

VOICE OF T·II CANN

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ADAPs Continue in Crisis. “Grass Roots” Advocacy Still the Key!

The politics of domestic federal spending and the fiscal conditions in many states have combined to make securing adequate ADAP funding both at the federal and at the state level a VERY difficult job for all communities affected by the American AIDS Epidemic.

New infection rates of 40,000/yr and the vastly reduced AIDS death rates dropping to 15,000 to 16,000/yr now guarantee more patients living longer and thus a pretty much automatic increase in need of around \$100 million each year. Add to that Medicaid cut backs at the state levels in frantic efforts to balance state budgets throwing more patients to ADAP; reductions in public insurance eligibility; and private insurance moves to dump “high cost” patients – the yearly need fast becomes more than \$100 million a year. Much more!

Rapid HIV tests and the much increased outreach efforts mounted with CDC (federal) money in combination with thousands of similar “get tested, know your status” efforts by hospitals, local health departments, corporate, and drug industry programs, not to mention faith based and private “AIDS Outreach” across the country, are sure to add yet more patients and thus more need for resources.

While almost everyone understands that without insurance,

access to quality HIV care and HAART, large numbers of our almost 1,000,000 HIV-positive Americans will sicken early and substantial numbers will die prematurely at astronomical personal and family expense – it’s less well appreciated that those deaths have huge impacts on hospitals, health charities, home health programs, and local social and religious volunteer and care provision programs. Not treating the HIV-positive is very expensive to the patient, his/her family, those economically dependent upon them, and on the health care infrastructure that will do it’s best to care for them – knowing that they may not be paid.

Understanding this, and recognizing the huge national social and resource damage caused by failure to treat HIV disease with our best – and finally available - medical knowledge, doesn’t translate automatically into “of course we should provide medications for all who need them – it’s in our national interest.” Quite the opposite! In times of fiscal restraint and “budget panic” many have a tendency to retreat to “silo thinking” where each “budget” function attempts to “save money” by shoving a known expense into someone else’s budget by any means possible.

That’s where we seem to be “stuck” right now. The federal level doesn’t want to spend “their” money on access to HIV medica-

tions. State governments want to cut their share of these costs and the cascading economic damage to HIV-positive patients, their families, employers, cities, towns, and communities is magically “someone else’s budget problem.” And, let’s face it; you can get away with a certain amount of this kind of “public policy” – but only until people start pointing out very publicly that the emperor has no clothes.

The key in our system to forcing political leadership to do both the “right” thing and even the intelligent, fiscally responsible, “cost effective” things is the political tool of advocacy. That means, at the local level, face-to-face by ordinary citizens, willing and able to vote, we (and you, and they) have to provide the motivation (and then the political credit) to get our governments to recognize what should be done and give them the necessary “push” and “reward” so that they can step out, lead us, and argue at all levels of government around issues like ADAP.

The HIV-positive American not in treatment lives near you. It may even be you or someone you care about personally. When the inevitable \$150,000.00 emergency room and hospital bills from untreated HIV disease pile up – it’s in your city or town. The “costs,” and make no mistake these are true money costs – can either be

Continued on page 10

West Virginia Waiting List Has Deadly Consequences

Two West Virginia residents died this past summer of AIDS-related complications while languishing on the state's ADAP waiting list, a scenario that may be repeated in other states as ADAPs struggle with funding shortages and ensuing program restrictions.

"There is a feeling of utter helplessness at the moment," said Faisal Khan, MD, MPH, Director of the HIV/AIDS and STD Program for the West Virginia Bureau of Public Health. "We are having to watch people die. We are having to watch others wither towards their death. There is just not enough money. We have improvised and re-routed funds, saved and collaborated, and networked to the maximum extent possible. But in the absence of additional federal funds there is only so much we can do."

The two patients – one died in June and the other in July – had advanced HIV disease and were in desperate need of antiretroviral treatment when they were put on

the state's ADAP waiting list in February. Both had either postponed the initiation of anti-retroviral therapy or were not diagnosed until late in their disease stages, and were thus unable to access life sustaining ADAP medications before officials imposed an ADAP waiting list in February.

"They were eligible for ADAP services but could not obtain the services because we did not have sufficient funds," said Khan. "We had capped the program." Khan called the circumstances surrounding the two deaths "disgusting."

"I don't think the dedicated people in the HIV/AIDS workforce have ever been this depressed or anguished," he said.

The West Virginia ADAP now has a waiting list of fourteen people – after two deaths. A few of the patients on the waiting list also have advanced HIV disease and "face a bleak future" without access to opportunistic infection

medications and antiretroviral therapy, said Jay Adams, the state's HIV Care Coordinator.

"I wish there was an end in sight," Adams told *The Voice*. "We don't have an end date for the waiting list or re-opening the program to new enrollment."

Adams speculated that other state ADAPs could soon report the deaths of patients on their waiting lists. "I wouldn't be surprised if this is not happening in other states," he said.

Fifteen state ADAPs have waiting lists or some type of program restrictions in place while four more ADAPs are expected to impose restrictions before the end of the current Ryan White fiscal year on April 1, 2004.

Strict Caps

West Virginia's ADAP is funded at about \$2.2 million in state and federal funds and serves about 256 patients on an ongoing basis. Even though the program received an increase of \$250,000 in the current Ryan White fiscal year, the increase is still not enough to offset ADAP funding shortfalls. As a

Continued on page 9

THE VOICE OF T•II CANN

Volume 7 Number 2
Published Bi-monthly
Annual Subscriptions: \$25.00

The Voice Editorial Board:

William Arnold Thomas P. McCormack
Gary Rose Daniel J. Schreiner MHS
Mabrey Whigham

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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, GlaxoSmithKline, Boehringer Ingelheim, Virologic, Virco, and Gilead Sciences. General activities of T•II CANN are supported by unrestricted education grants from 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.

National ADAP Conference Provides Invaluable Insights and Information

Part 1 of a 2 Part Series

This year's National ADAP Educational Conference accomplished many tasks, serving first and foremost as one of the nation's premiere health related conferences by providing invaluable programmatic, technical, and legislative expertise to more than 250 participants from every state and territory in the United States. It also enabled program participants to meet with colleagues from other states in order to share ideas, strategies, and best practice modalities. In the final analysis, this year's conference provided participants with new information, new insights, and new perspectives, re-affirming and strengthen-

ing the commitment to ADAPs and other programs that seek to enhance access to care for people living with HIV and AIDS.

The following are selected highlights from this year's National ADAP Educational Conference.

CBC Chairman Makes a Passionate Plea for More HIV/AIDS Awareness

The chairman of the Congressional Black Caucus (CBC), Elijah E. Cummings, urged the AIDS community to take a more active role in educating members of Congress

Continued on page 4

Premium Payment: Adding Clients to Their Spouses' and Domestic Partners' Job Health Plans

By Thomas P. McCormack

Health Insurance As A Dependent of Working Spouse

While many, if not most, of those eligible for state ADAPs are single, divorced, or widowed, small percentages are currently married. This means that married clients who have working-age spouses, even if they may be a small minority of the caseload, need detailed attention to uncover possible overlooked dependent coverage in their spouses' job health plans.

A number of key studies on health insurance enrollment show conclusively that lower income workers are unlikely to enroll their dependents in their job health plans. (These technical studies are available upon request.) This is due, in part, to the fact that for almost all employer-based plans, the employee must bear a costly premium surcharge to enroll his dependents. For most of those making, say, \$10 an hour or less (e.g., store clerks, etc.) this is simply unaffordable, even when the worker has a seriously ill dependent. After all, food and shelter come first at this income level.

This phenomenon also means that, even if a public program asks about other possible health insurance (e.g., which covers drugs) on its application forms, clients (somewhat misleadingly) may well answer that they have no such coverage. This omission may occur because they're not enrolled now, because they've forgotten a prior decision not to enroll, and/or because the employed spouse didn't share the decision to non-enroll with the spouse applying for the program. Therefore, to find out if an employer plan with offered dependent coverage is available from a working spouse's employer will require careful and precise telephoned or mailed questions to the program applicant, his or her spouse, and even to the spouse's employer's benefits office.

One possible way to begin to deal with this is to have the program's enrollment/eligibility/systems staff produce a list of those cases with spouses who've reported earned income (assuming that, in programs determining eligibility on family income, some data is kept on who has what sort of income). Such cases might then receive a mailing asking for the name and telephone number of the working spouse's employer, with follow up letters to the employer to inquire if there's a health plan, the dependent premium surcharge amount, the date of the next "Open Enrollment Period," and the plan's benefit package. Where a pre-existing condition waiting period applies, and, of course, this is far more rare than before thanks to the HIPPA legislation, cases would have to be monitored/recorded. All cases requiring premium payments and related monitoring/recording would obviously entail some added administrative effort.

However, such an extra effort to uncover non-election of offered employer health insurance should prove well worthwhile. The figures cited in the studies mentioned above, all suggest that not just a large number, but an absolute majority of couples with a working spouse in ADAP's income range have declined offered dependent coverage in health plans due to cost.

Health Insurance As A Dependent of A Working Domestic Partner

For ADAPs, there's still another key group of dependents of workers whose health insurance premiums can be paid by state Ryan White programs as a tool to stretch limited funds. These are those clients living with domestic partners who are working for employers that permit enrollment of such partners in the employer health plan. These are mostly gay

couples; but there are probably numbers of straight, unmarried couples too.

At www.hrc.org, at the "worknet" and then the "domestic partner" icons, are listed the 9 states, 136 or more localities, and many but not all of those enlightened, private employers that offer their employees the right to enroll their domestic partners in employer group health plans. There's even a query function to find out about particular employers as well as a "2002: State of the Workplace" report offering even more updated information about domestic partner health insurance offerings by progressive employers. Also see the list at <http://www.buddybuddy.com/d-p-1.html>. In addition, many employers not yet appearing on these lists also may provide domestic partner dependent health coverage, one must ask to find out.

As with traditional working spouses, lower-paid domestic partners may not have been able to afford to enroll their HIV-positive partners (i.e., ADAP clients) in the workplace health plan. However, even higher income partners may not have been aware that the benefit is available, or simply viewed enrolling in ADAP (at a big cost to ADAP's budget but not their own) as more convenient for them than enrolling in the employer plan.

Obviously, screening an ADAP caseload and new applicants for this type of possible alternate coverage will be even more labor-intensive than screening those with traditional working spouses. ADAP enrollees and applicants must be asked whether they have live-in domestic partners; if such partners are working; where they're working; whether the employer offers domestic partner health coverage; and what the plan premiums, coverage, and enroll-

Continued on page 9

about the importance of the ADAPs and other AIDS-related initiatives.

"I beg you to stand up – in this other arena—this political arena where we decide where these dollars go," said Cummings, a member of the House AIDS Working Group, during the keynote address. "Stand up in that arena because when you stand up in that arena, you not only affect your state and the people that you deal with everyday but you also affect people all over the country."

Cummings, who was elected chair of the CBC in November 2002, said Congress tends to paint issues such as HIV/AIDS with a "black face," and as a result the "issue suffers."

"A lot of times when African-Americans come forward and say there is a problem, policy makers say, 'here we go again,'" explained Cummings, a member of the House Task Force on Health Care Reform. "But as you well know, AIDS does not stop at color. AIDS does not stop in Maryland. AIDS is a very serious disease."

It is important to understand, Cummings said, that "most people with AIDS are not black." "That is a fact," he said. "And that is why I am speaking to an audience like this."

Cummings reminded the audience that the "squeaky wheel gets the attention," especially on Capitol Hill. "I think we have to be about the business of making your job easier and you make your job easier by sensitizing members of Congress as to what you are dealing with," he said.

You Are Valuable

Cummings, now in his fifth Congressional term, was not scheduled to be in Washington during the National ADAP Educational Conference in mid-May because Congress was not in session. But as he explained, "I came over here because I wanted to be with some very, very important people, and I wanted to acknowl-

edge the great work you do every day to affect peoples' lives."

"I know sometimes you get a bit discouraged," he said. "I can understand this when you see the budget situation in this country and you realize we just paid down \$80 billion on this (Iraq) war -- which I will not comment on. When you realize we are about to spend billions of dollars to give the Iraqi people a universal health care system."

"I am not saying you limit your humanitarian efforts," Cummings added. "I am not saying you don't do for other people outside of this country. I am just saying, 'if it is good enough for the Iraqi people, it should be good enough for Americans.'"

"By the end of the work week, many AIDS and ADAP directors are probably wondering why they are employed in the HIV/AIDS field, asking themselves questions such as 'Why am I making so little money? Why do I have to struggle to make ends meet? Why do I have to constantly tell people no because I don't have the resources to help them,'" stated Cummings.

"Let me give you the answer to those questions," he said. "The answer is, you have been placed here to make a difference. You make a difference for many, many people."

Cummings acknowledged, however, that certain problems are getting worse, making it even harder to run AIDS programs (including ADAPs) and to work in the AIDS field. During the past two years, for example, more than 2 million jobs have been lost in this country, increasing the number of unemployed to nearly 9 million. There are, in fact, about 8.8 million people out of work, about 60 million people in this country without health insurance. As Cummings points out, "when people lose their jobs, they lose their health insurance," which puts more pressure on programs like ADAP.

Congress, meanwhile, recently enacted a huge tax cut, and is now in the process of spending billions of dollars to fund wars in

Afghanistan and Iraq and to bolster homeland security, further reducing the amount of money available for domestic programs like the Ryan White CARE Act.

Staying in Touch

Cummings lives in the inner city of Baltimore, an area he represents in Congress. "I live in the inner city of Baltimore," he said. "I refuse to move out of the inner city because I want to stay in touch with people and what they go through everyday. Martin Luther King Jr. said, 'you cannot teach what you do not know, and you cannot lead where you don't go.'"

His involvement with HIV/AIDS goes back more than 20 years when he was first elected to the Maryland legislature and began holding an annual HIV/AIDS conference in his district. "I saw death staring so many people in the face and over the years, our number of (conference) attendees would increase," Cummings said. "But sooner or later we would see some people who were missing in action because they had passed on."

Cummings was also a leader of a Baltimore church group that helped and ministered to people with drug problems who were, in many cases, HIV-positive. "They would come to church to become members and one of the things that happened as a result of that is that we had a lot of people with a history of drug abuse," Cummings remembered. "They looked good and they came and started dating some of the young ladies in the church. They didn't tell anyone about their history and eventually we had church members contracting HIV."

Cummings watched his own brother-in-law die of the disease, a person who battled a 20-year addiction with drugs and who was, in Cummings' words, "one of the bravest men I had ever known."

"I will never forget going into the hospital and watching him day after day as his system shut down," Cummings said. "I used to hear people at funerals say, 'they

are in a better place.’ I am sure you have heard that and you have said that to yourself many times. But this was the first time, I ever went to visit someone and I wished that person would die because I saw him suffering so much.”

Sadly, American society has reached a point where “people’s lives are not valued the way they should be,” Cummings said. “When people look at other people with HIV/AIDS, they forget that one day there was a little boy or a little girl playing hopscotch and hide-and-go seek,” Cummings said. “Somebody struggling with his or her ABCs in kindergarten, someone when they were 10 years-old had a birthday celebrated by aunts and uncles, friends, and neighbors.”

How to Win Friends and Build Partnerships

Jesse Fry, Director of Government Affairs and Advocacy for Florida AIDS Action, unveiled the organization’s top 10 tips and strategies for building coalitions and advocacy partnerships, starting with how to partner with other disease conditions and ending with ways to make advocacy efforts creative, interesting, and engaging. The following describes each of the top 10 strategies.

NUMBER 1 – Partner with other disease conditions, especially those with high treatment and drug costs –

Fry encourages AIDS organizations to partner with cancer, multiple sclerosis, and transplant recipients, in particular, saying that these disease states tend to generate a great deal of support in state legislatures.

“In Florida, right now, there is a crisis around Medicaid and medically needy programs,” explains Fry. “And of course, there are a lot of AIDS patients in those programs.”

Florida’s governor, Jeb Bush, signed a bill providing temporary relief for the Medicaid program, a temporary victory primarily due to the efforts of advocates who told legislators about the plight of transplant recipients, many of

whom would not be able to obtain their anti-rejection medication without support from Medicaid, thus creating the potential for life threatening complications. These statements and presentations were compelling and persuasive, convincing state lawmakers to appropriate more money for the Medicaid program, at least temporarily.

“This is just one instance of how collaboration can help,” Fry noted. “There are many, many more.”

NUMBER 2 – Involve consumers whenever and as much as possible –

Fry encourages organizations to involve consumers as much as possible, especially in terms of state and federal advocacy efforts. Unlike organizations, consumers can develop one on one relationships with their elected officials, lobbying them on behalf of HIV/AIDS related issues and concerns. “In traveling the state of Florida on behalf of AIDS Action, I like to impress upon organizations to empower consumers and remind them of that unique relationship,” Fry said.

At the same time, consumers bring input and unique insights into organizations, perspectives that organizations lack, making them even more critical in terms of lobbying efforts.

NUMBER 3 – Join a health clearinghouse or start your own –

Fry defines a clearinghouse as a coalition of organizations representing various disease conditions that lobby on behalf of stated goals, objectives, and platforms – common issues or challenges confronting members of the association. The goal, Fry says, is to create a “unified response.” As he explains, “there is strength in numbers.”

“We take a clearing house platform around the state capital and get some pretty good results,” he says. “We get some good attention.”

Fry acknowledges, however, that Florida has certain advantages that other states may not have. “We are kind of spoiled in Tallahassee,” he says. “We have had a clearing

house in Florida in one form or another for 37 years. It was founded by a woman 37 years ago who is still leading it.”

NUMBER 4 – Use a variety of sources for recruiting members –

Fry encourages organizations to “think outside of the box” when trying to recruit members. “That is a very hackneyed term,” he concedes. “But people do not seem to be doing it a lot.” Fry suggests recruiting new members at consumer advisory boards, support groups, consortia, and council planning meetings, even staff meetings within your own organizations – provided, of course, that the facilitators or leaders of these groups grant permission.

“There is also no shortage of mailing lists and e-mail lists that you can use to promote your group,” Fry notes.

NUMBER 5 – Have a communications plan working for you no matter what strategies you use –

Florida AIDS Action puts out press releases, using them to generate publicity and press coverage but also to inform Florida AIDS Action membership about what is going on.

“One particular example is a press release we did on the national ADAP crisis,” commented Fry. The best advocacy partnerships mean little if people lack “awareness and comprehension about who you are and what you are doing,” Fry says.

Fry urged organizations to log onto a website specifically for advocacy and opinion sharing, Spinproject.org. “It is a great website,” he says. “They also have a book about advocacy efforts.”

NUMBER 6 – Include recognition in your advocacy efforts whenever possible –

Congressman Cummings told conference participants, “you are important because you value other people.” And then he repeated that statement. “How did that make you feel?” asked Fry. “Pretty good, huh? It made me feel good. That is the kind of recognition I am talking about.”

There are many ways to recognize someone, presenting that person with a tiffany bowl, for example, or even a certificate created with a laser jet printer, acknowledging an accomplishment or achievement. "That is recognition and that kind of stuff is important," Fry stressed.

NUMBER 7 – *Spread out the work equitably among coalition members –*

The quickest way to kill momentum is to burden a small group of people with most of the work, something that must be avoided, Fry said. "Otherwise you will lose people," he warned. "Many of you are familiar with the problem of burnout with consortia and planning councils."

NUMBER 8 – *Build on the models of advocacy and coalitions in other states –*

Fry urges advocates and organizations to "talk to people in other states to find out what they are doing." It is also important to network at conferences like the National ADAP Educational Conference.

Florida AIDS Action has a training institute that provides consultation on how to develop community advocacy networks, using models that have worked for Florida AIDS Action. "Recently, we provided consultation and assistance to Georgia, Alabama, Louisiana, Massachusetts, and North Carolina," noted Fry.

Florida AIDS Action in collaboration with Project Inform of San Francisco also worked with advocates in North Carolina to establish the North Carolina AIDS Action Network, chaired by Patrick Lee.

NUMBER 9 – *Support coalitions by helping them to use data to identify advocacy goals and messages –*

The penultimate advocacy strategy is for state employees, Fry says. Even though state employees cannot engage in direct lobbying efforts, they can play an important role in explaining HIV/AIDS data to wide and varied audiences, making it possible to use that data for advocacy purposes.

NUMBER 10 – *Use the Top 10 list as a framework for presenting information to a group of people –*

"Okay, I made this one up," acknowledged Fry, provoking laughter. "Who ever heard of a top nine list anyway?"

The 10th and final strategy entails "keeping it light," Fry said. "This is very serious business," he explains. "But you don't get brownie points for being earnest if you are losing people because they are dozing off or they are bored or they don't show up."

Fry urged organizations to "be creative by organizing your advocacy efforts around activities. When was the last time you had a meeting that was also an ice cream social?" Fry asked. "Or a pot luck dinner so that someone could roll out their favorite lasagna recipe?" Fry reminds us, "we are people, and we should interact as people and not meet in some dingy room with a florescent light."

How Medicaid Reductions and Restrictions Impact ADAPs

Nearly every single Medicaid program has implemented program restrictions and cutbacks during the past several months – reductions that have put even more pressure on the nation's beleaguered ADAPs. The extent of Medicaid coverage has a direct bearing on ADAP coverage, often determining the financial viability of the drug assistance programs. In most instances, a generous Medicaid program means a healthy ADAP. By the same token, a less than expansive Medicaid program has dire implications for a state's ADAP.

In Tennessee, changes in the state's Medicaid managed care program, TennCare, have resulted in dramatic increases in ADAP costs and utilization rates, doubling the size of the program within a year, says Del Vineyard, Director of AIDS Support Services for the Tennessee Department of Health. In July 2002, Tennessee officials revamped TennCare, the state's

Medicaid managed care program, reducing both the size and scope of the program while requiring people with HIV disease to meet an income requirement for the first time. In the past, a person with an HIV diagnosis automatically qualified for the program without having to meet an income requirement. In most cases, the state's ADAP, known as the HIV Drug Assistance Program (HDAP), provided medication assistance to a newly diagnosed person with HIV for about 90 days – until that person completed the necessary TennCare paperwork and transitioned onto that program. With the new requirements, it is much more difficult for someone with HIV to qualify for TennCare – that person has to meet an income eligibility requirement of 100 percent of the federal poverty level (FPL). The new requirements do not apply to people already on TennCare.

"If you are below 100 percent of poverty, you are eligible for TennCare," Vineyard explains. "If you are between 100 and 300 percent of the federal poverty level (FPL), you are eligible for HDAP. If you are over 300 percent of the FPL, I hope you have insurance, or you're on your own."

HDAP enrollment averaged 36 clients a month before July 1, 2002; it now averages 44 clients a month, a 22 percent increase. At the same time, the average number of clients who left the program and then were re-instated has jumped to 17 clients a month since July 2002, a 55 percent increase.

"We had 154 people receiving medications in April of 2002," explains Vineyard. "By April of 2003, we were up to 310."

The HDAP program spent more than \$1.4 million on medication purchases during the 2002 calendar year, but during the first quarter of 2003, it had already spent nearly \$723,000 on medications, meaning the program will spend close to \$2.9 million on drugs for the 2003 calendar year if that trend continues, a 98 percent increase, Vineyard says.

"Right now, we feel we can absorb the number of new clients

enrolling in our HDAP, but we are concerned about the rate of growth," says Vineyard.

Vineyard speculated that other factors may have also contributed to the HDAP increases – a possible jump in newly diagnosed HIV cases, for example, or even more people moving into the state to access an ADAP not hampered by a waiting list. During a five month period last year, the state required all TennCare recipients to undergo a re-certification process to determine if they were eligible for TennCare Medicaid, a standard Medicaid program, or TennCare Standard, a new category covering the uninsured and the uninsurable.

"The process did not go smoothly," Vineyard says of the re-certification process. "There were a lot of people who tried to get through the hotlines that were established and they couldn't get through."

Many were disenrolled from TennCare because they failed to respond to re-determination requests. Even though the governor granted a one-year grace period for those who were removed, some HIV patients may have sought care through HDAP, driving up HDAP costs and utilization rates, Vineyard says.

Interestingly, Tennessee operates a Centers of Excellence network for HIV/AIDS patients in the state, eight centers serving about 2,066 clients a year, and those centers also have been impacted by the reductions in TennCare eligibility. In 2000, TennCare covered 69 percent of the patients served by the Centers of Excellence Network; by the first quarter of 2003, that number had dropped to 52 percent. At the same time, the number of clients covered through Ryan White soared from 4 percent to 23 percent, an increase driven, in large part, by the number of clients who were forced to seek care through ADAP and other Ryan White programs because they were no longer eligible for TennCare.

"So far, luckily, we have not seen this type of increase in our HDAP program," Vineyard says. "But it is reason for concern."

Revamping TennCare

Vineyard gave a brief overview of the TennCare program, explaining why officials reduced TennCare eligibility and made other changes restricting access to the program. In January 1994, the federal government granted Tennessee an 1115 waiver, allowing the state to withdraw from the Medicaid program and to set up a five-year demonstration project known as TennCare in order to provide coverage for Medicaid recipients and others who would not otherwise qualify for Medicaid, which included the uninsured and those deemed medically eligible. As a managed care program, TennCare services are provided through managed care organizations and behavioral health organizations that receive a monthly fixed rate or capitation fee to manage the delivery of health care services for their clients.

The state authorized Ryan White case managers to enroll clients on TennCare until July 2002 when the rules of the program changed. TennCare covered 80 percent of individuals with HIV prior to July 2002, greatly reducing the pressure on HDAP and other Ryan White programs.

"In 2001, Tennessee had the lowest cost per person for any Medicaid person in the United States," observes Vineyard. But as he explains, "TennCare was still considered too expensive."

Even though the federal government provides 66 percent of the funding for the program, the state is required to come up with a 33 percent match, creating a 66/33 percent split that is still too much of a burden for many states to carry, especially a state like Tennessee where TennCare enrollment and costs are growing rapidly, Vineyard says. About 1.4 million state residents were enrolled in TennCare by 2002; 800,000 were Medicaid eligible but 600,000 were not Medicaid eligible, qualifying for TennCare by being uninsured and uninsurable.

Like other states, Tennessee has been struggling with large budget deficits. "Tennessee has a consti-

tutional amendment requiring a balanced budget, leaving the legislature struggling with what to do about TennCare," he said.

Vineyard sought to put the debate about TennCare into perspective, telling the audience that state legislators had a choice between raising taxes or enacting spending cuts in 2002, an election year.

"What do you think happened?" asked Vineyard, provoking laughter.

Many legislators ran on an anti-tax platform in 2002 and were swept into office by a groundswell of anti-tax sentiment that essentially turned the election into a debate about whether to raise taxes or reduce TennCare spending. "Two or three radio stations around town went on the radio every time they learned the tax debate was going on," Vineyard remembers. "The people who opposed the tax would circle the capital beeping their car horns and their big truck horns. This went on all day and you could hear it all over town."

Nearly every legislator who was elected or re-elected signed an anti-tax pledge, vowing not to raise taxes. This, in turn, gave state lawmakers a mandate to revamp TennCare.

"In the long term, instead of transferring off of our program in approximately 90 days and going onto TennCare, those who are above 100 percent of the poverty level will probably stay with us on HDAP," says Vineyard. "Our program will continue to grow." ■

Part two of this series will be in the next issue of The Voice and will cover the Caucus Sessions of the conference. Conference participants were divided into program and incidence-based caucus sessions, that produced some of the most constructive and insightful dialogue of the entire conference. This summary was provided by Martin Medical Services, Inc. (MMS), a health care research and consulting firm. For further information, please contact MMS President, Julia Lam, at (304) 262-2371 or email her at MMSJEL@aol.com.

ADAP Crisis Continues

Co-Infection Briefing on Capitol Hill Raises Awareness, Underscores Concerns Part 1 of a 2 Part Series

Editor's Note: Part 1 of this series, "Co-Infection Briefing on Capitol Hill Raises Awareness, Underscores Concerns" may be found in the May 2003 issue of The Voice. To receive a copy, please contact the T•II CANN offices.

Disparate Drugs

It is important to understand that "different communities do not all use the same drugs," Francis said. "Part of it is for reasons we do not understand and part of it has to do with the distribution of drugs," he explained.

In African-American communities, there is a greater tendency to use heroin and cocaine, drugs that are primarily injected and snorted, serving as prime vectors for HCV transmission. In Hispanic communities, the trend is reversed, there is more cocaine use than heroin use, and in the Caucasian community there is a greater use of alcohol and tobacco, with amphetamines serving as the drug of choice.

"We have to remember that in using drugs our behaviors change," said Francis. "The behaviors of people change and they tend to facilitate the transmission of many diseases, not only viral ones but bacterial diseases like sexually transmitted diseases." Francis stressed that "hepatitis C in the drug user is never by itself."

"We tend to look at things in a single issue but in the average drug user they have at least four major problems," said Francis. Many, for example, have co-morbid conditions like hepatitis B, or HIV compounded by mental health issues and a lack of housing. "Just to treat hepatitis C by itself is generally a failure," asserted Francis. "We have to keep cognizant of that as we develop our programs in terms of public health and policy."

Similar Transmission Routes

Various speakers cited the similarities between HIV and HCV, explaining that both diseases share similar modes of transmission – injection drug use, sexual contact, and blood transfusions before measures were developed to screen the nation's blood supply for HIV in the mid-1980s and HCV in the early 1990s. "If a person got HIV through one of these modes of transmission, he or she almost certainly has hepatitis C," noted one physician.

Six or seven years ago, the problem of HIV/HCV did not exist for most HIV-infected patients; the majority died long before their HCV became an issue. With the advent of highly active antiretroviral therapy (HAART), people with HIV disease are living much longer and as a result, HCV is becoming an increasing cause of morbidity and mortality among co-infected patients. Injection drug users who are co-infected with HIV and HCV have probably had HCV longer than HIV because HCV is more easily transmissible through injection drug use than HIV. Jules Levin, a former injection drug user, has had HIV for 20 years and he believes he contracted HCV 25 years ago. His situation is not unique.

"Many people have had hepatitis for 20 to 30 years," Levin said. "Go back to the 1960s and 1970s when many people got it. It is coming home to roost and now they are going to start to get sick and the health cost burden is going to start mounting."

Not surprisingly, the combination of HIV and HCV creates multiple problems for the co-infected, complicating treatment regimens for both diseases while exacerbating medication side effects. The presence of HIV also hastens progression of HCV in many patients, leading, in turn, to higher rates of morbidity and mortality in those

co-infected patients. Yet, very little is being done to address HCV in general and HIV/HCV co-infection in particular, prompting widespread criticism from speakers at the congressional briefing.

"We are here this morning because funding and attention lag far behind for hepatitis C," said Donna Christian-Christensen. She said funding for "needed research, treatment, and supportive care is but a drop in the bucket of what it should be compared to diseases that don't have the mortality or the impact that drives people, family, and communities as this one does."

Christian-Christensen urged people to be more "vocal and united than ever before" in order to increase funding for HCV and HIV/HCV co-infection. Jules Levin, meanwhile, said, "there is very little money to do treatment education for hepatitis in the non-infected community and the co-infected community."

"The medical care infrastructure is just not prepared to accept all the people with hepatitis and co-infection and to care for them properly," said Levin. "There are not enough doctors and the doctors that are around are not prepared to deal with co-infected patients. They are overwhelmed with the current case load they have for hepatitis."

Levin also addressed gaps in care, saying it is difficult for some people with HCV to access viral load and genotype tests and to obtain liver biopsies, basic diagnostic tests needed to diagnosis, treat, and care for people with HCV.

This summary was provided by Martin Medical Services, Inc. (MMS), a health care research and consulting firm. For further information, please contact MMS President, Julia Lam, at (304) 262-2371 or email her at MMSJEL@aol.com. ■

result, the program will run out of money by the last quarter of the current Ryan White fiscal year in January even with an ADAP waiting list.

“We have siphoned off what ever we can from Title II,” Khan said. “We have saved as much as we can on administrative costs. We have cut back on all other HIV CARE Consortium support services.”

Khan pointed out that ADAPs do not operate in isolation – ancillary services such as transportation and housing are vitally important to health care access and medication adherence. “It is not just a case of buying medicines, giving our patients medicines, and leaving them alone,” explained Khan. “There are all kinds of support that is needed – utility, transportation, housing, mental health services. We provide very little of that.”

West Virginia’s Ryan White program has strict caps on housing assistance and other services depending on the severity of need. “We try and save every cent and pump it back into the purchase of drugs,” Khan said.

‘Self Defeating Exercise’

The Centers for Disease Control and Prevention (CDC) unveiled a new initiative in April that calls for increased HIV testing to identify and bring HIV-positive individuals into care, an initiative that Khan said “is not well thought out in terms of priorities or the real crisis taking place on the ground.”

“Where is the logic in getting people tested and then putting them on waiting lists once they turn positive?” he asked. “We don’t have the resources to provide them with treatment services if they turn positive so what are we telling our clients?”

“The CDC’s efforts to reduce the barriers to early diagnosis of HIV infection by encouraging people to be tested are commendable. However, we are concerned that the next crucial step of providing treatment and care services to people who do test positive is being

ment details are. As with traditional employed spouses, this information might also require directly contacting partners’ job benefits offices to secure details and arrange premium payment and enrollment. Partners’ sensitivities to contacting the workplace must be accommodated too.

Since ADAP enrollees and applicants with live-in domestic partners probably outnumber those with traditional (straight) working spouses, this will be a new, even if hard-to-develop, alternate health coverage source. ■

Potential Consultant/Contractors Experienced with and Available for Screening Clients for Eligibility for Alternate Coverage and Third Party Liability Improvement Operations

COVANCE operates several PAPs from boiler rooms in Gaithersburg, MD and California
9801 Washingtonian Blvd., 9th floor, Gaithersburg, MD 20028
Krista Zodet, (240) 632-3400, krista.zodet@covance.com
Helene Kennedy, helene.kennedy@covance.com

THE LASH GROUP already runs several PAPs from its boiler room operation in North Carolina
3735 Glen Lake Drive, Charlotte, NC 28202
Jessica Black, (704) 357-5869, jblack@lashgroup.com
Susan Slaton, sslaton@lashgroup.com

PAREXEL already runs several PAPs* from its boiler room operations in Centerville, VA and California
5870 Trinity Parkway, Suite 600, Centerville, VA 20120
Mr. Coy Stout, (703) 310-2045, coy.stout@parexel.com
Angela Mitchell, angela.mitchell@parexel.com
Sara Webb, sara.webb@parexel.com

MCKESSON operates GSK’s PAP from boiler rooms in Scottsdale, AZ and Colorado
9700 North 91st Street, Suite 232, Scottsdale, AZ 85258
Jason Chocron, (480) 314-7202, jason.chocron@mckesson.com
Deanna Jones, deanna.jones@mckesson.com

PETERSON CONSULTING (NAVIGANT GROUP) serves as HRSA’s 3rd party billing consultant and did 3rd party consulting on related issues for the VA and other payers
1801 K Street, NW, Washington, DC 20006
Leonard Schossler, (202) 973-2446, lschossler@pcit.com

* PAPs—private, corporate Patient Assistance Programs, run by, or on behalf of, pharmaceutical manufacturers as a private charity, to provide prescriptions to those patients without any other current or potential coverage who are considered needy under individual company guidelines. PAPs are operated on behalf of manufacturers by the above contractors using centralized telephone “boiler room” staff trained in Medicaid, other public health benefit, VA, and private health insurance eligibility; only those patients whom these contractors screen and find to be not eligible (or not yet eligible) for such other coverage receive PAP drugs, if they’re needy enough; where necessary, patients are temporarily given manufacturer drug donations and case-managed while awaiting or being processed for coverage to begin in any alternate health coverage.

chronically under funded. It appears to be a self defeating exercise.”

Khan said HIV prevention must be coordinated and delivered in tandem with HIV treatment and care – and all must be funded adequately. “We

need to be able to turn around and say, ‘if you get yourself tested and you are positive, we will be able to provide treatment, care, and support services for you,’” said Khan. ■

Continued from page 1

prevented or delayed by proper treatment - or they can pile up in your financial backyard, or mine. Or, they can be minimized by early access to healthcare and treatment with costs shared between the patients, and state and federal systems. The resulting benefits and cost savings accrue to the patients, to the entire population, and to all the economic systems of the whole U.S.A.

There is no question that AIDS advocacy is on the rise again and not a moment too soon. Efforts like SAVE-ADAP are clear evidence that state level HIV/AIDS advocacy is on the rise. Not just in Florida, California, New York, Illinois, Texas, and other "high AIDS incidence" states, but in Georgia, North Carolina, Alabama, Arkansas, and quite a few more. That's wonderful - especially if you believe that "the Gods help them who help themselves."

More to the point, we are now at the stage where only "political action" will actually spur movement & change in the current "gridlock" over adequate funding for HIV/AIDS & ADAP (and also in many other healthcare and public health areas). Therefore every single HIV/AIDS program in the country needs to have an "AIDS Advocacy" arm and action capability. Clinics need a patient advocacy compo-

nent. Food banks need volunteers and board members to make phone calls and write letters. Churches, mosques, and synagogues with HIV/AIDS activities need an "advocacy committee." Health care providers need a committee to write to the White House and to Senators. Patients benefiting from access to HIV medications need to set aside time to work with other local people, AIDS service organizations, United Way, Red Cross branches, and church groups. AIDS Walks, local fundraising, local election activities to support your local members of Congress and the Senate - or their opponents if your existing leadership is not meeting your local HIV/AIDS needs. If we don't do this we can not expect others to do it for us - not in today's fiscal "climate."

Anyone with access to the Internet can link up with many organizations regardless of how remote an individual's location may seem. Try "AIDS ADVOCACY" in your search engine and you will immediately have a full day's worth of useful ideas.

Media has already begun to pick up the facts on a flurry of deaths among HIV-positive people "wait listed" for the Kentucky ADAP. Most of us have heard about the two deaths of HIV-positive patients while on the West Virginia ADAP "waiting lists" (see article on page 2). As waiting lists climb

more deaths will occur while people are "waiting." If eligibilities in Medicaid and ADAP are further cut to "save money," more HIV-positives will be lost - and these patients won't be recorded on any reported "waiting lists." However, they will be gone, sooner than is necessary, and with resulting social and economic damage to their heirs, families, and communities - which would be avoidable if timely access to medicines and HIV competent medical care were available in timely fashion.

It shouldn't be this way in the richest country in the world. Morally and medically it's completely unacceptable. Moreover this course of events wastes a lot of public and private money. Now we all have to make it politically unacceptable and that means by thousands from all the "grass roots" right up through our local and federally elected leaders, to directly with The White House and all who would like to occupy it.

We all have to SAVE-ADAP, and NOW. ■

The **SAVE ADAP** webpage is now linked to the ATAC site. You'll find all the alerts, press releases, and an archive of their 2002 work. Go to <http://www.atac-usa.org/adap.html>.



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