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Remarks of

Patricia S. Fleming

National AIDS Policy Director

to

Center for Women Policy Studies

September 25, 1996

GOOD MORNING:

Thank you for that kind introduction and for the opportunity to join you today for this important discussion. This is almost like a family reunion. So many friends and familiar faces. Sisters in the fight. People like Leslie Wolf, Helen Schietinger, Belinda Rochelle, and Kathleen Stoll.

Each of you in this room has made a major contribution to our national response to the epidemic of HIV and AIDS, especially by calling our attention to the impact this disease is having on women. As someone who has spent much of the last ten years fighting to raise the profile of women in the response to AIDS, I am very grateful to you for your work.

We have made a great deal of progress in addressing the very real needs of women infected and affected by HIV and AIDS. We now have a national natural history study of the epidemic in women. We have much greater enrollment of women in clinical trials. And we have changed the definition of AIDS so that more women are qualifying for disability benefits.

But we still have a long way to go and there are many new issues on our plate. One of the biggest is the topic of this meeting -- Medicaid and managed care. In many ways it is remarkable that we are still able to have this discussion. When the current Congress took office nearly two years ago, the new leadership was determined to do away with the Federal entitlement for Medicaid coverage and replace this program with an underfunded, poorly designed block grant. Those of us in the AIDS community knew this was a terrible approach to Medicaid reform. I myself was sharply criticized when I raised my voice against this proposal.

You and I know that Medicaid is a lifeline of support for people living with HIV and AIDS. In fact, today more than half of all Americans living with AIDS -- including more than 90 percent of the children with AIDS -- rely on Medicaid for their health care. Without that coverage they would have nowhere else to turn.

Thanks to President Clinton's steadfast support for Medicaid and his absolute opposition to this destruction of the safety net, Medicaid remains standing. The President vetoed the Republican budget that contained the

Medicaid block grant and made clear that he would do it again. He stood up to the Congress when they tried to attach a Medicaid block grant to welfare reform and they backed down again.

For women living with HIV or AIDS and for their children, the maintenance of the Medicaid entitlement is perhaps the greatest victory of the past two years. And we have women like you to thank for that victory. The President did this with the support of you and the organizations you serve.

But the President also recognizes that Medicaid can't remain unchanged. In fact, his Administration has worked with the states to provide flexibility for modernization of the program. But all along we have worked to protect the rights and needs of people with AIDS.

We have seen tremendous growth in the number of Medicaid beneficiaries enrolled in managed care plans. Today, nearly one-third of all beneficiaries are in managed care plans and virtually every state is operating a managed care program. For many men, women, and children the introduction of managed care into the Medicaid program has been a blessing. It has given them a consistent

source of care by skilled medical professionals in community-based settings. It has increased the amount of preventive care available and it has lowered the cost of care so that our Medicaid dollars can go further.

But managed care also creates new challenges, especially as it concerns individuals with costly, chronic diseases like HIV. There are, as you have recognized, a myriad of issues that have to be taken into account before we can appropriately enroll Medicaid beneficiaries with HIV into managed care plans.

The Clinton Administration has worked in partnership with the affected communities to identify and raise these issues with the states. I have to be honest with you, these are not questions that the states have been very happy to have raised. In fact, we have taken a great deal of heat from several governors who have seen their Medicaid waiver applications held up while we asked questions about AIDS care.

My office has worked very closely with HCFA to be sure that all managed care waiver applications are examined closely to see how people with HIV and people with AIDS are treated. The most important of these applications is the

one now pending by New York State. While I certainly can't tell you how the current discussions will end up, it is clear that the issue of care for people with HIV and AIDS has played a critical role in this process.

My office did not attempt to do this alone. We worked with groups representing caregivers and people living with HIV and AIDS to make sure that their concerns were represented. This level of cooperation is unprecedented and I expect it to become a model for the future.

We must work together to make sure that New York is not the exception but the rule. I am working closely with HCFA Administrator Bruce Vladeck and his staff to develop a process that can become standard for all managed care decisions. I encourage you to be part of this process.

While I think this process is essential to protecting the rights and needs of people who are living with AIDS, I am concerned that we have not yet come up with a process that addresses the needs of people who are living with HIV,

especially those who are in the very early stages of infection. It is on this point, in particular, that I would ask for your assistance now and in the future. (And those who are already in managed care plans and become infected.)

If we have learned anything over these last two years it is that we are at our most powerful when we work together. That is something that women have always known and that we must continue to teach our colleagues on the other side of the aisle.

Thank you again for the opportunity to meet with you today.

Remarks of

Patricia S. Fleming

National AIDS Policy Director

to

White Night Gala

Daytona Beach, FL

September 21, 1996

GOOD EVENING:

- Thanks and Acknowledgements -- Albert Richburg, David McVey, Terry Brady, Matthew Valiquette, Christopher Van Wagoner and Rick Caldwel, Bobby Hudson, the wonderful artists who contributed their talent and their love tonight, and the hardworking staff of Outreach Inc. and the Northern Florida AIDS Network. say something about Albert + Bobby

- Thank you all for coming out tonight. You all look marvelous. But I have to tell you that up north where I come from you're not supposed to wear white after Labor Day. white night gala - do they know I'm not white? Tell story of 3 sons - one gay homophobia.

- I bring you greetings from the President, who wishes he could be here tonight. He also wants to thank you all for your support of people with AIDS and the programs that serve them.

- The President has fought hard for the AIDS community. In four years he has increased funding for AIDS prevention, research, and care by more than 50 percent. That's remarkable in a time of frozen budgets and block grants. $ more than 50%

- We have doubled funding for the AIDS Drug Assistance Program that helps people with HIV and AIDS buy drugs like AZT and protease inhibitors. Doubled funds for ADAP

- We have increased funding for the Ryan White CARE Act by 150 percent, bringing care to thousands of people who have nowhere else to turn.

Ryan White ↑ 150%

- And, just this week the President won another victory for people living with AIDS when he got the Congress to increase funding for the Housing Opportunities for People with AIDS program by $25 million. That's vitally important money in states like Florida where the cost of housing can be very high.

HOPWA ↑ 25m

  - Have we done enough? Absolutely not.
  - Will we do more? Absolutely yes!

- The President has placed AIDS programs on his short, short list of priorities and it has remained there for four years.

short list of priorities for 4 years

And it will be there for another four years when the President is reelected on November 5.

we have to reelect him because

  - We have a lot of work to do.

keep on increasing funds for research

- We have to increase funding for AIDS research so that we can find the next piece of the puzzle -- a vaccine that protects everyone from HIV.

- We have to increase funding for prevention so that people don't become infected in the first place. And that's especially true of our young people -- and particularly young gay men. Two American teenagers are becoming infected every hour of every day. That's appalling and we have to put an end to it.

- We have to increase funding for the Ryan White CARE Act so that everyone who needs care gets care. That's especially true for women and communities of color who have such a hard time finding qualified doctors and nurses to care for them.

- And we have to find ways to make sure that everyone who can benefit from protease inhibitors can get them.

- That means fighting for more money for ADAP -- and the President is winning that fight right now.

- That means fighting with the drug companies to get them to lower their outrageous prices.

- And it means maintaining our Medicaid program that care for half of all people with AIDS and 90 percent of the children with AIDS.

Medicaid

Bob Dole was the chief sponsor of the bill that would have taken away the guarantee of Medicaid coverage for people disabled by HIV+ AIDS.

The President vetoed ~~the Dole-Gingrich Medicaid block grant~~ that bill and he will do

it again, and again, ~~and again~~. if he has to.

- This election is about --

- Caring for our brothers and sisters who are living with AIDS.

- Fighting for their health care and their civil rights. (Defeated the Dornan Amendment)

- Fighting for the resources we need to keep people healthy and productive.

- And most of all, it's about our future as a nation.

A future where HIV no longer hovers over us like a dark cloud.

A future where people with AIDS aren't political footballs.

And a future where men and women are allowed to love who they want, where they want, and when they want.

SO that's why we have to reelect Bill Clinton. That's why we need Florida to put him over the top. And I know you'll work hard to make that happen.

- Again, thank you for being here tonight and for including me.

Remarks of

Patricia S. Fleming

National AIDS Policy Director

to

Presidential Advisory Council on HIV/AIDS

September 8, 1996

GOOD MORNING:

It's a pleasure to see you all again. I'd like to take a moment to offer my congratulations to Debbie Runions and Phill Wilson for their wonderful remarks to the Democratic convention. I'm sure all of you are as proud of them as I am. I also should say that Mary Fisher and Hydeia Broadbent were also quite moving in their remarks to the Republican convention. It is important that the American people continue to hear these voices of reason and passion if we are to bring this epidemic to an end.

In his acceptance speech, the President articulated his hope for America with regard to HIV -- expressing optimism at the improvements in HIV treatments, and setting a normal lifespan for people with HIV as a national goal. The President's comments, I think, demonstrate two things: the increased visibility and leadership on HIV and AIDS we have seen over the last four years -- and, just as importantly, the changed scientific climate in which we meet today. First I am going to update you on a series of issues that we have been working on -- but then I am going to return to the challenges we face as a result of this improved scientific and medical picture -- and what it means for the work we set for ourselves over the next four years.

First, a brief overview of our legislative agenda. This is a busy time in Washington. Congress has just returned from its August recess and is prepared to deal with a long list of unfinished business. I have been working closely with committees in the House and Senate to make clear the Administration's urgent desire to see action on several key items.

I was pleased that earlier this summer Congress approved the Kennedy-Kassebaum bill, protecting insurance benefits for working Americans. This is an important step forward in our efforts to reform the American health care system. Clearly we have many more steps to take -- but this is definitely a start.

There are clear benefits in this new law for people living with HIV and AIDS -- especially those who are in the workforce. Insurance companies will no longer be able to refuse to sell policies to small businesses just because one or two employees have serious health problems. Workers who move from one insurer to another cannot be permanently excluded because of their pre-existing medical conditions. Self-employed individuals will receive the same tax deduction for their insurance expenses that the rest of us do. And viatical settlement benefits will be tax-exempt. These are important changes that will provide people with HIV a greater level of security.

The President also signed the welfare reform bill. I recognize that many of you have concerns about the impact of this legislation on people with HIV and AIDS. Let me say that we in the Administration share those concerns and, as the President has said, are working to alleviate them.

I was very pleased that we were able once again to kill the Republican Medicaid block grant, which the House had attached to the welfare bill. We were also able to protect Medicaid coverage for most of the people who may lose their AFDC benefits under the welfare reform bill.

Clearly more work is needed in the area of legal immigrants. I am working with the Justice Department and others to devise a list of programs that will be available to legal immigrants and we will make sure that programs like Ryan White, drug treatment, HIV and substance abuse prevention and HOPWA are included. I appreciate your willingness to assist us in that process.

The largest piece of unfinished business is the fiscal 1997 budget. The new fiscal year begins in about three weeks but Congress appears far from completing action on many of the appropriations bills. In fact, it appears quite likely that we will have some sort of an omnibus continuing resolution covering a good deal of the government.

Since we last met, the President has submitted to Congress two AIDS-related amendments to his FY 97 budget. The first one shifts $25 million into the Housing Opportunities for People with AIDS (HOPWA) program at HUD. The second increases the President's request for the AIDS Drug Assistance Program (ADAP) under Ryan White by $65 million to $117 million.

Amendments of this kind are extremely rare in this fiscal climate. They are certainly the envy of people working in other areas. But they again reflect the responsiveness of this Administration, this President -- to the ever changing nature of the epidemic and to the voices we hear from this Council and from throughout the community.

The FY 97 ADAP amendment is the second amendment to the program in less than six months -- it shows our willingness, as the data accumulate, to adjust our requests to reflect the need. The HOPWA amendment is a result of a new level of visibility for this program. I might add that the success of protease inhibitors lends new weight to the calls for increased support for AIDS housing. For without a stable and supportive living environment, it will be very difficult to adhere to this treatment regimen.

There has been some concern expressed by some in the community and even on this Council about the seriousness of these budget amendments. Let me be very clear: this was not a political exercise -- there was some very heavy policy and budgetary lifting associated with

these amendments. As we close the chapter on what is surely to be another "unusual" budget cycle -- I can assure you that these amendments -- as well as our ongoing requests for increased funding for Ryan White, research, and prevention -- will be part of the Administration's negotiating strategy.

In case you have any doubts, you should know that AIDS is, was, and always will be on the President's list of priorities in these negotiations -- just as it was last year. I can't predict the outcome but I can predict the intensity of our efforts. This is my top priority until the Congress leaves town.

The final item on our legislative agenda is the restoration of the budget authority of the Office of AIDS Research at NIH. All of us were disappointed that we could not convince Congress to do the right thing last year despite all of our best efforts. There is reason to be hopeful that this year the Congress will listen to reason. But members of Congress need to hear from everyone concerned -- in and out of government -- before they make this decision.

Now just a few other items. We had what I believed was a very successful meeting in Tampa last month with experts from around the country who work in substance abuse prevention and treatment and AIDS prevention and treatment. Terje Anderson can fill you in on this as well.

There was a real feeling of accomplishment in this meeting. Frankly, many of the men and women in the room hadn't met or spoken to their colleagues before. That fact alone made this meeting important.

But even more critical was the recognition that greater collaboration is not only desirable it is necessary if we are to attack these twin epidemics and make progress.

If I came away from the three days in Tampa with one message, it was that the Federal government -- through its own funding streams and programmatic directions -- creates far too many obstacles to the integration of HIV and substance abuse work at the community level. We are working with the relevant agencies and OMB to address this and create some real dynamic action. Again, we will need your continuing help in this area.

I know the issue of Medicaid managed care has been of concern to you. The Health Care Financing Administration is continuing to work with the state of New York on its proposed Medicaid managed care waiver. I am very proud of the work that HCFA has done. They have really turned the state around on the question of care for people living with HIV and AIDS. The terms and conditions HCFA has proposed set an important standard for Medicaid managed care. This process is not yet over but be assured that we will continue to stand up for the rights of people with AIDS and others with life-threatening illnesses that require extended and costly care.

The Vice President's work on drug development took a big step forward with the creation of the Forum for Collaborative HIV Research. In the last four years, the FDA has approved 24 new AIDS drugs, many of them under accelerated approval. But it is clear that there is much that we don't know about these drugs -- about the durability of their effect, about when to start treatment, when to stop, or when to switch. We need creative new ways to get those answers and this new forum should be a vital link to that information. Perhaps most important to this process is the inclusion of third party payers such as Medicaid -- this may well expand the reach of clinical trials to populations that have not had the same level of access.

It is certainly my hope that one outcome of the Forum will be making it easier for Medicaid recipients to participate in clinical trials, in the context of their ongoing care. I'd like to thank Alexandra Levine for representing the Advisory Council in the most recent meeting with the Vice President on this subject.

I want to talk briefly about the Vancouver conference and the new drugs. Several of you were at the conference with me and I am sure that you came back with the same kind of mixed emotions. On one hand, there is genuine hope for the future. Men and women across this country -- and several people in this room today -- are reporting remarkable results from their treatment with combination therapy including protease inhibitors. This is yet another example of how our long-term investment in basic science and AIDS research is paying dividends.

But there is also a great deal of trepidation. As I mentioned earlier, there are many unanswered questions about protease inhibitors and combination therapy. Getting the answers to those questions is our top scientific priority. The approval of these expensive new drugs also creates a host of public policy issues that must be dealt with rapidly. One of them is ensuring access to as many people as possible. The President's request for more money for ADAP is the first step in this direction.

But science is providing us with new and welcome problems -- as we see more and more people thrive on protease inhibitors. As I mentioned, we do not yet know the durability of this effect, but it is not too soon to think about some critical policy questions:

First, our care and services system is built primarily around serving people as they become disabled. Most people with HIV do not become eligible for Medicaid *until* they have CDC-defined AIDS. And yet -- everything about the science suggests earlier access to treatment is critical. We need to start a dialogue -- within government, with the community, within this Council -- about what changes we need to make to various programs so they become more focused on *preventing* disability, rather than responding to disability.

Second, protease inhibitors are giving us a glimpse of a world where HIV infection is not a constant, downward slope toward greater and greater disability. We have begun the discussions within the government to re-examine the assumptions of many of our programs so they have the flexibility to support people as they go on and -- we hope -- off disability.

Third, as the earliest possible intervention becomes the standard of care, we need to re-examine how we can convince people to seek voluntary counseling and testing and how we can assure linkages to appropriate care for people who test positive.

Finally, progress on the treatment front does not mean we can retreat on prevention. The only way we can truly improve the length and quality of a person's life is to make sure that they don't become infected in the first place. That's why we're fighting for the President's full request for CDC's prevention programs.

And that is why the microbicide initiative is so vitally important. We can empower women and men to protect themselves without relying on the cooperation of their partners. This will be a giant step forward in prevention and we must work very hard to get there.

(REGIONAL BRIEFINGS)

Later today, we will discuss the draft National Strategy on AIDS. This is the government's first cut at an outline of the overall goals and objectives of our nation's efforts to fight this epidemic. I hope some of these new challenges can be incorporated into our discussion of this document -- as you work with us, and the rest of the AIDS community -- in refining the missions of our AIDS programs.

We have a busy three days ahead of us. Jeff and I and our colleagues will be here to answer questions and to participate in your discussions.

Again, thank you for being here and for your service to our nation.

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legislation

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(Kennedy-Kassebaum)

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(Welfare Reform)

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(APPROPS)

The largest piece of unfinished business is the fiscal 1997 budget. The new fiscal year begins in about 3 weeks [redacted] but Congress appears far from completing action on many [redacted] of the appropriations bills. In fact, it appears quite likely that we will have some sort of an omnibus continuing resolution covering a good deal of the government.

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(TAMPA)

Now just

12

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(managed care)

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(Post marketing Studies)

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(USAID)

(Protease Inhibitors)

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