

T•II CANN'S COMMITMENT

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.

T•II CANN supports finding a cure for HIV/AIDS and ensuring that access to that cure is available for all people living with HIV/AIDS. Until a cure is discovered, T•II CANN will advocate for effective treatments for HIV/AIDS and universal access to those treatments for all people living with HIV/AIDS.

T•II CANN is a non-profit organization that relies on the generous contributions of all those concerned about the delivery of vital HIV/AIDS health care services to those in need. Tax deductible contributions may be sent to T•II CANN, 1775 T Street, NW, Washington, D.C. 20009-7124.

T•II CANN works for those who fund, evaluate, staff, volunteer with, politically interact with, or are served by the over 2,500 Title II funded entities and projects. Any individual, program, group, coalition, or other public or private entity sharing our commitment to universal access to quality care and services for all people living with HIV is welcome as a member. For more information on membership and its benefits, please fax contact information to T•II CANN at (202) 588-8868. ■

T•II CANN Presents

FIRST Annual Community AIDS Awareness Award

On April 7, 1998, T•II CANN presented the First Annual Community AIDS Awareness Award to Mario Rosilli, the Pulitzer nominated staff writer for *The Clarion Ledger* of Jackson, Mississippi. The presentation was part of the proceedings at the 3rd Annual ADAP National Education Forum, held in Washington, D.C. The award was presented to Mr. Rosilli by Ms. Laurie McGinley, the 1997 Pulitzer Prize Winner and staff reporter for the *Wall Street Journal*.

While Mr. Rosilli has already been nominated for a Pulitzer for his remarkable series of journalistic coverage of the HIV epidemic in Mississippi, T•II CANN believes that the recognition from those involved in community AIDS work

is also important. Mr. Rosilli's series of articles about the dilemma faced by Mississippians living with HIV and AIDS, the budgetary crisis experienced by the ADAP, and the portrayal of the affected community struggling to overcome the insurmountable odds has inspired innumerable readers nationwide.

The Clarion Ledger ran dozens of articles over the many weeks and months of 1997 that dramatically increased HIV and AIDS awareness throughout the state. The award ceremony included a display of Mr. Rosilli's articles as run by *The Clarion Ledger*. T•II CANN congratulates the editorial staff of the *Ledger* and Mr. Rosilli, as well as his co-reporter, Josh Zimmer, for this achievement. ■

ADAP

ADAP National Educational Forum

Contributed By: Jim Arvantis
PAREXEL International Corporation

The third annual ADAP National Educational Forum convened in Washington D.C. April 5 - 7, bringing together more than 200 AIDS Drug Assistance Program (ADAP) administra-

tors, state AIDS directors, clinicians, and advocates from throughout the country. William Arnold, Vice Chair and Chief Operating Officer of T•II CANN, chairing the forum, noted that

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M E D I C A I D

States Can Now Offer Medicaid to Working HIV Patients

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

If their states agree, working asymptomatic HIV patients with incomes well into the middle range, will be offered the right to purchase Medicaid. The patient must meet eased state-set disability tests before Medicaid may be purchased using income-related, sliding scale premiums.

The program, proposed by the Administration, was included in last year's Balanced Budget Act. The provisions allow states to offer Medicaid, at reasonable premiums, to working disabled persons with family incomes below 250% of the federal poverty level.

At first, the program faltered because of a misinterpretation of the law by the federal Health Care Financing Administration (HCFA) which required overly-strict income-counting. Then, T•II CANN asked for and received assistance from Vice President Gore and other Administration officials who ordered HCFA to alter its interpretation. The corrected rules are now being sent to the states so that they can offer this crucial benefit.

Under the program, working disabled persons may buy Medicaid coverage at state set premiums if their countable incomes are below 250 percent of the poverty level (\$1645 monthly for one person in early 1998). Before the income is counted, gross earnings are compared to the level out-of-pocket medical costs paid by the

patient and \$85 and half the rest of earning are subtracted. Only the remainder, then, gets counted. This means that those earning nearly \$40,000 a year could purchase comprehensive medical coverage from Medicaid!

In addition, asset test requirements must be met. These include: up to \$2,000 in savings; a separate \$1,500 burial account; a car and home of any value; up to \$6,000 of self-employment assets; assets being saved under an officially-approved Plan to Achieve Self Support; and reasonable household and personal goods. Applications will be taken at welfare offices, not Social Security offices. Medical disability will be determined by the usually-flexible State Medical Review Teams (SRTs or MRTs) in state welfare agencies, rather than the very strict and rigid Disability Determination Services (DDSs) used by Social Security (SSA).

A key disability test used by SSA and its DDSs is the substantial Gainful Activity (SGA) rule to determine whether a person is capable of, or actually is, working. The new federal rules tell states that they cannot consider SGA, they must decide whether a person is disabled on clinical signs and symptoms only. The effect of this will be to qualify many symptomatic HIV patients for purchasing Medicaid, even if the SGA test and other strict SSA, DDS rules would deny them SSDI and SSI. ■



Herbert Perry, LPA/EA, Chair and CFO of T•II CANN and Branscombe Richmond of the famous TV Series "Renegade"

Branscombe Agrees to be T•II CANN Spokesperson

Branscombe Richmond, who played Bobby Sixkiller on the syndicated TV Series "Renegade" has agreed to serve as T•II CANN's national spokesperson. "I have many friends, who have been both affected and infected by the horrible HIV/AIDS virus. Whatever I can do to help, I am there," stated Branscombe at a recent press conference. T•II CANN is happy to have Branscombe's energy and welcomes his voice in support of Title II of the CARE Act. ■

THE VOICE OF T•II CANN

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William Arnold	Herbert W. Perry, LPA/EA
James Carr	Gary Rose
Jeff Coudriet	Mabrey Whigham
Frank DiGiovanni	

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

PotoInc@aol.com or fax to (202) 588-8868.
Visit T•II CANN's website at www.t2cann.org.
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T•II CANN: What is community support like there for people living with HIV/AIDS and for your programs?

Lori: It's tough sometimes. There is a wonderful small group of very committed people out here working to support the programs, holding fundraisers, etc. But there are other social services issues that are faced, like lack of housing, jobs, and poverty that are more of a priority—and AIDS isn't seen like a big problem. Competition for grants from the United Way is incredible and they are overburdened already with requests from other social services agencies that have large caseloads. We have looked at support from foundations around the country and last year we got a \$5,000 grant from one in Atlanta to deal with issues surrounding how people are dealing with their disease. This is a very rural area. People feel isolated and alone. Support groups are hard to set up because of geographical barriers. Plus people have a real fear of disclosing their status—things like that get around a small town real fast. Also, we spend a lot of time educating physicians about what is going on in treatment and care, so there is a lot of educating to do on many, many levels here.

T•II CANN: What would you like to achieve in the next 12 months?

Lori: I would like to see more drugs on the ADAP formulary—all the anti-virals especially.

Also, we have a statewide AIDS conference every year in Boise, which really is mostly prevention and education oriented. Much of the audience for that event are educators. But I would like to see a lot more information at that conference on treatment options and advocacy assistance; topics geared towards people living with HIV/AIDS. It's a big void right now. There is just not much out there for them, and we need to change that. Also, the State Department of Education needs

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“this has become quite the event.” As at previous events, this year's conference served as a forum for faculty to identify emerging ADAP trends and to announce new initiatives.

Annete Byrne, Director of the ADAP Branch at the Health Resources and Services Administration (HRSA), for example, indicated ADAPs might soon be able to use targeted ADAP funds to purchase insurance policies and insurance continuation for their patients under existing law.

“The issue was referred to our Office of General Counsel and they indicated there may be a way of using ADAP funds for insurance purchasing or continuation under limited circumstances,” Byrne explained. “As soon as we have a definitive answer or policy we will be sharing that with you.”

Moreover, the agency has retained a consultant to develop guidance on the insurance issue.

to lift their restrictions on what kind of information schools can hand out—they have an “abstinence only” policy. Obviously, this isn't enough to get the prevention message out.

T•II CANN: Sounds like some more coalition building to me!

Lori: Oh yes!

T•II CANN: Well if you need some help, make sure you call us!

Lori: We will, I am sure. ■

The following are some key highlights from the meeting:

ADAP Trends

Joe Kelly, Deputy Executive Director of the National Alliance of State and Territorial AIDS Directors (NASTAD), presented findings from NASTAD's most recent ADAP survey, which examined ADAP trends from June 1997 to December 1997. The survey found:

- ADAPs experienced a 16 percent increase in the number of patients served during the last six months of 1997.
- Six ADAPs experienced client growth of more than 50 percent.
- Federal and state funding for ADAPs nationwide totaled \$391 million in 1997. That number climbs to \$422 million with the inclusion of manufacturer rebates and insurance coverage.
- Sixteen states do not provide support directly for ADAP but may provide support for other Ryan White programs.

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Title II

V O I C E S

Outside The Beltway

Editors note: T•II CANN Board Member Jeff Coudriet will write this regular feature about people making a difference in caring for and advocating on behalf of people living with HIV/AIDS, as well as the problems, challenges, and triumphs that they are experiencing.

For this issue, T•II CANN spoke with Lori Lochelt, the Executive Director of the North Idaho AIDS Coalition.

T•II CANN: I know many states have had problems with their AIDS Drug Assistance (ADAP) programs—what's going on in Idaho?

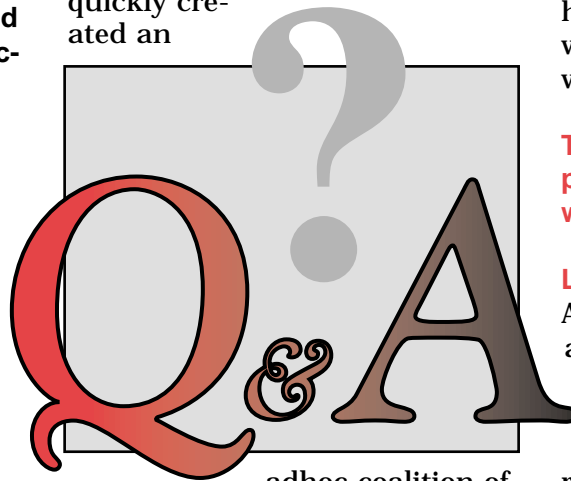
Lori: Well, we certainly have had our share of problems. Idaho was the only state in the nation to meet all of NASTAD's criteria for troubled ADAP programs. We have a waiting list for patients, ADAP budget shortfalls, limited access to the standard of care (covering only one protease inhibitor on our formulary list) and we have restricted access to the program based on medical status. We have some real problems.

T•II CANN: So what's the plan to change this situation?

Lori: This year the Department of Health and Welfare requested \$700,000 in their budget for ADAP. This is the first time a state agency has made a proac-

tive request of this nature—it was incredible.

Unfortunately, the Governor axed the budget request completely so we quickly created an



adhoc coalition of folks to advocate for this funding which included PWA's, AIDS service providers and advocates, physicians, and representatives from pharmaceutical companies. Gary Rose, T•II CANN's Director of Public Policy, was of invaluable help to us in building this coalition. We met with several members of the Joint Finance/Appropriations Committee and others and got a \$200,000 allocation for ADAP. Not as much as we need, but the first state AIDS funding we have ever received in Idaho. This is a real victory for Idahoans living with HIV/AIDS.

T•II CANN: So the coalition approach worked for you?

Lori: Yes! We had everyone down lobbying—an ordinary Idahoan housewife living with

HIV, a gay man with AIDS, drug company reps, you name it. It's especially important to bring people living with this disease to meet with the legislators because most of these guys have never met anyone living with AIDS before. I am sure it was an eye-opening experience!

T•II CANN: What are Title II funds paying for out in your part of the world?

Lori: A lot of money goes for ADAP, of course, but there are also four consortia in our state and we support direct services, primary medical care, case management, the full range of things. We are all feeling the pinch from the ADAP problems though and it is a priority, but there is a definite need for more funding overall, whether it's support from the State and the Federal government or private sources; to help pay for all the other things we need—support groups, assistance with transportation, huge dental expenses, and, frankly, more staff—it's really tough to do everything, from providing services and writing grant applications to everything else. It's a real burnout situation. My job, which is officially a half time position, is funded through Ryan White money as well as prevention money—and I'm the only paid employee in a five county area in the Idaho panhandle.

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TAEP to Examine Economics of HIV

Recently, the Board of Directors of T•II CANN announced the creation and organization of the Treatment Access Expansion Project (TAEP). This initiative is currently anticipated to operate in a two year developmental timeframe.

TAEP is based upon the development and wide dissemination of sophisticated economic models that will educate policymakers on the budgetary impact of treatment funding decisions.

The project was originally developed, in concept, by several member's of T•II CANN's board. An informal working group has been meeting since last fall and will formally be convened as a T•II CANN educational project.

TAEP will combine elements of labor economics, budget forecasting, pharmacoeconomic/health economic modeling, and other economic expertise to assess the impact of treatment interventions. The tools developed by the project will be made widely available through T•II CANN to assist in the health planning process of private, not-for-profit, and governmental organizations.

Products to be developed from this process include budgeting tools, reports, and articles for publication. Examples include the following:

- Published articles focusing on the results of the project and the social policy implications.
- Submitted presentations at national and international HIV treatment and service oriented events.
- A series of CD-ROM based interactive programs, enabling planning to be accomplished through interactive enquiry to forecast HIV treatment decisions over time and the resulting impact of those treatment decisions on the various social support systems, as well as the

greater economic costs. The first CD-ROM is anticipated for release at the International Conference on AIDS, to be held in Geneva, Switzerland. This tool will allow for "real time" comparisons of early versus later treatment of HIV with protease inhibitors.

Economic modeling for TAEP is provided by cooperating experts from Yale University and Price Waterhouse. The TAEP is supported through an administrative support grant from Hoffmann-La Roche. ■

MESSAGE FROM THE BOARD

Where Have All the Heroes Gone?

Lately we pick up a newspaper, or click on the radio or television, only to find ourselves bombarded with scandal, impropriety, or some alleged illegal activity. Finding those individuals with qualities worth emulating becomes increasingly difficult. More often, I have found my heroes in places that we typically don't search.

I have spent countless hours with many men and women infected with HIV/AIDS working in community coalitions, support groups, lobbying, and educating. They succeed in countless difficult tasks that are daunting to many in society that is often focused on "me first!" Add to this active service, the struggles and uncertainties of seeking out health care, making the rent or mortgage payment, sticking to complex treatment regimens, paying for drugs, working full or part-time, juggling



day care, etc., etc., etc. Many of my HIV positive colleagues are tireless in their efforts.

While engaged in this field of service, I have found many of my own heroes.

**Herbert Perry, LPA/EA
Chair and CFO of T•II CANN**

Editor's Note: Herb has served on numerous community AIDS related boards.

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- Nine state ADAPs have waiting lists for ADAPs.
- Seven state ADAPs have waiting lists for protease inhibitors.
- The ADAP Working Group, a coalition of industry and advocacy organizations calling for ADAP funding, is requesting \$175 million in additional targeted federal ADAP funds from Congress for FY 99. The Clinton Administration, however, has requested only \$100 million in additional targeted federal funds for ADAP.

“Over the next few weeks, the ADAP Working Group and others will attempt to get the remaining \$75 million from the Administration and Congress,” commented Arnold, who also serves as the co-chair of the ADAP Working Group.

Medicaid Waivers

- Several state Medicaid programs are developing 1115 (a) waivers to allow people with HIV and AIDS to enter Medicaid before they become disabled. People living with HIV would be able to access drugs and primary medical care through Medicaid before they experienced an AIDS defining illness, the current mechanism for qualifying for Medicaid.

“When those waivers get to town, it is my job and the job of my colleagues to make sure that the administration doesn’t dare do anything but approve [the waivers] expeditiously,” asserted Lubinski, Deputy Executive Director of the AIDS Action Counsel.

- HCFA plans to ask state Medicaid directors to appoint a Ryan White/Medicaid coordinator to work with Ryan White

grantees to assure that Medicaid pays first for patients deemed Medicaid eligible, said Judy Moore, HCFA’s Deputy Director for Medicaid and State Operations.

ADAPs Role

Program presenters repeatedly described ADAP as a life saving and sustaining program, key to reducing the number of AIDS deaths during the past few years.

“For the first time since the epidemic in New York City began, the death rate has dropped off,” noted Dr. Martin Markowitz, Staff Investigator for the Aaron Diamond AIDS Research Center in New York City. “I believe that is due, in large part, to the availability of antiretroviral therapy, particularly through the excellent ADAP program we have in New York.” ■



1775 T Street, NW
Washington D.C. 20009-7124