who never assumed they would be affected by HIV.”

“We have been increasing our efforts to educate these people about prevention and treatment,” he said simply. As a congressman, Foley represents Florida’s 16th district, an area encompassing seven counties in south/central Florida, not far from Miami and Dade County, one of the largest epicenters of the AIDS epidemic. As a result, Foley has a unique perspective about the ravages of HIV disease, developing a profound appreciation for AIDS and ADAP funding over the years.

By funding ADAP, Congress is, in effect, “sustaining life,” while allowing people to resume their activities - to earn a living, to pay taxes and to contribute to society. “So with the dollars invested, we are actually getting a return on our investment because people are working,” he said.

Foley also mentioned the dilemma ADAPs now face as a result of the combination therapies. By taking the regimens, many patients are no longer qualifying for Medicaid by becoming sick and disabled. Consequently, they are staying on ADAPs for much longer periods of time, putting additional financial pressures on the programs.

Foley said, however, that the combination therapies have “brought an advent of hope and opportunity for those who felt their lives were about to end.” He praised the pharmaceutical industry for developing the new products, saying “I want to tip my hat to the drug companies.”

“They take a lot of scorn because of the cost of drugs,” Foley said. “Yet, we can all point fingers and suggest drugs are expensive but without the research going on in our labs, in the private sector, we would not be able to announce the type of therapies that are now available.”

The congressional briefing also featured Lanny Cross, Director, HIV Uninsured Care Program for the New York State Department of Health and Joseph May, ADAP Program Manager, Florida Department of Health.

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