THE VOICE OF T•II CANN

Volume 3 Number 2 March/April 1999

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. We need you on the board! If you are a Title II funded service provider and are interested in serving on T•II CANN's board during the crucial Reauthorization debate, contact Bill Arnold or Gary Rose at (202) 588-1775.

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 Report Shows Increasing Expenditures

The National Alliance of State and Territorial AIDS Directors (NASTAD) and The AIDS Treatment Data Network (ATDN) are expected to release their third ADAP Monitoring Report in late February. Among the most important and often cited sources of data on Ryan White CARE Act Programs, the Report documents the status of state ADAPs from January 1, 1998 through June 30, 1998.

The key findings of this edition include:

•**Expenditures:** Monthly ADAP expenditures increased from about $26 million in July of 1997 to $41 million in July of 1998 (35%). From July of 1996 to July of 1998, ADAP budgets have risen by 274%. Five states (Alaska, Delaware, Nevada, North Carolina, and Oregon) reported increases of 50% or more, while five (Alabama, Idaho, Iowa, Montana, and New Mexico) reported decreases. Nationally, per client ADAP figures increased by 11% during the year from $664 per patient per month in July 1997 to $706 in June of 1998, 19% higher than expenditures from January to July 1997.

•**Categorical Expenditures:** Reflecting national epidemiological reports, expenditures on OI and other non-antiviral drugs decreased by 37% from $5,760,296 in July 1997 to $4,193,182 in June of 1998. Meanwhile antiviral expenses grew from $20,769,416 in July 1997 to $35,614,646 in June 1998, an increase of 171%. In the same period, the number of prescriptions filled grew from 130,336 in June of 1997 to 149,885 in June 1998, an increase of 13% while the number of protease inhibitor prescriptions rose nearly 60% from 21,951 in July 1997 to 35,040 in June 1998.

•**Clients Served:** The number of clients served nationwide has risen from 43,494 in July 1997 to 53,765 in June of 1998 (a 19% increase) while clients served per month increased by 856. Compared to July 1996, clients served have increased by 42%. Forty states reported increases in clients served from July 1997 to June 1998 while 3 states (Alaska, DC, and Oregon) reported over 50% increases. Nine states, meanwhile (Alabama, Mississippi, New Jersey, North Dakota, Rhode Island, South Dakota, Vermont, and Virginia) reported decreases in the period.

•**Budgets:** ADAP supplemental funding increased by 71% from $167 million in FY1997 to $285.5 million in FY1998. Title II base funding increased by 6% to $71.9 million and 13 Title I EMA's contributions increased 11% from $24.2 million in FY1997 to $26.8 million in FY1998. New York State EMAs contributed 69% of this total. Forty states contributed $119.4 million in general revenues to ADAPs in FY1998, an increase of 18% over FY1997. Twenty states increased their support and six states (Arizona, Colorado, Florida, Georgia, Indiana, Missouri, and New Mexico) more than doubled their contributions. Twelve states,

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BOARD PROFILES

Each issue of *The Voice* will highlight two members of the T•II CANN Board of Directors. This issue will highlight William E. "Bill" Arnold and Herbert Perry, LPA/EA.

Bill Arnold serves as the Vice Chair and CEO of T•II CANN and as the Co-Chair of the Washington, DC based, ADAP Working Group (of which T•II CANN is a very active member). The ADAP Working Group is an advocacy coalition of local and national AIDS organizations and pharmaceutical companies whose objectives, since 1995, have included adequate federal funding for access to HIV/AIDS drugs and support for the CARE Act, with advocacy and education efforts targeted towards both The White House, US Government Departments, and both Houses of Congress. The importance of access to treatment for PWAs and the levels of ADAP funding have been a priority for him since late 1995. The FDA approvals of the first Protease Inhibitor have caused his activities around access to therapy to become a full time job.

Bill has been based in Washington, DC since 1994, when projects involving Title II concerns often had him in Washington 10-15 days a month. In 1984, Bill served as president of an industrial brush manufacturing company, World Brushworks, Inc., in Kingston, NY. His career as a corporate CEO in this industry spanned 20 years. Upon closing down the plant, he inherited responsibilities for two teenagers and was suddenly drafted into the local grass roots AIDS response movement as a volunteer Board Member of ARCS (AIDS Related Community Services), now the second largest ASO in New York. From that commitment came 8 years of work with ARCS as Board Member and staff (in various capacities).

At the same time, Bill became involved with several other local AIDS not-for-profits which were gearing up to feed homebound PWAs and provide AIDS housing. He also served on CAB (Community Advisory Boards) for a number of medical clinics and AIDS programs, as they were developed. That led to AIDS political activity on behalf of The Dutchess County AIDS Consortium, The Ulster County AIDS Consortium, The Orange County AIDS Awareness Task Force and the networks in Rockland, Sullivan, and Putnam Counties. In the early '90s he became active in local politics working on Congressional campaigns and serving as campaign manager in local county level elections.

When Dutchess County, NY became a Title I EMA, Bill led a successful campaign to defeat attempts at disqualifying the 4 small EMAs which became eligible for Title I CARE Act funds that year (the others were in NJ, CA, and PR). He was assisted by the Governor, both New York Senators and the New York House delegation. He then spent almost a year in setting up the Title I Planning Council and two years as it's Chair. Despite a typical Washington, DC work schedule, Bill manages to squeeze in some travel time each year to Europe (where he attended school) and spends time with family and interests on several American and British islands in the Caribbean.

Herb Perry currently serves as the Chair and CFO of T•II CANN. He also serves in various functions in the following organizations:

- Member, Speaker's Bureau, National Association of People With AIDS (NAPWA)
- Recommended Speaker, Corporate Wellness (AIDS Awareness)
- Member, AIDS Action Council
- Member, National Association of People With AIDS (NAPWA)
- Member, Community AIDS National Action Network (CANAN)
- Legislative Chair, Nevada Society of Accountants
- Chair, CFO, The Ryan White CARE Act Title II Community AIDS National Network, Incorporated
- Public Affairs Director, Host and Producer of a one hour public affairs radio talk show on two Las Vegas radio stations
- Member, Nevada Attorney General's Charitable Solicitation Task Force
- Vice Chair, Nevada Chapter, Southern Division, March of Dime
- Member of the Board of Directors, Lutheran Social Services of Nevada
- Member of the Church Council, Christ Lutheran Church
- Member, Finance Committee, Christ Lutheran Church

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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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Rural Situations and Others Where Phone Access May be the Only "Safe" Private Way to Get HIV/AIDS Information

The T•II CANN community has another resource — the National HIV Telephone Consultation Service (Warmline). Warmline is a Ryan White/HRSA funded program based at San Francisco General Hospital. Physicians and other health care providers may find timely HIV clinical information and case consultation across the broad range of clinical HIV/AIDS issues. Warmline phones are answered by clinicians experienced in HIV care and the service is FREE. Most questions are answered immediately.

The Warmline is particularly focused on helping rural providers, providers at Ryan White-funded institutions, and providers who do not have ready access to other consultants. Warmline's website can be accessed through the T•II CANN's website (www.t2cann.org) or directly at http://itsa.ucsf.edu/warmline. Further information can be obtained at the website or by contacting Libby Smith, Ph.D., **(415) 502-7345**.

MESSAGE FROM THE BOARD

Reauthorization of the Ryan White CARE Act

The Ryan White CARE Act will expire in the year 2000. Discussions in Congress and elsewhere will take place during 1999 and in 2000, until the CARE Act is again reauthorized and extended.

Obviously this process directly affects thousands of community based HIV/AIDS programs and tens of thousands of people affected by HIV/AIDS who are served by the CARE Act. "Life and death" importance might not be too far removed from describing this legislative process.

The changes in the course of the AIDS epidemic and the changes in the lives and future prospects of HIV+ infected/affected Americans are no longer the same as they were in 1994 & 1995 when the last reauthorization took place. In various regions, while much has changed — much remains as it was, and, we are often dealing with "MORE" in terms of numbers and needs than we were. The near miraculous success of the new "combination therapies" offer huge promise for some — but not yet all.

I personally will remember my early days in AIDS, in '85 and '86 in the Mid-Hudson Valley of New York just 100 miles north of New York City. We had no treating physicians, no AIDS Service Organizations, no educated public, no federal money, no phone numbers to call for help or information, and no support groups. The first New York State funding was being whispered of among the hopeful. I also vividly remember chapter, after chapter, after chapter of horror stories lived by HIV+ people. I especially remember the deaths, and the funerals — all seemingly endless.

T•II CANN's Board of Directors has a large number of people living with HIV serving on it and a large number of people who remember what HIV/AIDS was like before the arrival of the Ryan White CARE Act. The Board and staff will be extremely active in many forums (including the United States Congressional process) to ensure that the national networks supported by Title II funding are strengthened, not damaged, and that those who depend on these programs get a reauthorized CARE Act, at least as effective as we have had for the last few years. If the CARE Act is changed in the process, T•II CANN will work to ensure that the changes offer promise for improvements. The process will likely be very "political," but we will be there as a voice and as very experienced and vigilant "watchdogs" for Title II interests.

William "Bill" Arnold
Vice Chair and C.E.O.
of T•II CANN

T•II CANN Joins Salvage Coalition

T•II CANN recently signed onto a consensus statement by The Coalition for Salvage Therapy. This Coalition will encourage expedited access for the growing number of people living with HIV, who have run out of options from the currently available armamentarium of anti-HIV medications.

In the 80's, many treatment activists worked together to open access to new HIV drugs through mechanisms such as expanded access and compassionate use. These programs were intended to help HIV-infected people for whom options were limited to gain access to promising new AIDS therapies.

While these programs still remain in place, many pharmaceutical companies do not offer access to their newest drugs until they are fairly close to being approved by the FDA. Now that the usefulness of highly active anti-retroviral therapy has been validated, however, it becomes even more urgent that new drugs offering better potency or different resistance profiles be offered to people who have failed on currently available combinations.

Other signers of the letter sent to Abbott and calling for access to that company's new protease inhibitor ABT-378 include the Treatment Action Group, Project Inform, Gay Men's Health Crisis, AIDS Treatment Data Network, and AIDS Project Los Angeles.

For more information on the Salvage Coalition, contact Spencer Cox of TAG at **(212)924-3935**.

Arkansas Activists And Pharma Companies Form ADAP Coalition

For many years, people living with HIV in Arkansas have been forced to live with an underfunded and overstrained ADAP and one of the least workable Medicaid programs in the country. However, in late 1998, these problems began to receive media coverage and the Governor's office responded with a request for a consultation. T•II CANN Public Policy Director, Gary Rose, was invited to provide technical assistance to the new state advocacy group by organizer Eric Camp and attended the first meeting with the Governor's staff just before Christmas in Little Rock.

By all accounts, the meeting was a success. It instigated a major story on the crisis in access by Erin Schulte in the *Arkansas Democrat-Gazette* and ended with offers by the Administration to look into filing a Medicaid expansion waiver, opening the Arkansas High Risk Insurance pool to PLHIV, and developing an ADAP supplemental funding request.

As of this date, T•II CANN is also involved in access coalitions in Nebraska, Connecticut, Pennsylvania, Florida, Colorado, Nevada, and Indiana and remains on the Coordinating Committee of the national ADAP Working Group.

For more information on Arkansas or if you want to join the Coalition, contact Eric Camp at **(501)375-7435**.

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Herb graduated from college with a MBA and has over twenty years experience in the small business bookkeeping and the individual income tax return preparation profession. He handles all phases of the various required accounting needs for his small and medium sized business clients. He is retained by many clients to assist them in budget and financial planning, as well as income tax planning. He has represented many of his clients before the Internal Revenue Service as an Enrolled Agent.

Herb resides in Las Vegas, Nevada. He is married, has two daughters, one son-in-law, and two granddaughters. He enjoys bowling, watching football, and reading.

President's Budget Released, Modest Increases in CARE Act Spending Included

Recently, President Clinton forwarded his $1.7 trillion budget to Capitol Hill, signaling the beginning of the 2000 budget process. As part of that budget, HIV programs funded under the CARE Act would receive increases over the 1999 budget. The following is the breakdown of the HIV prevention and CARE Act figures.

CDC HIV Programs	667M	+	10M
Ryan White			
Title I - cities	521M	+	16M
Title II - states	783M	+	45M
ADAP	496M	+	35M
Title III	130M	+	36M
Title IV	48M	+	2M
AETC - training	20M	+	0M
Dental	8M	+	0.2M

William "Bill" Arnold, Vice Chair and C.E.O. of T•II CANN noted:

"While the modest increases offered in the President's budget are appreciated, it's clear that, particularly with regard to the needs of ADAP and Title II, we will not have the resources to adequately serve the care and treatment needs of the people already known to be living with HIV — let alone be ready for those who may seek treatment in the next year. We must encourage Congress to increase these numbers, as we have in each of the last 3 years, and ask the White House for support for a larger resource need — if we are successful with Congress. Otherwise, statewide AIDS services and PWA's everywhere will again be dealing with epidemic effects with one hand tied behind their backs."

T•II CANN Board members, **Herb Perry**, **Bill Arnold**, **Gary Rose**, and **James Carr** at the **U.S. Conference on AIDS** held last fall in Dallas.

A NOTE FROM THE EDITOR

While reading *The Voice*, have you ever thought of something you would like to share with the Title II community? Now is your chance. We encourage your participation in your newsletter through the submission of short articles to *The Voice*.

Articles should focus on Title II related service, advocacy, or program management issues. Please keep articles between 300 and 350 words in length. Longer articles will be considered, but may be edited for length. Articles may be sumitted electronically to PotoInc@aol.com, or "snail mail" to The Voice, T•II CANN, 1775 T Street, NW, Washington, D.C. 20009-7124.

Articles will be reviewed by the editorial board for publication. Authors will be notified directly. Those articles printed in *The Voice* will include author credits and a brief bio.

We look forward to hearing from you! ■

The Editor

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meanwhile, (Alaska, Arkansas, Delaware, Iowa, Michigan, Montana, Nebraska, Oregon, Rhode Island, South Dakota, Tennessee, and Wyoming) contributed no state money to ADAP.

•Program Restrictions: Eleven states capped program enrollment during the period (Alabama, Alaska, Florida, Georgia, Idaho, Mississippi, Montana, Nebraska, Nevada, North Carolina, and South Carolina) and maintained active waiting lists of over 2,500 people. Five states imposed monthly or yearly per capita expenditure caps ranging from South Dakota ($5,000 per year) to Missouri ($16,000 per year). Six states have capped access to PIs or other antivirals (Idaho, Kentucky, Maine, Nebraska, and West Virginia), while two (Arkansas and South Dakota) continue to provide no Pis on their ADAP formularies.

While much in this edition of the ADAP report is heartening, especially the documented increases in the numbers of uninsured and underinsured Americans provided access to the standard of care through ADAPs, the challenges posed by continued increases in need will prove more and more difficult to meet. Federal and state appropriators and administrators will be unlikely to continue supporting increases in program budgets at the rates of growth necessary to provide medications to the ever-growing number of uninsured and underinsured people living with HIV. The program snapshots provided by the Monitoring Report strongly suggest that new methods of caring for these patients must be developed if we are to continue to improve the health and lives of all Americans living with HIV.

The full data sets from the ADAP Reports are available at the Monitoring Report website at http://www.aidsinfonyc.org/adap. We thank Arnold Doyle of NASTAD and Richard Jefferys of ATDN for an advanced look at this edition of the ADAP Report.

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